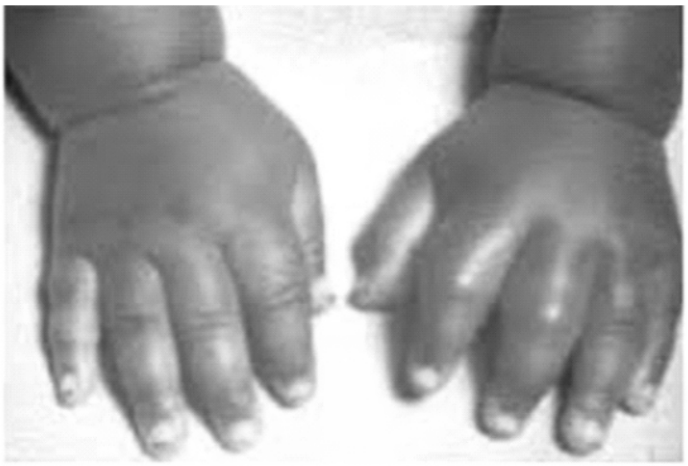
"ARO'MỌ L'ÉEGUN"
(HARBINGER OF BONE PAINS)



A STORY OF SICKLE CELL DISEASE, STIGMA, POVERTY, HOPE AND RESILIENCE IN SUB-SAHARAN AFRICA

A Memoir

MUIDEEN OWOLABI BAKARE

TABLE OF CONTENTS

FOREWORD

It is an honour to comment on the life experience of Muideen Bakare. This is a story of an extraordinary individual who has not only overcome obstacles that would have thwarted the dreams of most but of a person who had the intelligence and gifts to always go beyond expectations. Muideen quotes Walter Bagehot as saying "A great pleasure in life is doing what people say you cannot do." Muideen's life to the present certainly demonstrates his capacities to go beyond what people said he could not do. Perhaps it is the satisfaction he has achieved in accomplishing so much that keeps him going on his journey.

Mentors played an important role in the ultimate successes of Muideen, but Muideen does not credit his special capabilities that attracted the mentors to want to help him achieve his life goals. There is no doubt that sickle cell disease played a critical role in setting up the challenges that Muideen faced, but it is only a part of the many challenges Muideen faced and faces. Muideen's story is riveting not only for understanding the journey of one individual but for helping to understand how we all can overcome adversity and succeed. It is a story for all of us.

Muideen was fortunate, because of his superior intelligence and perseverance to have entered an educational system in Nigeria that recognized Muideen's strengths. Particularly, the College of Medicine at the University of Ibadan that maintained a focus on quality education in the midst of turmoil was sustaining. Mentorship in this institution was very special. Likewise the Department of Psychiatry at the College of Medicine under the superior leadership

of Dr. Oye Gureje in adult psychiatry and Dr. Olayinka Omigbodun in child and adolescent psychiatry defined the career path for Muideen.

Muideen's statement "When you live for something and have purpose, you are more likely to have hope and survive in the midst of adversity." This statement encapsulates the philosophy of Muideen and I think identifies a critical factor in Muideen's ability to persist…having hope. It transcends his exploration of faith as a sustainer and all the help he may have received from mentors. Where do hope and purpose come from? Muideen states that at one point in his journey he was labelled as the "iron man". Where does this strength come from? Perhaps the answer lies in Muideen's statement…"As a man thinketh in his heart so is he."The goal of becoming a physician grew out of the adversity experienced by Muideen and his constant exposure to physicians in the hospital setting, but it took Muideen's persistence to make this happen.

As psychiatrists we are aware of the importance of early childhood experience. In Muideen's early childhood one sees both early nurturance and the isolation brought about by illness. He has noted his prolonged breast feeding which certainly led to closeness to his mother and a special relationship that is enduring. Both his mother and father were attentive to Muideen throughout his illnesses and thus he was fortunate to have their manifest support and caring. The loneliness of his early years might well have fostered his ability to derive satisfactions apart from external acknowledgement and thus lead him to be able to endure against the persistent stigma he faced. All this conjecture is of no matter when we see how Muideen has achieved beyond anyone's expectations perhaps including his own.

From reading his memoir I do not believe that much of what Muideen attributes to good fortune is, in fact, the case. Mentors, supporters, caregivers gravitated to Muideen because they saw and felt his inner person. It should be noted that Dr. Kerim Munir once briefly introduced to Muideen has steadfastly guided the latter part of Muideen's career as a prominent researcher. The bonding and success was not by chance as I witnessed it.

Muideen is now a leader in the field of neurodevelopmental disabilities with unique contributions in sub-Saharan Africa. US National Institutes of Health and Harvard Catalyst support through Dr. Munir gave Muideen special competence in autism and other disorders. Muideen is now widely recognized in his own right as Secretary of the World Psychiatric Association Section on Psychiatry of Intellectual Disability. He is also an effective speaker at numerous symposia including the WPA, IACPAPAP and IMFAR.

This memoir encapsulates the dreams, philosophy and accomplishments of one individual but its lessons are meaningful for all of us.

Myron L. Belfer, MD, MPA

PREFACE

There are few things I dread more in this world than poverty. My fervent wish is that the resources of the Universe be equally distributed, but that is a utopia. Fingers are not designed to be equal.
What is however gladdening to the heart is that the resources of the Universe are available to all and everyone who has a good idea or dream to pursue. A good idea or dream attracts the required resources to get it executed. Although the road may be rough and convoluted, with persistence one can always arrive at the desired destination.
The subject of this book is about not giving up even in the most adverse or unbearable situation, because circumstances would always change. After all, the only constant thing in the world is change itself. Tough times, they say, don't last, only tough people do.
The lesson that life has taught me and is still teaching me is that; the Broken often becomes Master at mending. The psychologically traumatized who had worked through his/her trauma is likely to be the best Healer. The most wayward and sinful individual who had repented is likely to be the best Priest. God and the Great Energy of the Universe love to use the seemingly incompetent, incapable & broken people.
So, giving up no matter how broken, incompetent or incapable you think you are may not be a good option and a solution to the challenges we face in life as humans.
"Aro'mô l'éegun" is written to be a source of inspiration, to encourage young children and adults going through chronic illness or any other adverse circumstances.
According to Walter Bagehot, "A great pleasure in life is doing what

people say you cannot do".
Be encouraged!

Muideen Owolabi Bakare, M.B.B.S, FMCPsych, MNIM

ACKNOWLEDGMENTS

I am immensely grateful to Mr. Sylvanus Omoniyi, Mr. Abass Adetunji, Dr. Niran Okewole and Dr. Femi Oyebode who have contributed greatly to editing of this manuscript following its initial draft.

My appreciation also goes to Dr. Myron Belfer for offering to write the foreword to this book. His immense experience in the field of child and adolescent mental health, as it borders on themes of positive mental health and resilience in children and adolescents has been reflected in the foreword.

I am grateful to Dr. Olayinka Omigbodun, who mentored me in the formative years of becoming a specialist in the field of Psychiatry and Mental Health.

My gratitude also goes to Drs. Andrés Martin and Joaquin Fuentes. They are the brains behind the Donald J. Cohen Fellowship Program, a program that acted as a springboard for my career progression and had helped shape and is still shaping the careers of many other professionals across the world.

I have found a great mentor in Dr. Kerim Munir, an amiable individual, who is also constantly in pursuit of meaning by giving back to younger professionals. He has been contributing to my career progression through the process of leading and giving directions. To him, I owe immense gratitude.

To all who have encouraged and strengthened me along the journey of pursuing meaning, I appreciate you immensely. Also, to all who had said 'No' to me, I am grateful, because you have helped to re-shape my journey and destiny by saying no.

I promise that I will continue to give back to the world as much as I have received and am still receiving. That is the only road to pursuit of meaning.

Muideen Owolabi Bakare, M.B.B.S, FMCPsych, MNIM

Chapter 1
In Pursuit of Meaning

I was further in pursuit of meaning in my usual way as I attended various presentation sessions at the Calgary Telsus Convention Centre, Calgary, Alberta, Canada. I cannot afford to give up and not hang on as my strength permits, drawing further from my inner strength. Too many people around me had given up in the past, one of whom is my mother who is now better adjusted upon the death of her husband, my father some years ago. The event in Calgary was the 22nd International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) World Congress that took place in the month of September, 2016. The theme of the Congress resonated with me as it centred on positive mental health and promoting resilience among children and adolescents experiencing psychological or adjustment problems.

I reflected again on my childhood period, which had been laden with suffering from sickle cell disease, poverty and stigma associated with the disease condition in Sub-Saharan Africa and I became more convinced that I have a story to tell. The need to document my experience of living with sickle cell disease in the midst of poverty and challenges in Nigeria, West Africa became more compelling, so that through this process I may contribute and inspire resilience in others facing various adversity or challenges of chronic physical illnesses in the face of meagre resources.

My first attendance at IACAPAP World Congress was back in the year 2006 at Melbourne, Australia when I freshly qualified as a

psychiatrist. I have since then attended other subsequent Congresses held after this period with Magdalene, my amiable wife, who has been a great source of support since I met her a few years ago. Unfortunately, Magdalene was not with me at the Calgary Congress as the period marked the arrival of our first son, Michael who had just joined the family.

I have been having a happy and enjoyable practice as a Psychiatrist till date and I am happy I have been contributing to the body of knowledge in the field, especially with regards to peculiarities of Sub-Saharan Africa. I have been exploring and pioneering research in the area of neurodevelopmental disability among Sub-Saharan African children, with a special focus on Autism Spectrum Disorder (ASD) in Africa.

I have been living a happier life than many around me predicted during my childhood period in Nigeria, West Africa, when I was growing up as a child with sickle cell disease. I lived with discrimination and stigma and many around me thought I may not be able to survive into adulthood, which is a common observation among children with sickle cell disease born and raised in Sub-Saharan African countries. I believe my story would help and inspire other young children facing obstacles and challenges to hang on, develop enough level of resilience to survive the adversities they might be facing.

In the words of Helen Keller, 'optimism is the faith that leads to achievement. Nothing can be done without hope and confidence'. Adversity may hinder our pursuit of happiness, but tends to give us meaning to existence if we develop enough resilience to hang on in the face of obstacles. Pursuit of meaning is uniquely human, as it

involves giving back, while the pursuit of happiness is an attribute that cut across human race and animals. Having our desire satisfied brings about happiness, which is transient and temporary like every other emotion. On the contrary, finding a meaning, reason to live, reason to hang on, is more enduring and it involves giving back to our immediate society and human race in general. The pursuit of meaning brings about inner joy and satisfaction. It is therefore better to pursue meaning than to pursue happiness.

My Presentation Session at the 22nd IACAPAP World Congress in Calgary, Canada

Chapter 2
Early Years in Ibadan, Nigeria

I was born and raised in the city of Ibadan, a city with many firsts, located in southwestern Nigeria in sub-Saharan Africa. I was born two years after the Nigerian Civil War that ended in the year 1970, a war that left the country fractured along ethnic lines, its impact still felt more than four decades after it ended. Apparently the wounds are yet to heal totally, even in this my generation. I am a Yoruba man from southwestern Nigeria and I presently work and live in Igbo community, in Enugu, Enugu State, south-eastern Nigeria. This brings to me a daily experience of the persistent ethnic divide.

Ibadan is the state capital of Oyo State, one of the thirty- six states in Nigeria, a country located in the West African sub-region. According to oral history, the warrior Lagelu founded the city of Ibadan, an enclave which was initially intended to be a war camp for warriors coming from Oyo, Ife and Ijebu in south- western Nigeria. As a forest site containing several ranges of hills, varying in elevation from 160 to 275 metres, the location of the camp offered strategic defense opportunities. Moreover, its location at the fringe of the forest or *"Eba Odan"* (from which the city got its name) promoted its emergence as a marketing centre for traders and goods from both the forest and grassland areas. Ibadan thus had initially begun as a military state and remained so until the last decade of the 19th century.

According to HRH Sir Isaac Babalola Akinyele , the late Olubadan

(king) of Ibadan (Olu Ibadan means 'Lord of Ibadan'), in his authoritative book on the history of Ibadan, *Iwe Itan Ibadan* (1911), the first city was destroyed due to an incident at an *Egungun* (masquerade) festival when an *Egungun* was accidentally disrobed and derisively mocked by women and children in an open marketplace full of people. The then Alaafin of Oyo had ordered the old city destroyed for the act, which was seen as taboo and abominable. Lagelu was by now an old, frail man; he could not stop the destruction of his city, but he and some of his people survived the attack and fled to a nearby hill for sanctuary. On the hill, they survived by eating *oro* fruit and snails; later, they cultivated the land and made corn and millets into pap meals known as *oori* or *eko*, which they ate with roasted snails. They improvised a bit by using the snail shells to drink the liquefied pap (*eko*). This practice had largely been reflected in the praise chants of Yoruba people of Ibadan in Nigeria, who are usually eulogized as follows:

"Ibadan, Omo a j'oro sun
Omo a fi ikarahun fo oori mu
Omo a je igbin je ikarahun"

Ultimately, Lagelu and his people came down from the hill and founded another community referred to as *"Eba Odan"* (which over time metamorphosed to the present name, "Ibadan"). The new community instantly grew prosperous and became a commercial nerve centre. Shortly afterwards, Lagelu died, leaving behind a politically savvy people and a very stable community. The newly enthroned Olubadan made a friendly gesture to the Olowu of Owu by

allowing Olowu to marry his only daughter, Nkan. A part of Ibadan was historically an Egba town in Ogun State of South West Nigeria. The Egba occupants were forced to leave the town and moved to present-day Abeokuta under the leadership of Sodeke as a result of their disloyalty.

Ibadan is also fondly referred to as "Ile Oluyole" (The abode of Oluyole). Oluyole was a distinguished, dominating army commander from Oyo town. He rose to fame as *"Bashorun"*, a title he subsequently made famous, and was one of the leaders who contributed immensely to the military and economic development of Ibadan during the city's formative years, a period which had its share of tumult and uncertainty. With time, Ibadan grew into an impressive and sprawling urban center so much that by the end of 1829, Ibadan dominated the Yorùbá region militarily, politically and economically.

Ibadan is reputed to be a city of many firsts. The University College Ibadan, which later became University of Ibadan, is Nigeria's premier university. University College Hospital (UCH), the teaching hospital attached to University of Ibadan, was the first teaching hospital established in West Africa. The first television station in black Africa, now known as Nigerian Television Authority (NTA) was also established in the city of Ibadan. The city also housed the then tallest building in Nigeria, built with the proceeds of Cocoa exports (Cocoa House) at Dugbe, Ibadan. This building was the

tallest in Nigeria for a long time before the emergence of other skyscrapers in the country in recent times.

Overhead view of the City of Ibadan in Nigeria

I can't remember so much about my preschool childhood period, but I will rely on the information I got from my parents. I was told I was a child that never took artificial milk. I relied solely on breast milk and insisted on it. So, I underwent exclusive breastfeeding, which has

been documented to be a good source of balanced nutrition and confers immunity on a growing infant. But by the time I was supposed to change over to eating 'adult food', I was told that I had so much interest in yam. There was a particular Mr. Alabi who lived close to my parents then. I would always run to his apartment, asking him to give me yam by saying: 'Mr. Alabi, isu'. Yam is a root harvest like potatoes that is common among the people of West Africa. So, I was given that name because of my continuous request for yam. I was told I achieved quite quicker developmental milestones when compare to other children as I was informed that I started walking at about the age of nine months. Around the same time, I started experiencing crises from sickle cell disease.

Normal red blood cells are round, flexible and concave in shape, which enables them to travel through small blood vessels to deliver oxygen to all parts of the body. Sickle cell disease causes red blood cells to assume a crescent shape, like a sickle. The sickle-shaped red blood cells lyse (disintegrate) easily, causing anemia. Red blood cells with hemoglobin S live only an average of about 20 days instead of the normal 120 days for red blood cells with normal hemoglobin A. The damaged sickled red blood cells also often clump together and get stuck to the walls of blood vessels, blocking the normal stream of blood flow. This can cause severe pain (vaso-occlusive crisis) and permanent damage to the brain, heart, lungs, kidneys, liver, bones, spleen or any other organs by deprivation of nutrients and oxygen supply. Long bones are commonly affected by this blockage, leading

to excruciating bone pains, from where the disease condition derived its Yoruba name tag: **"Aro'mô l'éegun"**.

