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Exploring Healthcare Utilization Events towards Palliative Therapy in Sickle Cell Anemia

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Abstract:-Sickle cell anaemia, a hereditary blood disorder characterized by abnormal haemoglobin, poses significant challenges globally, particularly in resource-limited settings. Despite advances in treatment, access to care and resources remains a persistent issue. This study aims to comprehensively understand the healthcare utilisation events experienced by sickle cell anaemic patients undergoing palliative therapy. This study aimed to assess and evaluate healthcare utilization events related to palliative therapy and satisfaction in sickle cell anaemic patients. The specific objectives were to identify healthcare utilization events which was patient satisfaction and to examine factors influencing these events, including demographic characteristics, disease severity, and access to healthcare services.

In this study, a cross-sectional design was utilized to investigate healthcare utilization events and factors influencing these events among individuals with sickle cell anaemia receiving palliative therapy who were selectively chosen through simple random sampling, ensuring a representative selection from the target population. Data analysis was conducted using SPSS version 25.0 software, expressing continuous variables as means and categorical variables as frequencies and percentages.

The descriptive analysis of 209 participants highlighted a predominance of females (60.3%) over males (39.7%), with the majority falling in the 18-27 age group (94.3%) and holding a Bachelor's degree (77.5%). Unemployment was prevalent (72.7%), and most participants reported satisfaction with sickle cell treatment (91.4%). In both univariate and multivariate analyses, gender, educational level, employment status, disease severity, and access to healthcare emerged as significant factors affecting patient satisfaction. These findings ultimately emphasize the complex interplay of demographic, socioeconomic, and healthcare access factors towards shaping patient satisfaction with sickle cell treatment modalities.

Keywords:- *Sickle Cell Anaemia, Healthcare Utilization Events, Healthcare Access, Palliative Therapy, Patient Satisfaction, Disease Severity, Demographic Characteristics.*

I. INTRODUCTION

Even with recent advancements in medical care and treatment, access to care and resources for sickle cell anaemic patients remains a hindrance in most parts of the world, particularly in settings with limited resources. Sickle cell anaemia (SCA) is a hereditary blood condition marked by unusual haemoglobin, which makes normal red blood cells assume a rigid, sickle-shaped structure(Lonergan et al., 2001). This condition primarily affects millions of people worldwide, particularly those of African, Mediterranean, Middle Eastern and Indian origin (Serjeant, 1994). This hereditary blood condition results from a genetic alteration occurring in the haemoglobin gene (Hb), leading to the production of abnormal haemoglobin and the unusual, characteristic transformation of red blood cells from their normal, round disk-like structure into the rigid, sickle-shaped structure(Ballas, 2002). The characteristic transformation of the red blood cells (RBCs) suggests severe obstruction of blood vessels, leading to recurring pain crises, organ failure, and a variety of other complications, which often give rise to innumerable incidences of health utilization events such as hospitalizations, emergency visits and outpatient consultations.

As mentioned above, the underlying cause of SCA is a mutation in the gene responsible for producing haemoglobin, a protein found in red blood cells that carries oxygen throughout the body. This mutation leads to the production of abnormal haemoglobin known as haemoglobin S (Hb S). When oxygen levels are low, such as during physical exertion or at high altitudes, the abnormal haemoglobin causes red blood cells to become rigid and take on a sickle-shaped structure(Pauling et al., 1949). sickle cell anemia is still primarily managed palliatively, with supportive, symptomatic, and preventative therapies.

Empowerment and education are the most essential components of supportive care which authorize the SCA patients to be in control and live with their condition. Symptomatic care entails all necessary approaches that target with control and moderation of the symptoms of SCA including pain relief, blood transfusions, and organ failure treatment. Additionally, preventative therapy involves a variety of options that aim to reduce the frequency and severity of complications resulting from SCA, including the use of hydroxyurea for pain management, the use of

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prophylactic antibiotics to lower the risk of infections and transfusion therapy to prevent stroke.

The primary goal of palliative therapy in SCA is to alleviate pain, which is one of the most debilitating symptoms experienced by patients. Chronic pain in sickle cell anaemia is often severe and can occur as acute episodes termed vaso-occlusive crises (VOC). These crises are caused by the blockage of blood vessels by sickled red blood cells, leading to tissue ischemia and subsequent pains.

In addition to pain management, palliative therapy also addresses other complications associated with SCA. These complications may include anaemia, acute chest syndrome, stroke, infections, and organ damage. Palliative care teams work closely with healthcare providers to develop comprehensive treatment plans that aim to prevent or manage these complications effectively. For instance, regular blood transfusions may be recommended to improve anaemia and reduce the risk of stroke, while antibiotics may be prescribed to prevent infections.

Furthermore, palliative therapy recognizes the importance of addressing the psychosocial and emotional needs of individuals with SCA. Living with a chronic illness can significantly impact a person's mental health, leading to anxiety, depression, and social isolation. Palliative care professionals provide counselling, support groups, and assistance in navigating the emotional challenges associated with the disease. They also collaborate with patients and their families to ensure that their preferences and values are respected throughout the treatment process.

In conclusion, palliative therapy plays a crucial role in the management of SCA. By focusing on pain relief, preventing complications, and providing emotional support, palliative care aims to enhance the quality of life for individuals living with this chronic condition. It recognizes the multidimensional nature of SCA and ensures that patients receive comprehensive care that addresses their physical, emotional, and psychosocial needs.

A. Sickle Cell Anemia

SCA is one of the most severe, occurring forms of sickle cell disease (SCD). SCD is an inherited blood disorder that is identified by the production of abnormal haemoglobin molecules, affecting the red blood cells. Normally, red blood cells (RBCs) have a round disc shape structure and they move through small blood vessels to carry oxygen to all parts of the body. RBCs contain a protein pigment that is responsible for carrying oxygen to the tissues in the body, known as haemoglobin (Hb).

