

**ASSESSMENT OF COMMUNICATION BARRIERS BETWEEN HEALTH
CARE PROVIDERS AND CAREGIVERS OF CHILDREN WITH SICKLE
CELL DISEASE AT KENYATTA NATIONAL HOSPITAL**

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DECLARATION

This dissertation proposal is my original work and has not been presented for the award of a degree in any other university.

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DEDICATION

To the almighty God who gave me strength and wisdom to accomplish this work.

To all the caregivers who made this work possible, for their resilience, determination and inspiration.

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TABLE OF CONTENTS

DECLARATION	2
DEDICATION	3
ACKNOWLEDGEMENTS	4
TABLE OF CONTENTS	5
LIST OF FIGURES	8
LIST OF TABLES	9
LIST OF APPENDICES	10
ABBREVIATIONS	11
DEFINITIONS	12
ABSTRACT	13
1. INTRODUCTION	14
2. LITERATURE REVIEW	16
2.1 Sickle cell disease	16
2.1.1 Etiology	16
2.1.2 Prevalence.....	16
2.1.3 Pathophysiology	16
2.1.4 Clinical manifestations	17
2.1.5 Complications	17
2.1.6 Diagnosis	18
2.1.7 Management	18
2.2 Patient provider education on sickle cell disease.....	19
2.3 Communication in healthcare	21
2.4 Patient provider communication in paediatrics.....	21
2.5 The purpose of communication in the medical setting	22
2.6 The doctor-patient interaction.....	22
2.7 Benefits of doctor patient communication	23
2.8 Barriers to effective communication.....	25
2.9 Study Justification and Utility	28
2.10 Study question.....	29
2.11 Study objectives	29
2.11.1 Primary objective.....	29
2.11.2 Secondary objectives	29
2.12 Theoretical framework.....	29

2.13 Conceptual framework.....	31
3. RESEARCH METHODOLOGY	32
3.1 Research design	32
3.2 Study location	32
3.3 Study population	32
3.3.1 Inclusion criteria	32
3.3.2 Exclusion criteria	33
3.4 Sample size determination	33
3.5 Sampling method and participant recruitment procedure	34
3.6 Study procedure and data collection procedure	38
3.6.1 Study tools	38
3.6.2 Data collection procedures	38
3.7 Data management and analysis	41
3.8 Quality assurance procedure	41
3.9 Ethical considerations	42
3.9.1 Ethical approval	42
3.9.2 Consent	42
3.9.3 Privacy and confidentiality	42
3.9.4 Study risk	43
3.9.5 Benefits to study participants	43
3.10 Control of errors and biases	43
4. RESULTS	44
4.1: Characteristics of respondents	44
4.1.1 Caregivers	44
4.1.2 Health care providers	46
4.2 Perceived communication barriers	47
4.2.1 Caregivers' perceived communication barriers	47
4.2.2 Health care providers perceived communication barrier	50
4.2.3 Proportion of health care providers who experience challenges when communicating with caregivers	53
4.3 Caregivers' perceptions on communication with HCPs	54
4.3.1 Proportion of caregivers satisfied with communication (n=91)	55
4.3.2 Caregivers' knowledge about SCD	57
4.3.4 Source of information about SCD	59

4.3.5 Use of written materials during communication	59
4.4 Suggestions on ways to improve communication.....	61
4.5 Qualitative data analysis	62
4.6 Key informants interviews	63
4.6.1 Demographics of key informant interview participants	63
4.6.2 Finding from the key informant interview	63
4.7 Focus group discussions	65
4.7.1 Key findings from focus group discussions	65
5. DISCUSSION	70
5.1 Study strengths.....	73
5.2 Study limitations	73
5.3 Conclusion	73
5.4 Recommendations.....	73
REFERENCES	75
APPENDICES	84

LIST OF FIGURES

Figure 1: Conceptual framework	31
Figure 2 Sociodemographic characteristics of HCPs.....	47
Figure 3 Training on communication skills	51
Figure 4 Proportion of HCPs who have had challenges disclosing information	53
Figure 5 Proportion of caregivers satisfied with communication	55
Figure 6: Caregivers' reasons for dissatisfaction.....	56
Figure 7: Source of information.....	59
Figure 8: Use of written materials during consultation	60

LIST OF TABLES

Table 1: Models of doctor patient relationship	23
Table 2: Sample frame	34
Table 3: Stratified tabulation of caregivers in each ward and haematology clinic	34
Table 4: Stratified tabulation of each ward and haematology clinic	34
Table 5: Profile of caregivers.....	45
Table 6: Profile of health care providers.....	46
Table 7: Adequacy of consultation time	48
Table 8: Caregivers perception on health care providers communication behavior....	49
Table 9: Caregivers main communication barriers.....	49
Table 10: Effect of HCPs sociodemographics characteristics on communication	50
Table 11: Distribution of work limitation barriers among health care providers	51
Table 12: Distribution of training period among HCPs trained in communication.....	52
Table 13: Communication barriers faced by HCPs	52
Table 14: Caregivers' perception on communication with HCPs	54
Table 15: Caregivers' knowledge about SCD	57
Table 16: Caregiver suggested ways of improving communication.....	61
Table 17: HCP suggested ways of improving communication.....	63

LIST OF APPENDICES

Appendix I: Caregiver consent form in English	84
Appendix II: Fomu la idhini – Kiswahili	88
Appendix III: Health care provider consent form.....	92
Appendix IV: Caregivers questionnaire.....	96
Appendix V: Dodoso za watunzaji	105
Appendix VI: Health care providers questionnaire	114
Appendix VII: Focus group discussion topic guide for caregivers.....	119
Appendix VIII: Mada ya mwongozo wa mjadala wa makundi yenye malengo ya watunzaji	121
Appendix IX: Focus group discussion participants form (caregivers)	123
Appendix X: Key informant interview guide	124