Severe bone pain is an emergency condition referred to as acute vaso-occlusive crisis. There are a myriad of factors that could bring about vaso-occlusive crisis, but malaria and bacterial infections and dehydration are common triggers. Sickle cell disease is most common in Africans and African-Americans. It is also found in other ethnic and racial groups, including people from South and Central America, the Caribbean, Mediterranean countries, and India.

Based on documented history, sickle cell disease went unreported in African medical literature until sometime in the 1870s. This may be because the symptoms were similar to those of other tropical diseases in Africa and because blood was not usually examined then. In addition, children born with sickle cell disease usually died in infancy and were typically not seen by physicians. Most of the earliest published reports of the disease involved black patients living in the United States of America (USA).

African tribal populations were however all too familiar with the disease and created their own local names for it. It is interesting to note that all the local names carry repeating syllables - possibly to symbolize the repeating painful episodes. Such names include ahututuo (from the Twi tribe); chwecheechwe (from the Ga tribe); nuidudui (from the Ewe tribe); and nwiiwii (from the Fante tribe) and Aro'mo l'éegun (from the Yoruba tribe of Nigeria). Many of these local names were also imitations of the crises and moans of the sufferers or from such phrases as "body chewing" or "body biting"

which described the terrible torment of the sufferers. In some West African tribes, children who died soon after birth were called "ogbanjes" or "abikus" meaning children who die repeatedly following births; it is the belief of some African tribes that it is usually the same child that died that comes back to live in periods of repeated re-births. It has been suggested that out of many children with the phenomenon of "ogbanje" or "abiku", about forty percent of such children carried the sickle cell or homozygous hemoglobin S genes.

In the US in 1846, a paper entitled "Case of Absence of the Spleen" (from the Southern Journal of Medical Pharmacology), was probably the first scientific literature to describe sickle cell disease. It discussed the case of a runaway slave who had been executed. His body was autopsied and found to have "the strange phenomenon of a man having lived without a spleen." Although the slave's condition was typical, the doctor had no way of knowing this as the disease had not yet been "discovered." The first formal report of sickle cell disease came out of Chicago about 50 years later, in 1910. In 1922, after three more cases were reported, the disease was named "sickle cell anemia."

In 1904, Dr. James Herrick reported "peculiar elongated and sickle shaped" red blood cells in "an intelligent negro of 20." These sickled cells were discovered by a hospital intern, Dr. Ernest Irons, who examined the patient's blood and sketched the strange cells. The patient had come to Dr. Herrick with complaints of shortness of breath, heart palpitations, abdominal pain, and aches and pains in his muscles. He also felt tired all the time, had headaches, experienced

attacks of dizziness, and had ulcers on his legs. After noting these symptoms, the doctor took samples of his blood. This 'first' sickle cell patient had come to Chicago in 1904 to study dentistry in one of the best schools of the country and was likely the only black student there. He was a wealthy man from the West Indies; and, despite repeated hospitalizations for his illness, Walter Clement Noel completed his training, along with his classmates, three years later. He returned to Grenada and practiced dentistry until he died of pneumonia at the age of 32 years. Although the disease does not distinguish between the rich and the poor, it does single out those from the tropical and subtropical climates of the World.

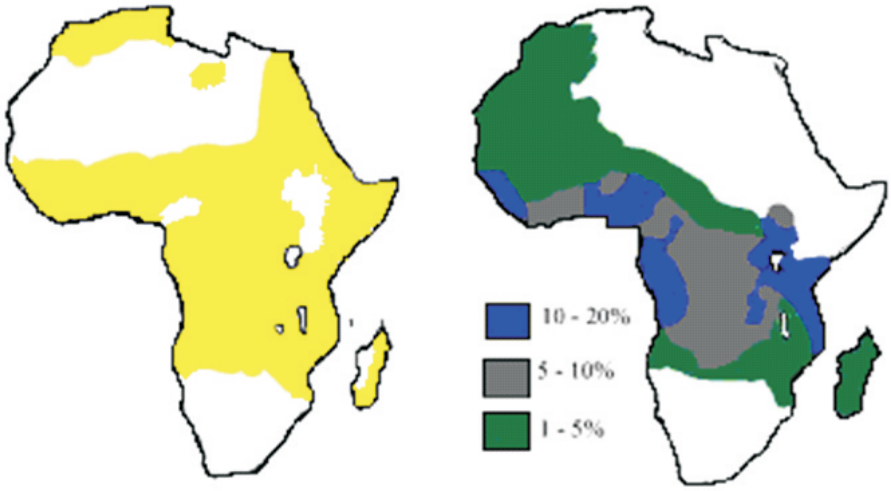
One long-held theory as to why it was so common in the tropics was its association with malaria. In the 1940s, E.A.Beet, a British medical officer stationed in Northern Rhodesia (now Zimbabwe), observed that blood from malaria patients who had sickle cell trait had fewer malarial parasites than blood from patients without the trait. Following this observation, a physician in Zaire reported that there were fewer cases of severe malaria among people with sickle cell trait than among those without it.

In 1954, Anthony Allison, continued to build on these observations and hypothesized that sickle cell trait offered protection against malaria. He suggested that those with the trait did not succumb to malaria as often as those without it; but, when they did, their disease was less severe. It is now known that, when invaded by the malarial parasite, normally stable red cells of someone with the sickle cell trait can sickle in a low oxygen environment (like in the veins). The

sickling process destroys the invading organism and prevents it from spreading through the body. This apparent ability of a genetic condition to protect carriers is particularly important in infants. Thus, in regions repeatedly devastated by malaria, people who carry the sickle cell trait will have a greater chance for survival than other individuals.

In the following years, evidence began to collect in support of this theory as well as some against it. When studies were restricted to young people, the hypothesis held -- the sickle cell trait did offer protection to children but not to adults since they were unable to develop antibodies to the malarial parasite. However, even though their immunity was partial, it did help them to survive but offered little additional advantage. Since the youngsters were not able to produce antibodies to the malarial parasite until their immune systems matured, it was the pre-immune malarial patients whose survival was protected by sickle cell trait. For them as well, although protection was only partial, they did survive longer. Since then, several studies of malarial epidemics have revealed a higher survival rate for sickle cell trait individuals than for those who lack the gene HbS. So, a mixture of normal hemoglobin A and sickle cell hemoglobin S has some protective effect on individual susceptibility to malaria, especially during the childhood period under the age of five years.

Malaria Zones and Distribution of Sickle Cell Disease and Traits in Africa



An English neurologist, Lord Brain, once suggested that although a double dose of the sickle cell gene (Haemoglobin SS) could be fatal, a single gene might increase a person's resistance to a disease. As more research was done, it was discovered that he was right, especially when it came to malaria. However, only those with sickle cell trait, not the disease, are protected against malaria. Those with sickle cell disease would either die from the blood disorder or die after coming into contact with malaria because of their weakened immune systems. But if someone with sickle cell trait contracts

malaria, the person's body is somehow shielded from this potentially fatal disease.

Scientists have found that the red blood cells of people with sickle cell disease trait break down quickly when the malaria parasite attacks them. Since the parasite must grow inside red blood cells, the disease does not have a chance to become firmly established. However, not everyone with sickle cell trait is protected either. Apparent resistance to the disease occurs only in children under the age of five years.

Studies have shown that African Americans, who have lived in malaria-free areas for as long as ten generations, have lower sickle cell gene frequencies than indigenous people of African descent. Similarly, the sickle cell gene is less common among blacks in Curacao, a malaria-free island in the Caribbean, than in Surinam, a neighboring country where malaria is rampant -- even though the ancestors of both populations came from the same region of Africa.
According to what I was told, I would always cry relentlessly as a result of the bone pains as a child, which continued and were recurrent. Throughout my preschool childhood period, I would always have joint pains which would make my joints to be swollen. These swollen joints will also make my joints to be inflexible. The times the pain occurred were trying periods. As a child under the age of five years, I was not quite cognizant of what was happening to me

and I had good moments of playing and interacting with other children. When it was time for me to be enrolled in school, my parents were quite protective of me, and they didn't want me to do anything on my own. They rarely permitted me taking initiatives. They found it difficult leaving me to use my own intuition. So, this made me to be dependent on people before I got enrolled into the elementary school.

Chapter 3
Elementary School Experience

I was enrolled into the elementary school at the age of six. The school in which I was enrolled, Ibadan Municipal Government (IMG) Primary School required that I walk a distance of about two kilometers to get to the school and there was a major busy tarred road to cross before getting to the school at Orita-Aperin in Ibadan. I had to make this trip to and from school daily. I had an older neighbor, who was attending the same school and always helped me to cross the road. I was new and fresh in school in the first year. On this particular day, my neighbor and I missed each other and I was forced to make the trip alone. Immediately I made an attempt to cross the road on my own, I was knocked down by an oncoming vehicle at Orita-Aperin . Like I mentioned earlier, I was never brought up to take initiatives and be independent up to that time. I had never attempted to cross a road, let alone a busy road like that prior to that event. I sustained fracture and some bruises on my legs. They took me home and immediately, I was taken to the hospital. That event led to changing my school in the second year, when I was to get into second year at the elementary school.

I was relocated to a nearby school, where I wouldn't be required to cross any road, very close to our rented apartment at Adesola, Orita Aperin in Ibadan. I would just easily move from my house and get to the school and the stressful walking of about two kilometer distance was also taken care of by the school relocation. I began to take initiatives on my own gradually when I was transferred to Omoyeni Memorial Primary School, Adesola, Orita-Aperin, Ibadan. Omoyeni Memorial Primary School, though a relatively new elementary school, stood out among the other elementary schools in that particular vicinity of Ibadan, not necessarily because of exemplary academic records, but because of the unique school uniform color, which was a light blue that gave an impression of sky blue serenity. When you see pupils' heads all over adorned in light blue colored uniforms, it exuded a form of serenity that most other elementary schools did not portray. This made Omoyeni Memorial Primary School unique. Other elementary schools pupils in the vicinity were adorned in brown khaki uniforms, a legacy probably left by the colonial Britons and you may not be able to differentiate pupils of one school from another at a glance, except with their school uniform badges, often sewn to the breast pocket of pupils' uniforms.

Young Muideen in Ibadan in 1978

I went through my primary education with repeated episodes of crises now and then, which most times punctuated my availability in school and had some negative effects on my studies, but not severe

enough to stop me totally from schooling as was the case with some other children with sickle cell disease that I knew then. Along the line, it was observed that my abdomen was gradually getting bigger. I was quite lean, and coupled with the repeated episode of sickle cell disease crises which made me appear stunted compare to every other child of the same age and gave me a kwashiorkor-like appearance. My classmates noticed that something was strange about me, but they couldn't really understand. My abdomen was getting gradually bigger due to my spleen over working because of repeated infections and other sickle cell crises. And therefore, because of my big abdomen, I was labeled and my classmates called me all sorts of names, teasing me and passing derogatory comments every now and then. They gave me a particular nickname that stuck. A derogatory nickname! They called me *'Ominikun*', which means, 'water-filled abdomen', to my peers in their limited understanding, my protuberant abdomen was filled with water. Having gone through medical school, I later came to understand that the spleen becomes very big at that age for a child with sickle cell disease. The liver too can also become very big. These are responsible for the protruded abdomen in a sickle cell child of that age. However, the people around me were ignorant of this, so I was given a derogatory nickname of *'Ominikun'* which sounded aversive and gave me a lot of inferiority complex with accompanying negative self-esteem as I was growing up. Each time they called me this aversive name, I felt very low in my mood because

other children didn't have the characteristic physique I had or that kind of protuberant abdomen. Because of the nature of my health and my parents coming to school to explain the nature of my health to the Head Teacher, my teachers would always exempt me from strenuous activities such as cutting grasses and playing football with other kids. My playing was limited and oftentimes, it made me feel segregated and with fewer friends, further nose diving my self-esteem.

My parents could be described as poor by every standard. However, we were able to acquire a refrigerator in a hot sub-Saharan African environment which brought a lot of excitement to me and my younger siblings. We had never before drunk cold water from refrigerator, let alone the ice-packs from the freezer compartment of the refrigerator that got me frenzied. I cultivated the habit of chewing these ice-packs repeatedly and hiding the practice from everyone. I developed a chest infection that made it very difficult for me to breathe. It could have been a combination of low immunity and repeated chewing of ice-packs that precipitated the lung infection. This I cannot certainly explain. The severe lung infection which was complicated with massive pleural effusion, when I was in the third year in elementary school, landed me in the in-patient children ward at the University College Hospital (UCH), Ibadan, where there was need to drain out the pleural effusion. I was operated upon and I had a posterior chest tube inserted which drained into a vacuum bottle by my bed side. I was pumped with analgesics and a lot of antibiotics because of the severe chest pain and infection. The scar left by the posterior chest

tube insertion was so big that it remained with me till date. I spent about two months in the hospital as an in-patient. This is one of the periods I would ever remember. Both my father and mother were by my side. Everyone was supportive but it cost me some school period, during which I couldn't attend to my studies..

I carried the wound of the plural effusion for some time. It was up to about three months before it eventually healed. Each time I coughed after my release from the hospital, the dressing of the wound, which was changed every alternate day, used to get soaked with fluid coming out of my pleural cavity. The wound remained for a long time and it was like someone who had gone to war with a gunshot wound scar to show for it. Living with sickle cell disease is like fighting a war, a war you fight physically and a war you fight in the arena of your mind. The battle is both physical and psychological. You would always have a story to tell!

In spite of the long period I spent as in-patient in the hospital and at home recuperating, I was able to cope with my academics without repeating a class. I often performed extraordinarily well, among my classmates. Once I resumed school and picked up the notes of the teachings they had received and copied it, I often spent most of my time studying, because I did not have so many friends to play with. Occasionally, I played football at home with other children in my neighborhood, but each time I played football, I would always be down with vaso-occlusive, long bone pain crisis, so I channeled all my energy into studying and reading my books. From my third year in elementary school at Omoyeni Memorial Primary School onward, after being discharged from the hospital , it became a regular event

for me to visit University College Hospital (UCH), Ibadan, Nigeria. By this time, I had already been registered at the hematology clinic of UCH. So, it became a regular practice for me to visit the University College Hospital, Ibadan either for regular follow-up appointments or for the fact that I was down again with one form of crisis or the other.

University College Hospital (UCH), Ibadan
First University Teaching Hospital in Nigeria

There, I started seeing these young student doctors who were not as elderly as the doctors that were attending to me. They were always in sparkling white coats, with stethoscopes hanging around their necks. I loved them and was fascinated by them because they looked smart and dignified. They were predominantly males, with only few females among them, a reflection of gender differences in medical school enrolments in Nigeria in the 1970s and 1980s. At any rate, there were few female qualified doctors too in those days unlike what we see these days, a reflection that gender inequality gaps in Africa are being closed, even though at a slower pace. I was greatly fascinated by these young people in white coats, so much so that I wanted to be like them. A seed was planted and a dream had started welling up in me. I wanted to be like them, not only because they looked smart and dignified, but also because I got an impression that if I became like them, I would understand better the nature of sickle cell disease condition that had subjected me to repeated suffering and at the same time had necessitated my repeated hospital visits.

So, on a particular day, I asked my doctor how these young people became student doctors, which was the name my doctor told me they were called. My doctor told me I should let them see me and examine me because they were medical students and would become the next set of doctors in the years to come. So, I told my doctor that someday, I would like to become like one of these medical students, with the intention of being a medical doctor also in the years to come. The

image got engraved in my mind and there was no looking back. Throughout my primary school days, I had a formation in my mind, I had a goal in my mind: to look like those student doctors. Later on, it was explained to me that to be a medical student, I had to be a good science student. So, I took my subject of Integrated Science very seriously, including Mathematics, which are the major subjects they indicated to me that I needed to master if I must follow this dream of becoming a future medical student and a future medical doctor. I continued with my mind focused on it. Whatever a mind conceives, it can achieve is an old saying I had learnt and held tenaciously.

I had repeated episodes of crises from my third to the sixth year in the elementary school. In that space of three years and on about three occasions, I had to go through blood transfusion due to severe anemia. The usual experience was that I would always easily get weak and tired, when I walked a short distance, I usually became breathless and my palms and lips were often becoming paper white. I would lose interest in what I enjoyed doing, which was my study. My attention and concentration were often greatly impaired. These are classical signs and symptoms of severe anaemia. By default, I was very frail and weak, but I would become weaker and frailer at these periods. The processes of blood transfusion were often like rejuvenation, it often restored the lost strength and put back at optimum my attention and concentration, restoring my interest in my academics and studies, which I had grown to enjoy so much.