The condition of sickle cell disease results from the presence of an unusual hemoglobin which affects the red blood cells, making them hard, sticky and assuming a sickle-shaped structure. The sickle cells rather have a shorter lifespan, resulting in a constant shortage of red blood cells. Upon travelling via small blood vessels since they are not flexible, these sickle cells become struck leading to the obstruction of the blood flow. This may in turn result in several attacks of sudden severe pain, which are termed pain crises. These pain crises may occur without warning, and an individual experiencing them is required to visit the hospital often for a more effective treatment.

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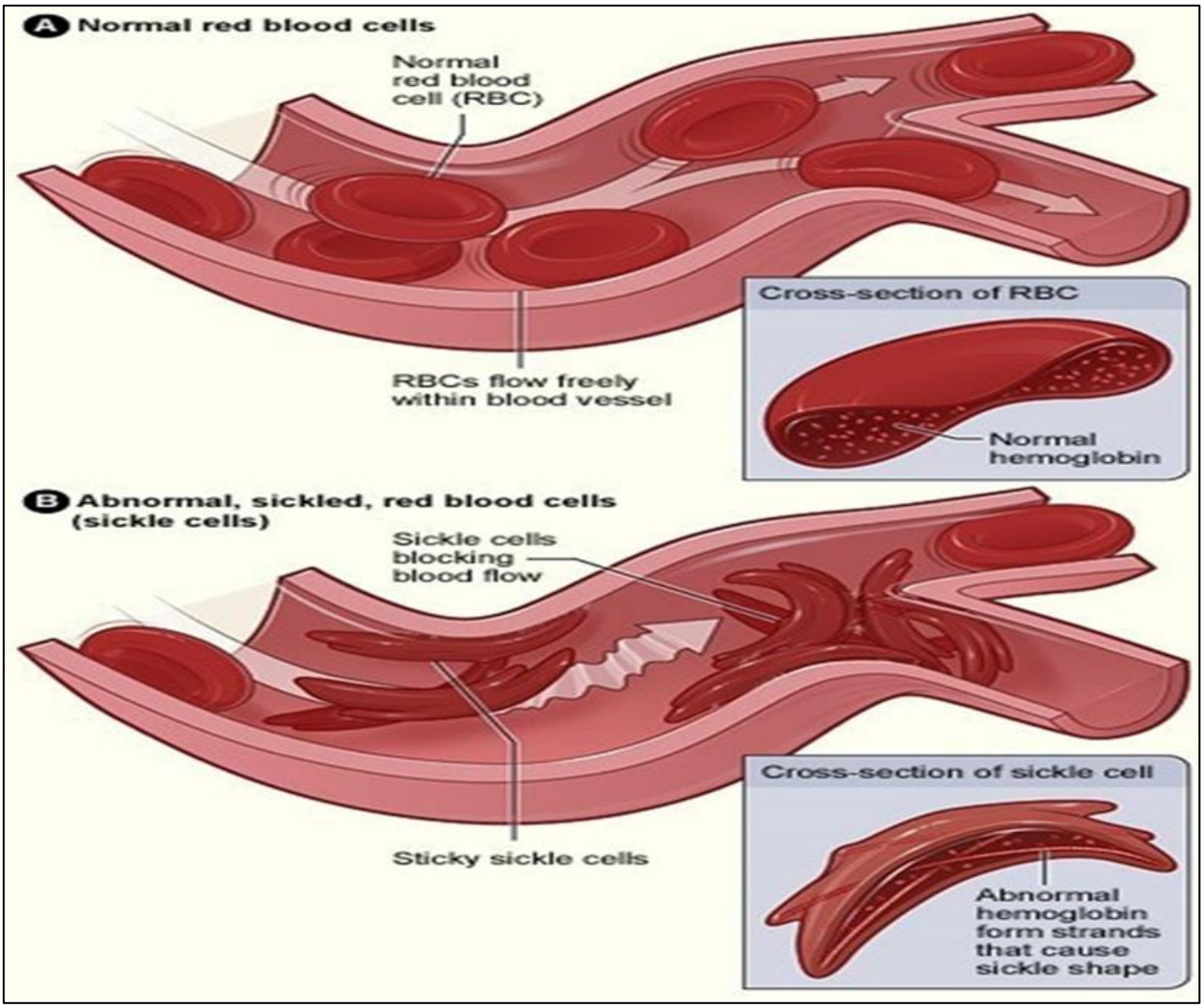

Fig 1: A Diagram Showing Normal Red Blood Cells and Sickled Red Bloods Moving Freely in a Blood Vessel Along with their Inserted Images Which Illustrate the Cross-Section of the Respective Cells; A Indicates Normal Red Blood Cells While B Indicates Abnormal, Sickled Red Blood Cells. (The above Diagram is Retrieved from a Web Source).