ABBREVIATIONS

ACS	Acute Chest Syndrome
CVA	Cerebrovascular Accident
CZE	Capillary zone electrophoresis
FGDs	Focused Group Discussions
HbAS	Haemoglobin AS
HbF	Haemoglobin F
HBM	Health Belief Model
HbSC	Haemoglobin SC
HbSS	Haemoglobin SS
HCP	Health Care Providers
HPLC	High performance liquid chromatography
HSCT	Hematopoietic Stem Cell Transplantation
IEF	Isoelectric focusing
KDHS	Kenya Demographic Health Survey
KNH	Kenyatta National Hospital
PI	Principal Investigator
RCTs	Randomized Controlled Trial
SCA	Sickle Cell Anemia
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
TCD	Transcranial Doppler Ultrasonography
UN	United Nations
WHO	World Health Organization

DEFINITIONS

Caregiver	Is defined as any person, usually an adult who is involved in providing goods and services for the welfare of the SCD child, including material and social support, and follows up the clinical management of the child. This may include but is not limited to a parent, other relatives or non-related guardian.
Communication	Is defined as the sharing of a meaning with the intent of influencing human relationships.
Communication barriers	Factors that hinder the achievement of effective communication.
Communication facilitators	Factors that enable the achievement of effective communication.
Effective communication	Communication that puts all the needed tenets to share the intended information to achieve particular goals.
Health care provider	Anyone that is in charge for the medical and/or psychosocial care of an individual. This can include primary care and other physicians, nurses, clinical officers, pharmacists and nutritionists.

ABSTRACT

Background: Sickle cell disease (SCD) is the most common genetic disease in the world and is associated with significant morbidity and mortality. Assessment of gaps in caregiver-provider communication is a crucial step in enhancing better practices in the future and improving the outcomes for the patients, providers and society as a whole.

Study objectives: To assess the barriers to effective communication among health care providers (HCPs) and caregivers of children with SCD at Kenyatta National Hospital (KNH). Caregivers' perceptions on the communication status and ways of improving communication was explored.

Methods: Mixed-methods. A cross sectional survey conducted among 91 caregivers of children with SCD and 72 HCPs (doctors, nurses and clinical officers) at KNH. Qualitative methodology employed comprised two focus group discussions (each with eight caregivers), and four key informant interviews with nursing matrons.

Results: Short consultation time (41.2%), use of technical terms by health care providers (18.2%) and lack of privacy during consultation (10.7%) were the main barriers of communication reported by the caregivers. High workload (86.8%), insufficient time (55.9%) and lack of training on communication skills (27.9%) were perceived barriers to communication reported by HCPs. The key suggestions provided by HCPs and caregivers were: ensuring communication is comprehensive, conducting seminars and trainings on communication skills and increasing the number of HCPs.

Conclusion: It was concluded that HCPs should be trained on effective communication skills particularly on the use of simplified medical terms. In addition, it is crucial to provide comprehensive information whilst ensuring privacy is maintained during the consultation. It was proposed that an innovative brief written guide with visual aids be incorporated.

1. INTRODUCTION

Health communication as defined by World Health Organization (WHO) is the symbolic exchange of shared meaning with the aim of impacting knowledge and bringing about a behavioral change (1). According to Parvanta et al, health education plays an integral part in maternal and child health practices and promotion (2). Effective communication is essential for every health promotion and disease prevention project (3). Choice of health communication tools include: websites and music videos at the social/macro level, billboards at the community level, text messaging, pamphlets at interpersonal/micro level lastly medical records at individual and population levels. The different levels interact with each other and the net result is a health outcome, whether desired or not (4).

The main objective of any health system is to have in place the best possible care for patients. Every patient has a right to demand the best possible care in hospitals in this modern era and the hospital staff member must ensure optimal patient management and patient contentment is in place. Doctors require information from their clients in determining exact diagnosis and successful treatment; on the other hand, patients too require information and the justification for its treatment. Hence communication between doctors and patients must be effectual and precise in order for a health care system to function effectively (5).

Several studies have shown that doctor's friendliness and courtesy; attentive listening; positive facial expression; social talk; information giving and seeking; emphasis on understanding the presented information; uninterrupted consultation, and adequate lengths of consultation are important components for good doctor-patient communication and relationship (6,7).

Communication still remains the fundamental means by which the patient and the doctor can exchange health information despite complicated technologies for diagnosis and treatment (5). Educating caregivers and patients on SCD and pain management is necessary for adaptive coping and enhanced disease management. Ensuring that they have precise and widespread knowledge may also lead to better health practices,

increased treatment compliance and improved perception on the control of the disease (8).

Patients perceived quality and satisfaction of their healthcare is related to good patient provider communication and shared decision making. Patients who communicate well with their doctor are more likely to be contented with their doctor and share critical information that enables better observance to treatment (7).

2. LITERATURE REVIEW

2.1 Sickle cell disease

2.1.1 Etiology

Sickle cell disease is a hereditary disease caused by an adenine to thymine point mutation that leads to replacement of valine for glutamate on the 6th amino acid of the beta globin chain. The result of this leads to formation of abnormal haemoglobin S (HbS). In the deoxygenated state, HbS forms polymers which lead to the physical deformation or sickling of erythrocytes (9).

Sickle cell is inherited in an autosomal recessive model which means both copies of the gene in each cell has mutations (10). Sickle haemoglobinopathies have different genotypes and they include sickle cell anemia (HbSS), sickle cell haemoglobin C disease (HbSC) and sickle cell B Thalassemia (SBThal) (11). HbSS is the commonest form in Kenya (12).