Myself (Arrowed), My Classmates and My Teachers at the Elementary School in My Fifth Year at Omoyeni Memorial Primary School, Oniyere, Aperin, Ibadan, Oyo State, Nigeria

By the time I was in primary five, avascular necrosis of femoral head was setting in my left femur. I started walking gradually with a limp. And the limp wouldn't leave. I experienced chronic pains in my left hip, but I persevered with it. I kept on with it. With time, there was a restriction in the movement of my left hip joint. I could only move it in one direction because, as I was told, the blood supply to the left hip had been compromised and the head of the left femur had suffered necrosis. Meanwhile, the chronic pains I was experiencing didn't deter me. There were repeated periods of taking

non-steroidal anti-inflammatory drugs like piroxicam among others. Like the Biblical Jacob, who fought all night with an unknown man and was left with a limp that would not leave and he refused to be deterred until he was blessed, I fought with sickle cell disease and I was left with a limp that would not leave and like Biblical Joseph, I remained focused on my dream. Since I could not engage in physically demanding play or activities like every other child of my age, I focused on my academics, diverting all my energy into my academics and studies. And the dream of hanging around my neck a stethoscope like the medical students I kept seeing on my visits to University College Hospital, Ibadan remained engraved in my mind. This dream became for me, a reason to hang on and continue living.

The stigmatizing names, including *"Ominikun"* that I was called stayed throughout my primary school days. Stigmatization is one of the cardinal things to fight when it comes to sickle cell disease and other chronic illnesses among African children. The world view of Africans had long been manipulated and taught to embrace stigmatization. This trend could be found in most Nigerian and African societies. It is the popular belief of most African people that a child with sickle cell disease cannot survive and are destined to die. They are tagged with traditional African concepts, such as *"Abiku"*, *"Ogbanje"*, among others, many of these words meaning children from the spirit world, who would soon return back to the spirit world after they are born, according to the various traditional myths of origin.

Chapter 4
High School Experience

I looked so much younger than my age, smallish and frail. Because of my small and frail physique, I was exposed to bullying, which I experienced on some occasions in my primary and secondary school days, because my peers, who appeared more matured and bigger than me in physique, knew that I was frail and weak. They would challenge me to unnecessary physical fights; do things to provoke me to get angry with the intent of wanting me to get engage in physical fights. I stopped engaging in childhood wrestling, of which I used to be very good before my secondary school days. This was after I developed avascular necrosis on the head of my left femur bone, which left me walking with a limp.

Eid-Kabir festival is a muslim festival that is usually celebrated world-wide. According to the Yorubas in South Western Nigeria, this festival is referred to as *Ileya festival*. '*Ileya*', literally means 'it is time to go home'. This period was usually a sort of mini extended family get together in South-Western Nigeria when I was growing up, during when everybody outside Ibadan and abroad would come home and congregate at the family house under the leadership of the

most senior male family member of the extended family (*Olori Ebi*). It was usually the period for the children of the extended family members to engage in ram fighting, a process where they set rams bought for the purpose of the festival against each other to fight and knocked their heads together. They would say 'a ram that did a backward movement did not retreat, but went back to re-energize'.

Ironically, it is not only the rams that fought, the siblings and cousins too usually did. Most of us got engaged in wrestling competitions. I was known to be notorious during the wrestling competitions and for my age group. I was usually the uncontested champion. I usually got invited to the level of children of higher age groups, where I was also known to have proven my prowess. Local African childhood wrestling had its own techniques and these I mastered quite well then. When I started walking with a limp, all that had to stop and I tried as much as possible to avoid childhood physical wrestling, which was then an exercise of fun and ego tripping for children in my generation.

It was a great experience for me that I passed my primary school leaving certificate examinations with flying colours, left primary school and proceeded to secondary or high school at Ibadan Christ Apostolic Grammar School (ICAGS), Aperin Oniyere, Ibadan. The school was a missionary school that had been ceded to the Oyo State Government in Nigeria, a school which had sustained the unique

doctrine and tenet of the Christ Apostolic Church (CAC), which established it in the year 1960. We would queue up in the morning assembly in our white shirts and brown shorts uniform and we would render Christian hymns from our hymn book. We would sing "*Onward Christian Soldiers marching as to war, with the cross of Jesus going on before. Christ, the royal master……"*. If our hymns did not give us away as students of the Christ Apostolic Church, the motto of the school boldly written in Yoruba language on our gates and on our uniform badges gave us away. "*L'o ruko Jesu*" (In the name of Jesus) - that was the motto. The school was an all-boys high school and Christian religious discipline was highly instilled in us. Although I had an Islamic background, I did not find it difficult to comply with the doctrine and tenets of conservative Christianity as espoused by the authorities of the school.

So, I got into the secondary school and my first year in secondary school was full of adjustments. There was no more a teacher, sitting with the pupils in classrooms monitoring their activities like it was usually done in Elementary schools. Every teacher came in to teach during their own subjects during their teaching periods. Every class did have a class teacher that would come in the morning to call out names of pupils from the attendance register, through which pupils register their presence in school for that day. I did have a male class teacher named Mr. Ojuawo. Mr. Ojuawo, apart from being my class teacher, also happened to be the teacher that taught us the subject of

Fine Art, a subject I quite enjoyed. My first year in secondary school was quite dramatic, in the sense that I had repeated episodes of crises that prevented me from fulfilling up to sixty percent attendance in school. I was absent from school for most periods during my first year in secondary school. Nevertheless, I was able to cope and I performed averagely, scoring about fifty percent in most of my subjects and out-rightly failing a few. This performance was in contrast to what obtained in my primary school years, when I was at my optimal level.

Mr. Ojuawo, obviously oblivious of the nature of my health state and exact circumstances that kept me away from school and noticing that my attendance in school during that year was abysmal, wrote in my report card at the end of the year: *"Muideen has a great room for improvement if he can desist from his acts of truancy, that is (Absenting himself unnecessarily)"*. Most teachers are not aware of common childhood physical and mental health conditions, and sickle cell disease is one of those conditions that the teachers in Nigeria and other African countries need to be educated about and get familiar with, so that they can relate with compassion and empathy with a child with sickle cell disease, helping to build his or her self-esteem which is often badly damaged. More education needs to be made available to teachers, so that they could understand what sickle cell disease is, and its effects on an average African child affected by it. The teacher in this case referred to act of truancy, which to him meant that I was absenting myself unnecessarily. The empathy would have been present if Mr. Ojuawo knew that it was not a case of deliberate absenteeism and that it was absenteeism imposed

on me by the disease condition I was suffering from.

By this time, the limping gait had become much more pronounced. And the chronic pains in my left hip joint persisted. By the way, avascular necrosis is one of the complications of sickle cell disease. It has to do with compromise of blood supply to the head of femur bone and in this particular case, to the left femur bone, which affected my left leg. Many of my classmates asked me strange questions on why I walked with a gait. Some asked whether I was involved in a car accident or whether I had polio infection when I was younger. This is a further reflection that many individuals in Africa, despite how common sickle cell disease is and the unique physique it imposes on average sufferer, do not easily recognize the disease condition. In the midst of these strange questions, suggesting that my limping may be attributable to involvement in a car accident and that I probably sustained fractured bones, I did not want anybody to know that I had sickle cell disease. I was always in a state of denial and I was afraid of the inherent stigma associated with sickle cell disease then. I had experienced what it meant to live with battered self-esteem resulting from being discriminated against and differentiated both by your fellow pupils and ignorant teachers alike. I lived in a never-ending state of denial. I always denied because it is a disease that was and is still highly stigmatized in the environment where I grew up and found myself.

Sometimes I would agree with them that the limp gait was as a result

of a car accident, even though I knew within me the response was a lie, just to avoid discussing the subject of sickle cell disease. Most times, I just wanted to be left alone, not to be bothered with questions about my limping gait when I walked. Aside suffering from the physical pains of sickle cell disease, I was also suffering from the psychological state of low self-esteem and damaging inferiority complex that had prevented me from developing good social competence like many of my peers. The only area of development that was probably left unaffected by sickle cell disease was my academic intellect, where I had diverted all my energy.

When you live for something and you have a purpose, you are more likely to have hope and survive in the midst of adversity. I had a goal, a goal that kept me going, a goal that kept propelling me, nudging me not to give up, even in the midst of adversity and low self-esteem that enveloped my existence. What kept me going was the ultimate dream I had of becoming a medical doctor one day, I dreamt about it nearly on a daily basis and saw myself through my inner eyes on many occasions, looking like those medical students at University College Hospital, Ibadan, wearing a stethoscope around my neck and adorning a sparkling white ward coat. I needed to understand the mechanism of the disease condition I was suffering from among other diseases. I wanted to get to the bottom of it. Though, till date I have not got to the bottom of it. Science and humanity have not got to the bottom of it! A whole lot of medical research is still required to unravel the mystery of sickle cell disease.

Amidst all the distractions, I remained focused on my goal. Many of

my classmates would admit that I stood out academically; it frequently amazed them that despite my state of ill-health that prevented me from attending most classes, I would, at the end of the day perform quite extraordinarily well above the majority. They queried repeatedly how often I was almost always top of the class in spite of my frequent absence from classes. I always held on to one or two of my classmates who had interest in me. I would get their lecture notes and copy them for those periods I was absent. I would study hard and after the examinations, I was often on top of my class.

I went through the experience of being exempted from strenuous physical activities that other children engaged in, such as cutting school grasses, undergoing severe punishment like kneeling down for a long period, and flogging with cane which is a common practice in most African elementary and high schools. This was because sometimes, my parents would come to inform my teachers of my condition. They would tell my teachers not to beat me or punish me severely, as crises may be precipitated by these actions. Honestly, I could not say for sure whether this exception was positive or negative as it made my fellow pupils to focus more on me, wondering the basis for my exception despite my obvious unhealthy physique. The stigmatization was further encouraged and because I often do my things in a very quiet and easy going manner, not engaging in anything involving excess physical strength, I was given another nickname. A nickname that made me uncomfortable whenever my

colleagues referred to me by the name. An uncomfortable, not necessarily stigmatizing nickname, which I got adjusted to overtime, because my colleagues would not let go, they referred to me as *'Jeje laye gba'*. This is a Yoruba phrase which literally means, *'slow and steady wins the race'*. This nickname was inferred from the fact that I walked slowly, did my things slowly and calmly and I was not involved in excessive physical activities or exertion. Therefore, I was given the name, and the name stuck until I left high school.

The high school period was punctuated with various episodes of sickle cell crises and I remembered one critical and severe episode in my penultimate year. I had been suffering from chronic infection that had been subtle over about six months and gradually my red blood cells were breaking down unnoticed, resulting in chronic anemia.. I kept experiencing easy fatiguability on walking some distance; I was able to notice this because I often trekked a distance of about one kilometer on going to school and coming back. More and more energy was required on weekly basis walking this usual distance. It got to a stage that I couldn't bear it again, I most time struggled to catch my breath and gradually covering a distance of about five metres became a herculean task. Once again, I was taken to the University College Hospital, Ibadan and I was again able to interact with medical students and for the first time, I got to know that there is a period of one year internship during which medical students who had completed their training underwent tutelage under supervision of Consultants in the practice of medicine. This time around I was attended to by some House Officers, as they were called. I got

friendly with them. Some of them were nice and showed empathy, while I noticed a few to be cocky and less friendly. On laboratory investigation, my packed cell volume (PCV) was found to be 8%, which was grossly low and possibly may not be able to sustain life, if the anaemia had been acute in onset. The normal packed cell volume (PCV) ranges from 35 to 45%.

Because of the low PCV and impaired oxygen carrying capacity of my blood, someone would need to hold my hand to be able to walk as I was constantly in a dizzy state. I landed at the hospital in an emergency state. I went through blood transfusion and the noise in my inner ears that had been persistent over a four months period gradually faded away. Tinnitus, or noise in the ears, is also one of the symptoms of anaemia, and this was usually very obvious and loud late in the night when the environment is dead silent and it often prevented me from having a good sleep prior to the intervention of blood transfusion. From being chronically lethargic I became active again and I noticed a significant improvement in my attention and concentration following the blood transfusion. This was not my first experience of blood transfusion. I had had a couple of blood transfusions following episodes of anemia in the past. However, this episode was slow in onset and was the most severe I had ever experienced.

I was discharged from the hospital and I came back to school to continue my studies. Many of my teachers grew to love me, I guess for two reasons: First, I was less troublesome and less stubborn compared to most of my colleagues in their perception. The 'slow and steady' nickname that my colleagues gave me manifested in everything I did. Second, they loved me because I was academically

sound and I was always one of those chosen to represent the school in various inter-school scientific debates. I had won prizes as the best student in physics, chemistry and mathematics on several occasions. However, my social competence had always been my Achilles heel. As earlier said, I was quite smallish in physique compared to my colleagues and my self-esteem was never at its best during this period. It is not uncommon for an average sickle cell child to look smallish or younger than his or her age. And many of my secondary school classmates would always tease me because of my appearance. However, the fact that I was smallish never eroded my strong will and resolve to achieve my life's ultimate goal of becoming a physician someday. I was strong willed, dedicated and focused, though with a damaged self-esteem. I focused on one thing at a time, to pursue meaning, and meaning to me at that time was to wear that white ward coat and handle the stethoscope, which is a symbol of respect in the society within which I grew up.

In as much as I received orthodox medical treatment during my frequent crises, it is imperative to mention that my parents, especially my mother made me experiment with local traditional treatments that were tailored to the beliefs of African psyche. The ultimate template is the belief that the disease condition originated from the spirit world and interventions or solutions could only be procured in the spirit world. Any disease condition that an African mind could not find an explanation for always originates from the spirit world and there would always be need to appease the ancestors or the gods.

On one occasion, I found myself and my parents in a sitting room of a

native medical practitioner. On one side of the wall were cowries that were used to 'decorate' a red cloth that was beautifully adorned on a carved statue of a woman, an image that was no taller than three feet in height. The native practitioner referred to this statue made of wood as *"awon iya mi*", meaning,'my mothers from the spirit world'. He pluralized this single sculpture as if it was symbolic of many women, belonging to the spirit world. Hanging loosely from the ceiling of the sitting room, that would probably be touching the head of a man of an average height was a leopard skin, which looked like it had been hanged for a very long time as it was looking stale and dusty. Scattered in the four corners of the room were other smaller symbolic images. "Sikiru", the native medicine man called out, and a boy that was about my age then, between twelve and fourteen years, appeared from the inner room. Sikiru was probably an apprentice and at the same time a child or a relative of the native medicine man. He sent Sikiru to go and buy two new razor blades, which Sikiru brought after a few minutes. The native medicine man made some concussion from the bark of a particular tree, and asked Sikiru to grind some pepper. He informed me that he was going to make me a small soup and that the two razor blades would be cooked with the soup. I was going to eat the soup, chew the two razor blades and eat everything completely. To my chagrin, the native medicine man brought out a

white handkerchief, tied each end of the handkerchief to a four legged stand and made fire under the handkerchief and he was using the handkerchief like a pot to cook the small soup, into which he put the two razor blades after using one of them to make incisions on my body. The handkerchief was not burned by the fire, and after few minutes, the soup got cooked and done and I ate it inside the handkerchief, including the two razor blades that tasted like fried dried potato chips in my mouth. After the incisions and eating the soup, the native medicine man promised me that I would never experience sickle cell disease crises again. Alas! This was not to be as I experienced another vaso-occlusive crisis in the space of three months after this ritual. There were quite a number of these experiences with native medical healers, or the people referred to as"*Baba Alawo*" or *"Onisegun"* among the Yorubas of Nigeria.

Another striking example was the native medical practitioner that banned me from eating chicken meat for the rest of my life. He requested my mother to buy a cock (a matured male chicken), which he rubbed all over my body while I was stark naked and at the same time was making some inaudible incantations while doing this. At the end of this process, he requested my mother to kill the cock, cook it with a stew and that I must be the only one to eat the whole cock meat until the stew finished. He then said thereafter, I should never in my life take a chicken meat again and that this would be the supposed

final solution to my sickle cell crises. His instructions were obeyed to the letter and I desisted from tasting chicken meat thereafter, no matter how tempting. However, within a space of four months after this particular ritual, I started experiencing crises again, suffering from excruciating bone pains, resulting from vaso-occlusive crises. I obeyed the restriction placed on me not to taste chicken meat for about two years, after which I could not find rational reason to keep the restriction as sickle cell disease crises refused to abate.

