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Article Title: **Raising Awareness of Sickle Cell Disease for Healthcare Assistant Practice; Nigerian Perspectives.**

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### **Abstract**

Raising awareness of Sickle Cell Disease for Healthcare Assistants (HCAs) is important if they are to understand not only key aspects of the condition but also if they are to communicate effectively with people and their families and carers that may be amid acute illness or its potentially devastating aftermath. Sickle cell disorder (SCD) is a life-threatening genetic disorder due to abnormal haemoglobin. The condition is most prevalent in Africa. Over 10%-40% of African people carry sickle-cell trait (SCT) leading to an estimated sickle cell prevalence of at least 2%. Nigeria has the largest population of people with SCD in the world. Over 25% of Nigerians are healthy carriers of SCT. Couples with SCT face a high likelihood of passing the condition to their children. This explains why over 150,000 babies with SCD are born in Nigeria every year. Having a working knowledge of the condition and its implications is useful for HCAs who may be working in areas of the UK with high percentages of Nigerian families in local communities such as the South East of England. This article provides a holistic insight into the condition for HCAs and key considerations for everyday clinical practice when working with individuals or families.

**Keywords:** Sickle Cell Disease; Sickle Cell Disorder; Haemoglobin 'S'; Awareness; Nigerian Public Health.

## **Introduction**

Healthcare practice now encompasses the care of a range of people with diverse healthcare needs. Understanding the perspectives of people from diverse patient caseloads and particular conditions is a key role of the healthcare workforce and is the fundamental basis of compassionate care and the capacity to demonstrate empathy in practice. Sickle Cell Disease (SCD) represents just one opportunity for HCAs to learn more about a condition that has such a profound impact on people diagnosed with it. A systematic review conducted by Asnani et al (2016), to describe the interventions for the prevention of SCD emphasises the relevance of health education, and suggests that individuals, caregivers and patients should be educated based on specified protocol, manual or management curriculum with the objectives of improving the knowledge and understanding of the people about the disorder and its management. Makani, Williams and Marsh (2007) suggested various factors and pharmacological agents which might increase the effective assessment of haemoglobin levels in Africa, an option for interventions that would improve quality of life and reduce mortality of individuals living with SCD. WHO (2006) supports that SCD can be managed effectively through increased partnership, training, education and awareness. This article uses research from Nigeria to highlight key issues for an understanding of SCD by healthcare providers in practice.

## **Global Demographics and Historical Perspectives of Sickle Cell Disease**

Each year, across the globe, approximately 300,000-500,000 children are born with SCD (Piel et al., 2013). The World Health Organisation (WHO) recognizes that the condition is a significant public health issue, necessitating responsive and timely research (Makani, Williams & Marsh, 2007; Piel et al., 2010; Rees, Williams & Gladwin, 2010). Official statistics from WHO reveal that 10%-40% of African populations carry the genetic sickle cell trait and that over 78% of sufferers currently reside in Africa (Rees, Williams & Gladwin, 2010; Piel et al, 2013).

## **Context Specificity of Nigeria**

Nigeria as an African nation has a population of over 120 million, of which 25% of adults have sickle cell traits; 'AS' (AS stands for Sickle-cell Trait in terms of being a genetic carrier of the condition) or Hb C (abnormal Haemoglobin) (Oludare and Ogili, 2013). Nigeria accounts for 50% of SCD births worldwide, with 2-3% of the overall Nigerian population suffering from active SCD (Oludare and Ogili, 2013). These incidence and prevalence rates have led to an increased likelihood in sickle cell passing to future generations, especially if those who choose to have children do not consider the practical implications of their genetics (Grosse et al, 2012). Those people planning their families are often young and their Sickle Cell traits are likely to be transmitted to their offspring (Taiwo, Oloyede and Dosunmu, 2011; Oludare and Ogili, 2013; Chelcun, 2014). Zounon et al (2012) has revealed a huge knowledge deficit among lay people in Nigeria. Only a minority used the correct judgment rule when assessing the risk of SCD. Similarly, the outcome of the work of Archanya, Lang and Ross (2009) suggests that some parents have significant misinformation about what it means to be a carrier of SCD or to have SCT. According to Magill et al (2010) motivational interview is a useful tool to enhance planning with the high-risk populations. Thankfully, the work of Olatona et al (2012)

suggests that health education of young individuals was significantly effective in improving their level of knowledge, attitude to SCD and screening uptake.