2.1.2 Prevalence

Sickle cell disease affects approximately 30 million people (13). In Africa, a total of approximately 240,000 children are born with SCD every year (14,15). The highest mortality is mostly recorded in children less than five years with infections being the leading cause of mortality in sub-Saharan Africa (15,16).

In Kenya, the frequency of sickle cell trait (SCT) varies from one ethnic group to another, however, no recent studies on the nationwide prevalence of SCD is available (17). Despite the scarcity of documented data, this condition is associated with high childhood morbidity and mortality with studies showing that there is shortened life span among SCD children born in Africa (18).

2.1.3 Pathophysiology

Polymerization leads to extravascular and intravascular haemolysis, obstruction of blood vessels by sickled red blood cell and tissue hypoxia leading to both acute and chronic complications. The sickled cells have a shorter life span than normal red cells causing chronic anemia in the affected persons (19,20).

Vaso-occlusion is triggered by several steps and different variables such as inflammatory reactions, increased viscosity and reduced flow (21).

Sickle cells exhibit increased adhesiveness to vascular endothelium, leucocytes, platelets and themselves, this is believed to propagate the occurrence of vascular occlusion especially in post capillary venules (22). Episodic microvascular occlusion in SCD results in ischemic reperfusion injury which sets the stage for increased inflammatory tone, causing elevations in total leucocyte counts, platelet counts and positive serum acute phase reactants (23,24).

2.1.4 Clinical manifestations

Variations in the presentation in patients with SCD result from erratic degrees of haemolysis and sporadic episodes of vascular occlusion which is the source of tissue ischemia and organ dysfunction (25). Severe haemolysis in infancy causes marrow hyperplasia of the skull and facial bones causing widening of the diploe spaces and thinning of the bone cortex, the so-called skull bossing. Pallor, jaundice, splenomegaly occur due to chronic haemolysis (26).

2.1.5 Complications

Vaso-occlusive crises pain is caused by microvascular occlusion which triggers the activation of nociceptive afferent nerve fibers. Patients may initially present with the hand and foot syndrome characterized by dactylitis that involves the small bones of the hand or foot, marked by swelling over the affected region. Dactylitis is one of the earliest complications occurring at less than one year of age (27).

Cerebrovascular accident (CVA) is considered one of the solemn complications of SCD. The rate of developing ischemic strokes is high with an incidence of 285 per 100,000 person years being reported in the United States prior to effective crucial stroke prevention (28). Stroke occurs in about 11% of patients with SCA (29). Transcranial Doppler ultrasonography (TCD) is used to detect intracranial arterial narrowing enabling early identification of those children at risk. Yearly screening is recommended for asymptomatic patients and chronic blood transfusions for high risk patients. These interventions are not readily available to patients in Africa due to limited accessibility to care (14).

Acute and chronic pulmonary complications are major causes of morbidity and mortality including prolonged hospital stay in children with SCD (30). Acute chest syndrome (ACS) is a frequent cause of acute lung disease, with more than half of the children with HbSS having an episode of ACS during the first decade of life (31).

Musculoskeletal complications secondary to avascular necrosis, osteomyelitis and septic arthritis can cause of morbidity and mortality (14). Approximately 10% of patients with SCA develop osteomyelitis during the course of their life, it often affects children and young adults and can occur in association with septic arthritis (32).

Infections commonly cause mortality in SCD. The main organisms isolated are encapsulated organisms, predominantly *Streptococcus pneumoniae* (33). This is due to a variety of immune defects, the most important being splenic dysfunction (34).

2.1.6 Diagnosis

Most affected persons in Africa lack vital diagnostic and clinical care hence children die from pneumonia, bacterial sepsis and severe anemia, yet SCA was the grave underlying diagnosis. Sickle solubility test, despite being the widely available method cannot distinguish the disease from the trait. Definitive diagnosis can be made through isoelectric focusing (IEF), high recital liquid chromatography(HPLC) or capillary zone electrophoresis(CZE) (35).

2.1.7 Management

Comprehensive care involves providing holistic care services and is seen to providing better outcomes in SCD evidenced by lessening mortality, hospitalization and blood transfusion rates. Comprehensive sickle cell centers are crucial in improving SCD outcomes. WHO recommends the setting up of special dedicated centers with a high degree of autonomy in those areas where haemoglobinopathies are common (36).

The control of SCD starts with public education and definition of strategies that prevents further spread of the trait. Carrier detection and genetic counseling have been shown to curb the spread of other haemoglobinopathies like thalassemia (37). At diagnosis, there should be proper education about the nature of the disease, possible

complications, prevention and treatment for the patient and caregivers. Emphasis should be sited on avoidance of known precipitants of SCD and the need to adhere to treatment (13). Management of SCD requires a multi-specialist team who should also be offered timely and regular medical education to improve their expertise and skills (38).

Apart from routine immunizations, children with SCD should get extra vaccinations to reduce their risk of *Streptococcus pneumoniae*, *Neisseria meningitidis*, hepatitis B and seasonal influenza infections. Oral penicillin, hydroxyurea and folic acid supplementation have also been shown to improve prognosis (39,40).

Hydroxyurea works by increasing the levels of fetal haemoglobin (HbF) and this has reduced vaso-occlusive events, chest syndrome, hospitalization and blood transfusions (41). Olielo P. found a noteworthy reduction in the frequency of blood transfusion in children with SCD at KNH and Gertrude's Hospital following 6 months of hydroxyurea therapy (42). Current National Institute of Health guidelines recommend the use of hydroxyurea in patients as young as 9 months of age (43).