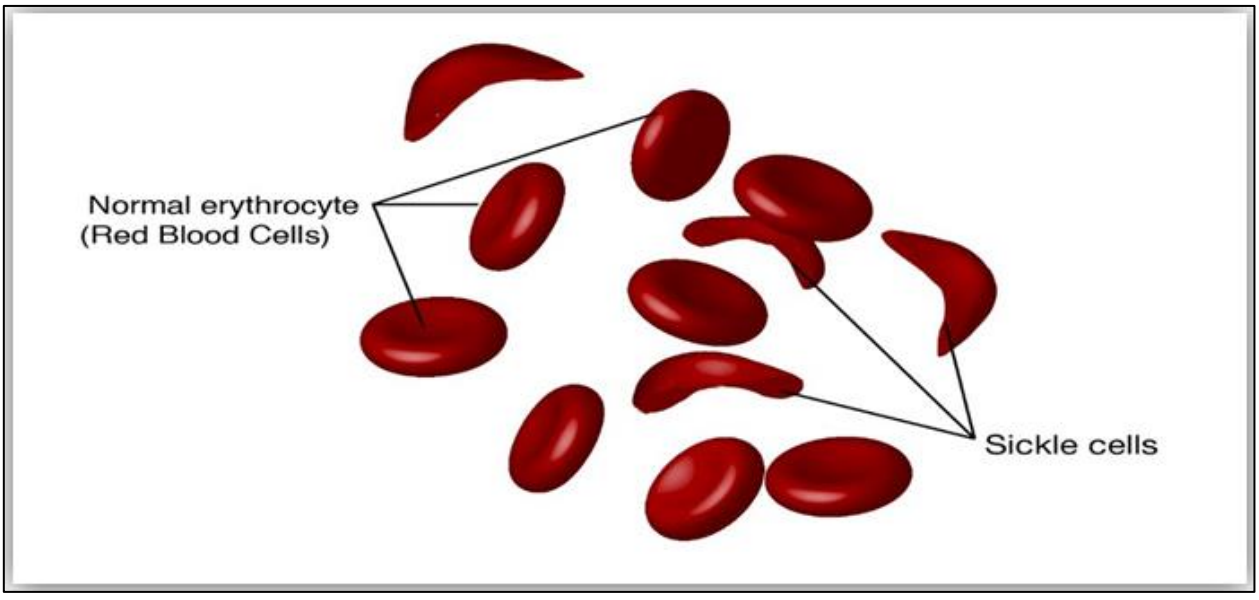

Fig 2: A Diagram Showing Normal Red Blood Cells and Sickled Red Blood Cells.
(The above Diagram is Retrieved from a Web Source).

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This blood disorder is determined by a genetic mutation in the haemoglobin gene, particularly a substitution of adenine for thymine in the DNA sequence, resulting in a modification from glutamic acid to valine in the haemoglobin protein (Ballas, 2002). This mutation makes this blood condition be considered an autosomal recessive disorder due to the nature and order of the inheritance pattern. Being autosomal means that the gene can be inherited from either parent and is not linked to the sex chromosomes. Sickle cell anaemia manifests itself in an individual if he/she acquires two copies of the mutated gene (one from each parent). However, if an individual inherits one normal copy and one mutated copy of the gene, they typically do not develop sickle cellanaemia but may be carriers of the trait.

- *Clinical Manifestations and Complications*

Being the most severe form of sickle cell disease, sickle cell anaemia is dangerously manifested in various ways and may vary in severity among individuals. Sickle cell anaemia is clinically shown through recurring and episodic pain crises, hemolytic anaemia, and exposure to increased risk of viral infections. In babies, the swelling in hands and feet as well as delayed growth are observed at the earliest stage of the disease. In some cases, vision problems may also be observed as another manifestation of sickle cell anaemia as a result of the obstruction happening along the blood vessels found in the eyes. Complications that arise along with sickle cell anaemia including stroke, acute chest syndrome, organ failure, spleen sequestrations (the enlargement of the spleen) and leg ulcers are common if the disease is left untreated for a prolonged time length.

- *Diagnosis and Screening*

The most reliable and usual method of identifying sickle cell disease, sickle cell trait, or other defective hemoglobinopathy in a person is by a specific type of blood test. To screen for hemoglobinopathies other than sickle cell disease, several tests are performed. These days, the most often utilized tests are deoxyribonucleic acid (DNA) testing, high-performance liquid chromatography (HPLC), and haemoglobin electrophoresis. Furthermore, if the results of blood tests are unclear, genetic testing might assist clarify the type of sickle cell disease you have or confirm a diagnosis. In the same way, genetic testing can determine if a person carries one or two copies of the sickle haemoglobin gene.

- *Treatment and Management Modalities*

Being a chronic disease, sickle cell anaemia can be quite complex and challenging to deal with. However, with a few medical interventions to lean on then it becomes tameable. Early on, the management of sickle cell anaemia has been entirely fixed on symptomatic relief, including pain management. Over the years, scientific advancements have been to state a difference by coming up with promising approaches that burn down the bridge on disease progression hence improving patient outcomes. One of the most promising approaches is gene therapy which favours the production of functional haemoglobin after an intentional manipulation of thepatient's hematopoietic stem cell (Garg et al., 2022). Notably, managing and dealing with SCA requires multimodal approaches that focus on reducing symptoms, minimizing complications, and improving the quality of life.

B. Various Treatment and Management Modalities are Readily Available for Individuals with Sickle Cell Anaemia, and these Include:

The utilization of hydroxyurea is at its peak in the treatment of SCA. Several recent studies have demonstrated that hydroxyurea can significantly reduce the frequency of pain episodes, the severity of acute chest syndrome, and the need for blood transfusion (Namazzi et al., 2024; Power-Hays & Ware, 2020). Even though it is considered safe for both adults and children, it has become the standard of care for individuals with recurrent vaso-occlusive events after it became the standard of care in 2011. There are times when hydroxyurea is not sufficient or is contraindicated in the treatment of SCA because of its toxicity. In these cases, regular blood transfusions are generally recommended. Transfusion of red blood cells can be extremely beneficial both in terms of increasing the number of healthy red blood cells and diluting the proportion of sickled red blood cells, as well as improving oxygen delivery to tissues. In this way, it is possible to prevent complications associated with vaso-occlusion and also improve symptoms associated with anaemia as well. However, long-term use oftransfusions may result in iron overload, necessitating concurrent iron chelation therapy.

