CAREGIVERS' PERCEPTION OF THE INFLUENCE OF INTERPERSONAL COMMUNICATION ON STEREOTYPING CONTENT SURROUNDING THE SICKLE CELL DISEASE

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DECLARATION

This research is my original work and has not been presented for a degree or any other award in any other university.

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DEDICATION

I dedicate this project to all the SCD warriors and their caregivers at the Children Sickle Cell Foundation (CSCF).

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AIDS	Acquired Immune Deficiency Virus
CSCF	Children Sickle Cell Foundation
HCPs	Health Care Providers
HIV	Human Immunodeficiency Virus
NBS	New Born Screening
NGO	Non-Governmental Organizations
NPO	Non-Profit Organizations
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
UN	The United Nations
WHO	World Health Organization

ABSTRACT

It is estimated that 14,000 children are born with Sickle Cell Disease (SCD) every year in Kenya. The absence of mass awareness and institutionalized newborn screening and management of SCD is a major concern leading to high morbidities and mortality rates among children under five years. The SCD is prevalent in Kenya, affecting 18 counties, with Nyanza, Western, Coastal and Nairobi regions leading among the counties. In 2008, the United Nations General Assembly ratified World Sickle Cell Day in order to increase awareness about the condition. Despite these efforts at the international level, Kenya, like most sub-Saharan countries, has yet to formally recognize SCD as one of the illnesses that need nationwide awareness as is the case with HIV/AIDS and cancer. More distressingly, there are numerous stereotypes surrounding SCD stemming from cultures and even individual tribes are a barrier to health-seeking behaviours thus making it difficult to diagnose and manage. Against this background, this study investigated SCD caregivers' perceptions of the influence of interpersonal communication on stereotyping content surrounding Sickle Cell Disease in Kenya. The study determined the content of stereotypical information surrounding Sickle Cell Disease as perceived by the caregivers visiting the CSCF clinic, established the perceived influence of interpersonal communication on SCD-related stereotype content by the caregivers visiting the CSCF clinic and determine the relationship between interpersonal communication, stereotyping content and management of SCD. The study specifically focused on caregivers who attend to SCD patients and visit the Sickle Cell Foundation (CSCF) Clinic at Baraka Health Center in Mathare, Ruaraka Sub-County, Nairobi County. The study also targeted the healthcare providers who offer services at the Baraka Health Centre. Using the sample size formula, 100 caregivers and health practitioners were selected. Focus group discussions, key informant interviews, and questionnaires were used to collect data. Data were analysed using SPSS Version 24 and NVivo 11 for quantitative and qualitative data respectively. Findings show that there is a high level of awareness among caregivers about SCD and could discern stereotypes linked with the condition. There is also a knowledge awareness gap among the general population based on caregivers' responses to how the rest of the public perceived them. Caregivers also cited that they live an atypical life because of the discrimination and stereotypes prevalent by the general public towards them as well as the patients. In conclusion, it can be inferred that interpersonal communication strategies used by the CSCF which include education, training, counselling, peer-to-peer support and dissemination of information, education and communication materials among the caregivers have been successful in dispelling stereotypical content associated with SCD among the caregiver.

CHAPTER ONE

1.1 Introduction and Background to the Study

Health communication entails the strategic use of communication channels to create awareness and shape people's perception of a certain aspect of health, as well as enhance knowledge, attitudes, and practices regarding communicable and non-communicable diseases (Richard, 2006). The objective of health communication is to support, engage and influence people to introduce, maintain, adopt, or champion a policy, practice or behaviour that will eventually enhance health outcomes. This discipline has different dimensions and multidisciplinary approaches to reach various recipients and share information related to health (Renata, 2013).

Health communication uses multiple channels and approaches key among them, interpersonal communication. Interpersonal communication is used in our normal day-to-day communication mostly in one-on-one or group meetings and daily conversations (Renata, 2013). Several cultural factors influence interpersonal communication behaviour. Although each person uniquely interacts with others, social norms, customs, and beliefs within a given community or section also play a significant part in how behaviour and messages are received and perceived. Social and other cultural factors are vital in interpersonal interactions and communication. Therefore, communication needs to be sensitive1to1belief and1attitude, which plays a key role in shaping our perceptions.

Perception is defined as the method through which a person selects and analyzes data to generate a meaningful understanding of the world. People's perceptions influence how they understand and respond to another person in the context of interpersonal communication (Solomon, 2013). Perceptions are highly influenced by the stereotypes held by interlocutors. Stereotypes often relate to oversimplified assumptions about individuals who fit into specific social groups. When people stereotype, it typically results in judgements, actions, and interpersonal communication patterns that support the stereotype. As a result, stereotyping has an impact on how individuals interact with others they have stereotyped.

This study will focus on caregivers' perception of the influence of interpersonal communication on stereotyping content of Sickle Cell Disease (SCD); most prevalent monogenetic illness with devastating effects such as physical deformities as well as high infant childhood mortality rates. Simply put, caregiving is the process or act of providing care services to others who, due to illness or condition, are lacking in or have lost the independent capacity to perform some basic functions on their own (Olagundoye & Alugo, 2018). Caregivers are important actors in caring for persons with SCD thus their views on the stereotyping of SCD are important in shaping how interpersonal communication can be employed to diminish the knowledge gap that creates a vacuum leading to the advancement of stereotypes which is a catalyst for social discrimination and societal prejudice.

1.1.1 Role of Interpersonal Communication in the Health Context

Interpersonal communication is essentially communication that occurs among individuals within the health communication sphere (Solomon, 2013). Interpersonal communication frequently takes place in face-to-face conversations and occasionally across a communication channel. Through interaction, individuals may express themselves both orally and nonverbally, using words, gestures, and body language.

According to World Health Organization (2003), health communication programs that aim to influence behaviour or society must prioritize interpersonal communication as a key action area. It includes conversations between healthcare providers and patients, counselling, and personal selling—two activities that can be applied to a variety of stages and facets of the communication process. Personal selling is a one-on-one interaction with individuals in their homes, places of work and leisure. It depends on active listening and is premised on social and behavioural theories, and the capacity to understand and relate to the requirements and cultural preferences of the target audience and effectively address them. Personal selling and counselling fall under this category.

Several cultural elements that affect how we perceive things have an impact on how we interact with others. Although each person uniquely interacts with others, social norms, customs, and beliefs within a given group community also play a significant effect in how behaviour and communication occur and are received and perceived. 1All encounters contain signs and symbols, both1verbal and1nonverbal, that add to the understanding of behaviour1and communication acts.

Parents with children suffering from sickle1cell disease who have shown to have good views about open communication, but who request greater help from healthcare professionals in the process, have been investigated more extensively Ulph et al. (2011). As a result of efforts from parents to shelter children from potentially distressing information, healthcare practitioners have had difficulty encouraging open family communication Ulph et al. (2010).

Additionally, interpersonal interactions and connections with people who formerly shared one's sociocultural values and views might be impacted by personal experiences (Theiss, 2013). Caregivers and children with SCD are likely to encounter numerous kinds of communication from various points of contact, as they grow and get socialized to their situation. A health-care professional's responsibility, for example, is to have frank and truthful conversations with relatives and minors; nevertheless, caregivers may fail to disclose data to spare the children from unnecessary grief (Ayme et al., 1993; Ulph et al., 2010).

The SCD patients' views of discriminatory encounters with healthcare1providers are linked to worsening adherence to medical advice, which might be a significant reason for health and health quality discrepancies within this patient population. Interpersonal channels (e.g., coaches of the intended audiences, family members, physicians, counsellors, parents, friends and clergy) provide a familiar environment for health messages to be shared and distributed in communities (Richard, 2006).

Perceived discrimination appears to influence adherence behaviours via the patient trust route. Improving connections between healthcare providers and SCD patients and caregivers may increase patients' trust in medical experts, which may lead to better results for this underserved patient population. In different cultures, signs and symbols can take on diverse meanings. Social cues, facial and idiomatic expressions, and posture, all have an impact on interpersonal relationships. Because stereotyped tendencies on SCD are culturally produced, transmitted, and moulded, it is crucial to be mindful of cultural differences when evaluating people's behaviour as they may have a significant impact on the dynamics1of1interpersonal behaviour.

1.1.2 Communication and the Management of SCD

There are several challenges in identifying, diagnosing, managing, and preventing/controlling SCD key among them being poor communication strategies. For many years, poor communication systems and mechanisms have kept the public and health-care professionals in the dark about the nature of the disease, its management, and its control aspects. Resource constraints at the national level have limited budget prioritization for disease management and further research (Mubyazi & Njunwa, 2012).

The effectiveness of sincere communication efforts is frequently undermined by a lack of comprehension of these disparities. Comprehending how cultural factors and how society interprets them often has a positive impact on interpersonal conduct vis communication. This could improve how the patients relate with the healthcare givers and their treatment. There is also a likelihood that a given group or population will be able to control the spread of disease, to name just a few potential benefits.

Interpersonal communication has been used in Kenya to help realize Sustainable Development Goals (SDGs) majorly in the field of maternal health, reproductive health, poverty alleviation, general health and well-being, sustainable environment and peacekeeping. In terms of health communication interventions, interpersonal communication has been of immense value. In certain situations, however, interpersonal communication has been used to propagate stereotypical tendencies regarding a disease. For example, SCD has been surrounded by cultural misconceptions slowing the management of the disease stemming from fear of discrimination and prejudice among patients and caregivers of the disease. Particularly in Africa, SCD is associated with countless myths, cultural connotations and beliefs. Buser et al (2020) noted that beliefs in the community are that SCD comes as a result of a curse, or “brought disease,” which locals call “nto yare.” or “duabo”. Many people had the opinion that the impacted family had sinned against the gods or had been bewitched. Some people believe that SCD is a generational issue that has been passed down from ancestors from a bygone era. The study's caregiver participants believed that there should be better public health education, and a push for increased regional and federal funding for SCD. According to them, public attention in raising awareness will aid in dispelling ingrained cultural misconceptions and beliefs that people with SCD are "devilish children" and descend from the "marine spirit" Buser et al., (2020).

Myths of SCD disease are a big part of how many African communities tried to explain the existence of SCD. The Igbo tribe of Nigeria views children with SCD as being malevolent ogbanje. A common believe among the Igbo people is that each and every person is an ogbanje (a form of reincarnation), but malicious ogbanjes stand out from other ogbanjes in that they are enthused by vengeance, manifest in lasting ailments, and go through several cycles of death and reincarnation, according to Nzewi (2001). Communities in the Upper East region of North Ghana, according to Boche, D, et al. (2010), hold that certain children are infanticide victims because they are thought to be spirit children sent "from the bush." The family had severe misfortune since the spirit children were thought to be acting maliciously. After being identified as spirit children, they were sent "back to the jungle" and allowed to perish.

To understand how early experiences with SCD in families with young affected children affect relationships within families, Marsh et al. (2011) did a study on the rural Coast of Kenya. As part of the story they uncovered, SCD is described in Kiswahili as *"homa ya mifupa"* (loosely translated as ‘bone flu’) or "*ukongo ya misozani*" in Kigiriama because it frequently manifests in childhood as a strange and terrible disorder. According to the study, women are frequently held responsible for SCD, especially when multiple children are affected. According to Yusuf et al. (2011), information and awareness-related initiatives are crucial parts of successful public health strategies for lowering morbidity and mortality among SCD patients. Following up on newborns who have positive New Born Screening (NBS), findings can provide a chance to advance the public’s understanding of and ability to prevent issues. Direct counselling, entertainment education, the supply of information materials, and referring to other sources are some of the potential means of delivering such information.

Misconceptions lead to stigma, which is one of the major challenges that persons living with SCD together with their caregivers face. According to Kombi et al. (2020), a population's ignorance and misconceptions about SCD have been cited as obstacles to sickle cell treatment. It is thought that witchcraft, magical spells, curses, or water spirits cause unexplained illnesses such as SCD. These false beliefs could result in hostility toward SCD sufferers. It is impossible to overstate the significance of health communication and information in dispelling myths and misconceptions about SCD. According to Oron, A. P.,et al. (2020), there are many myths and misconceptions of sickle cell disease (SCD), which emphasizes the significance of using interpersonal communication as well as indigenous or vernacular language and communication techniques to raise awareness and combat stereotypes about the condition.

1.1.3 Stereotypical Content as Barrier to Health Communication

In the classification of people, stereotypes are the categories of substance. People’s interactions with strangers are greatly influenced by the prejudices they hold (Settle, 2018). When people stereotype, they derive suppositions about the whole group founded on assumptions. Stereotypes which result in disjointed healthcare communication have a direct correlation to deferred treatment, improper diagnoses, medicine errors, harm to the patient, or patient death (Agyemang-Duah, et. al. (2021).

Jenerette and Brewer (2010) published extensively on the verbal and non-verbal abuse that persons with SCD and their caregivers face in healthcare on top of the pain associated with the condition. Health care professionals often have misconceptions or misplaced beliefs that individuals with SCD have greater rates of opiate addiction. Medical professionals frequently categorize SCD patients among drug addicts. These unfavourable attitudes among medical practitioners obstruct effective health communication and pain control in SCD Brennan-Cook et. al., (2018). Lack of proper pain management among SCD patients is also a cause of frequent hospitalization.

Due to the stereotyping associated with the condition and the feeling of bias and stigmatization around SCD, patients may believe they are receiving a different type of treatment or therapy and experience a lower quality of life Rodrigues et al., (2021). Studies by Leger et al (2018) have elaborated that stereotyping of dangerous ailments such as epilepsy, HIV/AIDS or SCD has proven that patients and caregivers are constantly faced with the dilemma of whether to disclose their condition for fear of associated stigma. Pain brought about by SCD and its complications have a detrimental effect on the family's physical, social, emotional, psychological, and divine well-being. The situation is worsened by communication barriers that are a result of stereotypical content surrounding SCD Adegoke & Kuteyi, (2012). When patients feel judged, they are less likely to observe their treatment plan Marsh et. al., (2011).

Health communication takes place not just between a health professional and other health professionals or clients but also between clients and the general public. Individuals' capacity to affect one another's attitudes and ideas about health and it's important to respect differing viewpoints. When making health decisions at various phases support, help and even advocacy of a non-professional may be required along the procedure (Van Rensburg, 1996).

An essential strategy for combating stereotypes can be found in understanding the societal causes of prejudice. Strategies for combating stigma associated with HIV/AIDS have been demonstrated to be more effective than depending just on individual counselling techniques and community empathy-building, including lobbying, mobilizing impacted groups, and social transformation through judicial and legislative initiatives is vital (UNAIDS, 2005).

The stereotypes surrounding SCD prompted an investigation into the influence of interpersonal communication on stereotypical content towards SCD patients. Misconceptions and stereotypes lead to stigma, which is one of the major challenges that persons living with SCD together with their caregivers face. According to Kombi et al. (2020), a population's ignorance and misconceptions about SCD have been cited as obstacles to SCD treatment. According to popular belief, witchcraft, magic spells, curses, or water spirits are to blame for diseases like SCD. These false beliefs could result in hostility toward SCD patients. SCD is associated with many myths and misconceptions, which highlights the significance of health communication and education in dispelling these myths and misconceptions that hinder effective health communication (Kehinde et. al. (2020).

1.1.4. Sickle Cell Disease in the Global and Regional Sphere

Since the discovery of the first case of SCD in the United States of America (USA), effective methods for the management and treatment of SCD as well as the avoidance of complications have been made possible by scientific advancements. As a result, those with SCD live longer and are more successful than in the past. However, recent studies by Leger et al. (2018) on the effects of stigma in grownups with SCD showed that there exists a communication gap which leads to stereotypes, misconceptions and stigma of SCD warriors. Due to their need for opioids for pain management and (in some circumstances) their inability to clearly communicate their treatment plan, those affected by SCD have frequently been labelled as "drug seekers" or addicts and denied access to effective pain medication.