Transfusion of red blood cells is an important therapy to manage patients with SCD who are in danger of adverse outcomes (44). Studies have reported that 75.3% of children with SCA were transfused before the 6th year of life (45). Hematopoietic stem cell transplant is the sole potentially curative disease modifying intervention in SCD (25).

2.2 Patient provider education on sickle cell disease

Sickle cell disease was initially linked to high rates of childhood morbidity and mortality but this has been reduced in developed countries by the introduction of newborn screening, socio-economic development, better education and improved access to medical care, this however may not be the case in low and middle-income countries due to limited resources (35,46).

Educating patients and their family members on SCD is vital for adaptive coping and improved disease management. Paediatric patients who were educated on SCD were found to be less anxious and better psychologically adapted than their counterparts who

were not. Researchers have shown that correct and comprehensive education on SCD may lead to good health practices and improved perception on the management of the disease (47). Education has also been shown to improve self-management which leads to improved health outcomes and reduces the disease burden on caregivers (48).

Counseling should be done to patients and their parents in order to avoid known precipitants of sickle cell crisis like dehydration, infection, undue physical exertion or exhaustion and regularly reminded on the importance of compliance to routine medication which include hydroxyurea, folic acid and oral penicillin at the time of diagnosis and during the subsequent medical follow ups (13).

Improving the knowledge of caregivers on SCD has been shown to improve adherence, create positive health beliefs and enhance their quality of life (49). Rahimy et al in 2003 conducted a longitudinal study on 236 children to evaluate the effect of rigorous parental education and sufficient clinical care on the course of SCD in children in Benin. They observed a marked drop in the frequency and severity of SCD related acute events (50).

Despite the importance of patient education, research has shown a dearth of public health knowledge on SCD (51). Gamit et al, 2014 conducted a cross sectional study to assess the knowledge about SCA in patients with positive sickle cell status in Bardoli Taluka. From the 276 patients included in the study, 16% knew correct symptoms of SCA, while approximately 90% did not know that it is an inherited disease (52). In Uganda, Sharifu et al, 2018 conducted a cross sectional study among 116 respondents to assess the level of awareness on SCD, only 48% knew that SCD was inherited while 44.2% did not know the cause of the disease (53). In Kenya, Macharia et al in 1997 conducted a study to assess the knowledge, attitude and beliefs of primary caretakers at Nyanza Provincial Hospital. Out of the 108 respondents interviewed, 78% knew SCD to be hereditary, 55% knew how the disease presents in childhood and only 42% associated SCD with increased risk of infection (54). All the three researchers concluded that more effort needs to be done to promote awareness on SCD.

2.3 Communication in healthcare

Communication is a process between two people in which one is free to express what he or she means in an understandable manner and the other person understands the meaning of the message fully and properly (5). Patient provider communication involve both verbal and non-verbal interactions which form a key aspect in the relationship between patients and their providers (55). On the other hand, verbal communication in health care is the exchange of information aimed at identifying the medical issues whereas non-verbal communication is the emotional tone of the interaction (56).

Communication in health care has changed as patients and caregivers now demand information, courtesy and time as opposed to the times when explanation, empathy and politeness were never expected of doctors. Good communication ultimately equals to good medicine (58). Chronic disease experts have called for the adoption of more collaborative patient-provider interaction styles that would enhance the patient's self-management (59).

2.4 Patient provider communication in paediatrics

Communication in paediatrics is triadic in nature, involving the patient who is a child, the caregiver and the health care provider. It is very important to communicate effectively with all the parties involved so as to improve treatment compliance (60).

In paediatrics, the caregivers play a critical role in disease management as the patients are the children (61). However, there is a moral and ethical responsibility to discuss health and illness with the child as this shows respect for their capacities and would enhance their skills in self-management in the future. Research has demonstrated improved adherence when the child is incorporated in his or her treatment plan (62).

It is important to understand the pre-existing relationship between the patient and the child. The family's cultural values and the developmental needs of the child should be taken into consideration. Caregivers and practitioners should decide together whether the child will be present at the informational consultations or whether the caregivers prefer the communication to be within the family (63).

2.5 Communication in the medical setting

Effective communication serves many purposes in healthcare because it solves identified problems during communication between the doctor and the patient which eventually results in an important fall in patient anxiety (64).

Effectual communication in medicine forms a core component in quality healthcare delivery as this facilitates exchange of information. For the patient, it helps regulate their emotions, facilitate comprehension of medical information and identification of their needs. The patient is also able to communicate vital information that allows the doctor to make early detection of problems which can prevent medical complications and expensive interventions (65).

Good communication is a pre-requisite for forming and maintaining interaction. The interpersonal connection that doctors and patients develop is defined by the way they interrelate with each other (66). Good communication and open discussion is important in maintaining an optimistic relationship. Physicians should recognize the roles of families and caregivers and fully incorporate them in the management of the patient (67).

2.6 The doctor-patient interaction

Physicians are the depositary of the medical knowledge to patients and because of this, physicians have control over the interaction. Physicians differ in the extent to which they share information with their patients and patients themselves differ on how active they are at seeking information (68).

Studies indicate that patient centered communication conveys empathy and increases satisfaction (7,60). Patient centeredness is a move towards medical management that embraces patients' preferences, experiences and expectations in which they are offered opportunities to participate in their care in ways that improve corporation and understanding (69).

Charles, Whelnan and Gafni illustrated various models to identify different doctor's communication styles: Paternalistic model, shared model and Informed model (5). In

the paternalistic model, the patient is provided with information that encourages them to consent to the doctor's preferred intervention. The doctor implements what he/she thinks is best for the patient. The patient is not involved in the process of making decisions.