Funny and laughable experiences with syncretic churches and prayer houses also abound, as they prayed and gave me multiplicity of holy water and oil, all geared towards curing my sickle cell disease. None of these attempts had ever passed the test of time. The only remedy that has sustained me is my endurance, my resolve, my inner will and the hope I derived from a set goal.

The orthodox medical practice admitted its limitation by acknowledging the palliative nature of its treatment, rather than laying claim to ultimate cure, which is the short coming of many traditional healing practices of African origin, where empiricism and evidence based practice are lacking.

A copy of my Passport Photograph that was used to register for High School West Africa School Certificate (WASC) Examination

The final West African School Certificate (WASC) Examination came and I passed in flying colours, making all my papers that were requisite for studying the course, Medicine and Surgery at the University. I never needed a career counselor to guide me, I knew where I was going from the beginning. Even in the midst of my disappointment for two consecutive years, I had difficulty meeting up with the cut-off mark of Joint Admission and Matriculation Board (JAMB) Examination as it was popularly referred to in Nigeria then. Everyone knew that Medicine and Surgery was one of the courses

where you needed to score very high in JAMB to be able to gain University admission then. University of Ibadan was the premier University in Nigeria and attracted the best of brains all over the country. There was no gainsaying that the admission process was competitive. My parents insisted that I did not have a choice other than to study at the University of Ibadan, under their watch, as they could not afford my leaving their sight for University education in an environment beyond their quick reach, because of the peculiar nature of my health. I was stuck with competing at the highest level for admission space into Medicine and Surgery at the prestigious University of Ibadan, Nigeria. For two consecutive years, I missed the opportunity of being admitted into the University of Ibadan for Medicine and Surgery by whiskers. I would have four or five marks left to meet up with the cut-off mark, thereby losing the opportunity for two consecutive years after completing the High School education.

This repeated disappointment made me to sink into a state of depression at some point. It was a state of depression that was complicated by another episode of sickle cell crises. I felt a deep pain and sense of disappointment in my heart that one day, I contemplated suicide. I wanted to kill myself. I wanted to end it all. Depressive state could co-occur with sickle cell disease, just like every other chronic illnesses characterized by repeated suffering. Life was worthless to me, if I could not study Medicine and Surgery, a course of my dream that was often exclusively the preserve of the children of elites in the society, a class my parents could not lay claim to based

on their socio-economic status.

I was looking for a way out of my acute depressive state, a ray of hope and Christianity crept in, with the promise that Jesus Christ was the solution for everything. I followed the faith from then on and it did alleviate my inner suffering a great deal for some period and gave me a sense of hope. I was able to summon courage and attempted JAMB examination again and this time around, the third attempt, I got to the cut off mark and was admitted into the College of Medicine of the University of Ibadan, the first and premier University in Nigeria, West Africa.

University of Ibadan Nigerian First and Premier University

In any case, my JAMB Examination scores in the two previous years qualified me to study Medicine and Surgery in some other Universities in Nigeria, like the University of Ife, University of Lagos, University of Ilorin among others, but my parents' insistence not to leave the city of Ibadan, my place of birth and abode cost me two years of waiting. I had long been overprotected and the trend continued to the level of seeking admission for college education. My parents insisted that if I were going to gain admission into any higher institution, it had to be in Ibadan, under their watch, where they could easily monitor me and take care of me.

Chapter 5
College Education Experience

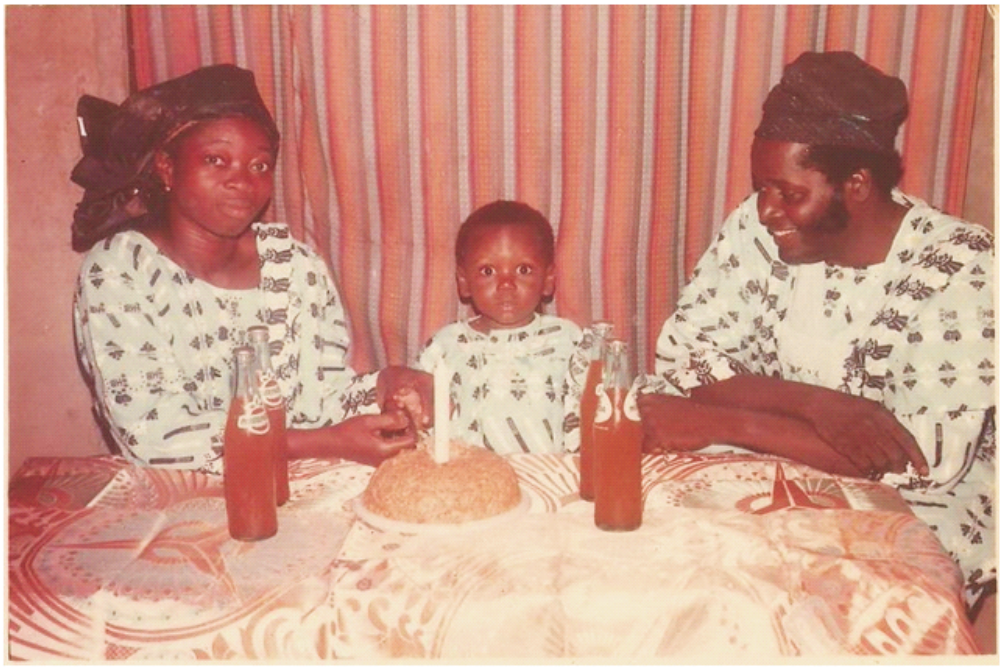
I had written the Joint Admission and Matriculation Examinations for the third time in the year 1991 to secure admission into the premier and prestigious University of Ibadan, since my parents did not want me in any other University aside University of Ibadan. Their reason was not because of the academic standard of the school, or its traditional name and status of being the first University in Nigeria. Their reason was solely so they could monitor me; look after me in their close presence because of the state of my health as an African child suffering from sickle cell disease. My woes were further compounded on the tenth day of October, in the year 1990 when my father died! He had been drowsy and unconscious continuously in the preceding forty eight hours from a possible bleed into the brain from cerebro-vascular accident, resulting from hypertension. Hypertension is one of the chronic non-communicable diseases commoner among the black race in sub-Saharan Africa. Unfortunately, little attention is paid to this deadly condition and a lot of sudden inexplicable death had resulted from it. The situation was not entirely different in the case of my father, Ayinde Oduola Bakare. He had rejected vehemently answering his Islamic name – Abdul Yekeen. This was because the name was interpreted to be the Angel of Death in Islamic parlance. So, Abdul Yekeen had been totally

omitted from his name till he died in the year 1990.

Only three months earlier, I had the premonition of his death. I dreamt about how the event would happen and how he was being buried. Since I subscribed to the Christian faith then, I found myself praying in the Christian way, speaking in tongues in my dream to avert the event that I saw vividly in my dream without any form of ambiguity. And when the death happened, the sequence of events followed the pattern of what appeared to me in the dream. Now that I do not subscribe to any faith, I believe in the enormous energy and power nature bestowed on the human race to have a glimpse of the past and a glimpse of the future as nature pleases.

Ayinde Oduola Bakare was an easy going man, reserved and avoided any form of trouble. He lived also with sickle cell disease. He had a milder form of sickle cell disease, with hemoglobin genotype SC. Sometimes, these groups of sickle cell patients do not frequently manifest the symptoms of sickle cell disease as those with homozygous sickle cell disease, with hemoglobin genotype SS, like myself.

My Father (Ayinde Oduola Bakare), My Mother (Durodola Apeke Bakare) and My Younger Sibling (Nurudeen Ayotunde Bakare) during his One Year Old Birthday Celebration in 1984



Ayinde Oduola Bakare died and his death at the point it happened could be likened to taking away the Shepherd, making the flock to scatter in different directions with loss of coordination. For a number of events followed that made me, my siblings and my mother never to be the same again from the moment of his death.

The blow was so devastating that my mother broke down with depression. The depression was severe, because it came with psychotic features. It was a case of complicated grief precipitating mental health problems. Again, because of ignorance and poor knowledge of mental health problems in the local community where I grew up, adequate and proper attention was not paid to her and the disease condition incapacitated her for a long time. [And there was no parent to care again. My parents insistence that I must have my University education under their supervision and care became less relevant at this stage. No parent to act as support and supervise everything with essential details again. I had been brought up as a laid-back child who often does not take initiatives on his own. I had little confidence as inferiority complex and low self-esteem had remained a companion of mine for a long time. This was a turning point in my life. I had to learn to adapt. As Charles Darwin put it; "*It is not* the strongest of the species that *survives*, nor the *most intelligent that survives*. It is the one that is most adaptable to change". I had to learn to step up.

Necessity, they say, is the mother of invention. When there are needs to attend to, and you find no one who could help, innovative thinking often provides a way out. You would never know how capable you can be until you are challenged. I was greatly challenged at this

critical point of my life that I had to stand up and learn how to cope alone. Being the first child and having younger ones, I had to stand up. I had to lead the way. Father had gone and mother's mind was uncoordinated. It was like a state of being lost in the jungle, without a sense of direction. Who was going to help in this critical state?

I stood up against the odds with the slightest help. I got admission into College of Medicine, University of Ibadan. The first year was the preliminary year in the medical school, where medical students are mixed with the general science students and we offered similar courses like Zoology, Chemistry and Physics and the essential courses selected from other departments, which in my case, I offered Culture and Civilization and Use of English. There was some initial help from my paternal uncle in the first year at the University, which soon dried up due to one reason or the other. In an African society, we are blessed by the presence of an extended family system that provides some sort of social support to the individual members of the family. That structure is waning and fast disappearing unfortunately. This was the fate I suffered; no one was there again after the first year of my father's death to provide support and succor.

By the second year, the reality dawned that life isn't a bed of roses. A glittering gold had to undergo the treatment of hot fire in the furnace. The reality dawned that the resources were not there to sustain a

patient like me with sickle cell disease in a medical school. Maintaining palliative stable health as a sickle cell patient is as costly as the cost of going through medical school when tuition fee and cost of books are to be accounted for. Globally, including sub-Saharan Africa, the cost of medical education is known to be expensive.

In this moment of distress and adversity, I stood up and summoned courage. I analyzed in my head possible sources of funding, putting into consideration my state of health. I did look for sources of funding. My father had died while in active service under the Ministry of Agriculture, Oyo State of Nigeria. Processing his gratuity and some other benefits were getting delayed because of the existing bureaucratic process of the civil service system in Nigeria.

I moved from one office to the other in search of help and I eventually approached the then Commissioner for Education in Oyo State of Nigeria, which is my State of origin. Getting to see the Commissioner for Education was like the proverbial camel passing through the eye of a needle, because I made several attempts before I could get to see the woman.

I explained my predicament to her when I eventually got to see her: the state of my health as a sickle cell patient in medical school and the threatening lack of financial resources to sustain me and my study and the fact that my father was in active service of Oyo State Government prior to his death.

She was able to eventually help by referring me to my Local

Government Area (LGA), Akinyele Local Government Area in Oyo State. Akinyele LGA was able to offer me some amount of money in form of scholarship that was able to sustain me for another period of three years in medical school. I had some alleviation regarding financial obligations for the first three years.

My second, third and fourth year in medical school were quite eventful: eventful of sickle cell disease crises, of excruciating pains and despair. There was however, an inner voice that kept nudging me to keep going, to keep the faith as my eyes were focused on a destination and a goal of graduating as a medical practitioner from the first and prestigious University of Ibadan in Nigeria. .

I could remember in my second year at the Kuti Hall, University of Ibadan, a nearly unbearable event that occurred. Kuti Hall had been referred to over the years as the Hall of Great Men. Possibly, it was not a coincidence that I was posted to this great Hall of Residence; I knew I was destined to be great like men who had passed through the Hall of Residence in the past. On this particular night, I was having a serious vaso-occlusive crisis and excruciating pain that pervaded most parts of my body and was beyond description as I wriggled on the bed in agony. My roommates were on ground and they rushed me to the University clinic, popularly referred to as Jaja Clinic at the University of Ibadan campus. I was admitted and treatment was commenced to alleviate the pains that had been giving me discomfort throughout the night.

Myself in front of Kuti Hall of Residence at the University of Ibadan in 1992

The doctor that took over duty in the morning from the doctor that had admitted me over the previous night while conducting his Ward Round, made a discouraging statement that hurt me to the marrow, probably more painful than the excruciating pain I had been afflicted

with all through the night. "You are a sickler" (colloquial language for sickle cell disease patients, which sometimes give the wrong connotation to the laymen that the attribute of any sickle cell disease patient is to be falling sick frequently), he said. "What are you doing studying Medicine and Surgery in the University? You, that would soon die. Don't you know medicine is more serious and rigorous? And as a sickle cell disease patient, you may not be able to cope", he further added.

Right beside my bed on hospital admission was another sickle cell disease patient, who happened to be from Faculty of Education in the same University. He corroborated the doctor's assertion that I should not have ventured into studying Medicine and Surgery to become a medical practitioner. He added that he didn't see any reason why I came to study Medicine and Surgery when I could possibly study education that was quite less stressful compared to Medicine and Surgery and simply become a teacher. However, I was resolute and I did not let the discouraging statements weigh me down. I told both of them that that was what I desired to study and it was medicine or nothing else. The look on their faces suggested that they thought I was embarking on an impossible mission. They had serious doubt about me being able to follow my dream to logical end. They doubted my ability to cope, but I had an inner resolve that both of them could not see.

Some days after, still on inpatient admission at Jaja Clinic, I saw

another doctor, a lady who was quite inspirational, and who gave me words of encouragement. She said to me: 'You have your life to live. The fact that you are a sickle cell patient doesn't mean you will die early'. "People die every day and the various causes of death are not limited to sickle cell disease, she said. "People die by accidents. They die by some other diseases" she added. She made me to have another perspective that being a sickle cell patient is not a death sentence, as it is frequently depicted in the society where I grew up. She said I should pay attention to my health and the symptoms I'm having and report to the hospital on time. I could remember her name because her words were encouraging and left a lasting impression on my mind. But I couldn't remember the name of the other doctor that spoke discouraging words to me. Dr. Kazeem was nice and caring. She remained in my memory for a very long time, even till date because she gave me the inspiration I needed at that point in time. I kept going, I kept moving on, one sickle cell disease crisis after the other. I paid more attention to my health from the time of my encounter with Dr. Kazeem at Jaja clinic. Along the line, her words kept coming back to me.

That would be my second encounter with Dr. Kazeem. My first encounter with her was during the general mandatory medical screening that the fresh students were made to undergo upon admission into the University of Ibadan. Among the laboratory tests

we were requested to do was 'sickling test', a test usually done to diagnose sickle cell disease and sickle cell traits, when the elaborate, more detail hemoglobin electrophoresis is not being considered. I could remember the sickling test I did came back negative, indicating that on a blood film under the microscope, no sickle red blood cell was seen. After submitting the results of my laboratory investigations to Dr, Kazeem, of which the sickling test result was inclusive, Dr. Kazeem took a good look at me and asked me, "do you suffer from sickle cell disease?". And I remembered responding 'yes'. The features and stigmata of sickle cell disease were written all over me and my physique appearance gave the diagnosis away, that a good and well trained African clinician would be able to make a spot diagnosis of sickle cell disease by merely observing me. Dr. Kazeem promptly sent me back to the hospital laboratory to do hemoglobin electrophoresis, of which the result came back, confirming homozygous sickle cell disease with hemoglobin genotype SS.

I had noticed a pattern to my sickle cell crises, especially those that were severe. The crises always coincide with the period of my examinations in the University, probably because of the stress involved in preparing for medical school examinations. I studied and observed myself keenly. I started taking malaria prophylaxis and

antibiotics, especially towards my examination periods. The prophylactic use of antimalarials and antibiotics was able to sustain me throughout my preclinical years in medical school, preventing major crises from being precipitated during the periods of my examinations.

As already stated, my life style was reclusive. I rarely had friends. Some people were nice by nature, while some other people were awful. Some awful people took advantage of my frail and helpless state by bullying me. I could remember the night I was in my room alone as a fresh student, my roommates had been away for one reason or the other. These hefty, suspected cult boys came in and demanded money from me, not knowing that I didn't even have money and that it was with a lot of effort I was in the school sustaining myself. I remembered they strangulated me and almost took breath out of me, I merely survived by a whisker. Subsequently, I reported the case to the appropriate school authorities and these boys ran away from Kuti Hall, where activities of University cult members were rarely tolerated. The Kuti Hall at the University of Ibadan is known as the hall of gentle and great men and that is an attribute the hall of residence has preserved over the years. It is a common observation

that an average sickle cell patient could be frail, and because of their frailty, some children and young adults that lack discretion and human empathy among their peers do take advantage of them and bully them. So, it is not uncommon for an average child with sickle cell disease, who is younger than his age in look, to have had experience of bullying as I did.