### **Defining Sickle Cell Disease**

Sickle cell disorder also referred to as sickle cell disease (SCD) is a hereditary disorder which can be directly attributed to abnormal haemoglobin (WHO, 2012). It is the most prevalent inherited disorder in the African-American population (National Human Genome Research Institute, 2016). Most infants with SCD are healthy at birth but present with symptoms later in infancy or early childhood after a physiological drop in their foetal haemoglobin levels (Chelcun, 2014). Characteristically, people with the SCD have an abnormal form of oxygen-carrying protein haemoglobin 'S' in the red blood cell leading to poor blood circulation. SCD leads to recurrent and unforeseen episodes of pain, haemolytic anaemia, stroke and numerous organ dysfunctions (Makani, Williams and Marsh, 2007). The individuals with SCD present with bouts of pain due to Vaso-occlusion episodes (VOEs), which can either be acute, chronic or a mixture of the two (Okpala and Tawil, 2002).

A seminar study conducted by Kim, Brathwaite and Kim (2017) to investigate rapid pain management for individuals with SCD suggests the implementation of Evidence-Based Practice Standard Care (EBPSC) as a crucial step for improving the management of VOEs. In that, EBPSC enhances the quality of care in the SCD population. Infants with SCD can present with pneumococcal sepsis, severe anaemia, jaundice, splenic sequestration, jaundice and splenomegaly (Reid et al., 2014). Additionally, there can be progressive damage in the brain, kidneys, lungs, respiratory system and exacerbations of frequent musculoskeletal pain, especially in older children with SCD (Rees, William & Gladwin, 2010; Hay, 2013). SCD can be managed by simple interventions as high fluid intake, healthy diet, folic acid supplementation, pain medication, vaccination and antibiotics for the prevention and treatment of infections and many other therapeutic measures (WHO, 2011).

### **Nigerian Perspectives**

Historically, prior to the discovery of the disease by Herrick in 1904, different names were given to SCD across Africa (Bazuaye et al., 2009). Traditionally in Nigeria, people, had distinctive interpretations of childhood mortality rooted in historical cultural perspectives. Based on these, some Nigerian people often maintained the belief that the death of sickly children was attributable to paranormal forces such as witchcraft or bad luck (Anie, Egunjobi and Akinyanju, 2010). The Yoruba tribes in Nigeria, based upon their perceptions, referred to 'sickly children as 'Abiku', which simply means 'children that die young', and the Ibos called them 'Ogbanjes' also interpreted as 'sickler' (Ilechwukwu, 2007). In Nigeria, the Igbo people superstitiously believe and call SCD people "Ogbanje" stigmatising them as people that have reincarnated, the Yoruba calls them "Abiku" meaning repeated cycles of birth, death and reincarnation (Anie, Egunjobi and Akinyanju (2010).

Therefore, most people do not want to marry them or even employ them. However, religious beliefs in terms of prayer play a positive role in coping rather than in preventing the disease, revealed by the study conducted by Anie, Egunjobi and Akinyanju, 2010. Similarly, participants identified that

prayer may not prevent SCD but that it could assist in coping with the disorder. The work of Jenerette and Lauderdale (2008) supported the fact that prayer was referred to as 'God's help' when a group of people were interviewed about their coping strategy for SCD. Most people with SCD interviewed by Jenerette and Lauderdale (2008) agreed that prayer supported them in managing living with the characteristically excruciating pain associated with SCD.

Children were also lost to SCD due to poor levels of clinical diagnosis and relative accessibility to medical care. Consequently, SCD was a major cause of child mortality due to primitive medical practice, inadequate information, available knowledge and diagnostic equipment (Bazuaye et al., 2009). Akinyanju (1989) long advised that measures aimed at achieving the sensitization of health professionals, policy makers, and resource allocators to the pertinent issues regarding the control of SCD are crucial to effective management of SCD.

However, in contemporary times, through technology and research, many interventions and health policies have been put in place to prevent and diagnose SCD (WHO, 2012). Currently, WHO (2012) advocates pre-marital screening and counseling of the young people as a useful strategy, effectively reduces the birth incidence and prevalence rates of SCD by over 90%. Several studies have revealed that children who inherit the abnormal gene from both parents will suffer from SCD while those who acquire the abnormal gene from either of their parents will have a sickle-cell trait- a condition that does not pose major significant health problems on its own (WHO, 2012). Wide-scale research has been undertaken across the globe to evaluate preventive programmes implemented to reduce the prevalence of SCD in Africa (Jenerette and Lauderdale, 2008; Bazuaye et al., 2009; Chelcun, 2014). Across Europe, North America and Australia, it is now a standard practice that genetic screening is undertaken for minority ethnic groups who are at risk of genetic disorder manifestation.