In the informed model, the patient gets all relevant information from the doctors and it is up to the patient to choose the medical interventions and for the doctor to execute it. Communication is one way, from the doctor to the patient. The shared model is the preferred model as communication is two way. Both doctor and patient discuss the treatment options and agree on the decision to implement.

Table 1: Models of doctor patient relationship

Analytical stages		Paternalistic model	Shared Model	Informed model
Information exchange	Flow	One way (largely)	Two way	One way (largely)
	Direction	Doctor ↓ patient	Doctor ↑ ↓ patient	Doctor ↓ patient
	Type	Medical	Medical and personal	Medical
	Minimum amount	Legal requirement	Anything relevant for decision making	Anything relevant for decision making
Deliberation		Doctor alone or with other doctors	Doctor and patient (plus potential others)	Patient (plus potential others)
Who decides what treatment to implement?		Doctors	Doctor and patient	Patient

Source: Charles, C., Whelan, T., Gafni, 1999. "What do we mean by partnership in making decisions about treatment?" *BMJ*, Volume 319:780-782

2.7 Benefits of doctor patient communication

Compliance

Good communication enhances patients understanding and adherence to therapy, parents who do not understand the disease process are less likely to adhere to therapy (58,60). Zolnierek et al in 2009 conducted a meta-analysis on physician communication

and patient adherence to treatment. 106 correlation studies and 21 experimental interventions were included in the study and they found that there is a 19% higher risk of non-adherence among patients whose physicians communicate poorly than among those whose physicians communicate well (70). Zullig et al in 2015 conducted a cross-sectional study on the effect of patient-provider communication on medical adherence in post myocardial infarction patients and they also concluded that effective patient-provider communication is critical for adherence (71).

Trust

Patients' trust in their HCPs has been shown to be associated with the interpersonal healthcare experience (8). A patient who trusts his or her physician is less likely to question the physician's decisions and lodge medical complains. Likewise, when physicians perceive that they are not trusted by their patients, they become more cautious and adopt defensive behaviors like ordering of drugs or tests that are not needed (72). Haywood et al in 2010 conducted a cross-sectional survey on adults with SCD to determine the association between provider communication and trust in the medical professional. They found that better ratings of provider communication were significantly associated with higher levels of trust towards the medical profession with a 10% increase in provider communication rating being associated with a 3.76% increase in trust scores($p < 0.001$, 95% CI) (8).

Reduction of malpractice

Effective patient-provider communication has been shown to improve patient satisfaction (73,74). Most HCPs are competent and patient complains as well as medical errors are more often due to poor communication than incompetence (75). Hamasaki et al in 2008 conducted a retrospective study where they analyzed 100 decisions of medical malpractice cases in Japan. From the study they found that only 36% of the doctor's explained the cases to the patients, and 45% incorporated the families during the management of the patient. They also found that acknowledged physician liability was lower when doctor's explanation occurred before treatment (76).

Satisfaction

Effective patient physician communication has been shown to positively influence patients and physician satisfaction with health services (72). By communicating effectively with patients and their families, providers can obtain insight on the patient's behavior and preferences which has the potential to increase adherence to treatment and improve health outcomes (57).

2.8 Barriers to effective communication

Communication ought to be based on the specific setting in which it is occurring. Various factors hinder effective communication and a better understanding of the various factors that affect communication could reduce the frequency of their occurrence, increase satisfaction and compliance with medical plans (80). Barriers to communication may be explicit (for example, when a patient regards the doctor as being "too young"), or implicit, such as in verbal/non-verbal mismatch (for example, when asked about family problems - a patient might say "things are fine at home" while simultaneously looking downcast and sad) (81). Other barriers to effective communication include lack of listening, use of jargon, insufficient consultation time, sociodemographic factors (7,72).

Communication and medical jargon

A review of studies on the subject has revealed that patients often failed to understand the meaning of many common medical terms, while doctors generally overestimated what their patients have understood (82). Others have opined that this is no coincidence, as there was evidence that doctors' use of medical jargon was linked to preserving their authority (83). Other authors held opposing views, maintaining that doctors should provide explanations at the patient's level of understanding (84).

Misunderstanding between caregivers and health care providers

Problems in communication between the doctor and the patient may also occur due to differences in their personal beliefs (85). Misunderstanding can occur when the caregiver challenges the doctors or when the caregivers do not follow the providers' instructions (86). Factors such as time, age, nationality and social class affect the interactions between doctors and patients. Thus, aside from the barriers imposed by language, other difficulties that doctors may have in communicating with patients of

different nationalities arise from their mutual ignorance of each other's assumptive worlds (78).

Length of time in communication

According to Norman Balint, the technique used in general practice for understanding the patient needed too much time (87). However, he thought that worthwhile interaction could still occur in a short 5 to 10-minute consultation. Some authors propose that a doctor's ability to communicate effectively may be largely a function of the time available for the communication, however the literature on the subject is not very clear. However, other studies showed that thorough communication required longer consultations (8,15). Waitzkin observed that there was less communication by doctors who saw more than 20 patients per day. Thus, a busy practice was related to the manner of communicating, as busier doctors gave fewer multi-level and non-discrepant explanations (84). In a study by Sabherwal et al, 2015, out of the 70 patients interviewed, 93% reported that physicians did not give them enough time to consult, while 80% reported language barrier (88).