I could remember the day I was walking with a limp gait to attend the daily early morning lecture. It had been a regular practice for me to walk alone from my hostel to the lecture theatre; this was because nobody would agree to walk alongside me because I was quite slow in walking due to my limping gait. A complication of sickle cell disease that is irreversible unless the patient goes through hip replacement surgery, a procedure that is laden with many complications in sub-Saharan Africa and around the period I was growing up. On this particular morning, Sunmolu Soyinka walked by my side, took care of my bag, and he said we would walk down to the lecture theatre together. That was such a kind gesture I had never experienced for a long time and this occasion was my first encounter with Sunmolu Soyinka, whom I later understood was my classmate in medical school. We eventually graduated together with Bachelor of Medicine and Bachelor of Surgery (MBBS) of the University of

Ibadan. He said he was going to attend the same lecture I was going to attend. It was a moment I will keep remembering. When you had experienced rejection as an individual from stigmatization again and again, an effort of kind gesture as offered by Sunmolu on that particular occasion can leave a lasting impression, which it did. That was why I said some people were good, some people were helpful, but some people were awful. Life is a mixture of the good, the bad and the ugly.

The political protest that followed the presidential elections of June 12th, in the year 1993, due to the annulment of the acclaimed best free and fair election we have ever had in Nigeria, that was said to have been won by Chief M.K.O. Abiola and annulled by the regime of General Ibrahim Badamosi Babangida, cut short our preparation for the first major examination at the University of Ibadan, an examination that was supposed to be the step from moving from pre-clinical medicine to the clinical training section of the course Medicine and Surgery. June 12th, 1993 was a landmark in political history of Nigeria. It was not until the interim Government was installed and General Ibrahim Babangida that came into governance through military coup had stepped aside that the situation became relatively normal and educational and occupational activities were resumed throughout the country. After then, we were able to eventually take the examination. I passed the examinations, which

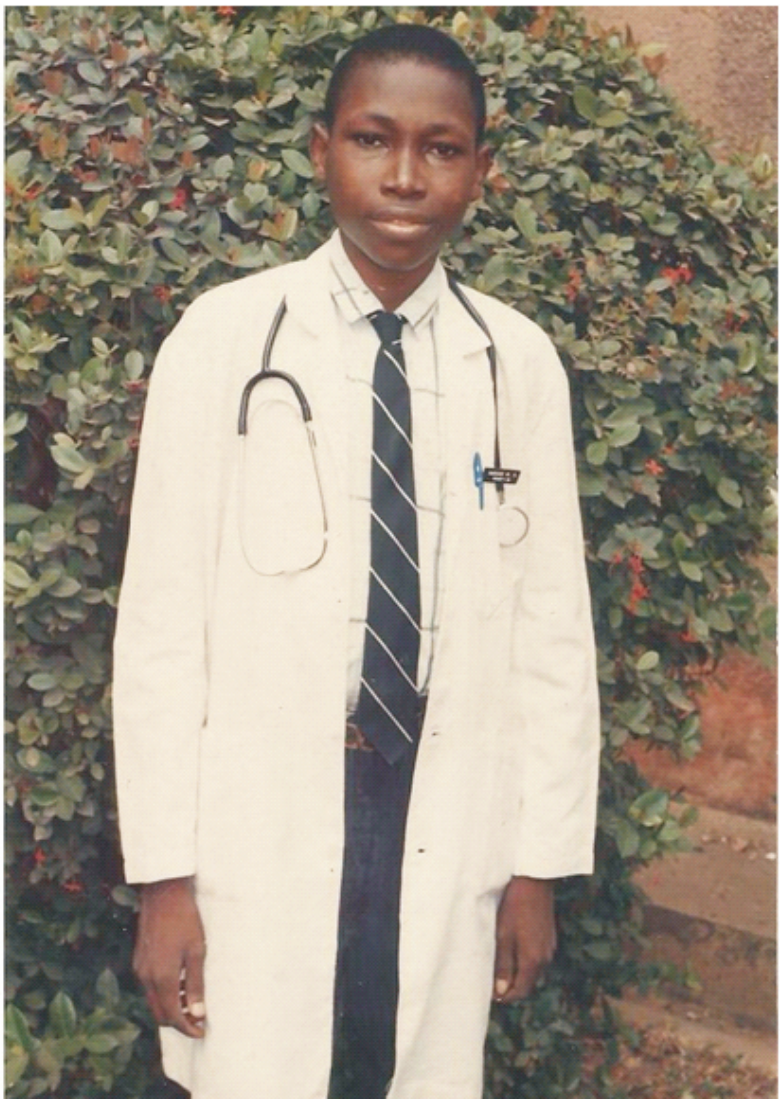
consisted of Anatomy, Physiology and Biochemistry and I moved ahead to the clinical training section at the University College Hospital (UCH), Ibadan in 1995. Our set of clinical students in UCH was popularly referred to as 1995 set.

We were accommodated at the renowned Alexander Brown Hall, which has always served as hall of residence for Clinical Medicine Students over the years at University College Hospital, Ibadan till date. I also wore for the first time as a clinical student, the sparkling white coat and I had a stethoscope hanging around my neck like I had dreamt and conceived. It was a dream come true, I could now claim to be a clinical medical student, the likes of those I had been seeing when I visited the University College Hospital as a patient and a child during my elementary and high school days.

Alexander Brown Hall, University College Hospital (UCH), Ibadan, Nigeria

The joy of achieving a goal soaked me like a waterfall and I was overwhelmed. But the question still remains, how do I push through? How do I complete this course? Yes, I have become a clinical student, and wearing the white ward coat, with a stethoscope around my neck, and can now also be referred to as a student doctor, but the question is, how do I get enough finances to sustain this highly expensive course of Medicine and Surgery? How do I get the financial resources to sustain my health? For the past three years prior to this period, I lived practically in school without support from any parent or relatives.

Myself as a Fresh Clinical Student at Alexander Brown Hall, UCH, Ibadan, Nigeria in 1995



Because the mental illness was poorly understood, my mother was taken to her family house. She was just kept in a room there. And once in a while, when she snapped out of her depression, she would attend school and teach. When she sank back into her depression, she kept to herself and lived in isolation in a room in her family house. She was not receiving any form of orthodox intervention. During that period, I was busy with my studies too and unable to go and see her as frequently in her family house. No financial resource was coming from home. I just had to sustain myself and keep my dream alive. There were issues of stigma everywhere. For my own sickle cell disease and for her own mental health problem, there was enormous level of stigma and segregation for the family to contend with, especially in a society where any disease condition of which cause is not understood is given a spiritual explanation or connotation.

My siblings were out there too, trying to cater for themselves. It was a very difficult period for the family. The death of my father was an awful experience for all of us. My own was worse because of the added burden of sickle cell disease. So I sat and thought through how to get further financial opportunity and support to sustain the clinical period of the training, so that I could become a fully licensed medical practitioner to practice in Nigeria. To understand the disease process of what had been happening to me as a sickle cell disease patient had

remained my ultimate goal. That had remained my dream, which I was not prepared to compromise. So, I kept moving on, hoping that by some grace, doors would be opened and opportunity would come, and that I would have grace to recognize the opportunity when it did come. I still remained reclusive in life style. I didn't have many friends and I didn't follow the crowd. I did my things my way. I have always done my things my way. In the University, there were many social gatherings, many social organizations, I was not known to join and participate actively in any of these social organizations in medical school. I was a lone ranger. I rarely did academic discussions with people, which was a common practice among the students. I was always on my own. Sometimes, I would feel like socializing, but the repressive self-esteem in me acquired over many years of stigmatization kept me at bay. The sickle cell disease held me down so much that I became reserved. Maybe it was more of self-perceived stigma, but I was unable to dismiss the many occasions of discrimination I had experienced over the years. However, on rare occasions, when opportunity presented itself, I could exhibit some social attributes. I am a good dancer and I had won prizes in local dancing competitions. I could be jovial on few occasions, if the environment and circumstances permitted. However, the restriction placed on me by the disease condition and the kind of environment I

found myself, and lack of adequate financial resources, made me to go through that period with subliminal depression. I was never overtly depressed because there was a resolve in me and I had a purpose, a sense of direction. There was hope and resilience pushing and nudging me ahead.

I used to enjoy and loved writing, my writings were mostly philosophical and thought provoking in nature. That was one of the talents the nature bestowed on me that I believe is probably presently repressed. There was an essay competition that was advertised then, and I put in for it. The essay competition was organized by Reporters' Collective, a group of journalists in the United Kingdom back then in 1996. The essay competition focused on freedom of reproduction and reproductive health of women in Sub-Saharan Africa. I won the second prize for the essay competition and the financial reward was in foreign currency. I think it was about a hundred United States Dollars then. That was a lot of money for a poor medical student like me in those days. I was able to exchange it for Nigerian Naira and it sustained me for some time during my clinical training in my medical school.

Myself receiving a Winning Prize for another Essay Competition Organized in the College of Medicine, University of Ibadan, Nigeria

At this point, I would mention Professor Wuraola Shokunbi: a great woman, a teacher, and a mentor, who has tremendously impacted on my life. As a medical student, when the pathology and pharmacology examinations came, I was in a crisis. It was a serious one. I broke down because of the examination preparation stress. I was on admission as an in-patient at University College Hospital, Ibadan for more than two months. I was preparing for the

examination on the hospital ward. I developed a leg ulcer around my right ankle. The examination came and met me on in-patient admission. I had to go write the theory papers and practical examinations using a wheel chair. I would be wheeled from the in-patient ward to the examination centers and back again at the end of the day.

Professor Wuraola Shokunbi happened to be the Consultant Haematologist attending to me then. She is a Consultant Haematologist of repute. Co-incidentally, she was the Chief Examiner for that year's Pathology and Pharmacology Examinations. I forced myself to write the examination, which I failed as my sudden acute illness prevented me from having a thorough preparation. I failed the two papers, both Pathology and Pharmacology, but I was able to put myself together and did a re-sit examination after a period of three months. For this period, I took precautions regarding my health state. This time around, I passed the two courses of Pathology and Pharmacology. I had left the hospital ward as an in-patient and was coming to the class and teaching sessions from the hostel, the Alexander Brown Hall at the University College Hospital, Ibadan. Alexander Brown Hall had remained over the years the hall of residence for clinical medical students that had passed through training at the University College Hospital, the first teaching hospital in Nigeria and the teaching hospital to the first and premier University in Nigeria, the University of Ibadan. However,

my leg ulcer had refused to heal and I was unable to wear shoes like every other medical student again. So, I improvised and resulted to wearing a pair of sandals.

Myself (first on the left) in the company of other Medical Students with one of our Teachers, Professor Adesola Ogunniyi

However, when things became a bit tougher, in terms of finances, I had to open up to my Physician and Teacher, Professor Wuraola Shokunbi and I told her about the problems I was facing. That I had been the only one sponsoring myself in medical school, and how lack of finances had been a hindrance, regarding my education and health. She advised me to join the sickle cell club that was established at the University College Hospital, Ibadan then. I joined the club and met quite a great number of people that we rubbed minds together.

I had to, along the line; apply to the sickle cell club for some financial assistance towards my health and education. I could remember they lent me some money for a period of time, which was helpful in sustaining me. I paid the money back when I started my internship or house-manship at University College Hospital, Ibadan, upon completion of my medical education. Let me state that help also came from unexpected sources, from the source I never knew. From an individual that wouldn't want to be mentioned. I got some financial support towards my education, by sharing my problems with Professor Shokunbi. That financial support was able to help me so much to be able to complete my education in medical school.

Myself and Professor Wuraola Shokunbi during our Cocktail Valedictory Party upon completion of Medical School Training

Chapter 6
On Becoming a Physician

The day our final result in medical school was released by the Court of Examiners and was pasted on the notice board at the College of Medicine, University of Ibadan, I went to check my result and saw my matriculation number on the list of students that had satisfied the examiners, I was full of joy. That is the language of examination results in medical school; *"The following under listed candidates have satisfied the Examiners"*. Medicine and Surgery training is an apprenticeship worldwide and the orthodox medical training has always portrayed this as a serious business, which must be done with good clinical and ethical standard. This is reflected in the original Hippocratic Oath that was sworn to by the earlier trained Physicians upon completion of their training. The Oath that goes as follows:

"I swear by Apollo The Healer, by Asclepius, by Hygieia, by Panacea, and by all the Gods and Goddesses, making them my witnesses, that I will carry out, according to my ability and judgment, this oath and this indenture.

To hold my teacher in this art equal to my own parents; to make him partner in my livelihood; when he is in need of money to share mine with him; to consider his family as my own brothers, and to teach them this art, if they want to learn it, without fee or indenture; to

impart precept, oral instruction, and all other instruction to my own sons, the sons of my teacher, and to indentured pupils who have taken the physician's oath, but to nobody else.

I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course. Similarly I will not give to a woman a pessary to cause abortion. But I will keep pure and holy both my life and my art. I will not use the knife, not even, verily, on sufferers from stone, but I will give place to such as are craftsmen therein.

Into whatsoever houses I enter, I will enter to help the sick, and I will abstain from all intentional wrong-doing and harm, especially from abusing the bodies of man or woman, bond or free. And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets.

Now if I carry out this oath, and break it not, may I gain for ever reputation among all men for my life and for my art; but if I transgress it and forswear myself, may the opposite befall

Swearing in Ceremony into the Medical Profession in 1999

I had not run in a long while because of my limp gait. I did run when I saw the final examination results, because I was full of joy. However, over a period of two to three days, the feeling of anti-climax over shadowed me and I started asking myself, "Is that it?", Is that all?, It is finished! I had become a medical practitioner that would soon be licensed after taking the necessary oath. It is official, what else? What do I want to do? I needed to pursue another meaning. Yes, I have always been pursuing some meaning all along the line. I have always been a regular visitor to the motherless babies' home, opposite the University College Hospital, Ibadan and out of

whatever I had, I have always dropped something for the children who are deprived of the privilege of having a home and experiencing love of parental caring. I needed another goal that would stimulate my excitement that would make me hang in there, contributing to humanity.

Becoming a medical doctor was an anticlimax for me. And I started asking myself again, which direction do I want to go? What am I going to pursue again? Service to humanity is the best. I remembered that first on the list; I had to pick up the crumbs of my life. I had to attend to my mother, who had been neglected for a long period of time. I went back to her and told her: 'Your son is now a medical doctor'. I guessed she couldn't understand what it meant. As an internist at University College Hospital, Ibadan, I took up the responsibility of caring for her. I placed her on antidepressants, with antipsychotics whenever her depression showed features of psychosis. Gradually, she came out of her state and her social and occupational functioning improved dramatically.

Along the line, she was able to complete my father's house that had been abandoned following his death. And she was able to move from her family house to my father's house. The significance of this in an African society is enormous and it is a sign of covering of one's shame when you have a roof over your head, a house or home of your own. She derived some level of psychological and social satisfaction from this achievement and there was positive improvement in her

health as well.