The pervasiveness of SCD in Africa is estimated to be at 2% in cases where the Sickle Cell Trait (SCT) exceeds 20%. According to the WHO (2009), the SCD has raised concerns in 40 out of the 54 countries in the African continent which 23 of countries are from West, Central and East Africa where the SCT is estimated to be between 20% and 30% in terms of prevalence in certain areas. Further, Western Uganda has the highest prevalence standing at 45%. To lessen the impact of SCD, the World Health Organization (WHO) has suggested a number of public health-focused policies. The solutions include raising awareness, promoting early detection, and enhancing the standard of care provided to those who are impacted (WHO, 2006).

Studies in Sub-Saharan Africa have noted a low level of awareness of SCD and the stereotypes that accompany the lack of awareness as a major impediment to the communicating care and management of SCD patients. Oron et al (2020) in a study on SCD stated that dealing with the stereotyping content of SCD is a crucial component of the public health package. Though not medical, it is one of its most difficult aspects and has thus far gotten little attention. The study recommended that to increase caregiver knowledge and collaboration, social acceptability, and provider competency, support awareness campaigns and sociological studies. It is critical to collaborate with and assist patients and caregivers as well as support and advocacy groups in this effort. Oredola et al (2022) recommended the use of native languages to help people learn about and comprehend the condition is crucial.

Antwi et al (2008) noted that any comprehensive care program's success for SCD is heavily dependent on educating parents and patients. Anionwu and Atkin (2001) observed that in Ghana and Benin, the caregivers of persons with SCD got comprehensive educational programmes on the care and maintenance of their children with SCD from the centres that had been set up by donors to support the newborn screening programme. The study by Antwi et. al. (2008) noted that public education through annual mass media campaigns is carried out to raise awareness about SCD in some parts of Ghana and Benin but that had not reduced the negative perception of SCD.

Research by Oyesomi et al. (2017) pointed out that in Nigeria's rural and some urban areas, where understanding of the issue is thought to be low, the use of indigenous language in media and interpersonal contact could assist combat misconceptions about sickle cell disease. There are various myths and misunderstandings about SCD. Oredola et al (2022) noted that the lack of understanding of the nature of SCD and the stigmatization of those who have it make it more difficult for patients and their families to cope. They have an influence on both the patients' and their families healthcare needs.

A study by Olupot-Olupot et al (2020), in Uganda revealed that it was astonishing how little the participants understood about SCD, particularly how it is acquired, even some of the most fundamental information. Many participants reported feeling stigmatized, which is a finding that is consistent with findings from other research by Marsh et. al. (2013) and Marsh, Kamuya, and Molyneux (2011). The study recommended the need for SCD education within the clinic and as well as the society at large.

1.1.5 Sickle Cell Disease in Kenya

Sickle Cell Disease (SCD) is the most common and has the worst prognosis worldwide in sub-Saharan Africa. Sadarangani et al (2009) noted the first notable survey on SCD in Kenya ran between 1987 and 1990. The survey revealed that the disease was more prevalent among communities in the lake belt of Western Kenya such as the Luo and Luhyas. In Coastal Kenya, the disease was prevalent among the Mijikenda as well as among the Somali and Turkana communities.

There have not been any recent comprehensive studies nationwide to determine the pervasiveness rate of SCD in Kenya. Williams et al. (2005) cite that the prevalence of Sickle Cell Trait (SCT) in Kilifi, on the Kenyan Coast is at 15%. Marsh et al (2013), defined SCD as a ‘silent’ problem with upsetting outcomes in the country. Kombi et. al. (2020), reported the prevalence of SCD to be 1.6% on the coast of Kenya. Suchdev et al. (2013) reported a prevalence rate of 1.6% with a mortality rate of 17% in western Kenya as cited by Kawuki et al (2019).

The first edition of the National Guideline for the Control and Management of Sickle Cell Disease in Kenya was unveiled in 2020. However, the guidelines do not speak to the framework to drive communications on SCD among stakeholders. Although the national guidelines acknowledge the stigma and day-to-day burden that confront caregivers and persons living with SCD, it does not elaborate on ways of integrating communication to create awareness of the condition and tackle stereotypical content that is associated with the disease. Further, the guidelines do not provide a roadmap for the implementation of national directives in the counties being that health is a devolved function.

The lack of a comprehensive strategy, communication policy and guidelines on SCD in Kenya has prompted non-profit and nongovernmental organizations (NGOs) to support groups in order to fill the existing awareness gap. However, most of them are poorly funded and poorly structured to carry out awareness creation on a large scale. Counselling, though interpersonal communication, is widely recognized as an essential aspect of controlling, managing and dealing with the social and economic burdens brought about by genetic problems. Wang et al (1992) Further, technology, social media, and advertising campaigns may all be used in interventions against stereotypes. Counselling and support groups for SCD warriors and caregivers may also assist reduce stigma and affirm patients' experiences (Kimberly et al., 2016).

The WHO (2006) proposed pre-reproductive screening and genetic counselling before marriage for couples intending to get married as it had been done successfully in countries such as Canada, Cyprus, the Islamic Republic of Iran and the Maldives. The WHO (2010) advises that New Born Screening (NBS), proper surveillance and training at the community level to ensure primary health care is enhanced and more awareness created on the associated problems caused by SCD in order to lengthen the survival rate of affected individuals. It is crucial to have better knowledge of how stereotyping which results in the stigmatization of genetic disorders, including testing, might happen before establishing risk-reduction initiatives like counselling, informed consent, and disclosure procedures. These have been highlighted in settings of developed countries by the implementation of SCD screening inside of public health initiatives (Marsh et al., 2011).

1.1.6 The Children Sickle Cell Foundation (CSCF)

At its 60th Session in 2010, the WHO Regional Office for Africa recommended that partnerships be nurtured among healthcare provides, patients, parents, interest groups, NGOs, and the media to support public education and encourage screening among community members. Due to a lack of awareness and advocacy for SCD by health ministries in African countries, NGOs and Non-Profit Organizations (NPOs) such as CSCF are taking it upon themselves to create much-needed awareness as well as support for affected individuals and their families.

Founded in the local community, the Children Sickle Cell Foundation (CSCF) is a non-profit organization that works to enhance the lives of those who have Sickle Cell Disease. The Foundation was established in 2001 by parents who had children suffering from SCD under the patronage of their haematologist. The CSCF was founded in Nairobi out of frustrations faced by adults and caregivers of SCD patients in seeking treatment and management of the disease.

Today, the CSCF has a membership of over 540 persons living with SCD and their caregivers. The foundation currently has branches with elected representatives in Homa Bay, Busia, Siaya, Kisii, Migori, Kuria, Mombasa, Port Victoria, Bungoma and Kisumu. The organisation aims to support all patients with SCD and their caregivers in coping with the staggering hindrances and emotional difficulties that are a part of living with a genuine, persistent sickness that is under-subsidized, underestimated and the objective of much obliviousness, biased and debilitating void protests and overflowing shame.

The CSCF runs a clinic at the Baraka Medical Centre in Mathare Sub-County, Nairobi County, where haematologists and doctors volunteer consultancy services to needy persons living with CSD who live in Mathare and other surrounding informal settlements. The foundation also works in collaboration with specific county hospitals across the country to provide support to patients living with SCD. Funds raised by the foundation go towards purchasing medication for the needy members of the foundation as well as organising events that include support group programmes as well as communication with its members throughout the country.

The CSCF also helps caregivers form support groups. The importance of support groups cannot be gainsaid. Telfair and Gardner (2000) wrote extensively about the pivotal role of support groups. Support groups can lessen some of the psychological and social problems associated with Sickle Cell Disease that are developmental and condition-specific (SCD). The role of support groups such as the ones convened by the CSCF is advocating for the rights of persons with SCD, involving initiatives to fundraise and amplify the focus on the illness. The CSCF Kenya is leading the effort in advocacy, especially to the government and the health sphere in general in order to raise awareness about SCD and initiate action.

The CSCF uses several communication strategies in creating awareness of the treatment and management of SCD among its members and the public. Interpersonal communication is used extensively at the CSCF in training, support group meetings, advocacy, and management among others. It is also used to share information among caregivers, and advance doctor-patient communication to reduce the pain and burden resulting from SCD.

1.2 Problem Statement

The survival of SCD patients is increasing in several countries in Africa owing to better access to healthcare, socioeconomic progress, and quality education (Sadarangani et al., 2009). Despite this progress, Kenya does not have comprehensive information, education, communication and care programmes on SCD to create public awareness on treatment and management of SCD as well as appropriate communication strategies to demystify the stereotypes, myths and misconceptions that exist about the disease.

Awareness campaigns against conditions such as HIV/AIDS and cancer, among others, have been by and large successful because of sound legal and policy frameworks as well as goodwill by the government of the day. More importantly, extensive research has been conducted in these areas lending credibility to policy actions. These investment efforts are conspicuously missing in the management of SCD. This could, in part, be explicated by the inadequate body of academic work on SCD management and the plight of caregivers and healthcare practitioners creating a perfect environment for stereotypes and myths around this condition. This study seeks to bridge the knowledge and evidence gaps by focusing on the lived experiences of SCD caregivers and healthcare practitioners.

Interpersonal communication creates, shapes, and transforms culture. Interpersonal communication drives human relationships, therefore, affecting the knowledge, attitude, practices and perceptions of society. Stereotypical tendencies occur because of limited knowledge and a lack of scientific perspective of the specific phenomenon in society including diseases such as SCD. Stereotypes surrounding SCD are a barrier to health-seeking behaviour and adherence to treatment thus impeding social relationships, and psychological and behavioural outcomes of persons living with SCD and their caregivers.

1.3 General Objective

The main objective of the study was to investigate caregivers' perceptions of the influence of interpersonal communication on stereotyping content surrounding Sickle Cell Disease in Kenya.

1.3.1 Objective of the Study

1. To determine the content of stereotypical information surrounding Sickle Cell Disease as perceived by the caregivers visiting the CSCF clinic.
2. To establish the perceived influence of interpersonal communication on SCD-related stereotype content by the caregivers visiting the CSCF clinic.
3. To determine the relationship between interpersonal communication, stereotyping content and management of SCD.

1.3.2 Research Questions

1. What are the content and types of stereotypes surrounding SCD as perceived by caregivers visiting the CSCF clinic?
2. What is the perceived influence of interpersonal communication on SCD-related stereotype content by the caregivers visiting the CSCF clinic?
3. What is the relationship between interpersonal communication, stereotyping content and survivors?

1.4 Significance of the Study

This study will help in bridging the existing policy gap related to SCD awareness from a health communication perspective while also informing the best communication practices for improving the quality of life among patients with SCD. Accordingly, the study findings will contribute to a comprehensive communication policy relating to SCD to dispel stereotypes. In so doing, there will be a reduction in infant mortality rate and severity related to the disease in the long term. Such a communication policy would also aid in driving SDG Goal 3 ‘Good Health and Well-being’ by reducing the neonatal mortality rate and premature mortality. The formulation of a policy will guide the conversations and debates around SCD. It will also help in the creation of a national database, implementation plan and communication strategy to ease planning in the management of SCD.

In addition, the study will also contribute to SCD care and management knowledge by providing additional literature in the field of communication, and interventions in the management of SCD. The study will also inform communication strategies in creating awareness against stereotypical tendencies based on recommendations from the study on dealing with available communication gaps in the mitigation of SCD.

1.5 Scope of the Study

The study focused on caregivers’ perception of the influence of interpersonal communication on stereotyping content surrounding Sickle Cell Disease. The study focused on caregivers who attend the Sickle Cell Foundation (CSCF) Clinic at Baraka Health Center in Mathare, Ruaraka Sub-County, Nairobi County. The study also targeted the healthcare providers who offer services at the Baraka Health Centre.

1.6 Definition of terms

Interpersonal Communication: Daily conversations among caregivers, patients, health care providers and the surrounding community on the disease.

Stereotype: The cultural and societal connotations and denotations influencing negative relationships with the caregivers and patients

Content of Stereotypes of SCD: Stereotype messages encompass stigma, prejudice and discrimination in relation to the SCD

Caregivers: Persons handling and or caring for patients with SCD

Healthcare providers: healthcare workforces including but not limited to doctors, nurses, counsellors, and aides that take care of SCD patients and caregivers.

Perception: Personal expression of one's worldview, which is influenced by several societal factors

Societal Culture: Commonly held convictions or ideals shared by the majority of the population interacting with caregivers and patients of SCD.

Societal Interaction: Connection and shared cultural qualities by SCD patients and caregivers

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Sickle cell illness causes aberrant haemoglobin S molecules to be produced. Deoxygenation, vaso-occlusion, and tissue necrosis are responsible for many of the clinical symptoms of SCD (Hassell, 2010; Brousseau, 2010). When red blood cells are deoxygenated or exposed to severe temperatures, the haemoglobin S molecules produce polymerization, which leads to the sickled shape and attachment to the arterial walls. As a result, sickled cells can cause blockage in capillaries and tiny arteries, resulting in discomfort, tissue necrosis, and finally anaemia, ischemic organ disease, stroke, physical disability or death (Edwards et al., 2005).

Complications arising from SCD may lead to the death of a majority of children under five years, adolescents and expectant women thus hindering the realization of the Sustainable Development Goals (SDGs). The World Health Organization, in 2006, estimated that SCD contributed to approximately 5% of the deaths of under-fives on the African Continent. The United Nations (UN) General Assembly at its Sixty-third (63rd) Session held in December of 2008 recognized SCD as a public health challenge. The UN emphasized the necessity of increasing public awareness of SCD to remove negative stereotypes linked with the condition. Member States and the organizations of the United Nations system were urged to raise awareness at the national and international levels on SCD on 19th June each year which also marks World Sickle Cell Day globally.

The impact of stereotypes associated with stigma on illnesses is becoming well-recognized (ILAE/IBE/WHO, 2003). Over 150,000 children are born with SCD in Africa each year, and this figure is projected to increase by over a third by 2050 (Oron et al., 2020). Any other social and psychological suffering brought on by stigma is likely to significantly increase related disability and suffering for illnesses like SCD. SCD is already linked to potentially serious physical problems (Anie et al., 2010).

The stigma dimensions describe how people will perceive a person if they possess a potentially stigmatizing trait. These aspects, therefore, help us to understand why some traits become stigmatizing while others do not. Visibility, danger or threat, recurrence, accountability, and disruptiveness are a few of the characteristics Katz (1981). The physical signs of SCD include jaundice, leg ulcers, and impaired physical development in some people (Dick, 2008). Gross physical symptoms such as gnathopathy and bossing of the forehead may be apparent when circumstances are severe, particularly if timely access to effective therapies is not feasible (Wessberg et al., 1980, Acquaye et al., 1985). Ten African and Caribbean mothers in Canada who had children with SCDs participated in in-depth interviews conducted by Burnes and colleagues (Burnes et al., 2008). SCDs clinic that specialized in the condition provided the mothers. During the interviews, it was determined how the moms coped and what they thought about stereotypes and unfavourable attitudes regarding SCDs. The study's findings showed that all but one of the mothers had experienced stigma because of their children having SCD.

Medical difficulties are occasionally dealt with in impoverished countries using cultural and customary remedies, which may or may not account for crucial clinical features. In many countries in Africa, people with SCD are treated as spiritual victims rather than patients (Adeolu, 2012; Olaide, 2012). Cultural and societal views, particularly in impoverished nations, are considered to influence attitudes regarding SCD (Anie et al., 2010; Ohaeri & Sokunbi, 2001). For the cause and care of SCD, most individuals resort to their faith, ethical principles, and spiritualism (Anie et al., 2010; Ohaeri & Sokunbi, 2001). This could be due to the environment and culture in which they live (Ohaeri & Sokunbi, 2001). The majority of study articles examined people's attitudes around SCD to better understand how they cope with the condition.

In Africa, SCD has been a common condition for many generations. According to reports, SCD was a common ailment in West Africa and the indigenous people gave it a number of regional names before it was found in USA Reid & Rodgers (2007). Sickle Cell Disease (SCD), which is a significant cause of child morbidity and mortality, is most prevalent in Africa. While insufficient funds have been committed, and despite the low cost of many preventative SCD measures; education and development have led to a reduction of the SCD burden in Africa.