Pain, being the hallmark feature of sickle cell anaemia makes managing it a critical aspect of (Benjamin, 2008). Nevertheless, the correct approach is to utilize pharmacological modalities, including the use of opioid analgesics like morphine for dealing with severe pain crises, NSAIDs such as ibuprofen for milder pain episodes and the use of prophylactic antibiotics as well. Although these medications offer far better relief, they must be closely watched because they come along with a risk of dependence and adverse effects.

Sickle cell anaemia patient's prognosis and quality of life have been greatly enhanced by the combination of the above treatment options, which include hydroxyurea, blood transfusions, and pain management modalities. The patient's clinical profile, the severity of their illness, and how they respond to certain therapies should all be taken into consideration when making therapy recommendations. On top of that, ongoing monitoring and regular follow-up appointments are essential to assess the effectiveness of treatment and make any necessary adjustments. Healthcare providers need to work closely with sickle cell anaemic patients to develop a personalized treatment plan that addresses their unique needs and maximizes their quality of life.

Disease-modifying therapies such as gene therapy and bone marrow transplantation are noteworthy to be mentioned since they have offered a promising direction in the medical world when narrowed down to improving patient outcomes in SCA, making them a curative approach. There is great hope for treating sickle cell anaemia with gene therapy since it is a potentially long-lasting or even permanent treatment option as it directly targets the genetic basis of the disease

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(eDever et al., 2016). The quality of life for those with SCA may be greatly enhanced, and it may be possible to reduce or completely do away with the need for continuing therapies such as blood transfusions or chemotherapy. In the same manner, the recent developments in bone marrow transplantation have also shown a promising direction in improving patient outcomes in SCA by reforming the normal haematopoiesis and providing relief to the symptoms that come with the diseasees (Iannone et al., 2005). Even though this kind of approach offers promise for a future where those affected by the disease can live healthier and more fulfilling lives, there is still a long run that requires further research and clinical trials to build the long-term benefits, risks and feasibility of these curative options for sickle cell anaemia.

Last but not least, other supporting care modalities also activate the lowering of the disease progression by dealing with challenges that come along with the complexity of the disease. It is approached by integrating comprehensive care models that team up healthcare professionals and psychosocial support networks to address and fulfil the unmet medical, emotional and other needs of sickle cell anaemic patients which usually may vary from person to person depending on disease severity.

Patients should also be informed about other alternative treatment options and encouraged to explore non-pharmacological approaches to managing their symptoms, usually, this kind of approach serves as a supportive measure and complements the pharmacological approaches for pain management (Williams & Tanabe, 2016). This may include heat therapy, oxygen supplementation, relaxation techniques and physical therapy.

- *Palliative Therapy*

The gigantic burden of chronic diseases, including cancer, human immunodeficiency virus infection, and others, such as sickle cell anaemia, related to physical and psychosocial suffering clarifies the famous requirement for palliative therapy in emerging nations (Ddungu, 2011).

Palliative therapy can be defined as a treatment plan that accommodates the patients and their families facing the complications resulting from the life-threatening illness by improving their quality of life, through symptom management, offering holistic support and lowering the associated risks of complications that are related to that particular illness. This treatment plan is entirely customized to accommodate the affected individuals across the age spectrum and can be listed as the main goal of care or along with curative therapy at any stage of illnesssince it is based on the needs of the patient rather than on the patient's prognosis.

Palliative therapy focuses on addressing the physical, emotional, social, and spiritual needs of the affected individuals and their families throughout a serious illness such as sickle cell anaemia. The above can be accomplished through symptom management, psychosocial support, and holistic care to emphasize comfort, dignity and respect, regardless of the stage of illness or prognosis. Healthcare providers work closely with patients to develop personalized symptom management plans which may include pain medications, physical therapy, relaxation techniques, and other complementary therapies to optimize the quality of life. Regular assessment and careful monitoring of symptoms allow for timely adjustments to the treatment plan to ensure that patients remain as comfortable as possible.

Palliative therapy also points out the emotional and psychological impact that may arise upon living with a chronic disease, both for patients and their families (Osunkwo et al., 2021). Psychosocial support services such as counselling and support groups may be an integral part of palliative care since they provide a safe room forpatients and their families to unload their feelings, concerns, and fears. They may receive guidance and support from trained professionals.

Furthermore, it adopts a holistic approach to care which covers all the dimensions of health and well-being such as physical, emotional, social, and spiritual. Healthcare providers work together with patients and their families to address their individual needs and preferences including cultural, religious and personal beliefs.

- *Key Goals of Palliative Therapy in Sickle Cell Anaemia*

The main goal of palliative therapy in sickle cell anaemic patients is to optimize their quality of life by addressing physical symptoms, providing relief to pain and suffering, promoting emotional well-being, and supporting patients in living as fully and comfortably as possible. SCA is often associated with chronic pain due to vaso-occlusive crises and other complications related to sickle cell anaemia. Palliative therapy aims to effectively manage pain related to sickle cell anemia through utilizing a combination of pharmacological and non-pharmacological interventions, to reduce the severity, frequency, and duration of the pain. In addition to pain, individuals with sickle cell anaemia may also experience various symptoms such as fatigue, shortness of breath and nausea, which may be controlled as well to improve overall comfort and well-being thus enhancing quality of life.

- *Factors That Contribute to the Success or Failure of Palliative Therapy in Managing the Symptoms of Sickle Cell Anemia*

A brighter side of integrating palliative therapy into comprehensive disease management is affirmed when it is applied alongside other therapies like curative treatment to reduce disease progression as well as improve quality of life. Rather, it is still a relatively emerging idea in most countries, especially those in the developing world and it is lacking, particularly in limited resource settings (Ddungu, 2011). With that being said, there should be a better way to adopt an approach that favours integrating palliative therapy in such settings.