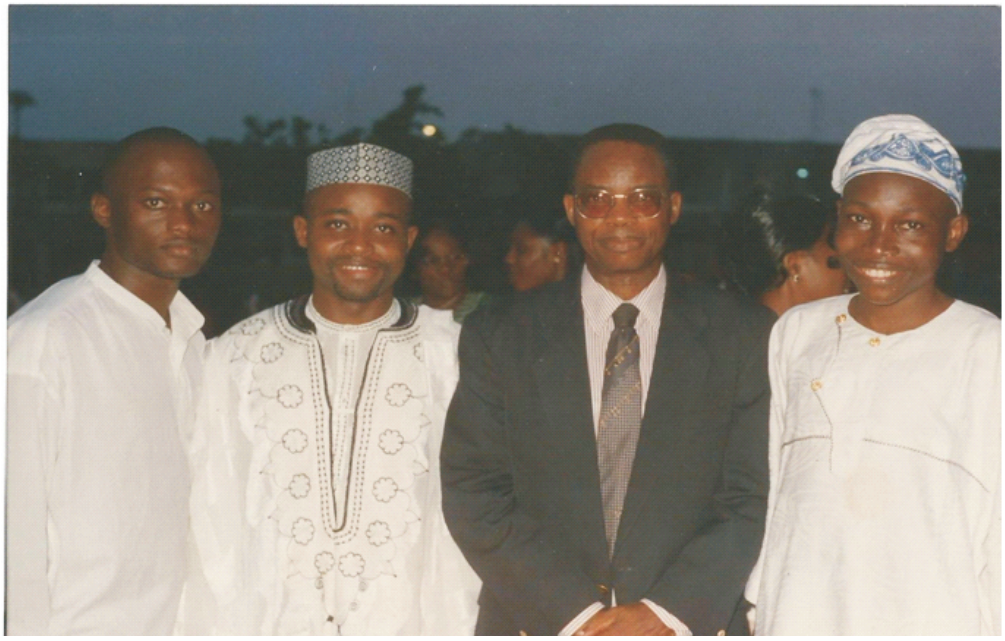
As an Internist, I started paying back all the money that I had owed to finance my education and that I used to take care of my health during the difficult periods. For the first three months as an Internist, all the money I received as emoluments were not mine as I deployed the fund to paying my accumulated debts. That was how I was able to face the struggle of financial difficulty and face the struggles of rigorous studies in medical school, and was able to become a medical doctor licensed to practice in Nigeria, which had always been my ultimate dream since my elementary and high school days. It came flooding back to me, the quotation; that anything you can conceive, anything you can believe, you can also achieve. That is why it was said that, "in pursuit of happiness, don't let anyone tell you that you can't, not even me".

So, getting an internship job at University College Hospital, Ibadan, despite being among the best graduating students, was posing a herculean task, because then, it was an unwritten rule of the hospital not to take or consider a graduating sickle cell disease patients for housemanship, because they think that the activities of housemanship at University College Hospital in Ibadan was very rigorous and tedious. This, I saw as another form of discrimination or stigmatization that I needed to overcome.

There was a turnaround through the influence of one teacher, one mentor, a mother, Professor Wuraola Shokunbi, who was my

Physician that took care of me during that trying period in medical school. She told me, 'do your best, be among the best, and I will speak for you!' And she did! She was at that time, the Chairman, Medical Advisory Committee in UCH, while the Chief Medical Director then was Late Professor Michael Olatawura, a renowned Psychiatrist of repute in Nigeria, who wholeheartedly accepted her suggestion and I was able to get a slot as an internist at the University College Hospital. I have always been a source of inspiration to many. I have been a survivor, trying to survive all odds.

Late Professor Michael Olatawura, Myself (first right) and two of my graduating Classmates at our Valedictory Cock-tail



I did brilliantly well during my internship year at University College Hospital, Ibadan. About six years later, another colleague of mine, Dr. Patricia Ibeziako documented her perspective of that period when we met again in Melbourne, Australia for a Conference in the year 2006. In a write up she titled, **"My Heroes"** she wrote about the year of our internship at University College Hospital in Ibadan between the year 1999 and 2000 as follows:

"One morning during my internship back home, I had a bout of malaria and was contemplating calling in sick when I glanced out of the window to see my classmate Muideen Bakare limping to work. Muideen is another one of my personal heroes, and an uplifting example of how resilience thrives in the face of the adversities of a developing country. Living with sickle cell anemia, he not only made it through medical school and internship, but was one of the first from our class to complete a residency in psychiatry. While my greatest worry about flying to Australia was jet-lag, Muideen's blood count dropped to critical levels days before the conference. Still, he insisted on traveling to Melbourne to present his poster on emotional aspects of sickle cell disease in adolescents — regardless of his own risk of developing a painful vaso-occlusive crisis during the long flight". – IACAPAP Conference, Melbourne Australia, 2006".

However, it was not all a bed of roses during the internship year. There were periods of stress and frustration, which is experienced by

most physicians. I especially came to face this type of experience during the internship when I went through three weeks rotation in Neurosurgery Unit at University College Hospital, (UCH), Ibadan, Nigeria. I documented my experience of the stress and frustration in the year 1999 after completion of the rotation in an excerpt I titled, **'Three weeks in a Trance'** which is reproduced below:

"The degree of injury I know not, whether concussion, contusion, or laceration, but I sure went into a state of trance. In the midst of pathetic situations tinted with a sense of frustration I found myself mainly because of emotional feelings I have for my patients. My spirit was really willing but the stressful environment kept at bay the response of my flesh to the dictates of the spirit to show service to humanity without reservation.

However, despite the dark cloudy sky of stress-induced lack of empathy, there are faint areas of bright sky interspersed with sparkling stars. Appreciation is lost of your effort to better the lots of the patients because objective and subjective improvement oftentimes are difficult to quantify. The psychological effect this can have on the doctors and patients' relatives is better imagined.
Pseudo-hope has been patients' and their relatives' companion because of their belief in doctor's ability to work miracles. A miracle worker is a doctor to an average man on the street. My opinion is that

truth has to be told, one has to be blunt where a candid opinion is required, but more difficult it is to be readily digested by the patients and their relatives. I woke up to the fact that the brain is the captain steering the ship of the whole body and preventing it from wrecking. What is a man without a brain? A mere vegetative structure he is.

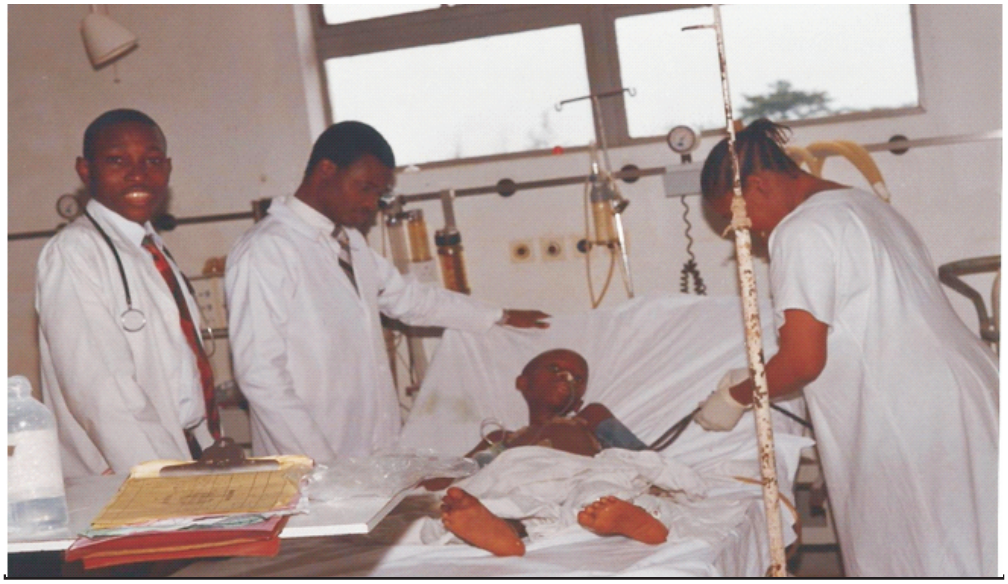
To keep a vigil in a bid to curb the nefarious activities of armed robbers is a common occurrence among our people. To keep a night vigil in order to praise and worship God is part and parcel of religious Nigerians because we are created to have a sense and perception of existence of a supreme being who is at the helm of affairs of what happen to man and his environment on the earth. Even as the doctors keep vigil to ensure well being of their patients, comatose patients surprisingly keep vigil in sympathy with their doctors. "Coma vigil" is the phrase that describes the state of a man who knows not when, where and who (not oriented in time, place and person) but keep his eyes open staring into space but seeing nothing.

Astonishing enough, Neurosurgery has something to say about that friend of Christ Jesus that was raised from the dead, or what shall we say of the phrase, ***"Lazarus response",*** *which describes the cortical motor response elicited in a patient who is said to be brain dead. In whom brain stem reflexes are completely absent.*

Neurosurgeons are said to be painstaking. If you do not take pains, sure you cannot go and tamper with that natural computer upstairs; hence you turn the stored information upside down. Contrary

however, is this assertion when it comes to odd hours of ward rounds where no pain is taking, rather we zoom with speed of light barely listening to patients' complaints. I underwent extra training on how to fill investigation forms all in the name of taking pains, though I found it worthwhile. What cannot be blotted out of my memory are periods of somnambulism and defective thinking when fatigue sets in. Disheartening is the fact that great oftentimes is the communication gap between the surgeons and their patients as some hydrocephalic children's mothers were not aware that their children have to carry the shunts for life. All in all, it has been a wonderful experience as I woke up from my trance. Then said I as a word of prayer, "O Lord, God keep the brain alert and protect Him from concussion, contusion and laceration for He is the captain of the ship."

My Internship Period at University College Hospital, Ibadan



Chapter 7
Serendipity

By the time I completed medical school and internship year, I was already having my mind made up to specialize in Haematology, a branch of Medicine that is concerned with diseases affecting the blood and blood components. After all, the objective of my coming for medical training was to understand in more detail the disease process I am suffering from, sickle cell disease.

So, I approached the then Head of Department of Hematology at University College Hospital, Ibadan to register my interest of wanting to have postgraduate training in Haematology. The then Head of Department who had the final say and decision, unfortunately, had bad news for me. "You cannot be a postgraduate trainee in hematology. Haematology is too demanding of a specialty and you would not be able to cope as a sickle cell disease patient", Professor Yetunde Aken 'Ova said. Again, I suffered another rejection from a senior medical colleague. It brought back flooding memories, the experience I had in my first year in medical school, when another senior colleague told me I would not be able to cope as a medical student because I suffered from sickle cell disease.

The Head of Department gave me an option though, that I would do better enrolling into public or community health postgraduate programme, an option that I considered with little or no enthusiasm

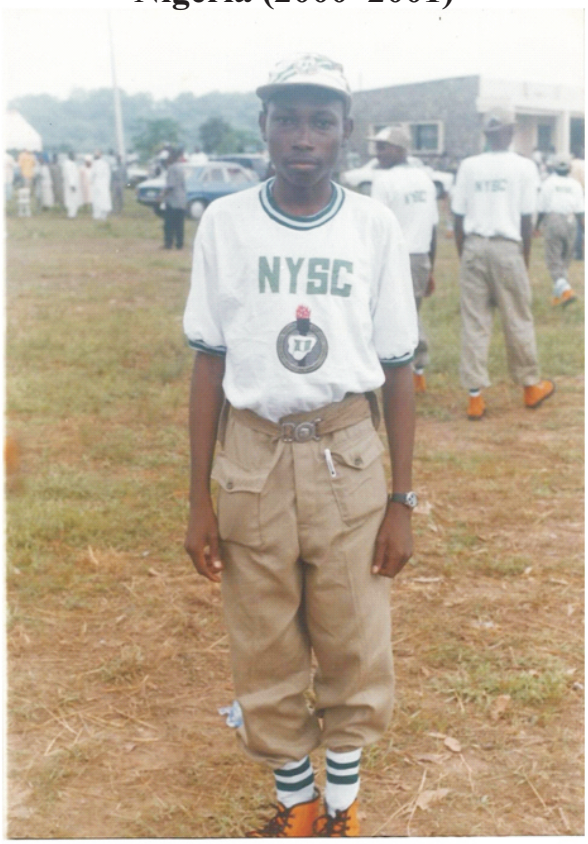
because that was not where my focus and interest was. I eventually wrote the preliminary examination (Primary Examination) required in gaining admittance into postgraduate training in public or community health, which I passed at first sitting. The next stage was to seek an opening, to get a post for this training position and I made effort to get a training position at University College Hospital, Ibadan and I was again denied of a position, without any definitive explanation.

After these events, I resorted to working as a Medical Officer with a Catholic Hospital in Ibadan owned by the Catholic Church; Our Lady of Apostle (OLA) Catholic Hospital, Oluyoro, Ibadan. I worked for this organization for about eight months after my internship and compulsory National Youth Service year which I spent at Federal Medical Center, Lokoja, Kogi State, Nigeria.

Myself (2nd right) and other Medical Doctor Colleagues at Our Lady of Apostle (OLA) Catholic Hospital, Oluyoro, Ibadan

Kogi State is the Nigerian Confluence State, where River Niger and River Benue met. It was once the seat of Colonial Government in Nigeria. The State is arraigned with the beauty of being surrounded by rivers and easy availability of fresh fish for consumption. The State is inhabited mostly by the minority ethnic groups in Nigeria, which consists of Igala, Ebira, Nupe, Ogori, Magongo among others. The larger ethnic groups present in the State include the Fulani, Okun (the Yoruba speaking part) and some Igbos who are mostly traders. The National Youth Service year provided me exposure to other parts of the country, a move which my parents had always vehemently opposed. I did enjoy this exposure because it did not only make me learn about other regions of the country, it also afforded me the opportunity of getting exposed to cultural practices of other ethnic groups in Nigeria. That, of course is the objective of National Youth Service, a policy that was implemented following the end of Nigerian civil war to promote re-integration and unity among the various ethnic group in the country.

Myself at the National Youth Service Camp in Kogi State, Nigeria (2000 2001)



I worked at Our Lady of Apostle (OLA) Catholic Hospital with another colleague of mine who is a good source of inspiration to me, Dr. Eze Uzoechi Chikezie. Then, serendipity smiled on me when Dr. Chikezie who was originally interested in Psychiatry and Mental Health as an area of postgraduate specialization was invited for an interview at Federal Neuropsychiatric Hospital, Calabar, Cross

River State in Nigeria and he requested that I accompany him to Calabar. I had never been to Calabar prior to that time. History has it that Calabar served as one of the ports of entry for slave trade activities between the indigenous and the then colonial traders, before Nigeria as a country was eventually colonized by the British.

I was enthusiastic about seeing Calabar and about the possibility of changing my mind to pursue Psychiatry and Mental Health as a postgraduate study as an alternative, since I was not originally interested in the public health I was forced to consider. The problem then, was that I never passed Primary Examination in Psychiatry and I did not apply for a position in that institution. How can I be considered for a position, if I accompany my friend in anticipation of trying my luck? Try my luck I did, though even when serendipity showed me a good direction, I never paid attention. The then Medical Director of the Institution, Late Dr. Michael Ekpo, a mentor and a teacher permitted me to join the interview process since he claimed the hospital needed more hands then. Very few medical graduates were considering the option of psychiatry as a possible postgraduate area of study then. Pursuing postgraduate programme in psychiatry and mental health or being a specialist in the field of psychiatry and mental health carries its own burden of stigma in Sub-Saharan Africa. I was eventually offered a job as a trainee in Psychiatry and Mental Health at Federal Neuropsychiatric Hospital in Calabar, Cross River State, Nigeria.

After about three months experience in training, it dawned on me that I was in the area of specialization I should have pursued in the first instance, as it exposed to me a lot of adjustment problems I had experienced as a child and adolescent with sickle cell disease growing up in sub-Saharan Africa. The mechanism of the sudden mental health problem my mother experienced following my father's demise within the grieving period became clearer to me. As undergraduate medical students, we had been exposed to about two to three weeks of psychiatry and mental health posting, which did not allow us to grasp the concept of psychiatry and mental health as a potential interesting area of specialization upon completion of undergraduate medical education. Psychiatry is an area of specialization in Medicine that exposes an individual to all round knowledge ranging from Medicine, Science, Art, Sociology, Psychology, Philosophy, Religion among others. The training became part of me and I became part of the training, and by the time I completed my training in year 2005 my orientation about life had totally changed. I now have a different perspective. I had lost all interest in religious doctrine as a source of hope, but my level spirituality has soared. I agree with Albert Einstein when he said, *"Everything is energy and that is all there is to it. Match the frequency of the reality you want and you cannot help but get that reality. It can be no other way. This is not philosophy. This is physics"*.

However, I acknowledge religion as a coping mechanism for individuals going through one trial or the other. Religion does provide hope and alleviates anxieties about uncertainties of tomorrow. For those who believe in their various faiths, religions serve a means of coping in periods of adversity.

I have presently adopted a more liberal approach of embracing spirituality, acknowledging that all religions are symbolic and admitting that spirituality is the connecting chain that links all faiths and religions together.