SCD is a highly severe and awful blood illness that is translated as "Sege Arun inu Eje" in the Yoruba language of Western Nigeria. From a primal or cultural standpoint, there are numerous perspectives and concepts about this SCD. The most prevalent nickname for this mindset is "Abiku," which literally translates to "Born to Die" due to their short lifespan. The majority of SCD newborns die before their fifth (5th) day of life. It is supposed to be a strange illness with no known treatment because of the gods' retribution (Nnodu, 2014).

Many people in Nigeria's western regions believe that having a child with SCD is a curse since they observe the amount of work put in by all family members in terms of finances, care, affection, and rushing about all the time when the child has painful episodes. In the majority of instances, despite all of the above attempts, the child dies and the entire family is subjected to great misery especially if the youngster in question is the family's only child. As a result, different cultures or families have different ways of sustaining a child with SCD, such as conducting several rituals to try to keep the child alive. The absence of follow-up counselling and screening, according to papers on prenatal sickle cell screening education, is caused by a number of factors. Another important aspect that contributes to low follow-up rates is the lack of knowledge about newborn screening programs. Only if the parents of children with SCD are informed on the importance of the screening will the likelihood of follow-up for screens increasing sharply (Yang, Andrews, Peterson, Arvind, & Cepeda, 2000).

Many women who have been diagnosed with SCD feel helpless and afraid. Further, Hill (2001) found that clinicians provide minimal advice to mothers on how to manage their SCD children. This data also reveals a lack of information and awareness on SCD resulted in strained patient-physician relationships. Stereotypes associated with stigma add to the hardship of individuals and families impacted by Sickle Cell Disease. SCD is becoming a serious public health concern that is gaining greater attention. Despite this, there is very little information regarding SCD and health-related stigma in the literature.

2.2 Health-Related Stereotypes

Research on stereotypes related to health by Felicia et al (2015) and the University of Southern California (2015) are critical in considering health-related stereotypes. Two conclusions can be drawn from this research. First, "healthism" according to Gekoski and Knox (1990), exists in society. In that regard, people have prejudices about people who are sick and devalue them. Stereotypes include dependency on others, loss of functional competence, and being on the verge of death. Such stereotypes can cause people to be negatively judged because they highlight traits that are outside the generally accepted range of human functioning and are frequently connected to illnesses that are seen as incapacitating and outside of the person's control (Bloom, Grazier, Hodge & Hayes, 1991; Scott, Grazier, Grazier, Grazier, Hodge, & Hayes, 1991).

Second, according to Merluzzi and Nairn (2003), it appears that health-related features elicit negative stereotypes. Because of the higher rates of the disease and expectations of health deterioration linked with later adulthood, unfavourable health stereotypes may become more prevalent as people get older. Previous studies have found evidence that health status is linked to adverse outcomes irrespective of age and that age alone does not explicate predispositions in interpersonal judgments Gekoski & Knox (1990) It is crucial to consider how health stereotypes may impact older people as a result. James & Haley (1995)

Due to health-related stigmatization, the clinical symptoms of SCD frequently result in unexpected periods of discomfort and feelings of insufficiency about the care they receive (Strickland et al, 2001). Many infectious diseases including HIV/AIDS and mental health illnesses are the focus of research on health-related stigma (Switaj et al, 2009; Zelst, 2009). For the past 20 years, stigma connected to HIV/AIDS has had a massive negative influence on people's health and well-being all over the world (Parker & Aggle, 2009).

Stigma causes discrimination against a person or an institution in a variety of spheres of life by evoking negative attitudes and sentiments, according to Sartorius (2006). This degree of stigma can result in unfair disadvantages for those who are stigmatized, such as overt discrimination at work, in institutions of higher learning, and even within families, as well as a lack of timely and high-quality medical care. People who are shunned because of their health may experience detrimental effects for the rest of their lives.

Chronic illness patients are also stigmatized. Inadequate support from doctors, family, friends, the community, and the job, they may feel isolated from the healthy world and shamed (Slade, 2009; Halding, 2010).

2.3 Relationship between Interpersonal Communication and Health

Effective interpersonal communication, research shows, is one of the most potent ways of improving client health outcomes and well-being. Patients who understand their condition, and its management and have a good interpersonal relationship with their healthcare providers have a greater degree of fulfillment with their treatment and have a higher likelihood of adhering to the treatment schedule. Even though the significance of interpersonal communication is recognized by various practitioners, it is not often highly rated in medical education.

Strong evidence from industrialized nations shows that good communication leads to better health outcomes. Provider-client communication has been connected to changes in physiological indicators including blood glucose levels, blood pressure and functional status measurements, patient satisfaction, the memory of information, adherence to therapy regimens, and appointment keeping (Hall et al, 1988). As a result, knowledge gained from experience in the developed world suggests that healthcare professionals might enhance their interpersonal skills to produce better health results. The research reported here investigates whether these results are reliable and repeatable in emerging nations.

Unfortunately, good communication does not always come naturally or is not something that can be learned quickly. Even if they both hail from the same region and speak the same language, clients and providers frequently, come from diverse socioeconomic, cultural, and educational backgrounds. They could also have different expectations for the medical interaction or confront additional issues, such as a lack of privacy or time restraints brought on by a high patient load.

Extended conversations brought about by improved communication allow patients to divulge important details about their medical issues and medical professionals to diagnose patients' conditions with greater accuracy. Improved health education and counselling are brought about by effective communication, which also improves patient compliance and treatment that is more suitable plans. Because of improving efficiency and cost-effectiveness, good interpersonal communication also improves the health system as a whole. As a result, enhanced provider-client interactions are in the best interest of clients, providers, administrators, and policymakers.

2.4 Relationship between Caregivers and Patient

In the care of persons with a chronic disease, the family caregiver plays an essential part. The patient directs and manages his or her care, but it is up to the caregiver to carry out self-care practices. Clinical results may be influenced by the quality of caregiver-patient interactions, as it is in other diseases Bassola et al (2021). Current development in the management of chronic illness is the shift away from a treatment paradigm that is mostly hospital-based Hayes et al.,(2015). Family caregivers may be direct family members, but other relatives and friends may also be involved (Alzheimer's Association Facts and Figures, 2013). Family caregiving is generally described as a broad range of unpaid care provided to an elderly family member, spouse, friend, or neighbour who is chronically ill or functionally impaired in response to illness that goes beyond the assistance typically offered within households.

In terms of caregiver load, the findings revealed that almost half of the caregivers faced problems while caring for the patients. The caregiver' challenges were mostly connected to their perceptions of the severity of the patient's sickness, which displayed erratic behaviour, and their appreciation for caring for the patients from others. Previous research (Darwin et al., 2013) backed up the findings (Kate et al., 2013).

2.5 Caregiver-Health Provider Relationship

Any healthcare delivery system's principal goal is to provide the best possible treatment for patients. In our contemporary day, every patient has the right to expect the finest possible treatment in hospitals, and hospital staff members must guarantee that optimal patient management and patient satisfaction are in place. Doctors need information from the patients to make an accurate diagnosis and provide effective therapy; patients, on the other hand, demand knowledge regarding their medical condition and the reasons for its treatment. Therefore, good and precise communication between doctors and patients is essential for a healthcare system to function properly.

According to several studies, a good doctor-patient relationship and communication depend on a doctor's approachability and manners, active listening, reassuring facial expressions, social interaction, patient data handling and desire to understand the information presented, uninterrupted consultations, and adequate consultation lengths (Mehta, 2003). Despite advanced diagnostic and treatment technology, communication remains the primary way through which a patient and a clinician may share health information Kattel (2013).

For adaptive coping and improved illness management, caregivers and patients must be educated on SCD and pain management. Assuring that they have exact and extensive information may result in enhanced health behaviours, treatment compliance, and perceptions of disease control Haywood et al (2010). Good patient-healthcare practitioner communication and common decision-making are related to patients' evaluations of the quality and satisfaction of their medical care. Good communication between patients and their doctors increases the likelihood that both parties will be happy with one another and that vital information will be shared, improving treatment compliance (Ha & Longnecker, 2010).

To develop and maintain interaction, good communication is required. The way physicians and patients interact with one another defines the interpersonal relationship they form. Even when there is apprehension about the medical outcome, good communication ensures an open dialogue and a positive connection. This relationship works best when physicians acknowledge and completely incorporate the roles of families and caregivers in the patient's care Katz et al (2004).

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2.6 Relationship between the Patient and the Health Care Providers

Patients with SCD, especially those who do not use suggested medical therapy, must develop trust in their medical personnel (Haywood et al., 2010). For a number of reasons, including not being treated as partners in the hospital, and downplaying the severity of SCD pain, patients with Sickle Cell Disease come to distrust doctors Haywood et al. (2010). Adults suffering from SCD are probably more aware of their condition than some medical professionals are, according to Haywood et al. (2010), but many patients have reported this in qualitative studies Altman et. al. (2018).

In addition, studies on doctors' interactions with patients of African descent have revealed that doctors pay less attention, empathy, and civility to these patients Haywood et al., (2010). In one study, Haywood et al. (2010) discovered that doctors gave African-American patients poorer ratings for intelligence, educational attainment, and the likelihood of disobeying medical advice and misusing medications. According to the findings of a study by Haywood et al. (2010), there is a connection between sickle cell disease patients' trust in their healthcare providers and the way they communicate with them. Communication directly affects a patient's openness to his or her doctor Haywood et al., (2010).

Communication is seen as one of the most essential components of medical therapy in the setting of doctor-patient relationships. In fact, a high majority of malpractice depositions analyzed by Consumer Reports (Consumer Union, 1995) cite communication problems as a major contributing element in litigation. According to a 1973 US government survey, the majority of malpractice claims were brought because of inadequate communication between patients and their physicians (DeVita, G. 2000).

Recent studies on malpractice lawsuits have revealed that a sizable majority of patients who consider suing do so due to a bad interpersonal experience rather than physical injury or a technically flawed procedure. Levinson (1994). In fact, studies reveal that doctors who have more malpractice claims and legal disputes also experience more complaints about their interpersonal abilities Hickson et. al. (1994).

Communication research—especially interpersonal communication—aims to comprehend how patients and medical practitioners might negotiate in order to further both their shared interests in patient health improvement and interpersonal happiness. Patients desire knowledge, relationship building, good discourse, and some social chat from their contacts with physicians, according to both popular and scientific publications Roter, (1992). Patients are happier with doctors who encourage them to ask questions, discuss probable drug side effects, and overall put them at ease Consumer Union, (1995). While the physician retains responsibility for medical results notwithstanding all efforts and desires for an equitable partnership, both parties share responsibility for personal happiness and communication quality Cline, (1983).

The significance of communication and the role of the clinician in HIV/AIDS adherence has also been stressed in HIV studies. The importance of interpersonal communication in the context of improved patient adherence was discussed by Dahab et al. (2008) as echoed in a study of a workplace anti-retroviral treatment program in South Africa. Penn et al. (2011) demonstrated the importance of patient-pharmacist communication in antiretroviral (ARV) adherence, as well as the cultural and linguistic obstacles that exist in this interaction. Govender and Mash (2009) mentioned the therapeutic relationship's impact on tuberculosis (TB) care in South Africa in their TB adherence study. Another research on the perspectives of patients with diabetes-related gestational revealed the societal biases that exist in other chronic diseases not just in HIV, as well as the need of exploring the patient's real environment in disease care (Burkett, 2015).

2.7 Theoretical Framework

2.7.1 Stereotype Content Model (SCM)

Susan Fiske and her colleagues proposed the Stereotype Content Model (SCM) (Fiske et al. 2002; Fiske, 2012; and Fiske, 2017). According to the SCM, people stereotype new groups based on two factors: warmth (the group's perceived goal and likelihood to help or hurt) and competence (their capacity to help or harm). Perceived rivalry and prestige, meanwhile, influence warmth and competence, respectively. The combination of warmth and skill produces emotions of adulation, anger, envy, and pity. The behavior from the intergroup effect and stereotypes (BIAS) map predicts active and passive, constructive and destructive behaviors based on these intergroup emotions and stereotypes.

The SCM predicts how people will react if you have a potentially stigmatizing characteristic. As a result, this SCM aid in understanding why certain characteristics become stigmatizing while others are not. Katz (1981) and Jones et al (1981) Visibility, threat or peril, chronicity, responsibility, and disruptiveness were some of the characteristics of stigma associated with these factors. The "Visibility" dimension measures how obvious, aesthetically challenging, or concealable a feature is to other people. According to SCM, the more apparent and disfiguring a characteristic is on a person with SCD, the more stigmatizing it will be. The researcher broadens the understanding of this relationship beyond basic notions of stereotypes to wider understanding about the affective reactions to such behaviours likely to appear because of these responses while using the doctrines of SCM to explain stereotype tendencies surrounding them.

2.7.2 Symbolic Interaction Theory

There are many theories in the social sciences; the key among them is symbolic interaction. According to this view, symbols both inform and guide facts. Meanings are the cornerstone of this idea. The study of symbolic interaction focuses on the question, "Which symbols and meanings develop from the interaction between individuals," and examines the meanings that come about because of people engaging with one another in a social situation. Since the 1970s, the dynamism of symbolic interactionism, which views the individual as a social entity, has diminished. Compared to the Mead and Blumer era, new symbolic interactionism offers a more unique and integrated viewpoint. There is now a Fine phase Slattery (2007). In light of theorists like Dewey

(1930), Cooley (1902), Parks (1915), Mead (1934, 1938), among others, the symbolic interaction theory has evolved and the differences in viewpoints are evident in symbolic interactionists' work.

Interactionists concur that when human interaction is the source of data. Additionally, there is a consensus among symbolic interactionists that the focuses of symbolic interaction are participant viewpoints and their capacity to build empathy (Stryker & Vryan, 2003; Berg, 2000). According to Schenk and Holman (1980), symbolic interaction denotes dynamic theory because it holds that objects have meanings inherent to them and that people develop their actions based on how they see themselves and the people and objects around them. According to this concept, the social actors give items meaning. George Herbert Mead is the most significant representative of the symbolic school of thought. Mead is a pragmatist and an anti-dualist philosopher. He thinks that the ego and the mind are byproducts of civilization.

Mead thinks that symbols are a tool for communication and thought that also helps the mind develop (Ashworth, 2000). Mead focused on how people create order and purpose in their daily lives through symbolic interactions. White & Korgen (2008). The first person to use symbolic interaction was a Mead student named Blumer. Because of this, he is occasionally referred to as the creator of symbolic interaction. According to Bulmer (1969), there are two ways that human shapes might have "meaning": (1) Everything that is given meaning to things, events, phenomena, etc. (2) People "physically attach" significance to things and experiences. Blumer (2005) contends that group interaction rather than the intrinsic qualities of the object Tezcan determines to mean.

Human connection produces meaning, and meaning enables people to create some of the facts that make up the sensory world. These data have to do with how humans create meaning. As a result, the fact is the interpretation of many meanings. Thomas (1928), "whether or not the interpretation is accurate is not significant." According to him, the reality is dependent on individual perspectives and historical developments (Berg, 2000). Three principles underlie Blumer's symbolic interaction approach: Meaning, language (which provides instruments [symbols] for disputing meaning), and the organizing idea. The symbolic interaction advances that all human behaviour has an underlying meaning and language carries meaning to individuals through symbols. (Nelson, 1998). According to Blumer, symbolic interaction is built on three fundamental claims (Paloma, 1999: p. 1224–225; Tye & Tye, 992, p. 36); Humans form their attitudes about things in accordance with the interpretations that those objects offer, these interpretations are based on how "one of them interacts with its addressees" and alter these meanings.

The second issue with the symbolic interactionist paradigm is emphasized most strongly and plainly; paying little attention to social structure and paying little attention to human emotions. These two abilities show that symbolic connection is not purely social and that symbolic engagement is not entirely psychological (Meltzer et al., 1975). According to this idea, meaning is something that spontaneously appears during contact under specific circumstances. The fundamental social environment in which the contact is situated is not taken into consideration. As a result, it fails to generate the sources of meaning.