Gender and communication

Many studies have demonstrated that male and female physicians conduct their medical visits differently (89,90). Female doctors tended to have longer visits and engage in more partnership building, emotionally focused and positive talk, and psychological exchanges than male doctors (89,90). Ainsworth-Vaughn found that, in the USA, female doctors were interrupted by patients more often than their male colleagues (91). In another study by Thorson et al in 2004 cited by Govender, female patients of low income status do not play an active role in obtaining information about their health and are often not adherent to medication because they need to consult with their husbands and families, however other studies have shown that women are more expressive and talk about psychosocial issues (92).

Communication and social class

Patients' education and social class were also predictors of doctors' tendency to give them information (93). Thus, college-educated patients tend to receive more information than patients who did not go to college. Patients from upper class positions received more of the doctor's time, more total explanations, more multilevel

explanations, and more non-discrepant responses, than did patients of lower middle-class or lower-class background (84,93). Yet, there was no difference between poorly educated, lower-class patients and better educated, upper-class patients in their desire for information. Nevertheless, doctors misperceived this desire much more commonly for poorly educated or lower class patients. Further, this confirmed what other researchers already had observed, that lower-class patients usually ask fewer questions (84). Thus, the conclusion was that lower class patients may want more information than doctors think (82).

Doctors' training in communication

Seven essential sets of communication tasks have been recommended as providing a useful framework for communication oriented curricula and standards for doctors: (a) build the doctor-patient relationship (b) open the discussion (c) gather information (d) understand the patient's perspective (e) share information (f) reach agreement on problems and plans, and (g) provide closure (94). However several authors still perceive a need for more training for doctors to develop good communication skills (58,72).

Doctors' communication behavior

Doctors should be honest, show concern, give reassurance and show empathy during consultations (95) Patients who are more engaged report better health outcomes, which is brought about by the good physician communication behaviors and comprehension of treatment regimen by the patients. Good physician communication behaviors have been associated with adherence to treatment (95).

Work environment

A flourishing work environment must have support from the management like availability of medical equipment, safety for both patients and health care professionals and hospital rules and regulations that would enhance communication (77). Katell, 2010 conducted a study to evaluate doctor patient communication in a teaching hospital in Bangladesh and he concluded that minus hospital and management support, doctors can face problems of communication and there needs to be rules and regulations that would enable patients and doctors to be conscious of the patients' rights (5).

Cultural differences

Culture can be defined as a system of beliefs, values, rules and customs that is shared by a group and is used to interpret experiences and direct patterns of behavior (98). Culture and beliefs may affect communication because people from different cultures hold different beliefs about health, illness and communication like people with strong fatalistic views would not believe in screening tests or treatment thinking that if they were meant to die from a particular illness, they will (2). It is important to identify and address perceived barriers and benefits of treatment to improve patient adherence to medical plans by ensuring that the benefits and importance of treatment are understood (7).

2.9 Study Justification and Utility

Health care communication is critical to safe and effective medical practice. Ineffective communication can result in improper diagnosis or lack of adherence to prescribed treatment. This hinders positive medical outcomes desired by both the doctor and the patient. Few studies have been done on the barriers to communication between caregivers and health care providers of children with SCD. This is despite the fact that ineffective communication has been identified as one of the barriers in the care of children with SCD (96). Findings from the studies available have shown a significant proportion of caregivers are dissatisfied with the communication they are receiving from their health care providers and this has led to deterioration in caregiver-provider relationship. Local studies to establish the barriers to communication among health care providers and caregivers of children with SCD are limited.

The burden of SCD in the African region continues to increase with the increase in population. WHO recommends comprehensive health care management for SCD of which parent and patient education forms a core measure which ultimately helps reduce morbidity, prevent complications and improve quality of life. Current research indicates that ineffective communication brought about by communication barriers can cause medical errors and patient harm.

This study attempts to identify gaps in the provider-caregiver communication, find barriers in communication and give recommendations to enhance better practice in the future.

2.10 Study question

What are the barriers to communication between caregivers and health care providers of paediatric patients with sickle cell disease at Kenyatta National Hospital?

2.11 Study objectives

2.11.1 Primary objective

- i. To identify the barriers to effective communication between health care providers and caregivers of children with sickle cell disease at Kenyatta National Hospital.

2.11.2 Secondary objectives

- i. To establish the perceptions of caregivers on communication about sickle cell disease at Kenyatta National Hospital.
- ii. To identify ways of improving communication between health care providers and caregivers of children with sickle cell disease at Kenyatta National Hospital.

2.12 Theoretical framework

Communication theory serves as an origin for understanding the behavior of a human being. Two theories can be used to evaluate doctor patient communication and gain understanding on the factors that hinder effective communication, Barnlund's Transactional Model of Communication(1970) and Health Belief Model (HBM)(1958) (5,91).