I know that the only thing that sustains anybody in the face of adversity is having a set goal to achieve. Having a focus of where you want to go. With a set goal in mind, it is easy to resolve to stay around until that goal is achieved. This has happened to me and I know that for sure. Define why you are here on planet earth. Define why you are existing and interacting with the rest of humanity. Define the goal that you want to achieve. And you will be able to sustain yourself in the face of obstacles. Serendipity brought me into psychiatry and mental health and I came to realize this is actually the area specialization where I belong. This could be likened to the Biblical quotation of "All things work together for good, for those who love God and walk according to His purpose". Psychiatry and mental health specialty is a discipline that takes care of the mind first. And I have come to realize that if you can actually take care of the mind, and the mind can be healthy, whatever is happening to the body could also be taken care of and the body would be healthy. Therefore, the state of our mind, I

have come to realize, is more important than the state of our physical health. So I found myself in psychiatry, which till date, I have enjoyed practicing. I have also had a lot of insight. I have changed my orientation about a whole lot of things. My perception of life has changed. The way I see the world has changed. All my life, I have always been told: 'Don't step out of your comfort zone'. I don't know why I have always defied these injunctions. It is when people tell me not to step out of my comfort zone that I am more resolute to step out; showing negative people how wrong they could be gives me so much delight. A great pleasure in life is doing what people say you cannot do.

Whatever your dream is, whatever your goal is, don't let it die. In pursuit of meaning, in pursuit of happiness, never let anyone tell you, you cannot. You are capable of all things. You are made in the nature of God. You are a part of the abundant, infinite energy of the universe. And you can actually tap into the overwhelming and unlimited resources of the universe. In pursuit of meaning, let your direction be set.

I presently practice psychiatry and mental health in Nigeria and I find interest in history, biographies, child physical and emotional development. I have been mentored by specialists in the field of psychiatry and mental health worldwide. Notable mentors who have contributed immensely to my carrier growth included Drs. Olayinka Omigbodun, Kerim Munir, Andres Martins, Joaquin Fuentes and Myron Belfer, to mention but a few.

Chapter 8

Epilogue - Define the purpose, don't get lost in the crowd

Moving forward, I have resolved that I am human and I have to live my life like every other human. I am not prepared to live my life with a label of hemoglobin electrophoresis referred to as genotype. Robert Louis, a victim of pulmonary tuberculosis when cure for tuberculosis was still elusive once said, "Life is not a matter of holding good cards, but playing a poor hand well". One would realize that children and adults with chronic physical illness who have successfully mastered the physical, social and emotional hardships associated with their illness well illustrate this point made by Robert Louis. Individual's reaction to adversity determines their attitude; it is the individual's attitude to any adversity that would dictate whether the individual survives or becomes extinct.

Every human has two parts to him or her: a physical appearance, which is the outer-man, whom everyone can see and through which our capacity and capability could be probably assessed and rated by other people. The second part is our inner-man, the inner resolve, the inner capacity and capability, whom no one can see, difficult to assess unless you give that inner being a hands-on opportunity to prove the unseen capacity and capability.

The Biblical story of King David's anointing by Prophet Samuel

illustrates clearly this analogy. The story can be found in the book of I Samuel 16:1-13. However, my point is driven home by verses 6 and 7:

…….. "When they arrived, Samuel saw Eliab and thought, 'surely the LORD's anointed stands here before the LORD". But the LORD said to Samuel, *"Do not consider his appearance or his height, for I have rejected him. The LORD does not look at the things people look at. People look at the outward appearance, but the LORD looks at the heart".*

The **'heart'** is our individual inner-man. Despite the physical, social and emotional limitations sickle cell disease or any other chronic illness may pose, the inner-man (inner resolve) can be strengthened by changing your attitude to your circumstances.

As a growing child or adolescent with sickle cell disease, you may look frail, you may look weak, but who you actually are is a dictate of your INNER-MAN. Changing the outcome of most adverse circumstances starts with a decision, a resolve followed by actions. Heaven only helps those who help themselves. You have your destiny in your own hands.

Because of the known negative reports about prognosis and outcome of sickle cell disease and the psycho-social beliefs of the people about this disease in Sub-Saharan Africa, the tendency is high for an average sickle cell disease patient from this environment to live below his/her potentials. The tendency is for the children with sickle

cell disease living in Sub-Saharan Africa to think of themselves as weaklings or nonentities. If the mind is pre-conditioned to this state of thought process, the chain of events is for the body to respond correspondingly. The body would be weak; less progress would be made mentally and physically in response to the dictates of the mind. "As a man thinketh in his heart, so is he". Who you are and what you are today are usually products of your thoughts years earlier. The intangible, that occupies the sub-conscious metamorphoses into tangible in a matter of time over the years. In view of this, every sickle cell disease patient needs a change of attitude and thought reformation in order to live a worthwhile life. Here comes the need for psychological therapy, which needs to be an essential component of managing children with sickle cell disease or any other chronic illness. While working on a change of attitude and reformation of thought process, discouragement would come and would not leave until it left some elements of poison in the mind. Positive confessions and acts would go a long way for an average child or adolescent with sickle cell disease or any other chronic illness. Periods of depression, whether sub-clinical or clinical depressions do come and often they are inevitable. With faith, keeping a strong mind, a turbulent period could always be endured. Tough times don't last, only tough people do. Passing through a dark tunnel could be a great, herculean task; the sustaining grace is that there would always be light at the end of the tunnel.

Great heights could be attained by children with sickle cell disease or any other chronic illness if they could think of themselves as being great, if they could think themselves tall and see themselves going places. This is the process of building a veritable INNER-MAN. Any child that suffers from chronic illness should not allow himself/herself to be relegated to the background in any aspects of life or endeavours he/she chooses.

Growing children from disadvantage environment need to be taught to be people of great minds because it is only great minds that achieve great things. Life and success are not for quitters, they are for winners. Breakthroughs are for people who persist despite the obstacles they face. Success is actually for those who turn these obstacles into stepping stones. Children with chronic illness need to be taught that disability is not inability. Everything is in the mind.

In achieving a goal and living optimally, a sense of direction is needed. No one can define the purpose for another individual. Defining the purpose is an individual's responsibility. We all ask every day, the question about purpose. This is even more important during the adolescent period of development, when personality is being formed, when an individual adolescent is trying to assume their identity. The question of; "Why am I Here?" comes up every now and then. It is important an individual adolescent navigate this stage and be able to answer the question of; "why am I here?". Otherwise, it is easier for an average adolescent growing up not to be able to

define their individual identity and get lost in the crowd.

Goals and purpose help us to stay focus. A child or adolescent with sickle cell disease like every other human need to discover and find out why he or she is in this world or existing. What is his/her purpose? What does he/she need to achieve? Answering these questions reinforce hope and sustain the fight to triumph. So, why are you here? Unfortunately, I cannot answer this question for you or any other individual. However, I have an idea of what can guide every individual in answering the question of; "why am I here?". The idea is found in the words of Albert Einstein when he said;

"Strange is our situation here on earth. Each of us comes for a short visit, not knowing why, yet sometimes seeming to divine purpose. From the standpoint of daily life, however, there is one thing we do know: That we are here for the sake of humanity ……..... for the countless unknown souls with whose fate we are connected by a bond of sympathy. Many times a day I realize how my own outer and inner life is built upon the labors of my fellow human beings, both living and dead, and how earnestly I must exert myself in order to give in return as much as I have received and am still receiving".

The above quotation could be a guide; the summary is that our existence revolves around service to humanity.

Also, from the words of 28th President of the United States of America, Woodrow Wilson we can derive some sense of direction in answering the question of, "why am I here?". Woodrow Wilson said,

"You are not here merely to make a living. You are here in order to enable the world to live more amply, with greater vision, with a finer spirit of hope and achievement. You are here to enrich the world, and you impoverish yourself if you forget the errand".

This quotation signify that we all need to impact the world and our immediate environment with additional value before we leave the scene and that by not adding value we indirectly impoverish ourselves. The words of Albert Einstein and Woodrow Wilson are a guide for everyone to individually define their purpose and not get lost in the crowd. Well defined purpose would be the fuel that would keep the engine of fighting spirit steaming. Well defined purpose would be the motivation that would keep the flag flying.

Chapter 9
Appendix One - Sickle cell disease: A brief introduction

Because many people living outside Africa and the tropics may be unfamiliar with sickle cell disease, a brief introduction on the disease condition would be highlighted in this chapter.

Sickle cell disease is a disease of haemoglobin (that part of the red blood cell that helps in carrying oxygen round the body). In as much as haemoglobin is a component of blood, the disease could be said in layman terms to be a disease of the blood. It is an inherited disease that occurs among black Africans. The prevalence and distribution of the disease condition also extends to the Mediterranean and among Arabs.

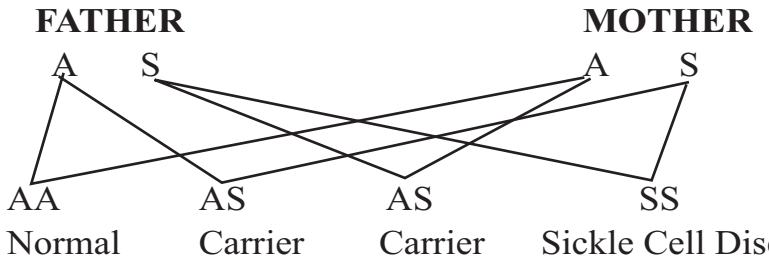
Close to three percent of the black African population is suffering from this disease condition. The disease as earlier said is inherited from both parents and has been part and parcel of the individual so affected right from birth. However, the symptoms and signs do not manifest until after about six months of age when the largest percentage of fetal haemoglobin has been phased out. The fetal haemoglobin is believed to create a buffer effect, dampening the manifestation of symptoms and signs of S-haemoglobin. Every newly born, up to 3 months of age is served by the fetal haemoglobin that has been present since life in utero (inside the mother).

It is to be noted that close to twenty five percent of the black African

population are carriers. That is, they share the normal haemoglobin A and abnormal haemoglobin S in equal distribution within their blood system. Close to seventy percent of black African population have the normal haemoglobin A only without a mix with the abnormal haemoglobin. This group consists of the apparently healthy individuals with genotype AA.

Mode of Inheritance

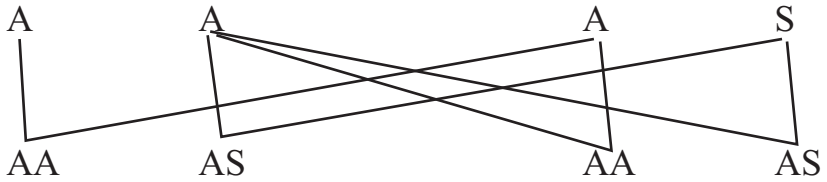
It is worthy of note that the child could inherit sickle cell disease when both parents happen to be carriers (that is, they are both of genotype AS). The possibility of a child inheriting sickle cell disease also arises if one of the parents is a sickle cell patient and is married to a carrier, then in this case the genotype SS and AS will pair. **The diagrammatic representation below depicts the situation if both parents are carriers of sickle cell disease gene**



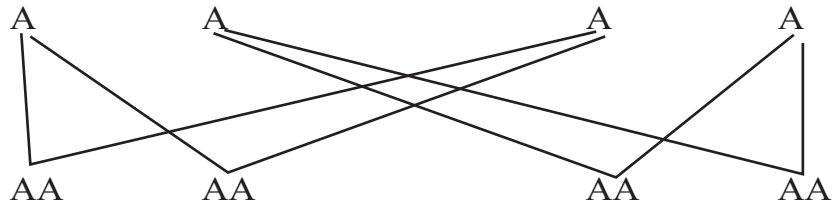
Based on the diagrammatic representation above, the probability of producing a child with sickle cell disease out of four children if two sickle cell disease gene carriers are paired as parents is one out of

four. However, it should be appreciated that this is only probability. Cases have been seen of carrier parents that have four children and all the children unfortunately happen to be sickle cell disease patients and what has also been reported on the other hand is a case whereby out of four children of carrier parents, no sickle cell patient was produced as offspring.

It is obvious that the probability of producing a sickle-cell child is guarded against if a person with normal haemoglobin AA and a carrier AS paired as parents or if two person of haemoglobin AA are paired as parents. The possibilities are shown below:



The probability in the above pairing is the production of a normal individual or a sickle cell disease gene carrier, while the pairing of two individuals with normal haemoglobin cannot produce offspring with abnormal haemoglobin.



It is imperative to mention at this juncture that haemoglobin S is not the only abnormal haemoglobin that exists in human. Mention has to be made of haemoglobin C, D and so on. Here emphasis will be laid on haemoglobin C, because it is the next commonest abnormal haemoglobin after haemoglobin S among people of African descent.
In view of the existence of haemoglobin C, various haemoglobin genotypes like SC, AC and CC do exist among people of African descent. Individuals with Haemoglobin genotype SC are also sickle cell disease patients but experience has shown that they run a milder course of the illness.
Individuals with Haemoglobin genotype AC are also carriers of abnormal haemoglobin C. They exhibit no symptom of sickle cell disease. Most of the individuals with Haemoglobin genotype CC have been found to live a normal life, crisis free. The mode of inheritance of Haemoglobin C is likened to the same situation as occurred in inheritance of Haemoglobin S. It is to be noted that sickle-cell disease gene carriers (Haemoglobin genotype AS) do not manifest symptoms and signs of sickle cell disease unless under hypoxic condition (low oxygen tension), for example, during mountain climbing and sea diving.

Crises in Sickle Cell Disease

Sickle cell disease is characterized by a number of crises which do occur in the sufferer. These crises have been classified for the

purpose of simplicity; this does not mean they cannot occur at the same time simultaneously. The types of crises experienced by sickle cell disease patients are highlighted below:

Haemolytic Crisis:

This particular crisis is most of the time heralded by change in colour of urine that ranges from yellow to "coca cola" coloured and yellow sclera on looking into the eyes. Gradually the level of red blood cells in the patient diminishes because they are being continuously destroyed. This process is referred to as Lysis. The child or patient then begins to complain of weakness, on mild to moderate exertion or even at rest, depending on the degree of the anaemia, which has resulted from the destruction of the red blood cells.

Blood contains numerous cells that cannot be seen with the naked eyes. These cells are basically of three types. The White Blood Cells, the Red Blood Cells (which are attacked in the haemolytic crisis) and the Platelets that help in enhancing coagulation and clotting of blood following injury.

In haemolytic crisis, the target component of blood is the red cells. Mothers can open the eyes of their children and observe that the conjunctivae are white and the sclera is tinged yellow. This phenomenon is referred to as Jaundice. It is important to mention that a red blood cell with haemoglobin S because of its fragility is liable to destruction easily by various forms of insults when compared to the

one with normal haemoglobin A. Various forms of insults that can result in the destruction of Haemoglobin S red blood cells include:

- Malaria infestation/infection
- Bacteria infection – This is a broad term that can refer to infection in any part of the body system; if it does occur in the respiratory tract, it is called respiratory tract infection; if it is in the urinary tract, it is called urinary tract infection and so on.
- Dehydration – This refers to depletion of body water. This is common mostly in children and sometimes in adults. Precipitating factors for dehydration include, living in hot environment or climate, diarrhea and vomiting that can result in loss of enormous amount of body water.
- Cold climate – Just as very hot climate can wreak havoc in sickle cell disease patients, extreme cold environments can too. This could lead to problems because channels through which blood passes (veins and arteries), that act like pipelines in the body constrict in cold environment and as such, hinder free flow of blood. This sluggish flow of blood can precipitate the destruction of some red blood cells.

Bone pain crisis or vaso-occlusive crisis

This is another form of crisis in sickle cell disease patients. It is usually the first type of crisis that alerts the parents about the possibility of their child being a sickle cell disease patient. This bone

pain could sometimes be associated with swelling of the joints affected when there is inflammation, resulting from super-imposed infection.

Between the ages of one and two years, it is usual that painful hands and feet swellings occur in a child with sickle cell disease. This serves as a warning signal to very inquisitive parents. This phenomenon is referred to as dactylytis or hand and foot syndrome. Bone pain crisis in sickle cell disease patients can also be precipitated by any of the factors incriminated as causative factors of haemolytic crisis. Mention however, should be made of stress as another important factor that precipitates bone pain crisis in sickle cell patients. Stress could be physical exertion, psychological and emotional stress. Anxiety on the part of the patient could be responsible for both psychological and emotional stress.

Sequestration crisis

This phenomenon is characterized by pooling of large quantity of blood volume into the spleen thereby resulting in sudden depreciation in the amount of blood volume available to sustain normal body metabolic activity. The after effect of this is complaint of weakness, dizzy spells and easy fatigability. The mode of management is blood transfusion or surgical intervention in form of spleen removal as a last resort.

Aplastic Anaemia:

This type of crisis occurs rarely, however this is not to say that it does not occur. It is characterized by failure of bone marrow, the factory of blood cell production to perform its role. The resultant effect of this is that there would be depletion in the quantity of all the blood cells available, the red blood cells, white blood cells and platelets. Management is by blood transfusion as required. Steroid use has been employed in some cases.