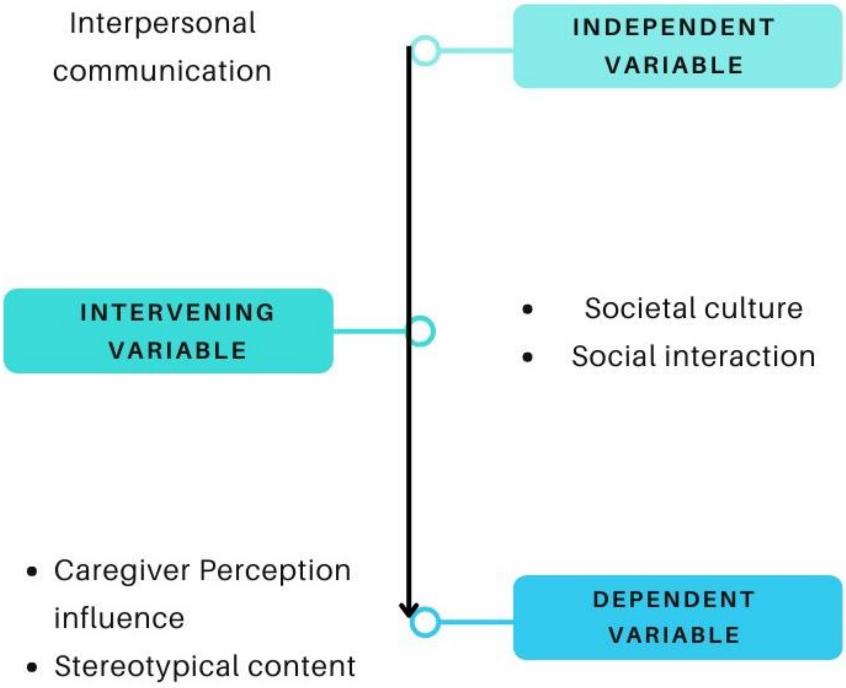
Symbolic interactionism forgoes attempting to explain society on a larger scale because it sees no social reality other than the one that people interpret and construct via their interpretations (Slattery, 2007, p. 338). In conclusion, the presence of an event is the primary prerequisite for the development of meaning. Experience of these experiences constitutes the next criterion. The significance of things guides action, as Bulmer notes (O’Shaughnessy, 1992).

Understanding human concepts and connotations is a precondition for understanding human activities. Elements include social roles, conventional structures, laws, objectives, and norms. Give them the tools they need to create definitions. In this setting, symbolic interaction emphasizes interpersonal communication, definitional dispute, and taking an active part in interpersonal relationships. In sociology, symbolic interactionism is a micro-level theoretical viewpoint that examines how people connect in meaningful ways repeatedly to build and sustain society.

Which illnesses are stigmatized and which are not, which are regarded impairments and which are not, and which are thought to be contestable depend on our society, not nature. Society creates different symbols to connote and denote patients of SCD. This is driven by cultural practices, which are dependent on the communication patterns of a given society. Therefore, the symbiotic relationship between communication and culture drives the creation, transmission and shaping of symbols that define culture. Culture gives an interpretation of SCD, which then guides a given society’s interactions with patients with SCD.

2.8. Conceptual Framework

Figures 2.1 Conceptual Framework Model for the study



Humans require communication to function in their social lives. If undertaken on a broad scale, communication, which takes verbal and nonverbal perspectives, the interaction between two or more interdependent individuals, would help to maintain preconceptions. As a result, stereotyping is a continuation of social categorization. What kinds of mental connections people have are based on which stereotypes are regularly replicated in the culture people grew up in, what they learned as children and personal interactions with members of various social groups. Interpersonal communication is inextricably bound to perceptions thus affecting stereotypical content and as a result, the standard of living for those with SCD. Societal Culture and Social interaction affect interpersonal communication, perceptions, stereotypical content and the quality of life of persons with SCD.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter explains the research strategy that was employed in the study, including sampling methods, rationale, data collection procedures, and ethical considerations. The study technique is critical as it influenced the research's validity as well as how the findings are used, particularly in an SCD treatment clinic environment (Creswell, 2003).

3.2 Research Design

The term "research design" refers to the researcher's overarching strategy for rationally and cogently integrating the many elements of the study, ensuring that research issues are adequately handled. It acts as a guide for collecting, measuring, and analyzing data (Johnson & Christensen, 2010). A study design is a plan of action or a strategy that links the subject of the study to the intended result (Creswell, 2003). There are three basic research approaches, even if there are other study designs.

This study used the descriptive cross-sectional study of mixed approaches (Creswell & Clark, 2011) design involving the collection of both qualitative and quantitative data to bring out a rich story about sickle cell disease, interpersonal communication, and stereotyping content. The mixed method cross-sectional studies also referred to as one-time or status studies are the most widely used design in the social sciences. This method works best for studies that examine a cross-section of the community to ascertain the frequency of phenomena, circumstances, issues, problems, or attitudes. They aid in creating a comprehensive "image" of the situation at the time the research was conducted. They are designed to investigate a phenomenon by acquiring a complete cross-section of it (Babbie 1989, p. 89). Such studies are cross-sectional in that they consider both the study population and the time under examination.

Since the researcher was interested in knowing and understanding the sentiments and views of the participants concerning SCD (Johnson & Christensen, 2010), both qualitative and quantitative research approaches were used in this study. Based on the foregoing, the researcher employed these research methods to better comprehend the attitudes, values, and behaviours associated with sickle cell illness Mugenda and Mugenda (2008).

3.3 Location of Study

This study was undertaken at the Baraka Medical Centre in Mathare Sub-County, Nairobi County which offers haematology clinics to patients of SCD through the Children Sickle Cell Foundation. The Children Sickle Cell Foundation has an estimated 540 patients countrywide. The foundation was used to identify study participants among the caregivers of SCD survivors and some SCD survivors who gave insight into how interpersonal communication has influenced their coping mechanisms when faced with stereotypical content.

3.4 Target Population

According to Babbie (2013), the term "population" refers to all elements (people, things, and events) that meet the criteria for inclusion in a sample. The 540 caregivers registered at the foundation made up the study's population. Caregivers are in charge of providing physical and emotional care and support to persons who are unable to care for themselves due to disability, accident or disease (a condition that affects major life activities in a person’s life).

The target population, from which the research sample is drawn, is part of the accessible population (Mugenda & Mugenda, 2008). The study's accessible population were caregivers who visit the CSCF clinic with their patients who have SCD and are part of the SCD support system.

3.5 Sampling Design

The method for collecting a sample is referred to as a sample design (Kothari, 2008). The two types of sampling techniques are probability and non-probability sampling approaches. Non-probability methods entail selecting a ‘sensible’ number of populations who have an equal chance of being selected (Mugenda & Mugenda, 2008).

Because of the clinic's inconsistent attendance, convenience sampling was used to pick caregivers to participate in the study. Convenient sampling is picking instances or units that are readily available and have the necessary data (Mugenda & Mugenda, 2008). In this scenario, the sample was drawn from caregivers of persons with SCD who visit the Baraka Health Centre. As a result, their clinic visits are sporadic and this necessitated the use of convenience sampling over a period of two months or 60 days within which the specified sample size was reached. The appointment register at the centre was useful in determining the number of caregivers likely to visit the clinic on a given day. Walk-in caregivers that were willing and well enough to participate in the study during their visit also took part in the study.

3.6 Target Sample and Sample Size

A sample size is a portion of a population (Mugenda & Mugenda, 2008). The target population in this study was 540 caregivers registered by the Children Sickle Cell Foundation and attending the Clinic at the Baraka Health Centre. Purposive sampling was employed to choose respondents from among the caregivers who attended clinics. According to Mugenda and Mugenda (2003), a part, usually 10-30% of the target population is necessary to reach the target audience. The researcher chose 30% of the target group, resulting in 162 needed caregivers over 60 days.

Based on Mugenda's (2003) guideline, the sample was arrived at based on the formula below:

$N=540$

$30=? \quad n= 30XN/100$

$30 \times 540/100 =162$

3.7 Data Collection

The researcher collected data using questionnaires that were administered to caregivers. Focused group discussions were conducted on selected direct beneficiaries who were well enough to participate in the study during their visits to the sickle cell foundation clinic. In addition, Key Informant Interviews (KIIs) for staff at the foundation were also conducted.

3.7.1 Questionnaires

A questionnaire is a data-collecting instrument that includes a set of questions. Closed and open-ended questions are the two sorts of questionnaires (Kothari, 2012). The survey questionnaire included both open-ended and closed-ended questions.

3.7.2 Focus Group Discussions

Two Focused Group Discussions (FGDs) were conducted with the help of an FGD guide. The aim of the FGDs was to establish the opinions, perceptions and experiences of the caregivers regarding the Influence of Interpersonal Communication on Stereotyping Content of the Sickle Cell. A study by Ting'aa (2018) noted that during FGDs, participants tended to disclose what they would not have otherwise divulged if interviewed alone.

The primary investigator ensured the consistency of the responses conducted by all FGDs. Two research assistants were recruited, trained and took part in the FGDs. Each FGD had between six and eight participants and lasted an hour. The haematological clinic was the location of the FGDs. To make the discussion simpler, the participants' chairs were arranged in a circle. The audio recorder was set up on a table that was placed in the centre of the group. The caregivers signed the confidentiality form before the FGDs began. The researcher audio recorded during the FGDs and took notes verbatim including the participants' body language.

3.7.3 In-depth Interviews

Key informant interviews were conducted to capture professional insights of technical staff at the foundation regarding the subject area under investigation.

3.8 Pretesting the Data Collection Tools

A pretest is a term used to describe the initial administration of the data collection tool in order to establish where there are errors linked to its structure. When data is collected using a questionnaire, it is imperative to establish whether the respondents comprehend the questions and directives therein. The pretesting of a questionnaire is what this is known as (Kothari, 2012; Babbie, 2013). At the pediatric haematology clinic at Kenyatta National Hospital, the researcher pretested the data collection method.

Beginning with the examination of the data collecting instruments by at least three seasoned researchers, including my supervisor and reader, the content of the validity and dependability of the data was established. By pretesting the tools to make sure that, the content was comprehended and in line with the study goals, the reliability of the data was confirmed. To confirm the authenticity and dependability of the data, it was triangulated using several distinct data collection methods.

3.9 Data Analysis Method

The data analysis started with confirmation that the correct data is gathered, which was done by counting the number of questionnaires. Errors, legibility, and relevancy were verified on the questionnaires. To analyze the data, a mixed analysis method will be utilized, which entails using both quantitative and qualitative analytical tools within the same framework (Onwuegbuzie, 2010).

Using SPSS Version 24 and Microsoft Excel, the quantitative data were coded, data entered, cleaned, and analyzed. Using NVivo 11, the qualitative data was entered into a qualitative data analysis frame and coded based on the emergent themes. Cleaning and analysis of qualitative data were performed for the final analysis, the data were quantified and combined with the quantitative data.

3.9.1 Ethical Consideration

Researching necessitates not just knowledge, but also trustworthiness and integrity. This is done to acknowledge and defend human beings' rights. When dealing with caregivers of SCD patients, having ethics was extremely crucial (Johnston, 2008). The right to self-determination, anonymity, secrecy and informed consent were respected to make the study ethical (Kothari, 2004). The researcher sought permission from the National Commission on Science, Technology, and Innovation (NACOSTI) and the Children Sickle Cell Foundation's administration.

In addition, respondents were briefed about the aim of the study, the methods for gathering data, and the fact that there were no potential hazards or expenses associated with participation in the study. By employing codes instead of names in data collecting systems, the researcher protected the respondent's confidentiality. Self-determination was upheld as an ethical value. Respondents had the option of opting out. Finally, to prevent subjective cooperation, the researcher generated results with the help of an impartial statistician.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.0 Overview

This chapter presents analyzed data from caregivers' perception of the influence of interpersonal communication on stereotyping content surrounding Sickle Cell Disease. The study was conducted on caregivers seeking services through CSCF from Baraka Medical Centre in Mathare Sub-County, Nairobi County.

4.1 Data Presentation and Interpretation

This section presents data that was collected and analyzed from the questionnaires administered to the respondents. It also analyses data collected from the key informants using in-depth interviews as well as data from the focused group discussion on the caregivers.

The data collected is presented in the form of text, tables, frequencies and percentages.

4.1.1 Instrument Rate

In this study, data was collected using questionnaires from the caregivers of persons with SCD attending the haematology clinic at the Baraka Medical Centre in Mathare Sub-County, Nairobi County. The target population was 162 caregivers. However, actual data was collected from 100 respondents that took part in the study resulting in 61.7% of the target population, which is considered sufficient for data analysis in this research. According to Kothari and Gang (2014), a response rate of 50% is satisfactory. Respondents were cooperative during the study.

4.1.2 Demographic Information of the respondents

Demographic information of the caregivers with respect to their gender, years of membership in the CSCF, age and level of education were also sought in this study. The purpose was to establish the characteristics of the caregivers of persons with SCD attending the CSCF haematology clinic at Baraka Medical Centre in Mathare Sub-County, Nairobi County.

The introductory part of the questionnaire was to aid in obtaining information on the demography of the respondents. A number of researchers (Marsh et. al 2011; Ohaeri & Shokunbi, 2002; Makani et.al. 2007) have explored the concept of gendered forms of stigma in SCD and the possibility of males being reluctant to recognize their responsibility in SCD caregiving.

The question on the length of membership to the CSCF was meant to establish the number of years the caregivers had received counselling, education, training and peer-to-peer support at the CSCF. Previous studies have reported the existence of significant rates of stress and sadness among those who care for people with chronic illnesses like SCD (Ohaeri & Shokunbi, 2002; Van Den Tweel et al., 2008; Tunde-Ayinmode, 2007). There is a strong correlation between being in a support group and the ability to deal with the burden of caring for SCD patients better (Adegoke & Kuteyi, 2012).

The question of the age was to establish the age category of caregivers and determine which age group is more involved in caregiving roles. The degree of social and professional accomplishment of each caregiver will probably influence many areas of their quality of life (QoL), which are affected by the significant financial and emotional obligations placed on them by caring for children with SCD. The question on academic qualification was important because it is assumed that the more educated a caregiver is, the better they are at understating the disease and dealing with it as a genetic condition. Marsh et. al. (2013) reported that the incidence of parental blaming and the gender-discriminatory effects of SCD were both influenced by a mother's educational and socioeconomic status.

4.1.3 Distribution of Respondents by Gender

Table 4.1: Distribution of Respondents by Gender

What is Your Gender?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	FEMALE	82	82.0	82.0	82.0
	MALE	18	18.0	18.0	100.0
	Total	100	100.0	100.0	

From this study, 82% of the caregivers that took part were female while 18% were male. This finding indicated that males are slowly getting integrated into SCD management. Previous studies have noted that male caregivers typically assist with care arrangements or money, whereas mothers and other female caregivers mostly do the physically demanding caregiving responsibilities (Kwena, 2021; Hounsell et al., 2019). Further, the probability of women being caregivers is increased by gender role stereotyping of the male and female roles.

4.1.4 Distribution of Respondents by Year of Membership in the CSCF

Table 2 shows the distribution of the respondents according to their years of membership in the CSCF.

Table 4.2: Distribution of Respondents by Year of Membership in the CSCF

How Long Have You Been a Member of the Sickle Cell Foundation					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0-2 YEARS	13	13.0	13.0	13.0
	3-5 YEARS	28	28.0	28.0	41.0
	5-10 YEARS	19	19.0	19.0	60.0
	Above 10 years	40	40.0	40.0	100.0
	Total	100	100.0	100.0	

60% of the members have been with the CSCF for less than 10 years. This implies the need for continuous support for the caregivers who are mostly taking care of their children who are under the age of 10 as they head to their teenagehood. The CSCF organizes the caregivers into support groups for perpetual peer support. Studies have shown that caregivers join support groups for a variety of reasons, including psychosocial support, knowledge exchange, peer-to-peer counselling, safe spaces to vent, access to programs for SCD patients, and participation in lobbying and advocacy campaigns to raise awareness and demand legislative change (Kwena 2021, Burnes, 2008).

4.1.5 Distribution of Respondents by Age

Table 4.3 below shows the age patterns of the respondents in the study.