Beforehand, it is important to note and consider factors that influence the success or failure of palliative therapy in managing a chronic, weakening disease. Some of these factors include access to healthcare services, the availability of trained healthcare professionals, cultural beliefs and

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attitudes towards end-of-life care, and financial constraints. By addressing these barriers, we can work towards ensuring that palliative therapy is more widely accessible and effective in improving the overall well-being of patients with chronic illnesses.

Access to healthcare services such as pain medications, emergency care, and specialist care is noted as a significant factor that may influence the effectiveness of palliative therapy in managing the symptoms of SCA. In settings where the healthcare systems are inadequate, there is a higher risk of poorer pain management. Therefore, the barriers to access such as socioeconomic factors should be addressed. Similarly, the chance of incorporation and utilization of palliative care in a population also varies from place to place with hospital characteristics being fixed as another factor. This is largely influenced by geographical location and social status. The type of hospital can show some indication about the rate of chances of receiving palliative care services in managing the disease and improving the quality of life. Resource-limited settings have lesser chances of providing such services to their surrounding population.

The availability of trained healthcare professionals can determine the success or failure of palliative therapy in managing the symptoms of SCA. These trained professionals empower and guide sickle anaemic patients by addressing all concerns of the disease. The management of SCA requires a multimodal approach due to its complex nature, which is then followed by a multidisciplinary care team consisting of doctors, nurses, pharmacists, haematologists, pain specialists, psychologists and social workers. A comprehensive care team is essential to address the multifaceted aspects of the debilitating condition and offer holistic support as well.

Cultural beliefs and attitudes towards end-of-life care can also determine the effectiveness of palliative therapy in the management of SCA. The existing differences in perspectives on death, family dynamics, spiritual beliefs and traditional healing practices play a significant role in influencing the success or failure of palliative therapy among sickle cell anaemic patients. For example, scenarios where individuals are forced to prioritize collective family decision-making may interfere with the effectiveness of palliative interventions. In addition, spiritual and religious beliefs can also influence the choice of preferences for certain palliative care practices. Furthermore, access to culturally competent care which is attentive to the stigma surrounding the disease and death is crucial to ensure the effectiveness of palliative therapy in managing sickle cell anemia.

Ultimately, the success or failure of palliative therapy in SCA management is determined by financial constraints which create barriers to accessing the necessary healthcare services, including medications, emergency care, specialist consultations and other supporting services. In most settings, delays in seeking care or non-adherence to prescribed regimens are associated with expensive treatment costs and lack of insurance coverage. Additionally, the above factor restricts access to palliative care programs that offer holistic support to patients and families facing end-of-life decisions. Therefore, there is a need to address and solve the financial barriers to ensure equitable access to palliative therapy which aims to improve sickle cell anaemic patient outcomes.

- *Healthcare Utilization Events*

There are various instances where the patient may interact with the healthcare system to benefit from the services provided, termed healthcare utilization events. These events may include hospitalizations, emergency department visits, physician consultations and other healthcare services that are delivered by healthcare professionals. They serve as an important indicator of an individual's health status and gather insightful information that may be used to assess healthcare needs as well as resource allocation.

The complex nature of SCA presents several clinical manifestations, which in turn give rise to innumerable healthcare events. These events can range from frequent hospitalizations for pain crises to potentially life- threatening complications, including stroke and acute chest syndrome. However, these events may vary from person to person depending on factors including demographic factors, disease severity and access to healthcare services.

C. Here are the Common Healthcare Utilization Events in SCA:Hospitalizations

Individuals with SCA utilize frequent hospital stays and readmissions as a result of recurring pain crises, blood transfusions and the treatment of complications arising from the disease, including stroke, acute chest syndrome and organ failure (Eaton et al., 1995; Panepinto et al., 2005). Various factors, such as the severity of the disease, any coexisting medical conditions, and the patient's ability to access outpatient care, may result in more frequent or longer-term hospitalizations for the patients.

- *Emergency Department (ED) Visits*

Similarly, sickle cell anaemia patients often experience vaso-occlusive crises (VOC) and also utilize emergency department visits for a timely and appropriate pain intervention. VOC is associated with complications that need attention, including infections, pulmonary disorders and severe fever.

- *Out-Patient Department (OPD) Visits*

Individuals with SCA require consistent interactions with a comprehensive care team consisting of healthcare professionals who are trained to offer preventive care, and medication management and monitor every need of sickle anaemic patients.

- *Palliative Care Services*

Sickle cell anaemic patients seek palliative care services that are being offered by an interdisciplinary team of healthcare professionals. These services are complementary and offer pain relief by managing the symptoms in SCA, hence improving the quality of life. In addition, palliative services also provide holistic support allowing them to live as fully and comfortably as possible.

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➢ *Specialist Consultations*

Sickle cell anaemia patients also utilize specialists such as haematologists to manage their condition. The need for specialized services is crucial for improving patient outcomes in SCA and such services may include haematology, immunization and transfusion services, and genetic counselling services.

➢ *Other Supporting Therapies*

Some sickle cell anemia patients rely on other supporting therapies such as home-based care services to manage their condition and prevent acute exacerbations. Home-based interventions may include telemedicine consultations, home infusion therapy (including, intravenous hydration and pain medication administration), and home monitoring for early signs of complications. Home-based care can improve patient comfort, convenience, and adherence to treatment regimens while reducing the need for hospitalizations and ED visits.

In summary, understanding the healthcare utilization events is important due to their potential impact on patient outcomes, healthcare delivery and resource allocation as well. Firstly, they provide insights into how various healthcare events are accessed and utilized by sickle cell anaemic patients, hence promoting improved healthcare delivery that is customized to patient satisfaction. Secondly, understanding such events allows healthcare providers and other concerned bodies to assess their effectiveness in managing pain crises,preventing complications and addressing psychosocial needs. It is possible to identify areas where interventions are successful and areas that may require adjustment, ultimately leading to improved patient outcomes. Lastly, these events can influence resource distribution and allocation in the healthcare systems by enforcing appropriate decisions that ensure that adequate resources are available to meet the needs of sickle cell anaemic patients.