Complications of Sickle Cell Disease

Sickle cell disease carries along with it various complications that can occur in the individual as he/she grows up. The manifestation of these complications in every individual is variable. Some patients experience certain complications, while some do not. It is pertinent to emphasize here that the frequency of crises in the life of every sickle cell patient varies with genetic make-up of the concerned individual as well as their background.

It is an established fact that sickle cell patients from affluent backgrounds tend to live a life of less frequent crisis compared with those at the other extreme of economic status. Various reasons can be attributed to this. These include good nutrition and access to good education. It is of importance to make it clear that education has gone a long way in improving the quality of life of sickle cell disease patients as they tend to be more aware of their health problems and in

this line, take necessary precautions as required. Among the complications that have been identified in the study of sickle cell patients in Nigeria and other parts of Africa are:

Low Level of Immunity:

It has been established scientifically that the immune status of an average sickle cell patient is at low ebb when compared to an individual of the same age and status who lives with normal Haemoglobin A. The consequence of this low level of self-defense against micro organisms is easy susceptibility to various forms of infection caused by bacteria, viruses, fungi and other forms of micro organisms. It is to be noted that infection in general has been incriminated as one of the precipitating factors of crisis in sickle cell disease patients.

Cerebro-vascular accident (CVA) or Stroke-like syndrome:

This is another complication that has been noticed among sickle cell disease patients in Nigeria and other parts of the world. This is usually due to infarction of some areas of the brain because of deprivation of blood supply, thereby subjecting that part of the brain to nutritional deficiency. The effect of the infarction is manifested in the part of the body that the particular part of the brain affected controls. Weakness and disuse of the affected limbs are the clinical presentation.

Eye Problem:

This is another common complication that occurs as a result of sickle cell disease. Various types have been noted and all these problems are put under the umbrella of one term - sickle cell disease retinopathy. One common eye problem that has been noted in sickle cell disease patients is vitreous haemorrhage. This, if prolonged, can lead to retinal detachment from its neural pole, thereby leading to irreparable loss of eyesight in the eye so affected.

Enlarged Liver and Spleen:

This is usually seen in the early years of life in sickle cell patients. Basically, this results from apparent inefficiency of the bone marrow to cope with red cell production when compared to the rate of loss from haemolysis during early years of life. The Liver and Spleen then get enlarged to supplement the effort of the bone marrow in red blood cell production at this stage of life. The grotesque picture these problems confer on sickle cell patients' physique at this stage is not pleasant to the sight. They now have protuberant abdomen, with thin, lean upper and lower limbs. It is at this time that the concern of the mother arises – the abdomen of her child has become so big and a solid firm mass can be felt on the left side, apparently referring to the spleen. It is gladdening that as the child grows, this grotesque picture regresses and does disappear with time.

Retardation in physical growth:

It is not uncommon for a twenty year-old sickle cell patient to be mistaken for a twelve year-old by an average individual unfamiliar with the patient. This is mainly because most sickle cell patients experience retardation in growth physically. They tend often times, to maintain a smallish stature, even when they have reached adulthood and this gives a wrong impression. It is imperative however to add that, although sickle cell patients might experience retardation in physical growth, their mental or cognitive development is mostly unaffected.

Osteomyelitis (Infection of the bone):

Due to repeated bone infarction which results from deprivation of blood supply to the long bones causing bone pain crisis, the long bones are predisposed to bacterial infection resulting in Osteomyelitis. This usually results in softening and weakening of the bones.

Avascular necrosis of the head of femur:

It is not unusual to see an adult sickle cell disease patient limping, depicting a deformity in one of the hip joints. Avascular necrosis of the head of the femur is a common complication in sickle cell disease which occurs as a result of deprivation of blood supply to the head of

the femur, resulting in degeneration or necrosis of the femoral head. Therefore, producing the limping gait observed in many of these patients. This complication is amenable to hip-replacement surgery which is successfully done abroad but not without its own complications of bone infection among others.

Chronic leg ulcer:

The word chronic means protracted. This is another complication that is seen in sickle cell disease patients. It usually occurs close to the medial maleoli (medial aspect, close to the ankle joint proximally). It is usually a consequence of inadequate blood supply to the area concerned. This makes the healing of the ulcer difficult once it is established. This is another worrisome complication that disturbs the psychological state of these patients. Healing does occur in some cases, but with adequate care. It is pertinent to note that it is not only in sickle cell disease patients that complication of chronic leg ulcer occurs. It also occurs in other common diseases like diabetes mellitus and underlying osteomyelitis, to mention but a few.

Priapism:

This is described as continuous sustained painful penile erection. This complication has also been noted to occur in some sickle cell patients. It does occur without any sexual excitation. As has been described earlier, the experience is painful and sometimes the need for analgesic and rarely surgical intervention may arise to relieve the

condition. This complication does not arise invariably in every sickle cell patient. A lot is anchored on the genetic make-up and background of every sickle cell patient. At times the occurrence of these complications is also a game of chance and event.

Chronic Renal Failure:

This is a condition that occur when the kidneys fail or are failing to perform their function optimally. This is one of the complications that occurs in sickle cell disease and usually could result from prolonged use of analgesic like paracetamol and other non-steroidal anti-inflammatory drugs or from repeated infection of renal parenchyma. The condition, chronic renal failure, does occur in normal individuals who are not known sickle cell patients. Management of this condition would depend on the stage of the renal failure and the underlying cause.

Chapter 10
Appendix Two - What Friends and Family Say

Patricia Ibeziako (My Medical School Classmate and a Child and Adolescent Psychiatrist practicing in the USA)
"One morning during my internship back home, I had a bout of malaria and was contemplating calling in sick when I glanced out of the window to see my classmate Muideen Bakare limping to work. Muideen is another one of my personal heroes, and an uplifting example of how resilience thrives in the face of the adversities of a developing country. Living with sickle cell anemia, he not only made it through medical school and internship, but was one of the first from our class to complete a residency in psychiatry. While my greatest worry about flying to Australia was jet-lag, Muideen's blood count dropped to critical levels days before the conference. Still, he insisted on traveling to Melbourne to present his poster on emotional aspects of sickle cell disease in adolescents — regardless of his own risk of developing a painful vaso-occlusive crisis during the long flight". – IACAPAP Conference, Melbourne Australia, 2006.

Henry Ezihe (A doctor and previously my Medical Student at Enugu State University Teaching Hospital, ESUTH)
Sir, this is Soul lifting and an energizer. We are the only stumbling block to our own success. Come out of your comfort zone and never

go back. Failure is necessary to attain success.

Rotimi Coker (A Senior Colleague in Psychiatry in Nigeria)
Ride on bro. Blow that trumpet for the whole world to hear your motivational story.

Nkire Chisom (My Psychiatrist Trainee at Federal Neuropsychiatric Hospital, Enugu, Nigeria)
Sure!!!! Nothing stops a man until he stops himself. This is inspiring. Tell your story my boss.

Niran Okewole (A Psychiatrist and Colleague)
Conqueror of the rough road. I salute you!

Lekan Onijingin (My Colleague during the Youth Service at Lokoja, Kogi State, Nigeria)
My Doc, even the days of NYSC, despite all the stress, you always showed strength.

Obindo James Taiwo (A Psychiatrist and Colleague)
There is a story behind the glory! The "devil" limiting us is actually within.

Femi Sanni Skenky (A Classmate at University College Hospital, Ibadan, Nigeria) Yeah we know you ....well-done bro. God Almighty will continue to protect you and bless you and your home. You are such an inspiration to us!!!

Joseph Chukwuemeka (A Nurse at Federal Neuropsychiatric Hospital, Enugu, Nigeria)
Tell your story my Dr. The whole world is interested in your motivational life story.

Vivian Izundu (A friend and Nurse)
Awesome MOB, ride on!

Mobolaji Iyun (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
It is well, Bakare. I remembered how frail you always were and walked with a gait.

Kikelomo Ogunlela Anunobi (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
Looking forward to hearing it! Inspirational that you chose to pursue happiness rather than live in the opposite!

Mofolashade Onaolapo (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
Absolutely! MOB. I am with you all the way. You are an inspiration to us all.... Please tell your story, let the world hear.

Yewande Oshodi (A Psychiatrist and Colleague)
Yes you have done truly well....and much more greatness awaits you!

Karren Visser (A friend living in Kenya)
I'm not surprised. Your quiet strength and sense of humor - not so quiet! - Hints at a life lived with deep purpose.

Nonye Umeike-Barrow (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
Excellent, I am really proud of you and your achievements.

Lekan Isijola (A High School Classmate at Ibadan Christ Apostolic Grammar School, Aperin, Ibadan, Nigeria)
I've known you for about 30yrs now and I can testify to it, that story is long overdue.

Uche Mozie Onubogu (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
Yes, you sure have a story and it is inspirational.

Adetayo Ayoade (A High School Classmate at Ibadan Christ Apostolic Grammar School, Aperin Ibadan, Nigeria)
My one and only irrepressible "JEJELAYEGBA". Ride on!

Monday N. Igwe (A Psychiatrist and Colleague)
"We never know how much we are capable of until we are challenged" - Bakare. Those are your words and I got lots of inspiration therein my boss.

Isaiah Owoeye (A friend)
No limitations for a willing heart. If you can picture it, you can capture it. More dreams, more accomplishments as your heart could carry. Greater testimony awaits you sir!

Alaba Ojapinwa (A NYSC Colleague at Lokoja, Kogi State)
Bakare!!!!! May God continue to make you inspiration to others especially the up and coming generation. Better days ahead brother.

Ovayoza Makoju-Adeleye (Medical School Classmate at University College Hospital, Ibadan, Nigeria)
Please write a book to inspire kids with sickle cell disease. It is only a disability if you cannot make the good days meaningful. Lord get us all through our bad days and help us make the good days more meaningful. Keep on shining and remain blessed.

Mohammed Said Jidda (A Psychiatrist and Colleague)
Highly inspiring. A message that would serve the public too.

Mabel Effiong (A Nurse and friend)
Dr. Muideen Owolabi Bakare had been my very close friend from the day he arrived my hospital (Federal Neuropsychiatric Hospital, Calabar) for his residency in psychiatry. I first saw him at the out-patient observing things but I thought he was a patient and I said please can you move forward because it seems you came early. I was later informed that he is one of our new doctors. I was his first friend in Calabar and was always dropping him home when he got his first accommodation and I picked him up to spend his very first Christmas with my family in our house. Everyone loves Dr Bakare including my late mum because he was and is still a source of inspiration to many facing challenges, he never let his health status disturb him in anyway. Upon all, Dr Bakare is very intelligent, very witty and always very cheerful with me his best friend but you will never know these attributes unless you are close to him. I am always happy to see him moving higher in his career as a doctor and as a consultant psychiatrist. We should never give up in life. I personally will emulate him and never give up because giving up makes one a failure. May God continue to preserve his life and use him as an example to encourage others in similar circumstances.

Nurudeen Ayotunde Bakare (My Younger Sibling)
Your resilience is highly inspirational. It is more than a sickle cell patient studying medicine. It is also about a sickle cell patient surviving with no adequate source of money to take care of his health, food, shelter, clothing among others. I am proud of your spirit in this direction.

Michael Olukorede Odubanjo (A Senior Colleague in Medical School)
Muideen, I salute your resilience you are truly an inspiration to all. Ride on brother and more grounds to break , more achievements on the way.

Etop Etim (A Psychiatrist and Colleague)
My Boss, kudos to you. We are waiting to read your book once published.

Omolaraeni Beyioku (A friend and Nurse)
Hmm! Brother, you reminded me of those crises days at Oluyoro Catholic Hospital Oke Ofa, Ibadan. Of a truth, your life has been an undiluted testimony…….but we give glory to our Maker who preserve you to emerge the best among your contemporaries..

Temitope Ogunkanmi (High School Classmate at Ibadan Christ Apostolic Grammar School, Aperin, Ibadan, Nigeria)
It is the Lord's doing, just an amazing grace, what you have said is true, I recalled our days at Ibadan Christ Apostolic Grammar School (1983 - 1988). To God be the glory.

Muideen Owolabi Bakare as I knew him – **Abass Adetunji** (High School Classmate at Ibadan Christ Apostolic Grammar School, Aperin, Ibadan, Nigeria)
I feel very highly honoured and immensely elated writing about my illustrious classmate Doctor Muideen Owolabi Bakare. Muideen, as we then addressed him, is now a consultant psychiatrist and, indeed, a jolly good fellow. I must add that his current choice of career is a fulfillment of his life-long ambition of wanting to be a medical practitioner for which we are all happy for him. We all had our different childhood experiences and no matter how arduous or easy, experiences they still are, and some of these are what have defined our existence till this day. However, some kids had a sweet-bitter experience of sort, and while some were palatable, the others were not something to relish.

I first met Bakare Owolabi Muideen in 1983 when we were both enrolled in Form 1 at the prestigious Ibadan Christ Apostolic Grammar School, Aperin-Oniyere, Ibadan, Oyo State. He had cut

the image of a cool guy, with a calm mien, and he was indeed quite calm. But, beneath this legendary calmness was a troubling, seemingly life-threatening challenge with the knack to devastate him, threaten his very existence, as well as emasculate his future career plans. It just happened that due to no fault of his, Muideen suffered from sickle cell disease, and he was not much of a normal child like we were, or, so we thought!

Many of us did not really come to terms with the debilitating effects of the ailment as well as the possible complications as we all believed that his life was never going to be cut short, and I am extremely happy to realize that several years after we had left school, my former classmate and friend still trudges on, living a normal life, excelling in his chosen field, and serving as a source of courage to several people who are afflicted with this vicious ailment and struggle daily to live against the odds. Indeed, our hope was never misplaced.

Despite all of these difficulties, however, he was a brilliant fellow who had carved an enviable niche for himself particularly in the Sciences and Mathematics. He emerged as the best student in Mathematics in Form 2, and in form 3; he won the coveted prizes in Physics and Chemistry. I can never forget his exploits in Further Mathematics too, despite the difficulty level, he was able to really cope well and he did excel. He had wished to study human medicine in the university, but his extreme fondness for Mathematics and Further Mathematics can only indicate that he is quite a cerebral

fellow, versatile individual, and a determined guy who never allowed his condition to weigh him down.

It is true that he fell ill frequently, and no thanks to this seemingly incurable ailment, nonetheless, his determination to live and excel knew no bounds. He even occasionally struggled to partake in sports despite all of these limitations, and even when he was never allowed to do so at a competitive level, the fact that he ever ventured into it is a glowing tribute to his avowed determination not only to live and excel, but to do so at the very top, even whilst he remained realistic that it was not going to be a walk over.

He did well in the GCE examinations which some of us wrote in 1987 when we were in Form 4,and in the WASSCE, he earned five distinctions and three credits, and that easily was one of the best performances in the whole of Aperin –Aremo Zone in that year's examination. Access to university education was low, and Muideen's insistence to read the most competitive course, medicine, compounded that, and it means he really stayed at home for sometimes before gaining admission to the university.

His first UME did not engender a positive outcome, despite his modest inputs; he re-enrolled in 1990 and also got 215 out of the possible 300. The score was not only encouraging, but outstanding, but he lost out again, but was offered admission to the polytechnic to study Engineering, after he had nicked an impressive score of 193 out of 300, and that itself was very phenomenal.

I remember meeting him occasionally whenever I came around from school and impressing it upon him to consider alternative courses, he always thanked me, but still remained adamant that he would not fall by the wayside in his quest at becoming a medical practitioner. Rather than quitting the stage, he had another go in 1991, and whereas most of us had gone for other courses in the sciences and engineering, Bakare was admitted for medicine at the prestigious university of Ibadan, and he came out in flying colours. We lost contact in deference to the dictum that "ogun omode ko le sere pe ogun odun", but it is to the glory of God that we eventually reconnected

This book will be a source of inspiration to all those who suffer from the debilitating ailment called Sickle Cell Disease, in addition to giving them the tips that work. Afterall, he wears the shoes and definitely knows where they pinch, and I am sure the hands-on remedies and actions he took will definitely lift the courage of the fellow sufferers who are definitely no less human being than the rest of us. It will indeed make them and the rest of the society reflect that as much as the disease is not desirable, it is definitely not a death sentence.

In all, I thank God for my bosom friend and I wish him many more fruitful, crises free years on the earth in order that he continues to contribute to the growth of mental health in Nigeria, Africa, and the world at large.