Table 4.3 Distribution by age

What is Your Age?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-28 YEARS	39	39.0	39.0	39.0
	28-38 YEARS	36	36.0	36.0	75.0
	38-48 YEARS	20	20.0	20.0	95.0
	Above 48 Years	5	5.0	5.0	100.0
	Total	100	100.0	100.0	

75% of the respondents were less than 38 years of age. Implying that majority of the caregivers are youthful. This implies that SCD poses a socio-economic burden to the caregivers who have to give up their most productive years of life to take care of their children with SCD thus advancing poverty.

4.1.6 Distribution of Respondents by Academic Qualification

Table 4.4: Distribution of Respondents by Academic Qualification

What Is Your Highest Education Background?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Primary	30	30.0	30.0	30.0
	O- Level	38	38.0	38.0	68.0
	Diploma	15	15.0	15.0	83.0
	Bachelor's Degree	11	11.0	11.0	94.0
	Postgraduate Degree	6	6.0	6.0	100.0
	Total	100	100.0	100.0	

A majority of the respondents (70%) had O-level qualifications in terms of education implying that they were likely to have high awareness levels and the ability to understand the medical condition. A study by Shiundu (2019) noted that educated caregivers are more aware of the condition and actively seek out information; communication with them was easier.

4.2 Data presentation and interpretation

This section contains data and its interpretation. The data is systematized in line with the objectives of the study.

4.2.1 Statement on Stereotypical Information Surrounding SCD

The first study objective was to determine the content of stereotypical information and surrounding sickle cell disease as perceived by the caregivers visiting the CSCF clinic. The questions asked in this question, sought the perceptions of the caregivers on the stereotypes surrounding SCD.

Table 4.5: Statement on Stereotypical Content Surrounding SCD

Is SCD a Curse for Cultural Defiance?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	53	53.0	53.0	53.0
	Disagree	28	28.0	28.0	81.0
	Neutral	3	3.0	3.0	84.0
	Agree	5	5.0	5.0	89.0
	Strongly Agree	11	11.0	11.0	100.0
	Total	100	100.0	100.0	

The majority of the respondents at 81% believe that SCD is not a curse because of cultural defiance meaning the respondents attending the clinic at the CSCF have reliable up-to-date information on the origins of SCD. The CSCF uses interpersonal communication methods to counsel, train, educate and encourage peer-to-peer support which happens during clinic visits and during outreaches.

Table 4.6: It is Women/Men Who Defy Culture that Spread SCD in the Community

Who between Women and Men Defies Culture that Spread SCD in the Community?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	73	73.0	73.0	73.0
	Disagree	5	5.0	5.0	78.0
	Agree	9	9.0	9.0	87.0
	Strongly Agree	13	13.0	13.0	100.0
	Total	100	100.0	100.0	

78% of the respondents did not agree with the view that men/women who defy culture are the spreaders of SCD in the community. This implies that there exists a heightened level of awareness levels on the origin and nature of SCD among the caregivers at the CSCF, therefore, denouncing negative cultural connotations which define stereotypical tendencies.

Table 4.7: SCD Patients are a Bad Omen to the Community

Are SCD Patients a Bad Omen to the Community?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	44	44.0	44.0	44.0
	Disagree	11	11.0	11.0	55.0
	Neutral	11	11.0	11.0	66.0
	Agree	17	17.0	17.0	83.0
	Strongly Agree	17	17.0	17.0	100.0
	Total	100	100.0	100.0	

A simple majority of the respondents (55) covering 55 % disagreed that SCD is a bad omen to the community implying that there should be more comprehensive approaches to knowledge dissemination that encompass both verbal and non-verbal interpersonal communication skills to counter stereotypical tendencies surrounding SCD within communities at maximum levels so that it is all-inclusive by reducing the awareness gap.

Table 4.8: Do people fear they could get infected with SCD if they were to be in contact with you or your patient

Do people fear they could get Infected with SCD if they are to be in Contact with you or your patient?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	13	13.0	13.0	13.0
	Disagree	13	13.0	13.0	26.0
	Neutral	17	17.0	17.0	43.0
	Agree	7	7.0	7.0	50.0
	Strongly Agree	50	50.0	50.0	100.0
	Total	100	100.0	100.0	

The majority of the respondents (57) representing 57% noted that people fear they could be infected with SCD if they were to be in contact with their patients. Implying that there exist low awareness levels among the wider population and stereotypical content surrounding SCD.

Table 4.9: Stereotypical Content on SCD Influences Your Perception of the Patient

Does Stereotypical Content on SCD Influences your Perception of the Patient?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	71	71.0	71.7	71.7
	Disagree	1	1.0	1.0	72.7
	Neutral	1	1.0	1.0	73.7
	Agree	16	16.0	16.2	89.9
	Strongly Agree	10	10.0	10.1	100.0
	Total	99	99.0	100.0	
Missing	System	1	1.0		
Total		100	100.0		

A majority of the respondents (72) representing 72.7% disagreed with the view that stereotypical content on SCD influenced their perception of their patients. This result is consistent with the findings by Kwena (2021) on the coping and resilience nature of caregivers who go above and beyond in caring for their children. However, a contrary study by Carter (2019) noted that other factors might affect a caregiver's perception and weaken their coping strategy. Situational stress and periods when a child is critically unwell have been noted to weaken resilience. Healthcare professionals may step in to help patients cope better during such times through supportive counselling or connecting caregivers to support groups (Jenerette et. al., 2010).

When asked about what leads to the stigmatization of persons with SCD 52% of the respondents noted that there exists a knowledge gap which leads to stigmatization. A majority of the caregivers (60%) reported that some people fear they could get infected by interacting with their patients. From these findings, it was evident that the caregivers believed that the stigmatization of people with SCD was mostly because of a lack of knowledge and awareness. The CSCF offers information and awareness on SCD by organizing and facilitating support group meetings at the clinic and on other days which have led to high levels of awareness among caregivers.

On the question of how society relates or defines their children with SCD in relation to culture, 60% of the respondents noted that cultural beliefs tend to shape societal relationships with children suffering from SCD. This is evident from the responses accrued by the researcher. A study by Marsh et al (2011) noted that in looking for a cause of SCD, the community pointed to underlying cause processes that were either perceived as being natural, with justifications derived from biological traditions or supernatural; notably ancestral curses, the devils or spirits. This points to the need for more education on SCD among affected families and the wider community to counter the misinformed notions surrounding the occurrence and spread of SCD.

55% of caregivers noted that counselling by the HCP, training on best SCD management practices, peer-to-peer support and dissemination of IEC materials at the CSCF played a big role in patient status discloser. For many caregivers, receiving news that their child is sick with an incurable disease was not easy. Counselling helped them to cope better as there is a propensity to blame mothers for health challenges affecting their children connected to a patrilinear social structure.

One of the caregivers interviewed at the Baraka Clinic stated:

> ‘Were it not for the counselling that my husband and I received when our daughter was diagnosed, he would have left me and married another woman.’

Counselling has played an important role in disapproving of the gendered stereotyping of SCD.

A respondent at the Baraka Clinic stated:

> ‘My sisters and other members of the family blamed my wife for bringing a strange disease. After being tested and counselled, I have come to accept my part. I now play an active role in caring for our two children who are SCD warriors.’

From the research, it is clear that counselling is an important aspect of the management and appreciation of SCD.

When asked whether they disclose the status of their children to strangers, half of the caregivers (50%) responded that they disclosed the status of their children to strangers who ask because they feel that they have a duty to create awareness of SCD. Interpersonal communication reduces uncertainties between communication parties, therefore, allowing the parties to be vulnerable to each other hence the sharing and disclosure of information with the hope of getting help in dealing with SCD. A respondent stated;

> ‘I tell anybody who cares to listen about my son’s condition because I feel that people need to know about it, know ways of preventing it or for those caring for a person with SCD like me, to find great ways of managing and caring for warriors of SCD.’

The other half of respondents (50%) stated that they do not reveal the status of their patients to strangers for fear of being judged or stigmatized. There is a need to conduct more one-on-one dialogue and conversations around SCD to get the other half of the respondents to reveal the status of their patients to concerned members of society to reduce levels of stigma which is an avenue for discrimination and stereotypes. Programmes that incorporate interpersonal communication should be embraced in counselling to promote psychosocial support and the emotional well-being of caregivers. A study by Goldsmith (2009) emphasizes that the importance of interpersonal communication cannot be gainsaid through tools like telemedicine, e-health conferences, online support groups, and communication technologies that have affected how individuals find, handle, and use health information. By introducing new channels for discussing health and sickness information, giving and receiving social support, and conversing and negotiating with healthcare professionals, these technologies have an impact on interpersonal communication (Turner, 2003, Thompson et. al., 2011).

4.2.2 Statement on the perceived influence of interpersonal communication on SCD-related stereotype content

The second objective of the study was to establish the perceived influence of interpersonal communication on SCD-related stereotype content.

Table 4.10: Interpersonal skills among SCD patients are affected due to fear of rejection by other children during play session

Interpersonal Communication Skills Among SCD Patients are Affected Due to Fear of Rejection by Other Children During Play Sessions					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	42	42.0	42.0	42.0
	Disagree	1	1.0	1.0	43.0
	Agree	13	13.0	13.0	56.0
	Strongly Agree	44	44.0	44.0	100.0
	Total	100	100.0	100.0	

A majority of the respondents (57%) equal to fifty-seven caregivers agreed that interpersonal skills among patients are affected due to fear of rejection by other children during the play session. Implying that the fear of rejection will in turn affect the interpersonal communication of persons with SCD by reducing levels of interaction because of the fear of being stigmatized hence elevating stereotypical tendencies. A study by Claster and Vichinsky (2003) stated that in many developing nations, the psychological prognosis for children with SCD is still problematic. Ola et al. (2013) noted that a study in Nigeria discovered that children with SCD had disproportionately high rates of psychopathology and poor communication skills compared to other healthy children. The recommendation from the study was that a less stigmatizing attitude can only be achieved by linking to greater contact or familiarity with those who have SCD and teaching about SCD in formal education.

Table 4.11: People living with SCD face rejection from their peers

People Living With SCD Face Rejection from their Peers					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	13	13.0	13.1	13.1
	Disagree	8	8.0	8.1	21.2
	Neutral	18	18.0	18.2	39.4
	Agree	34	34.0	34.3	73.7
	Strongly Agree	26	26.0	26.3	100.0
	Total	99	99.0	100.0	
Missing	System	1	1.0		
Total		100	100.0		

A majority of the respondents (60%) caregivers agreed that people living with SCD face rejection from their peers. This finding is in line with a study that was done by Ola et.al. (2013) who noted that a sizeable number of peers in Nigerian secondary schools had unfavourable opinions and little knowledge of SCD. Less than half of the children would invite a fellow student with SCD to their birthday celebration. The findings of the study clearly suggest that peers have a high amount of negative sentiments toward SCD. It matters how other students view school-aged children with SCD since bullying and peer rejection might result from stigmatizing attitudes. Buhs et.al.(2001). Continuous education on SCD should be integrated into the school curriculum to enhance acceptance.

Table 4.12: People living with SCD face verbal and non-verbal abuse in school, community and health facilities

People Living with SCD Face Verbal and Non-Verbal Abuse in School, Community and Health Facilities					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	9	9.0	9.0	9.0
	Disagree	5	5.0	5.0	14.0
	Neutral	20	20.0	20.0	34.0
	Agree	25	25.0	25.0	59.0
	Strongly Agree	41	41.0	41.0	100.0
	Total	100	100.0	100.0	

66% of the respondents agreed that people living with SCD face verbal and non-verbal abuse in school, community and health facilities. This implies that there is an awareness gap. Day and Chismark (2006) noted that on average, students with SCD disease miss up to 30 days of the school year. These absences cause students to lose out on important academic material. The difficulties brought on by missed lessons are made even more difficult by subjects like mathematics that draw on prior knowledge. Academic advancement is additionally hampered by the neurocognitive issues that might accompany SCD. This has led to many children with SCD being labelled as academically challenged (Crosby et.al., 2021).

Jenerette et.al (2012) noted that the general public, doctors, and then families were cited by participants in their study as the three groups that stigmatize persons with SCD most. The social, physical, psychological, emotional, and spiritual provinces of affected patients and their families are negatively impacted by the pain associated with SCD and its comorbidities. Persons living with SCD and their caregivers have reported feelings of inadequacy in the community. Complications from SCD also significantly affect a patient's sense of self-sufficiency and efficacy (Sankar et al., 2006; Reed 2005). Many persons with SCD are labelled as lazy due to the tiredness, functional restrictions, emotional impact, exhaustion from lack of sleep, the stigma associated with the condition and its treatment, and fatigue have all been in previous studies by (Odesina et al., 2010, Adegbola 2015; Jenerette & Brewer 2010).

Brousseau et al (2010) noted that because they require opioids for pain treatment, patients with SCD are frequently characterized as "drug addicts" or ‘users’ and denied access to proper pain relief. Sometimes they are unable to clearly express their care strategy. In other cases, inappropriate triage or insufficient pain management results from physician ignorance or unreasonable fear of "addiction.”

Table 4.13: Stereotyping by Health Care Providers (HCPs) Influences your Care-Seeking Behavior

Stereotyping By HCPs Influences Your Care-Seeking Behavior					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	17	17.0	17.0	17.0
	Disagree	7	7.0	7.0	24.0
	Neutral	15	15.0	15.0	39.0
	Agree	8	8.0	8.0	47.0
	Strongly Agree	53	53.0	530	100.0
	Total	100	100.0	100.0	

61 caregivers representing 61% of the respondents agreed with the statement that the relationship with the health care providers influences their health-seeking behaviour. Implying that stereotypes stemming from the HCP's treatment of patients and caregivers influences health care-seeking behaviours. Haywood et al (2014) noted that people who have experienced discrimination are more

prone to disregard medical advice and have poor levels of confidence in healthcare professionals. Studies by Waits et al (1996) and Roter et al (2001) illuminated that it is challenging to improve communication between patient-provider when stigma is present.

When respondents were asked about the factors/barriers to the interaction of children with SCD with other members of society, 52% of the respondents stated crisis attacks of the patients, 68% stated fear of discrimination/anticipated stigma while 58% stated societal seclusion driven by perceived fear of social connotations and constructions.

On the question of cultural connotations placed on their children, 62% of the caregivers confirmed that they had experienced some form of cultural connotations placed on their children with SCD. Some of the connotations included that their child is possessed by demons, cursed or sacrificed to black magic. This finding implies that there is a need to create awareness of the existence of genetic disorders including SCD. This will help reduce negative cultural connotations placed on children with SCD.

When asked about the challenges they experience when interacting with others, 78% of the caregivers reported that they had had unpleasant experiences. The caregivers are faced with difficult choices that affect their social interactions and that of their children who are patients of SCD. Kilonzi M, et al. (2022) observed that due to the limited time they may spend at work, many caregivers claimed that they had few opportunities to seek jobs. As a result, they are stereotyped for lack of employment. Caregivers illuminated that because they spend the majority of their time caring for a child who has SCD, they have few opportunities to interact with others or work in jobs with time-consuming tasks and challenging objectives.

4.2.3 Statement of the relationship between interpersonal communication, stereotyping content and management of SCD

The third objective of the study was to determine the connection between interpersonal communication, stereotyping content and management of SCD. The respondents confirmed that communication and their perceptions on the stereotyping content that surrounds SCD for example referring to SCD warriors as ‘dead people walking’ or associating the disease with witchcraft did affect the management of the SCD. It was evident that many of the stereotypes the caregiver had faced such as abusive tendencies were through interpersonal communication with their neighbours, friends, extended family, community and health practitioners. It was also evident that despite the various stereotypes that caregivers face as caregivers of persons with SCD, it did not influence their perception or care for their patients.