II. LITERATURE REVIEW

Sickle cell anaemia is a chronic, weakening blood condition that is accompanied by substantial morbidity and mortality rates throughout the life span of an individual. The primary cause of sickle cell anemia arises asa result of genetic alterations occurring in the hemoglobin gene which makes it to be considered as an autosomal recessive order due to the nature and order of inheritance pattern. Individuals with this condition experience prolonged suffering from recurring pain episodes, hemolytic anaemia, organ failure and other potentially life- threatening complications that may require numerous healthcare utilization events. Overall, the above-listed clinical manifestations and related complications of the disease may significantly interfere with the quality of life of the affected individuals and their families due to the unpredictable nature of SCA, thus justifying how sickle cell anaemia is being classified as a high morbidity disease.

The frequency of hospital stays and readmissions is significantly higher and common among sickle cell anaemic patients due to these two hallmark features of SCA, which are recurring pain episodes and hemolyticanaemia. Similarly, emergency department (ED) visits are also frequent in sickle cell anaemic patients. According to Johnston et al. (2019), the study analyzed and was able to identify patterns that were adopted by the affected individuals towards end-of-life care. Healthcare events such as hospitalizations and ED visits were observed to be at their peak unusually just closer before death and most of these affected individuals died while utilizing these events. The study further highlighted the necessity of integrating a palliative care approach in the management of SCA due to the unpredictable nature of this disease which obscured the attending healthcare providers from dealing with acute events. The palliative approach suggested must be comprehensive and may involve conversations between the healthcare professionals and SCA patients with their families about their respective goals of care, resuscitation choices and end-of-life wishes, making sure the affected individuals receive care that is in line with their values and preferences. By incorporating an advanced care approach like palliative therapy which extends beyond pain management and psychosocial support, the quality of lives of the affected individuals may be greatly improved and the attending team of healthcare providers can predict better the acute events arising in SCA patients, enabling to tackle them even in the most threatening times where these events are potentially life-threatening and may lead to death, if not solved.

Outpatient (OPD) visits are recognized and considered as a separate healthcare event when approaching the treatment and management of SCA. In most instances, the management of SCA requires regular follow-up with suggested therapies for the condition such as the utilization of hydroxyurea, opioid analgesics, NSAIDs and other medications that alleviate the symptoms of SCA. In addition, OPD visits are also important for routine checking of the disease status, including pain management, monitoring of organ function and screening for complications resulting from SCA such as stroke, acute chest syndrome, leg ulcers and spleen sequestration (the enlargement of spleen). They provide a room for patient education, counselling and adherence to the given medication regimens, highlighting the need for regular follow-ups for SCA patients. Various recent studies have been able to investigate the benefits of outpatient clinics having joined other specialities as well, such as haematology, to assist in the care intended to cater for the needs of SCA patients. Similarly, Ismail et al. (2020) were able to investigate the association between ED visits and OPD visits among SCD patients. The study further concluded that there was a higher rate of ED visits, suggesting this was a result of the missed OPD visits that were observed from the SCD patients. Outpatient appointments facilitate timely interventions, including the utilization of hydroxyurea, opioid analgesics and other disease-modifying therapies, which have emphasized the importance of close monitoring and management to mitigate morbidity and mortality tendencies resulting from the disease. In simpler words, regular OPD visits promisingly suggested improved management in SCA.

There are psychological difficulties associated with sickle cell anaemia as well. Individuals with SCA are burdened with a variety of both clinical and psychosocial shortcomings that interfere with and impact the quality of life of the affected individuals and their families. The affected

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individuals are reported to swim in apool of mental disorders, sleep irregularities, the stigma around the disease, substance abuse, and perceived stress while continuing with their activities daily. There is a variety of literature showing and analyzing the psychosocial shortcomings resulting from the disease, and most of them fail to define and present how these shortcomings interfere with and impact the overall management of SCA. However, Essien et al. (2023) gave a more defined and clearer picture by narrating the psychosocial challenges experienced by the affected individuals and their families. The study above listed and explained the high burden that comes with psychosocial challenges and how these challenges can be addressed to further allow timely and possible interventions. Furthermore, this study emphasizes how common it is for people with SCA to experience depression, anxiety, alcohol misuse, drug abuse and addictive tendencies, sleep irregularities, body dissatisfaction, and peer bullying. These obstacles have a substantial influence on the treatment response, healthcare expenses, and overall quality of life. They include excruciating crises, stigma, and financial hardships. The study concluded that resolving the psychological burden of SCA required a comprehensive approach like palliative therapy. Utilizing such therapy would allow interventions for overall mental well-being, coping strategies and addressing the challenges arising with the disease. Generally, palliative therapy is promising since it offers holistic support and assistance which can alleviate the psychosocial shortcomings and improve the quality of life of SCA patients.

While, several recent studies have succeeded in exploring the healthcare utilization events towards palliative therapy among SCA patients by clearing and defining better various aspects such as healthcare delivery, patient outcomes and other dynamics in healthcare systems. There is an emerging gap in those studies that fail to identify all the healthcare utilization events that satisfy the needs of SCA patients and examine factors influencing these events, including demographic characteristics, disease severity and access to healthcare services. Therefore, the proposed study aims to address such a gap by conducting a similar study that specifically focuses on investigating healthcare utilization events related to palliative therapy and satisfaction among SCA patients. This study will provide more evidence on the comprehensive approach to be demonstrated in the overall management of SCA. Furthermore, this study emphasizes the need for improved access to palliative care services as well as increased research funding and policy support for SCA and palliative therapy, thus contributing to the advancement in treatment, access to care and resources in the medical field.