WHO revealed that affordable genetic screening programmes exist in some parts of Africa but little research has been undertaken regarding the genetic screening of young adults in Nigeria (WHO, 2012). Although advances in modern healthcare practice and evidence-based medicine have enabled diagnosis and identification of preventive strategies for SCD, theory based intervention is imperative to raise awareness and channel effective strategies (Jenerette & Lauderdale, 2008). Whilst it is not the role of HCAs to proffer advice to families on genetic screening, their compassionate approach and understanding of living with such a complex can provide an invaluable part of care within the context of HCA practice. As such an underpinning knowledge of history, incidence and prevalence can be useful in practice. Key areas can be identified about this in relation to the everyday role of the HCA (see Table 1 below):

**Table 1: Caring for People with Sickle Cell Disease in Practice**

<b>Invaluable Skill Bases for HCAs</b>	
Compassion and Care	Despite the fact people living with SCD can now potentially live much longer, their lives are impacted upon by severe and unrelenting episodes of pain, which are often are living longer, but their lives are impacted even more by the unpredictable intermittent or constant pain that is often poorly managed (Benjamin, 2008). The HCA role in the context of compassion and compare is invaluable within this context in that the support they provide to medical and allied healthcare practitioners and the nursing workforce is effectively irreplaceable.
Effective Communication	Effective communication, particularly within the context of settings where patients are undergoing consultation about SCD prognosis, outcomes and genetic screening is a pivotal area where effective and compassionate communication with HCAs can provide reassurance and empathy during life changing decision making processes. Whilst it is not the role of the HCA to provide clinical advice, their understanding and warmth in the context of clinical consultation is invaluable in practice based settings (Cox et al, 2017).
Individualised Support	A key role of the HCA is the personalization of individualised care. Ensuring that there is a need to remain accountable and allegiant to guidelines is a pivotal part of all healthcare practice but what truly distinguishes HCAs is their capacity to make people feel valued on a one to one basis, that more task based healthcare practitioners may not have the time to undertake (MacFarlane and Stafford, 2016). This level of individualised support provides the wider health team with a basis for ethical integrity in practice.
Recognition of Scope of Practice	Recognising the scope of practice that an HCA has, is vital with all patients. The need to delineate how compassion and care do not necessarily need to be underpinned by stringent clinical advice is important here. In terms of scope of practice, it is important that HCAs do not make assumptions or proffer knowledge about SCD with patients but that they use their knowledge of the condition to reflect on how best they can support and reassure patients at times when they may just need someone to 'be there' or understand the perspectives of the people for whom they provide care (Lavander, Meriläinen and Turkki, 2016).
Resilience and Coping Strategies	By directly addressing the need for resilience in action it is possible for a sustained level of empathy and compassion for patients to be maintained (Austen, 2016).

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### **Living with Sickle Cell Disease**

According to Jenerette and Lauderdale (2008), people living with SCD clinically manifest with pain. In that, pain accounts for most of the lifetime problem of individuals living with SCD. Their qualitative account of these people revealed a discourse and narrative embedded in the terms; 'throbbing' and 'stabbing' in relation to their experience with the pain of SCD. Patients with SCD have expressed deep dissatisfaction with the pain-relief regime they received both as inpatients and on a domiciliary basis, expressing that both have resulted in a poor quality of life (Booker et al, 2006). Although in the last four decades, the life expectancy of people living with sickle cell disease has increased from around 14 years to mid-40s, evidence from many studies reveals that most of the people living with the condition lack the skills of self-care required to sustain their quality of life. This, consequently, leads them to frequent episodes of hospitalisation, extensive medical care and the need for the implementation of effective long-term management strategies (Lanzkron et al., 2013; McGann et al., 2013; Quinn et al., 2010). Research by Archarya, Lang and Ross (2009) revealed that there is a significant misinformation about what it means to be a carrier of the SCT and its associated health and reproductive risks. Siddiqui et al (2012) suggests that health education should address variability in health literacy, cultural and linguistic diversity, and reproductive decision-making, as well as implications of health outcomes for individuals.

## **Conclusion**

SCD remains a significant public health problem in Nigeria. Some of the key factors associated with SCD, its health implications and management have been highlighted in this literature review. With optimism, HCAs and other healthcare personnel will find increased insight into this condition and its management. Furthermore, they can empathise more with this particular group of patients and identify the individual need of the individuals living with SCD, informing the understanding and compassion required to care for the people living with SCD. WHO in Africa has recommended a wide range of public health interventions for SCD such as disease-awareness programs for improved interventions. Other initiatives include primary prevention, early detection of SCD, improvement of access to healthcare provision and diagnostic testing for newborns in particular. Incidence rates of SCD could potentially be improved if individuals and health policy makers, tertiary institutions work collaboratively and are committed to SCD prevention and control in national health plans. Providing conducive environments for various stakeholders to facilitate the reduction of SCD prevalence, morbidity, and mortality will be crucial. As many people move from their homes in Nigeria to establish new lives in the UK, having an awareness of the difficulties and challenges faced by people living with SCD will be pivotal in providing care that is authentic, compassionate and empathic services, adequate to potentially curb the prevalence of the devastating condition.

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