Table 4.14: People Living with SCD and their families Experience Normal Life in the Society

People Living With SCD Experience Normal Life In The Society					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	62	62.0	62.0	62.0
	Disagree	4	4.0	4.0	66.0
	Neutral	7	7.0	7.0	73.0
	Agree	23	23.0	23.0	96.0
	Strongly Agree	4	4.0	4.0	100.0
	Total	100	100.0	100.0	

66% of the respondents disagreed with the statement that people living with SCD experience normal life in society; suggesting that SCD patients and their families deal with a variety of difficulties on a daily basis. According to Karadag et al (2018), chronic illnesses like SCD can impair a patient's social and academic life as well as their physical, economic, and mental health. Further, families dealing with a chronic illness such as SCD may feel guilty, helpless, anxious, or angry, and they may find it difficult to deal with these negative emotions as a result of their caregiving responsibilities, their children's frequent hospitalizations, the financial strain that comes from medical expenses, and concerns about their children's future. Families may therefore occasionally require psychological support (Wonkam et al., 2014). A study by Boulet et al (2010) discovered that the families of children with SCD experienced financial hardships, were unable to spend quality time with their other children, and that their social life and interpersonal communication skills had declined.

Table 4.15: People Living with SCD Get a sense of belong among their Peers

People Living With SCD get a Sense of belonging among their Peers					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	56	56.0	56.0	56.0
	Disagree	10	10.0	10.0	66.0
	Neutral	6	6.0	6.0	72.0
	Agree	23	23.0	23.0	95.0
	Strongly Agree	5	5.0	5.0	100.0
	Total	100	100.0	100.0	

66% of the respondents believe that people living with SCD do not get a sense of belonging among their peers. This implies that there is a significant burden on persons with SCD who fail to get warmth and acceptance from their peers. There is growing awareness of the stigma's potential link to psychosocial challenges in SCD. Ola, B., Coker, R., & Ani, C. (2013) noted that adolescents with SCD frequently have delayed sexual maturity, which may exacerbate negative body image and feelings of stigmatization from peers. Kwena (2021) noted that SCD patients with low self-esteem have poor interpersonal communication skills.

Table 4.16: Caregiving role hindering their Interaction with the Community

Caregivers Hindering their Interaction with the Community					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	6	6.0	6.0	6.0
	Disagree	6	6.0	6.0	12.0
	Neutral	7	7.0	7.0	19.0
	Agree	16	16.0	16.0	35.0
	Strongly Agree	65	65.0	65.0	100.0
	Total	100	100.0	100.0	

81% of the respondents agreed that their roles potentially hindered their interaction with the community. This finding is in line with a study by Kwena (2021) who noted that caregivers were susceptible to difficulties with their physical, mental, and social well-being. Caregivers are more susceptible to caregiving difficulties due to these vulnerabilities, which negatively affect life and regular functioning. Further, caregivers have been reported to experience frustration, social exclusion, stress from their responsibilities, longing for normalcy, depression over missed opportunities, decreased life satisfaction, disenchantment over a lack of comprehension, sleep disturbances, irritation, psychological anguish, emotional fatigue, stigma, fear of infection, and ambiguity about the future nature of the illness (Theis et al, 2008; Anie 2005; Gesteira, Bousso, & Misko, 2016).

A majority of the respondents (71%) agreed that societal communication practices influence stereotypical behaviour and management of SCD. Symbols were created to construct a society that perceives SCD patients as outcasts in society necessitating the need to bridge the knowledge gap by promoting communication patterns that are geared towards mitigating the magnitude of the illness.

70% of the respondents noted that SCD patients may experience stigma and discrimination because most participants appear to view the disease unfavourably in terms of marriage and employment. This is consistent with findings from earlier studies have shown that people with SCD frequently report stigma connected to SCD.

On the question of how caregivers learnt about SCD, the majority of respondents (78%) noted that they learned about SCD through a healthcare professional after their child tested positive for SCD. This indicates that little is being done outside of healthcare settings or systems to spread awareness of the condition. In addition to not knowing about the disease, a far smaller percentage of forty caregivers (40%) stated that they knew about its causes, symptoms, and prevention, which points to a much bigger issue that could impede control measures and medical uptake.

4.3 Qualitative Analysis of the In-depth Interviews and Focused Group discussions

This section contains the qualitative analysis of the in-depth interviews that were conducted with the three care providers at the CSCF. This section also contains the analysis of the focused group discussion that the researcher had with the caregivers. All the in-depth interviews and focused group discussions were conducted at the Baraka Clinic in Mathare which is run by the Children Sickle Cell Foundation.

4.3.1 Qualitative Analysis of the In-depth Interviews

The interview was conducted using the interview guide that was administered among three key informants who were all health care providers. In terms of the level of education, all of them had achieved tertiary education. The study sort to establish caregivers' perception of the influence of interpersonal communication on stereotypical content surrounding Sickle Cell Disease.

The main themes from the in-depth interview with key informants were:

Theme 1: Culture

Theme 2: Literacy level

Theme 3: Stereotypes

Theme 4: Counselling

Theme 5: Awareness Creation

Theme 1: Culture

Cultural connotations drive prejudice and stereotypical tendencies towards patients leading to situations of withdrawal from the medical regime where there is no counselling, training, education or peer-to-peer support in support groups. The health care providers noted that there were deep-rooted traditions that discourage SCD patients/caregivers to seek help from medical care providers with some citing stigma as a barrier to seeking medical help. The key informants noted that a caregiver's attitude, knowledge and practices would sometimes limit their access to information on Sickle Cell Disease.

> HPC1
>
> 'The problem we face as health practitioners are dealing with people who believe that SCD is a result of some form of witchcraft and will not stick to prescribed medications alone. When you mix prescribed medication together with other forms of non-conventional treatment, the outcome of the patient is severely affected. In the time that a patient is seeking alternative medicine, they do not come to the hospital. They end up coming to the hospital when the situation has worsened'
>
> HPC 2
>
> 'Culture presents a challenge in dealing with SCD emergencies or crises because cultural connotations enable victimization leading to death following fear of stigmatization. It is noted that some caregivers keep SCD patients at home even when they need help.

The third key informant indicated that the challenges were two-fold; covering the cultural and awareness levels. The study revealed that cultural connotations placed on children with SCD affect communication with patients especially those who have lost children or members of the family.

This is because there is fear that they might be treated as outcasts. Therefore, they are not always willing to share information. In many cultures in Africa, supernatural explanations for bad luck are prevalent. Due to the lack of treatment for genetic disorders such as SCD, many families migrate between several healthcare specialists over time, as well as between other causes. Marsh et al (2011) noted that low awareness levels of SCD lead to a slow acceptance process and that behaviour makes it hard to demystify the disease because of insistence on traditional medicine.

> HCP 3
>
> 'It is easier for me to talk to a caregiver who does not have a predetermined perception about the SCD than who has cultural perception of the disease. A caregiver who believes that their child is doomed to die soon will not keep up with the treatment process of their child properly.'

Theme 2: Literacy level

When asked whether the level of education help in debunking SCD stereotypes by health care providers to the patient, the three HCPs agreed that it was easier to counsel and follow up a treatment regime with educated caregivers. In their experience, education plays a big role in debunking some of the most common perceived myths and stereotypes that make SCD a stigma-related disease. Informed caregivers can seek conventional treatment methods enhanced by counselling that empower caregivers with the right information and education.

> HCP 1
>
> 'I find it easier to communicate with educated caregivers. They normally ask relevant questions and even go ahead to seek more information from other sources such as the internet on the best practices in the management of SCD'

Theme 3: Stereotypes

Stereotyping content surrounding the disease suggests that Sickle Cell disease has been gendered as a disease brought about by women and that a patient may be reserved and not open up to an HCP if they are stereotyped. Mothers of children with SCD are susceptible to stigmatization within families, and these findings may apply to other similar situations in Africa and have significance for other genetic disorders. To address the stigma and discriminatory impacts of having a child with SCD, proper interpersonal communication and SCD management are crucial. The possibility, nature, and form of stigmatization all point to this Marsh V. M. et al. (2011)

HCP 2

> ‘I have witnessed cases where when a child tests positive for SCD, the man blames the woman for bringing about the disease. Most of the time, it is the woman that bears the brunt. If you look at the statistics of our clinic, the number of single mothers caring for their children with SCD is very high’

The respondents also indicated that they sometimes develop a prejudice against SCD caregivers or patients who disregard their advice.

HCP1

> ‘I am aware of my own prejudice. Carriers of SCD who continue to have more children with SCD even though they are not married in complete disregard of medical advice against having more children with SCD disappoint me. However, my work is advisory. I inform the concerned parties of the implications involved. If they decide to go ahead and have more children, it is up to them ’

Theme 4: Counselling

The key informants agreed that interpersonal communication between caregivers and the community shapes stereotypical tendencies surrounding Sickle Cells Disease and advocates for awareness campaigns to alleviate ignorance surrounding the disease by encouraging patient disclosure. Interpersonal communication as a component of counselling conducted through face-to-face interactions, electronic devices or social media platforms may help the public to understand that Sickle Cell Disease is a hereditary condition and not a culturally constructed disease, which can lead to a change in health behaviour to be a health-seeking behaviour. The key informants (respondents) also agreed that the language used should not promote negative cultural practices against patients with SCD.

Further, the key informants agreed that there should be more awareness of SCD even among HCP. It was evident that stereotyping of SCD by HCP affected access to medical facilities.

HCP 1

> ‘There are health facilities where people do not understand what SCD is. Patients with SCD who go to such facilities end up with more health complications or succumb if they do not receive the right treatment on time’

All the respondents acknowledge that the existence of counselling, training and education sessions, support group meetings and peer-to-peer sessions helps in the disclosure and management of SCD based on the fact that those avenues of interaction use interpersonal communication to achieve their goals. Counselling and peer-to-peer support help the patients and caregivers to achieve self-acceptance although some patients and caregivers tend to shy away from them. The respondents agree that interpersonal communication as a technique in counselling can be used to accelerate health-seeking behaviour towards the management of Sickle Cell disease as well as altering attitudes among caregivers. The respondents noted that caregivers and patients fall back to their cultural beliefs when explanations given to them during counselling sessions are not satisfying or comprehensive.

> HCP 2
>
> ‘Interpersonal communication plays a key role in counselling caregivers as well as patients. When caregivers meet in support groups, they share their challenges and best practices in caring for their children with SCD and the results of such interactive sessions have been far reaching’

When asked how they help patients of SCD cope with the stress associated with revealing the disease and health status, the HCPs stated that they offer to counsel both at the individual and organizational levels counselling to caregivers. Further, the CSCF facilitates peer-to-peer support, advocacy and the creation of awareness of SCD.

> HCP 3
>
> ‘We try to impart knowledge on SCD to patients and caregivers early as soon as their children test positive for SCD before the negative stereotypes get to them. We interact on a regular basis with as well’

Theme 5: Awareness Creation

The HCPs acknowledge the continuous progress being made in the country in pre-marital testing and genetic counselling for SCD by couples intending to get married in certain religious institutions. One HCP stated that most churches now require couples intending to marry in the church to do testing for SCD and other genetic diseases. The HCPs hoped that premarital testing and genetic counselling could be incorporated into law as a primary means of driving down the number of births with SCD.

4.3.2 Qualitative analysis of the Focused Group discussions

The FGDs were conducted on 18th February 2022 and 11th March 2022 at the Baraka Health Centre during a CSCF haematology clinic. The two FGDs had six participants each resulting in a total of 12 participants. The Caregivers were coded to maintain their anonymity.

Table 4. 17: Profile of Caregivers in the FGDs

Variable	**Frequency (n=12)**	**Percent (%)**
Age		
18-28	4	33
28-38	5	42
38-48	2	17
Above 48	1	8
Gender		
Male	3	25
Female	9	75
Marital Status		
Single	3	25
Married	5	42
Divorced/Separated	3	25
Widow/Widowed	1	8
Duration of Membership in CSCF (in Years)		
0-5	5	42
5-10	6	50
Above 10	1	8
Education Level of the Caregiver		
Primary	2	17
Secondary level	7	58
Tertiary level	2	17
Bachelor's degree or higher	1	8
Occupation of Caregiver		
Formal employment	1	8
Casual employment	3	25
Self-employed	3	25
Unemployed	5	42

The main themes that came up in the qualitative FGD were as follows:

Theme 1: Awareness Levels

Theme 2: Stereotyping Tendencies

Theme 3: Stigma and Social Isolation

Theme 4: Interpersonal Communication

Theme 1- Awareness Levels

On the question of how family and friends perceive caregivers of a child with SCD, seven out of the twelve respondents noted that low awareness levels in the wider community have supported the unfair treatment of caregivers and patients with SCD as they are treated with discrimination on accounts that they are products of witchcraft and are sometimes forced to go through primitive rituals.

A caregiver responded;

> ‘One time, a neighbour told me that it is not normal for my child to suffer lack of blood in the body (anaemia) so often unless an evil spirit is taking away the blood. She recommended a witchdoctor that I should visit to have my child ‘treated’’ (Caregiver 5 at FGD1, 18th February 2022)

On the question of what can be done to demystify SCD, ten out of the twelve respondents were of the view that public awareness and education through the mass media should be embraced in creating sensitization and awareness on SCD to improve the management and treatment of SCD.

Theme 2: Stereotyping Tendencies

On the question of how the community treats children living with SCD narratives, nine out of the 12 respondents noted that they face stereotyping tendencies from family, friends, the community and healthcare centres. This is consistent with the conclusions of a study by Kwena (2021). Stigma arises when caregivers are labelled as having children who do not thrive, are constantly ill, are unwell, or are thought to have an infectious disease like HIV/AIDS.

> ‘My family and friends do not visit me much. The SCD keeps them away’ (Caregiver 2 at FGD1, 18th February 2022)

> ‘Some family and friends have encouraged me to get another wife or at least get some children out of wedlock who are healthy’’ (Caregiver 6 at FGD2, 11th March 2022)

On the question of what the community think or how the community perceive SCD seven out of the twelve respondents noted that SCD is seen as a burden driving child mortality and hindering mobility. It is seen as taking a financial toll on the caregivers. The caregivers reported being treated with disdain based on the fact that they are always looking for financial assistance. The caregivers noted that their interactions are affected as society sees SCD patients and caregivers as contagious likening them to another stigmatized disease such as HIV/AIDS. The caregivers noted that a lack of interpersonal communication leads to a lack of empathy for the caregiver and the patient.

> ‘Many people do not know about SCD. They just make their conclusion when they see my child sick or looking different from other children. A neighbour once said that our child has HIV/AIDS’ (Caregiver 1 at FGD2, 11th March 2022)

On the question of what hinders communication on SCD with HCP, eight out of the twelve caregivers noted that stigma, healthcare providers’ attitude, incomplete information on SCD and treatment plan were major hindrances to communication with healthcare providers. This finding is consistent with that of Brennan-Cook (2018). Although there is no proof to back up the idea that people with SCD are opiate addicts, medical professionals frequently categorize SCD patients as such. These experts' harsh views make it difficult for SCD patients to manage their discomfort effectively. Inadequate clinician and patient knowledge also lead to incomplete information as noted by Haywood et al (2009).

> ‘Due to my child’s recurrent sickness, he is always in pain. I take him to the hospital a lot. One time, a healthcare provider said my teenage child is pretending and just addicted to the strong pain medication’ (Caregiver 3 at FGD1, 18th February 2022)

> ‘Sometimes doctors are not in the mood to explain to you everything. They just give you orders on what to do. It is so frustrating’ (Caregiver 4 at FGD2, 11th March 2022)

Theme 3: Stigma and Social Isolation

When asked about their experiences when communicating with members of the community who have no knowledge of sickle cell, eight out of the 12 caregivers reported that they may distance themselves from those who hurt them. The respondents reported that they steer clear of uninformed individuals in the community who backbite and equate persons with SCD to contagious diseases or famine, assume patients fake their symptoms or are spoilt, or call them names like "macho mayai," which is a slur for someone who has jaundice. These findings agree with other studies by Adegoke and Kuteyi (2012), Burnes et al (2008), and Davis, (2009). When responding to the question on their experience of taking care of children with SCD, a caregivers stated:

> ‘My son is in Grade 2 but I still carry him to school. My neighbours wonder why I carry such a big boy to school and why he is too lazy to walk. I try to explain to them that my child has SCD and as a result, he is always too tired to walk to school by himself. I am worried whenever I leave the house or travel far leaving my son behind because he may fall sick and no one can care for him as I do.’ (Caregiver 5 at FGD2, 11th March, 2022)

When asked how friends and family perceive caregivers to persons with SCD, eight out of the twelve caregivers reported that they get alienated from the community when they don't participate in important social activities that form the fabric of society, especially if others react negatively and label them as social misfits. Other times, individuals isolate caregivers to avoid being asked for financial assistance or to distance themselves from the illness and the stigma attached to it. To avoid embarrassing situations, those who don't know how to help may avoid caregivers. The caregivers reported that in some instances, social groups deprive caregivers of social responsibilities, which lowers their self-esteem and increases emotions of timidity.