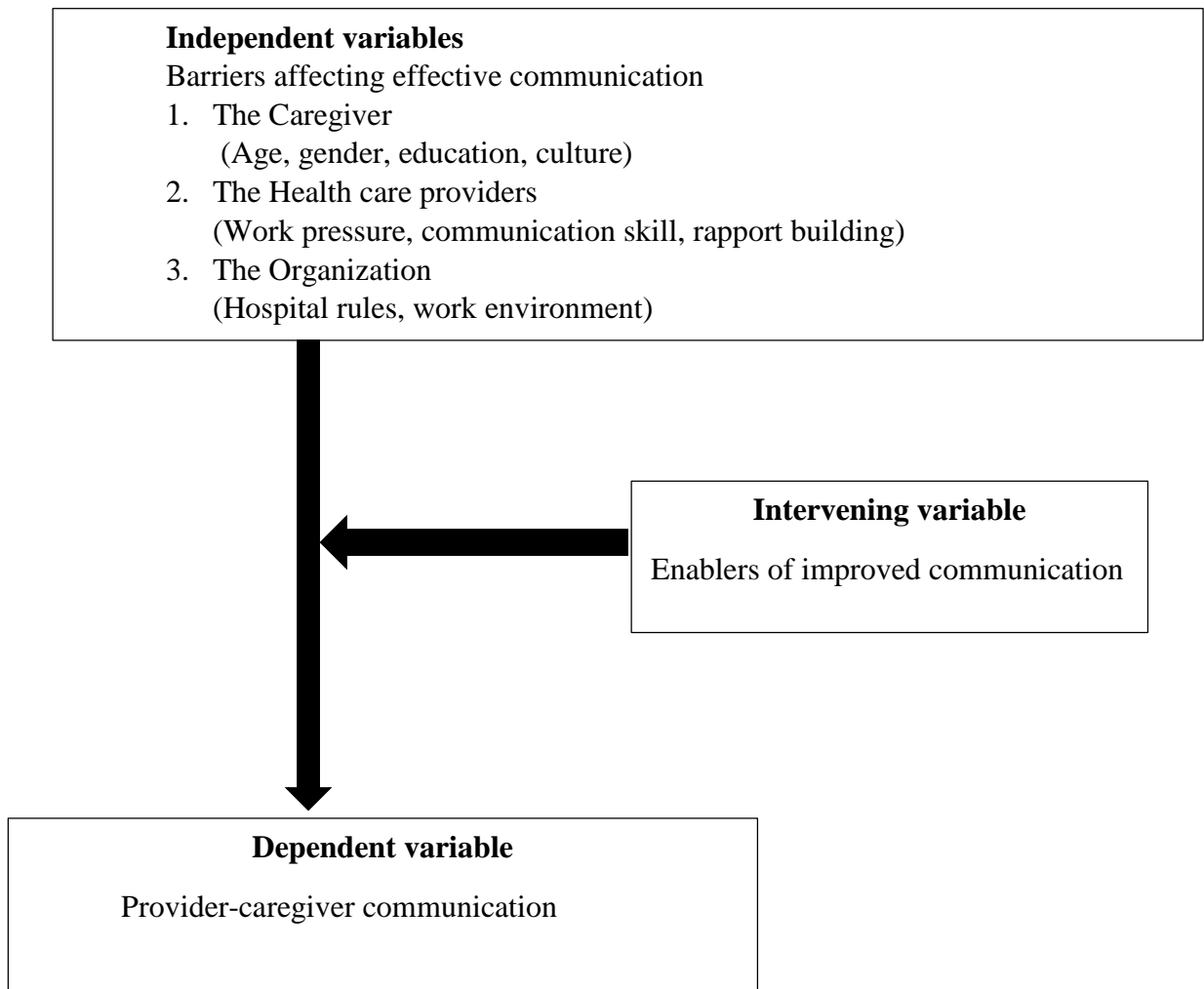
The Barnlund's Transactional Model identifies that communication is a simultaneous and interdependent process, in which the sender serves as the receiver and the receiver serves as the sender. The word transactional indicates that the communication process is an ongoing and continuously changing process. The transactional model focuses on the communicator's background, prior experiences, attitudes, cultural beliefs and self-esteem. The transactional model assumes that people are connected through

communication, that communication affects all parties involved and each player is a sender and receiver, not just a sender or receiver.

The Health Belief Model was originally intended to explain why people did not participate in programs that could help them diagnose or prevent diseases. The major assumption of this model is that in order to engage in healthy behaviors, intended audiences need to be aware of their risk for severe or life-threatening diseases and perceive that the benefits of behavior change outweigh potential barriers or other negative aspects of recommended actions. HBM is one of the first theories developed to explain the process of change in relation to health behavior. It has also inspired—among many other influences and models—the field of health education. Health education is defined as “any planned combination of learning experiences designed to predispose, enable, and reinforce voluntary behavior.

2.13 Conceptual framework

Figure 1: Conceptual framework



3. RESEARCH METHODOLOGY

3.1 Research design

This was a cross-sectional study that adopted both quantitative and qualitative approaches. The quantitative approach was conducted by carrying out interviews to assess factors affecting communication between health care providers and caregivers of paediatric SCD patients seeking care at KNH. Through the qualitative approach, the barriers to communication between caregivers and health care providers were explored.

3.2 Study location

The locations of the study were out-patient Haematology Clinic and the paediatric wards 3A, 3B, 3C and 3D at the Kenyatta National Hospital. The haematology outpatient clinic specializes in the care of haematology patients and is carried out every Monday. The venue is usually the KNH clinic number 23. Annually approximately 480 paediatric SCD patients are seen at the clinic. The staff running the clinic comprises approximately 5 doctors and 2 nurses. Annually, approximately 300 paediatric SCD patients are admitted in the wards and they are managed by approximately 18 paediatricians, 32 registrars, 4 medical officers, 30 nurses, 8 clinical officers, 2 nutritionists, 2 physiotherapists and 5 social workers at any given time.

3.3 Study population

The study population included caregivers of paediatric patients with SCD and health care providers working in the paediatric wards and haematology clinic at Kenyatta National Hospital.

3.3.1 Inclusion criteria

Inclusion criteria:

Caregivers

- i. of children with a diagnosis of SCD made via a confirmatory test (e.g. haemoglobin electrophoresis),
- ii. aged \geq 18 years old,
- iii. gave consent to participate in the study

Health care providers

- i. working in the paediatric wards and haematology clinic at KNH,
- ii. gave consent to participate in the study, were eligible to participate in this study.

3.3.2 Exclusion criteria

- i) Children who were not with their caregivers when the research was being conducted.