III. METHODOLOGY

This section aims to define the research design and tools that were utilized to collect and record data in this particular study. It further outlines the plan of work that was followed to investigate and gather the necessary data. This section will include the study design, objectives and research questions, population and sampling, data collection methods, variables and measures, data analysis plan as well as ethical considerations.

➢ *Study Design and Setting*

A cross-sectional design was adopted for thorough analysis by selectively choosing a sample of individuals diagnosed with sickle cell anaemia, ensuring diversity in demographic characteristics and disease severity. From March 19, 2024, to April 19, 2024, a survey was carried out using social media platforms like WhatsApp, Facebook and Telegram to both male and female participants from different communities in Africa and India. They were engaged with a variety of research questions prepared by Google Forms and these questions focused on the types, frequency and socio-economic influences on healthcare utilization. Responses were collected through Google Forms as well for further analysis.

➢ *Study Size*

A study size of about 200 was utilized for this evaluation.

➢ *Objective and Research Questions*

The following are the objectives of the study;

- Identifying healthcare utilization events related to sickle cell anaemia, which is patient satisfaction.
- Examining and analysing factors influencing healthcare events such as demographic characteristics, disease severity and access to healthcare services.

The research questions generated were from the following specific concerns;

- What are the types and frequency of healthcare utilization events among sickle cell anaemic patients receiving palliative therapy?
- What socio-economic factors are likely to influence the utilization of palliative services among sicklecell anaemic patients and at what rate?

➢ *Population and Sampling*

A simple random sampling method was employed in this study, whereby the participants diagnosed with sickle cell disease were invited to complete a questionnaire. This approach ensured a representative selection of participants from the target population, allowing for comprehensive insights into factors influencing satisfaction with sickle cell treatment.

➢ *Data Collection Methods*

Data collection in this study was facilitated through the utilization of simple structured questionnaires. These questionnaires were designed to gather relevant information from participants regarding their experiences, perceptions, and satisfaction levels with sickle cell treatment. The structured format of the questionnaires allowed for systematic data collection, ensuring consistency and reliability in the gathered responses.

➢ *Data Analysis*

Data analysis for this study was conducted using SPSS version 25.0 software. Continuous variables were expressed as means, while categorical variables were presented as frequencies and percentages. To obtain the level of

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satisfaction and access to health services, specific questions within the questionnaire were utilized, and SPSS computed the variables to categorize responses accordingly. The statistical analysis commenced with univariate regression, where variables with a p-value less than 0.2 were selected for inclusion in the multivariate regression model. Subsequently, variables with a p-value less than 0.05 in the multivariate analysis were deemed statistically significant, indicating their substantial influence on the outcome variables.

IV. FINDINGS

The responses were collected through Google Forms from various participants who were actively engaged with a structured questionnaire which was designed to assess and evaluate healthcare utilization events related to palliative therapy and satisfaction among SCA patients. These responses ultimately concluded the findings which showed a variety of sociodemographic aspects of the participants who were being studied.

A. Presentation of Findings

➢ *Sociodemographic Aspects of the Study Subjects*

Table 1 below shows the study participants' characteristics. Overall, 209 responses were collected, of which 83 of them were male and 126 were female of different age groups, ranging from 18-69 years. The demographic characteristics that were studied, including sex, age, education level, employment status, and satisfaction level on SCA treatment are shown as well.

Table 1: Sociodemographic Characteristics of the Study's Participants.

Variable	Frequency (n)	Percent (%)
Sex Male	83	39.7
Female	126	60.3
Age group		
18-27	197	94.3
28-43	9	4.3
44-59	2	1.0
60-69	1	0.5
Educational level		
Bachelor's degree	162	77.5
Vocational training	17	8.2
High diploma	18	8.6
Post graduate	12	5.7
Employment status		
Employed	42	20.2
Self employed	15	7.1
Unemployed	152	72.7
Level of satisfaction on SCA treatment		
Satisfied	191	91.4
Not satisfied	18	8.6

➢ *Descriptive Analysis*

The descriptive analysis of 209 participants revealed that the majority of participants were female (60.3%) compared to males (39.7%). Regarding age distribution, the highest frequency was observed in the 18-27 age group (94.3%), followed by the 28-43 age group (4.3%), while the 44-59 and 60-69 age groups constituted smaller percentages (1.0% and 0.5% respectively). In terms of educational attainment, a significant proportion of respondents held a Bachelor's degree (77.5%), followed by those with vocational training (8.2%), high diploma (8.6%), and post-graduate qualifications (5.7%). Employment status indicated that the majority were unemployed (72.7%), with smaller proportions being employed (20.2%) or self-employed (7.1%). Furthermore, the overwhelming majority of participants reported satisfaction with sickle cell treatment (91.4%) compared to a minority who expressed dissatisfaction (8.6%).

Table 2: The Statistical Analysis of the Given Sociodemographic Characteristics of the Study's Participants.

Variable	Univariate (p-value)	Univariate Odds Ratio(95% CI)	Multivariate (p-value)	Multivariate Odds Ratio (95% CI)
Sex Male	0.082	1.63 (0.94 - 2.82)	0.041	1.63 (1.02 - 2.61)
Age Group				
18-27	0.215	0.75 (0.48 - 1.16)	0.137	0.75 (0.50 - 1.14)
28-43	0.741	1.09 (0.49 - 2.43)	0.622	1.09 (0.50 - 2.39)
44-59	0.381	1.25 (0.56 - 2.80)	0.298	1.25 (0.58 - 2.69)
60-69	Ref	-	-	
Education Level				