When asked what the community think or perceive of SCD, seven out of the 12 respondents stated that some members of the community see the condition as a form of witchcraft or punishment from the gods. Sickle Cell disease is also seen as a curse and a bad omen because of the pain and high child mortality rate that it comes with. Children with SCD in some cases are seen as burdensome because, despite all the effort made to keep the patient alive, he/she dies. This has led to culture being given preference over scientific treatment.

> ‘My first child was so sick and had very yellow eyes. The doctor said that he did not have blood in the body. He soon died. As soon as I came back from the City Mortuary, my daughter also got so sick. We were admitted to HDU. My daughter also had yellow eyes and I was told that she too did not have blood in her body. I felt so lost with one child in the morgue and another one critically ill in the hospital. My friends and family said that my children are bewitched and suggested that I visit a witchdoctor’ (Caregiver 1 at FGD1, 18th February 2022)

> ‘I lost my first and second child to SCD at ages two and four respectively. When I gave birth to my third child and she also started getting sick, my husband left (Caregiver 2 at FGD1, 18th February 2022)

Theme 4: Interpersonal Communication

When asked whether communication with the community influences their attitude towards their SCD patient, nine out of the twelve caregivers who took part in the FGDs noted that when SCD patients are stigmatized it affects their social well-being leading to low self-esteem, stress and poor interpersonal communication. The caregivers have to cope with the fear of isolation from their children, anxiety and feeling of helplessness. SCD-related stigma leads to broken marriages where husbands abandon their wives and vice versa. Most of the respondents reported that SCD patients are discriminated against as people think they have other stigma-related diseases such as HIV because of pale eyes, swelling of hands and feet, craniofacial alterations, smaller bodies, leg ulcers and frequent visits to hospitals.

> ‘Some of my friends think that my child has SCD because of a curse that runs in the family. My child looks different from other children. There are instances where other parents tell their children not to play with my child because they think that their children will get infected with SCD.’ (Caregiver 6 at FGD2, 11th March 2022)

On the communication factors that define stereotypical behaviour toward SCD, seven out of the twelve caregivers felt that verbal and non-verbal abuse through interpersonal communication which leads to stigma is a burden. Persons with SCD have to deal with a social process replete with segregation and rejection that comes from the social judgment of SCD. Stigma through verbal or non-verbal communication leads to limited social interaction because of being socially judged or excluded. Successive pain episodes in persons with SCD also drive stigma based on HCP-caregiver interaction. SCD patients according to the respondents’ fear being viewed as stubborn. Effective communication by HCPs will help provide reassurance and empathy in the management of SCD through continuous awareness creation.

CHAPTER FIVE

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Overview

This chapter discusses key findings, derives conclusions and makes recommendations for the study.

5.2 Discussion of Key Findings

Content of stereotypical information surrounding Sickle Cell Disease as perceived by the caregivers visiting the CSCF clinic

Based on the findings, it is evident that most respondents (81%) did not believe SCD is a result of a curse based on cultural defiance. Further, a majority of the respondents (78%) did not believe that men/women who defy culture are the spreaders of SCD in the community. These findings imply a high awareness levels level among the caregivers attending the clinic at the CSCF. The CSCF takes advantage of clinic days to counsel, educate, train and conduct support groups meeting which has helped in heightening knowledge and awareness levels among the caregivers. These findings imply that the stereotypical content surrounding SCD as perceived by the caregivers attending the CSCF clinic at the Baraka Health Centre is not internalized stereotypical content but societal/external stereotype content.

Most respondents (55%) in this study did not believe that SCD is a bad omen. This finding implies that although a majority of the respondents do not associate their patients with being bad omens in society, 45% of the respondents associate the condition with bad omens. Studies by Marsh V. M. et al. (2011), Anie (2010), and Babalola (2019) noted that there is a need for a comprehensive approach to knowledge dissemination to scale down stereotypical tendencies synonymous with SCD in society. The public should also be made to understand that Sickle Cell Disease is a genetic disorder and not a culturally constructed disease, which can lead to a change of health behaviour to a health-seeking behaviour this, provides a basis for proper health communication. This implies that awareness conducted through interpersonal communication can help to demystify the disease.

A majority of the respondents, (57%) indicated that people fear that they could be infected with SCD when they come in contact with patients. This points to a knowledge gap and low awareness levels among the masses. This is in line with the research by Kwena (2021) that highlighted the challenges of stigma and social isolation that caregivers are faced with. The study noted that the caregivers are stigmatized because they are viewed as parents whose children do not thrive, are constantly ill, are unwell, commonly labelled *'sicklers'* or are suspected to be suffering from an infectious disease like HIV, which is also a highly stigmatized condition. There is also a need to conduct general awareness through mass media and public campaigns that embrace other interpersonal communication strategies.

Low SCD advocacy and awareness campaigns, provide a foundational basis for the cultural construction of the disease through negative practices that, have been considered normal in the socialization process. This finding is in line with the study by Kwena (2021) who noted that the caregiving roles of children with SCD are mostly left to women and that only a few men are willing to take part in active caregiving roles. This study had 82% female caregivers and 18% male caregivers. This finding is in line with previous studies that found more women caregivers actively involves in caring for the sick suffering from chronic illnesses (Adegoke & Kuteyi, 2012; Mbugua, et.al. 2011).

The CSCF uses different forms of interpersonal communication to educate caregivers and to promote advocacy and awareness of SCD. Disclosure connects people and promotes acceptance, which reduces stereotypical tendencies around the disease ensuring that the patients are embraced by society providing them with warmth. Interpersonal communication is extensively used in peer support group sessions, as well as through the group conversations that caregivers use in keeping abreast of the best practices on SCD management.

It is clear from the study that CSCF offers information and creates awareness of SCD through various interpersonal communication through one-on-one counselling, supports group counselling and engagements, peer-to-peer support, social media engagement, health websites, and online support groups. The impact of the foundation's efforts in awareness creation can be seen in the high percentage of caregivers that no longer associate SCD with cultural notions or suffer internalized stigma. However, a lot more needs to be done in the wider society that stereotypes SCD as noted by the respondents in this study that the stigma they face is external. Interpersonal communication could help in knowledge dissemination and the creation of awareness that dispels uninformed notions about SCD. Changing the stereotypical notions held in the wider society may increase caregivers' psychological support and emotional health to encourage disclosure among the 50% of caregivers from the study who are not willing to openly disclose the status of their children.

Perceived influence of interpersonal communication on SCD and related stereotypes

This study noted that 66 % of caregivers perceived that interpersonal communication of children with SCD was affected when they faced rejection from peers as well as when they encountered verbal and non-verbal abuse in schools, the community and health facilities. The labelling of persons with SCD and their caregivers with slurs impacts negatively their interpersonal communication among family and friends, schools, community and health facilities. The physical, social, emotional and psychological, wellbeing of patients and their families are negatively impacted by the pain associated with SCD and its comorbidities.

A majority of the caregivers from the FGDs agreed that there should be a multifaceted approach which effectively incorporates interpersonal communication in dealing with the stereotypical content surrounding SCD from lower primary school to higher institutions of learning. Interpersonal communication is considered a critical element in the management of SCD as it provides warmth and helps the patients deal with the fear of rejection. Interpersonal communication provides an avenue where SCD patients are integrated and accepted in the community. The researcher also found out that verbal and non-verbal abuse towards SCD patients is prominent within different social spheres. Interpersonal communication is considered an avenue for reducing verbal/discriminatory labels on SCD and enhancing warmth and acceptance for SCD patients. Using courteous language both in nonverbal and verbal expression with a key focus on cues that improve SCD management.

Interpersonal communication using both verbal and nonverbal modes of communication shapes stereotypical tendencies surrounding Sickle Cells Disease and advocates for awareness campaigns to eradicate ignorance surrounding the disease. The key informants in this study also agreed that the language used should not promote stigma and negative cultural practices against patients of SCD and their caregivers. It is impossible to overstate the value of health information and communication in debunking myths and misconceptions about the SCD. This is backed by the study by Opeyemi et al. (2020) which noted that SCD is associated with numerous mythologies and fallacies tied to it and thus highlights the importance of incorporating interpersonal communication as well as indigenous or vernacular language and communication methods in eliminating stereotypes associated with SCD.

The relationship between interpersonal communication, stereotyping content and management of SCD

A majority of the respondents 66% noted that they do not experience normalcy in life. This points to the burden and challenges resulting from dealing with a chronic illness like SCD. Societal opinions/views on SCD determine the patient’s medical uptake routine, most respondents were of the view that societal opinions distorted the patient’s medical routine because through those opinions, prejudice was encouraged making the patients avoid medication in a bid to appear normal.

A majority of the respondents (81%) viewed their caregiving roles as a hindrance to their interaction. This is in line with a study by Kwena (2021) which noted that caring for family members especially children with SCD acts as a barrier to effective interpersonal communication among caregivers. Caregivers are limited in engaging in economic, social or physical activities, resulting in difficulties that lead to vulnerabilities in the areas of mental health, relationships with others, finances, and physical health.

Interpersonal communication, according to this study can be used to promote normalcy in the lives of SCD patients by reducing the prejudice that defines the disease. Interpersonal communication when well implemented can be used to alleviate misconceptions surrounding the disease about social interactions. According to this research, interpersonal communication can be used to promote recognition of the importance of warmth in the management of SCD. Interpersonal communication has the power to shape perceptions and define constructions that fundamentally affect the management of SCD.

Societal opinions and views determine the medical regime of SCD patients. A research by Solomon and Theiss (2013) suggests that one of the essential and unavoidable requirements in life is interpersonal communication, which contributes heavily to socialization. Every interaction with others is influenced by the person's cultural background. Interpersonal communication is always shaped by culture. Communication reflects the culture and is shaped by it. As a result, the signals that individuals convey expose their culture as well as the myths and prejudices that they believe.

The Ministry of Health of Kenya should develop messages that address our cultural biases when drafting campaign messages to create awareness of SCD.

Interpersonal communication through face-to-face interaction or through digital devices can be used to promote conversation about SCD in society. A majority of the respondents (70%) agreed that societal communication practices influence stereotypical behaviour and management of SCD. According to the respondents, stereotypes lead to a difficult co-existence of the caregivers and the community because it leads to social isolation. When caregivers are forced to quit groups that form their social capital, it impairs their social functioning. If they are fired from work due to frequent absenteeism while taking care of their children or family members, they lose economic functionality and social networks. In the end, it affects the quality of their caregiving

5.3 Conclusion

On the content of stereotypical information surrounding sickle cell disease as perceived by the caregivers, it is evident that interpersonal communication strategies used by the CSCF which include education, training, counselling, peer-to-peer support and dissemination of information, education and communication materials among the caregivers have been successful in dispelling stereotypical content associated with SCD among the caregiver. From this study, it is clear that the stereotypes, associated with stigma, abuse, misconception and misinformation, faced by the caregivers are not self-perceived but from the wider community. Lack of interpersonal communication/insufficient interpersonal communication with the wider society in awareness creation on the origin, nature of SCD and inheritance patterns of SCD leads to a knowledge gap. The vacuum brought about by low awareness levels leads to the advancement of stereotypical content which is a catalyst for victim blaming, mocking, dependency, labelling, isolation, helplessness, and pessimism are widespread, not to mention the stigmatizing impact of some prevailing lay ideas about the illness, social discrimination and societal prejudice. There should be concerted efforts by stakeholders to create high awareness levels of SCD in the wider society.

On the perceived influence of interpersonal communication on SCD and related stereotypes, it is clear that caregivers and patients of SCD are faced with a lot of verbal and non-verbal abuse which affects their effective interaction with others in schools, the community and health centres. When used correctly, interpersonal communication provides warmth and helps patients deal with the fear of rejection. Interpersonal communication can also provide an avenue where SCD patients are integrated and accepted into the community. Effective interpersonal communication by HCPs will help provide reassurance and empathy in the management of SCD.

On the relationship between interpersonal communication, stereotyping content and management of SCD, this study found that interpersonal communication is important in influencing behaviour, attitudes and awareness levels in the management of SCD as it provides an avenue for mental strength, knowledge and information sharing and peer-peer conversations. Interpersonal communication is fundamental in eradicating misconceptions and myths that advance stereotypical tendencies toward SCD. Interpersonal communication provides an opportunity to establish a support network that provides a safe space for the promotion of counselling among SCD patients hence interpersonal communication is critical in ensuring societal acceptance of SCD patients.

In conclusion, interpersonal communication should be treated as a key component in managing sickle cell disease and the approach should be integrated into guidance and counselling for a holistic approach to the management of the disease.

5.4 Recommendations

Recommendation on dealing with the content of stereotypical information surrounding sickle cell disease as perceived by the caregivers

Policymakers should ensure continuous sensitization on SCD through comprehensive health communication, health education and health promotion through different forms of interpersonal communication that incorporate verbal, non-verbal and proverbial means. Policies should also be reviewed to incorporate education on SCD in formal learning to improve the care of SCD patients in learning institutions as well as promote public awareness of genetic testing and counselling. There is a need for policymakers to integrate a communication module during the training of specialized HCPs dealing with SCD disease. Policymakers should also encourage a Public Private Partnership (PPP) to ensure comprehensive media campaigns are done to promote awareness and counter stereotypical tendencies surrounding SCD.

Lawmakers should pass laws related to communication guidelines that guide counselling and screening for genetic disorders before marriage to reduce infant mortality rates. Further to this, a comprehensive pediatric health law that will ensure every child born within Kenyan borders undergoes compulsory screening at birth for all forms of genetic disorders and records kept to promote early interventions and management. Laws should also be enacted that promote nondiscriminatory measures on SCD in all spheres of life for caregivers and persons with SCD.

Recommendation on the perceived influence of interpersonal communication on SCD and related stereotypes, interpersonal communication

It is important in the creation of societal norms that would eradicate or advance stereotypical tendencies of SCD. It is therefore important for communities to advocate for positive/constructive interpersonal communication to assist in disapproving stereotyping content. Interpersonal communication using vernacular and other indigenous languages should also be used by Government agencies, media, non-profit organizations and other stakeholders in debunking myths and misconceptions about SCD in the wider society.

Recommendation on the relationship between interpersonal communication, stereotyping content and management of SCD

Interpersonal communication should be part of SCD management through a comprehensive counselling programme because it is through communication that a relationship between HCP and a patient/caregiver can be established through which detection, counselling, disclosure and management of the disease can be done hence reducing the severity of the disease. Having direct interactions through social media platforms without the need for formalism can provide for immediate one-on-one interaction for the caregivers, patients and health providers which may help in breaking communication barriers in the healthcare of SCD patients.

5.7. Suggestions for Further Studies

Further studies can be done in the following areas:

1. Media representation of SCD,
2. Factors influencing conversations on SCD in the age of new media
3. The relationship between communication, culture and SCD.
4. An investigation into the health communication practices in the management of SCD
5. The impact of behavior change in SCD management

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APPENDICES

Appendix I: Consent Form

Caregivers' Perception on the Influence of Interpersonal Communication on Stereotyping Content of the Sickle Cell Disease

1. Consent to take part in research
    - ☐ I……………………………………………… willingly consent to take part in this study.
    - ☐ I am aware that even if I agree to participate right away, I can opt-out at any moment or decline to answer any questions without facing any repercussions.
    - ☐ I am aware that I have two weeks following the interview or Focused Group Discussions (FGDs) to withdraw consent to use the data from my interview; in that event, the information will be erased.
    - ☐ I received a written explanation of the study's objectives and methodology, and I was given the chance to ask any questions I had.
    - ☐ I am aware that taking part in this research won't directly benefit me.
    - ☐ I consent to have my interview audio recorded.
    - ☐ I am aware that any information I give will be kept private and confidential for this study.
      I am aware that any report on the findings of this study will not reveal my identity.