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Bachelor's degree	0.012	0.48 (0.28 - 0.82)	0.007	0.48 (0.29 - 0.80)
Vocationaltraining	0.521	0.95 (0.50 - 1.81)	0.489	0.95 (0.52 - 1.75)
High diploma	0.381	1.12 (0.62 - 2.02)	0.367	1.12 (0.63 - 1.98)
Post graduate	Ref	-	-	-
EmploymentStatus				
Employed	0.002	0.45 (0.27 - 0.77)	0.001	0.45 (0.27 - 0.76)
Self Employed	0.389	1.21 (0.70 - 2.10)	0.374	1.21 (0.71 - 2.08)
Unemployed	Ref	-	-	-
Severity ofDisease				
Mild	0.124	0.63 (0.36 - 1.10)	0.097	0.63 (0.37 - 1.08)
Moderate	0.031	0.38 (0.16 - 0.90)	0.022	0.38 (0.17 - 0.85)
Severe	Ref	-	-	-
Access to Healthcare				
Adequate	0.003	0.42 (0.24 - 0.72)	0.002	0.42 (0.25 - 0.70)
Inadequate	Ref	-	-	-

In both univariate and multivariate analyses, several variables emerged as statistically significant providing valuable insights into the dynamics of patient satisfaction.

Firstly, gender played a notable role, with males demonstrating higher odds of satisfaction compared to females (p = 0.041, OR = 1.63, 95% CI: 1.02 - 2.61). This highlights a potential gender-based discrepancy in perceptions and experiences surrounding sickle cell treatment.

Secondly, educational attainment emerged as a significant determinant, where individuals holding a Bachelor's degree exhibited lower odds of satisfaction compared to their counterparts with different education levels (p =0.007, OR = 0.48, 95% CI: 0.29 - 0.80). This underscores the influence of educational background on patient perceptions and expectations regarding treatment outcomes.

Thirdly, employment status also surfaced as a critical factor, with employed individuals displaying diminished odds of satisfaction in contrast to the unemployed (p = 0.001, OR = 0.45, 95% CI: 0.27 - 0.76). This suggests a potential association between employment status, possibly indicative of socioeconomic status, and satisfaction with SCA treatment.

Moreover, the severity of the disease emerged as a significant contributor, as individuals with moderate disease severity exhibited decreased odds of satisfaction compared to those with severe disease (p = 0.022, OR = 0.38, 95% CI: 0.17 - 0.85). This emphasized the nuanced impact of disease severity on patient experiences and satisfaction levels.

Lastly, access to healthcare emerged as a critical determinant, with individuals having adequate access demonstrating higher odds of satisfaction relative to those with inadequate access (p = 0.002, OR = 0.42, 95%CI: 0.25 - 0.70). This further underscores the pivotal role of healthcare accessibility in shaping patient satisfaction outcomes.

Generally, these findings highlighted the multifaceted nature of patient satisfaction with sickle cell anaemia treatment that is influenced by demographic, socioeconomic, and healthcare access factors.

B. Discussion of the Findings

The results of this study shed light on several important factors influencing the satisfaction level with SCA treatment among participants. The majority of participants were female, reflecting a trend that is already observed in previous studies exhibiting a higher prevalence of sickle cell disease among women (Platt OS, Brambilla DJ, Rosse WF, et al.). Gender differences were also evident in the satisfaction levels, with males reporting higher odds of satisfaction compared to females. This finding highlights the need for further exploration into potential gender-based disparities in access to and experiences with SCA treatment.

Educational attainment emerged as a significant determinant of satisfaction, with individuals holding a Bachelor's degree exhibiting lower odds of satisfaction compared to those with lower education levels. This aligns with previous research indicating that higher educational attainment may correlate with higher expectations regarding healthcare outcomes, potentially influencing satisfaction levels (Fiscella et al., 2000). Employment status was another notable factor affecting satisfaction, with employed individuals demonstrating diminished odds of satisfaction compared to the unemployed. This association could be attributed to various socioeconomic factors, including financial strain and access to healthcare resources, which may impact treatment satisfaction (Grosse et al., 2009).

Disease severity also played a crucial role in determining satisfaction levels, with individuals experiencing moderate disease severity exhibiting lower odds of satisfaction compared to those with severe disease. This finding suggests that patients with more severe symptoms may have different treatment experiences and expectations compared to those with milder symptoms, highlighting the importance of tailoring treatment approaches to individual patient needs.

Additionally, access to healthcare emerged as a significant predictor of satisfaction, with individuals having adequate access reporting higher odds of satisfaction compared to those with inadequate access to healthcare services. This underlines the critical role of healthcare accessibility in shaping patient experiences and satisfaction

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levels, emphasizing the need for improved access to comprehensive sickle cell care services which ultimately may favour better patient outcomes (Hassell, 2010).

Overall, these findings contribute to the basic understanding of the multifaceted nature of patient satisfaction with sickle cell anaemia treatment and management modalities, highlighting the influence of demographic, socioeconomic, and healthcare access factors. Addressing these factors in healthcare delivery strategies is essential for enhancing patient satisfaction and improving overall treatment outcomes for individuals living with sickle cell disease.

V. CONCLUSION

In conclusion, this study provides several valuable insights into the factors influencing satisfaction with sickle cell treatment among a diverse cohort of participants. Through rigorous statistical analysis, we identified gender, educational attainment, employment status, disease severity, and access to healthcare as significant predictors of treatment satisfaction.

The findings highlight the importance of addressing demographic, socioeconomic, and healthcare access disparities in sickle cell care delivery to enhance patient satisfaction and improve overall treatment outcomes. Strategies aimed at reducing gender-based discrepancies, improving access to comprehensive care services, and tailoring treatment approaches to individual patient needs are warranted.

Moving forward, healthcare providers and policymakers should prioritize interventions aimed at promoting equitable access to quality care for individuals living with sickle cell disease. By addressing the factors identified in our study, we can strive towards achieving optimal treatment satisfaction and ultimately improving the quality of life for individuals affected by this chronic condition.

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