Signature of research participant -----------------------------------

Date--

Signature of researcher---------------------------------------

Date---

Appendix II: Focus Group Discussion Topic Guide for Caregivers

Thank you for agreeing to participate in this focus group, and welcome. Since your perspective is crucial to this study, you have been asked to join this group. The study is entitled **"Caregivers' Perception on the Influence of Interpersonal Communication on Stereotyping Content Surrounding the Sickle Cell Disease."**

Introduction

In order to identify elements that improve or function as barriers to communication, the purpose of this discussion will be to explore your experiences, thoughts, and perceptions about communication with care providers. The data from this study will be used to tell the hospital about how to enhance your experiences in the future. It will take around an hour to have the concentrated group discussion.

Set Guidelines

1. One speaker at a time is always present.
2. Please wait until someone has completed speaking before you begin.
3. No response is right or wrong.
4. You're not required to talk in a specific order.
5. Please speak up when you have something to say, regardless of what the other group members may think.
6. You are not required to share the group's opinions.
7. Does anyone have a question?
8. If you are willing to take part in the research, kindly sign the consent form.
9. Introductions

Then let's begin

Questions

a) How do your friends and family perceive you as a caregiver to someone with SCD?

b) How does your relationship with an SCD patient affect your interaction with the community?

c) What are your thoughts on how your community treats your child living with SCD?

d) What experiences have you had when communicating with members of the community who have no knowledge of sickle cell?
e) What does the community think or how does the community perceive SCD?
f) Does your communication with the community influence your attitude towards the SCD patient?
g) What communication factors define stereotypical behaviour toward SCD?
h) What do you think hinders communication on SCD with healthcare providers?
i) What can be done to demystify SCD?

Conclusion

I appreciate your participation. This conversation has been quite educational. Your input is a crucial component of this study. We hope the discussion was worthwhile, and the researcher will be in touch with you to share the results.

Thank you

Appendix III: Questionnaire

Dear respondent,

My name is **Winnie Mandela Adhiambo,** a final year student at the University of Nairobi, pursuing a Master of Arts degree in Communication Studies. As part of my program of study, I am carrying out research on **“Caregivers’ Perception of the Influence of Interpersonal Communication on Stereotyping Content Surrounding the Sickle Cell Disease.”** Kindly take a few minutes to respond to the questions outlined in this questionnaire. Be assured that the data collected will be treated with utmost confidentiality, and anonymity and will only be used for this research.

General instructions:

Please note; your name is not required.

Section A: Personal Information

1. What is your gender?
   Female [ ]
   Male [ ]
2. How long have you been a member of the Children Sickle Cell Foundation?
   0-2 years [ ] 3-5 years [ ]
   5 -10 years [ ] Above 10 years [ ]

3. What is your age
   18-28 years [ ] 28 -38 years [ ]
   38 -48 years [ ] Above 48 years [ ]

4. What is your highest educational background?
   Primary [ ]
   O- level [ ]
   Diploma [ ]
   Bachelor’s Degree [ ]

Postgraduate Degree [ ]

Section B: The content of stereotypes surrounding sickle cell disease as perceived by the caregivers visiting CSCF clinic.

To what extent do you agree with the following statements on content of stereotypes surrounding Sickle Cell Disease. Use a scale of 1 to 5 where 1 is strongly disagree, 2 is disagree, 3 is Neutral, 4 is agree and 5 is Strongly agree.

Statements on stereotypical content surrounding the SCD	**1**	**2**	**3**	**4**	**5**
The SCD is a curse for cultural defiance					
It is women/men who defy culture that spread SCD in the community					
SCD patients are a bad omen to the community					
People fear they could get infected with SCD if they were to be in contact with you or your patient.					
Stereotypical content on SCD influences your perception on the patient.					

1. In your opinion what leads to the stigmatization of persons with SCD? Explain.

2. How does society relate or define your child with SCD in relation to culture?

3. What role does counselling by HCPs play in patient status disclosure?

4. Do you disclose the status of your child with SCD to strangers? If yes, why? If not, why?

Section C: The nature and influence of interpersonal communication on the SCD stereotyping content on the caregivers.

To what extent do you agree with the following statements on the nature and influence of interpersonal communication on the SCD stereotyping content? Use a scale of 1 to 5 where 1 is Strongly Disagree, 2 is Disagree, 3 Is Neutral, 4 is Agree And 5 is Strongly Agree.

Statements on The nature and influence of interpersonal communication on the SCD stereotyping content	**1**	**2**	**3**	**4**	**5**
Interpersonal skills among SCD patients are affected due to fear of rejection by other children during the play session					
People living with SCD face rejection from their peers.					
People living with SCD face verbal and non-verbal abuse in schools, community and health facilities					
Stereotyping by HCPs influences your Care-Seeking Behavior					

1. What factors/barriers limit the interaction of your child/children with SCD with other members of society?

2. Are there cultural connotations placed on children with SCD? If yes, what connotations?

3. What challenges do you experience as a caregiver when interacting with others?

Section D: Relationship between interpersonal communication, stereotyping content and management of SCD.

To what extent do you agree with the following statements on the relationship between interpersonal communication, stereotyping content and management of SCD. Use a scale of 1 to 5 where 1 is strongly disagree, 2 is disagree, 3 is Neutral, 4 is agree and 5 is Strongly agree.

Statements on the relationship between interpersonal communication, stereotyping content and management of SCD	**1**	**2**	**3**	**4**	**5**
People living with SCD experience normal life in the society					
People Living with SCD Get a sense of belong among their Peers					
Caregiving roles Hindering their Interaction with the Community					

1. Do societal communication practices influence stereotypical behaviour and management of SCD? Explain.

2. Do societal opinions/views on SCD determine the patient's medical uptake routine?

3. Do societal perceptions, knowledge of SCD and behaviour affect access to medical care for persons with SCD? Explain.

THANK YOU FOR YOUR PARTICIPATION

Appendix IV: In-depth Interviews Schedule for Health Care Providers

1. Does stereotypical content surrounding Sickle cell disease influence the perception of the patient?
2. How does stereotypical content affect the management of a sickle cell disease patient?
3. From the stereotypical content surrounding SCD do you find communicating with the patient difficult?
4. Do cultural connotations influence the way you communicate with a patient?
5. Does the stereotype of SCD affect the patient acceptance process?
6. Does the level of education help in debunking of SCD stereotype by health care providers to the patient?
7. Does the patient's social interaction affect his/her cognition of sickle cell?
8. How does stereotyping influence interpersonal communication between health care provider-patient and caregiver?
9. Do any significant differences exist in stereotypical content defining male or female?
10. Are you aware of your own stereotypical tendencies toward Sickle cell disease as a healthcare provider?
11. What role do you play in reducing stereotypes surrounding Sickle cell disease?
12. Does stereotyping of Sickle cell disease patients impact access to medical facilities?
13. Do individuals with Sickle cell disease alter their care-seeking behaviours based on their stereotypical experiences?
14. How does stereotyping of Sickle cell disease affect patient-provider relationships?
15. How do you help patients of Sickle cell disease cope with the stress associated with revealing the disease and health status?

Appendix V: Researcher's NACOSTI License

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This is to Certify that Ms.. Winnie Mandela Adhiambo of University of Nairobi, has been licensed to conduct research in Nairobi on the topic: A caregivers' perception on the influence of interpersonal communication on stereotyping content surrounding the sickle cell disease for the period ending : 15/October/2022.

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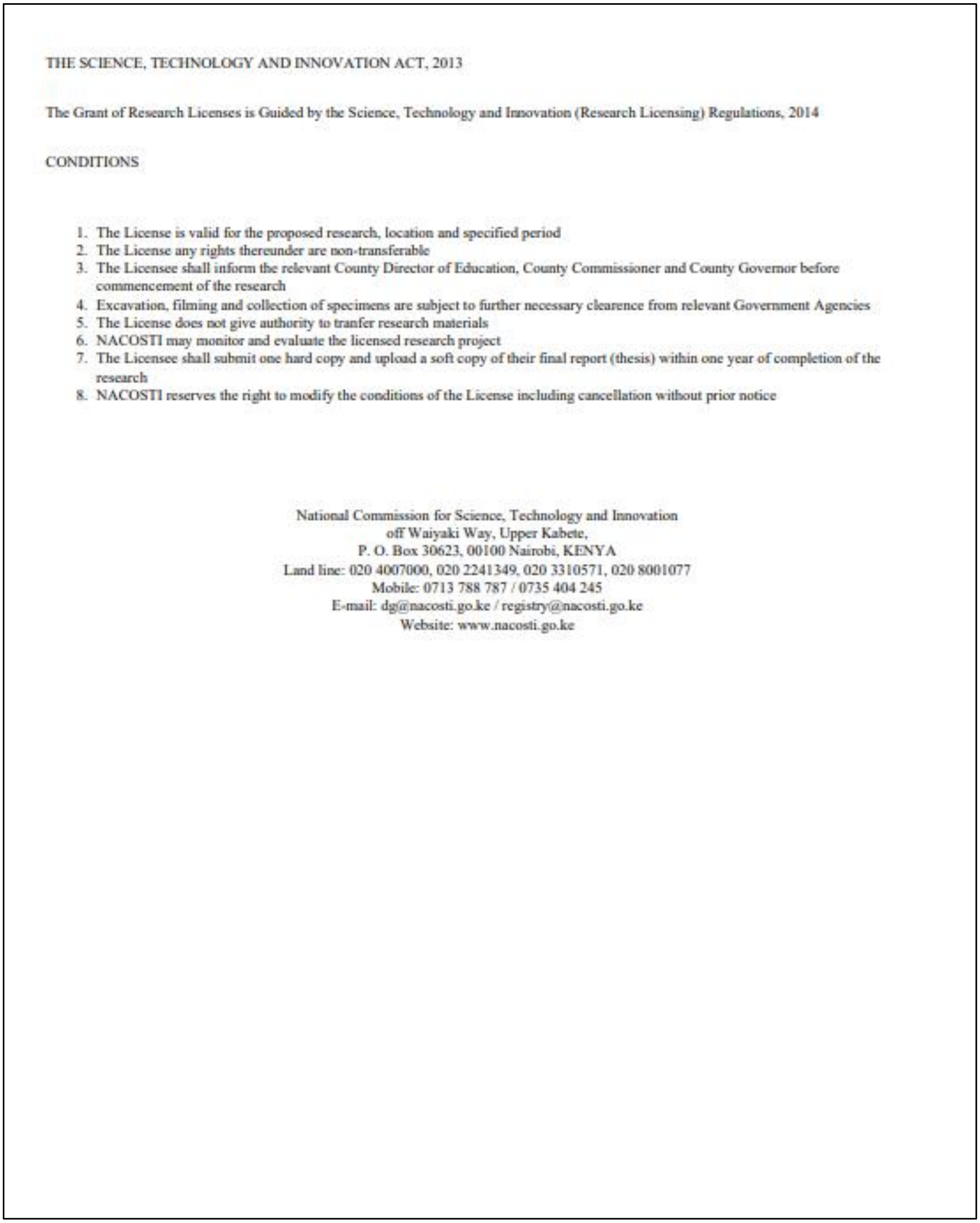

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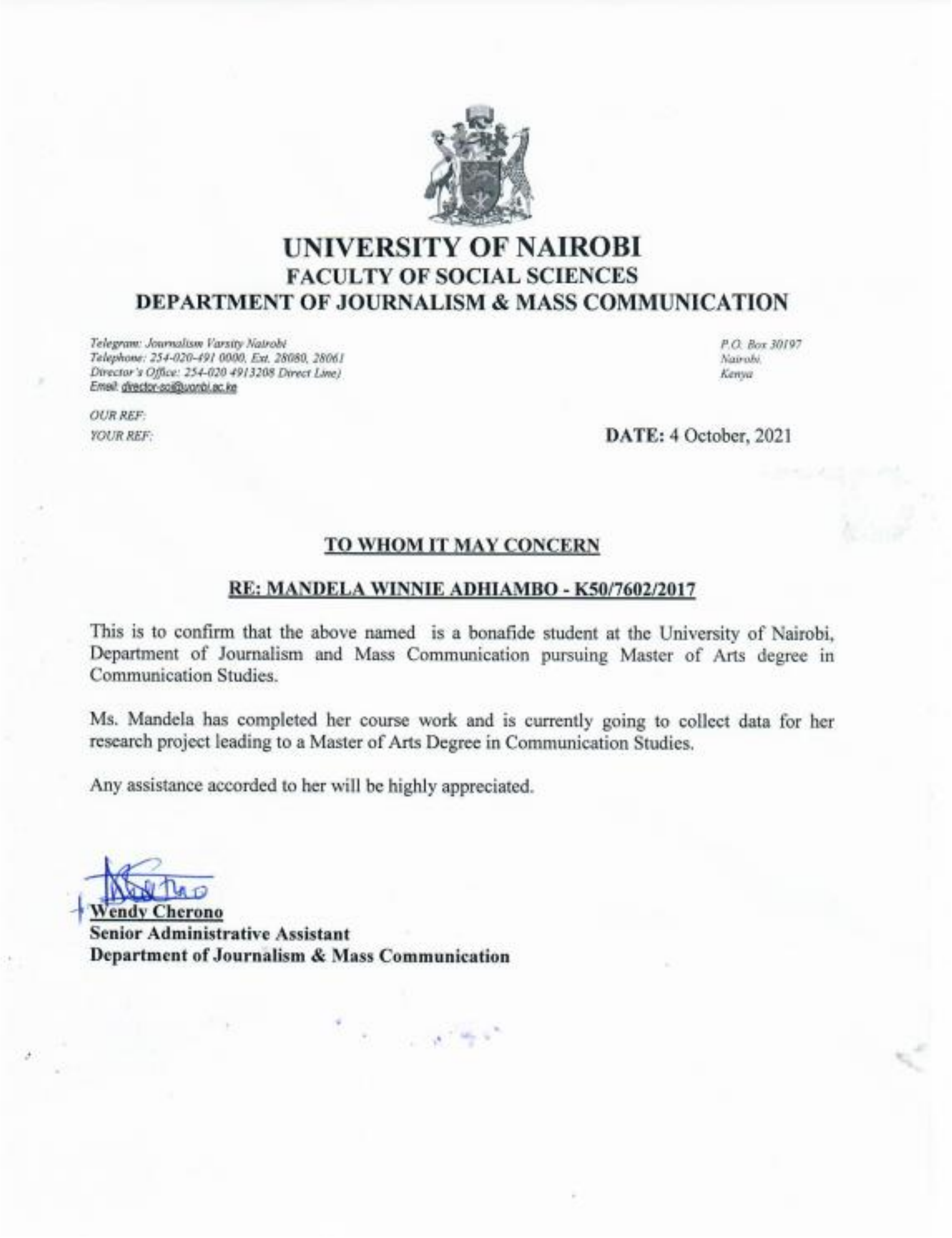
Appendix VI: Researcher's Letter of Introduction to Fieldwork



UNIVERSITY OF NAIROBI
FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF JOURNALISM & MASS COMMUNICATION

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Email: director-soj@uonbi.ac.ke

P.O. Box 30197
Nairobi,
Kenya

OUR REF:
YOUR REF:

DATE: 4 October, 2021

TO WHOM IT MAY CONCERN

RE: MANDELA WINNIE ADHIAMBO - K50/7602/2017

This is to confirm that the above named is a bonafide student at the University of Nairobi, Department of Journalism and Mass Communication pursuing Master of Arts degree in Communication Studies.

Ms. Mandela has completed her course work and is currently going to collect data for her research project leading to a Master of Arts Degree in Communication Studies.

Any assistance accorded to her will be highly appreciated.

Wendy Cherono
Senior Administrative Assistant
Department of Journalism & Mass Communication