3.4 Sample size determination

Since this was a cross-sectional study, the Fishers formula for estimating proportions was used to determine the minimum sample size required for this study and adjusted for finite population.

$$m = \frac{Z_{\alpha/2}^2 p(1-p)}{e^2}$$

Source: Fleiss, Statistical Methods for Rates and Proportions, formulas 3.18 & 3.19

Where;

p = proportion of respondents who report **knowledge on SCD** provided by HCP (here 50%)

Z_{α} = Represents the desired **level of statistical significance** (typically 1.96 for 95% confidence).

e = **error margin** (5%)

m = **Sample size for infinite population** (here m=384 caregivers)

Adjusting the sample size for a finite population,

$$n = \frac{m}{1 + \frac{m-1}{N}} \text{ Where}$$

N = estimated population size (N=120) within a period of 3 months.

n = sample size adjusting for finite population (n=91).

From 120 caregivers estimated to visit the clinic during the 3-month period of the study.

The sample size calculated was 91.

The same formula was used to determine the number of HCP required for this study; from 88 HCPs, the sample size was calculated 72 for this study. The sample was distributed proportionately across the cadres: - (Doctors 57%, Nurses 34% and Clinical Officer (COs) 9%)

3.5 Sampling method and participant recruitment procedure

Table 2: Sample frame

Strata	Population	Percentage (%)	Sample
Caregivers	120	76	91
Doctors	54	57	41
Nurses	30	34	25
COs	8	9	6

Sample frame for caregivers and stratification for different areas where recruitment was carried out

Table 3: Stratified tabulation of caregivers in each ward and haematology clinic

Ward	Percentage (%)	Sample
Haematology clinic	56%	51
3A	11%	10
3B	11%	10
3C	11%	10
3D	11%	10

The sample at the haematology clinic accumulated to 56% giving a sample of 51 respondents due to the fact that patients at the haematology clinic were seen every week, and there was certainty in getting the respondents, thus ascertaining the big percentage in the sample stratification. Sample from different wards was evenly distributed using a stratified sampling technique while simple random sampling was used to sample respondents in each strata.

Sample frame for health care providers and stratification for different areas

Table 4: Stratified tabulation of each ward and haematology clinic

Ward	Percentage (%)	Sample
Haematology clinic	6%	5

3A	24%	17
3B	24%	17
3C	24%	17
3D	22%	16

The sample at the haematology clinic accumulated to 6% giving a sample of 5 respondents due to the fact that there are five fixed consultants placed at the clinic. Sampling from different wards accumulated to 24% giving a sample of 17 respondents and followed by simple random in each stratum given the fact that most of the health care providers are in the wards and the phenomena under investigation was homogeneously distributed.

Sickle cell disease patients check in for follow up at the haematology clinic every Monday, the clinic's operational hours run from 8.00am to 2.00pm. KNH has a centralized records department where all the patient files are kept. Two days prior to the clinic, the files of the patients booked for that particular clinic are retrieved from the central records department and kept in the records department situated in the paediatric outpatient clinic. This was also the same place where patient's next visit was communicated. After the clinic, the files were returned to the centralized records department. The researcher went through the records office every Friday prior to the Monday clinic for twelve weeks. The researcher then reviewed the doctor's notes and those files which had a confirmatory test (e.g. Hb electrophoresis) were kept aside.

The researcher made a list of these patients whose diagnosis was confirmed. The haematology clinic has a nursing station at the entrance, 6 consultation rooms and an additional 4 clerical points where the doctors sat and reviewed patients. When a patient came for the clinic, his/her file was retrieved from records and taken to the nursing station where they were arranged on the basis of first come, first serve. The researcher reported to the clinic every Monday morning at 8.00am for a period of twelve weeks. The nurses and the doctors were informed of the ongoing study.

The researcher interview was conducted in one of the side rooms in the clinics. The researcher waited at the nursing station to observe the patients coming in and confirm

that the names on the files match the ones on the researcher's list. From the stratification, a total of 51 care givers were sampled from the haematology clinic for the 3 month period. Approximately 10 paediatric SCD patients were seen in the Monday clinic. A maximum of 4 respondents were interviewed by the researcher selecting every odd number caregiver on a first come first serve basis (i.e. caregiver number 1, 3, 5 and 7).

Once a patient was identified, the researcher approached the caregiver before they entered the doctor's office and informed them that researcher wished to talk to them about an ongoing research which the researcher believes they would provide relevant information. Once the caregiver was done with the doctor, the researcher requested the caregiver and patient to accompany him/her to one of the available consultation room to ensure privacy was maintained during the interview. The caregiver was then informed about the study and assured of privacy and confidentiality if they participate. They were told that the study was voluntary and of minimal risk. The management of the patient was uninfluenced by their participating or not participating in the study.

Caregivers who met the inclusion criteria and agreed to participate in the study were requested were requested to sign the consent form and enrolled in the study. Those who declined to participate in the study were thanked and excluded from the study.

In the paediatric wards, ward rounds were conducted daily from 8.00am to 2.00pm. The research was conducted after 2.00pm to ensure that the daily ward activities were not interfered with. The caregivers were approached prior to the research and briefed on the nature of the exercise and why their participation was appreciated. Those who agreed to participate in the study were taken to the doctor's office where the interview was conducted. This ensured privacy and minimized interference. Convenient sampling was used to recruit caregivers who were identified in the wards.

Health care providers involved in the care of SCD patients were invited to take part in the study. This was done after health care providers they had completed their ward activities and agree to be part of the research process. They were purposively sampled so as to have a heterogeneous group comprising of healthcare providers of different cadres with varying years of experience enabling the researcher to explore the different

opinions and perceptions of different cadres. From the stratification, a total number of 67 health providers were interviewed from the wards. A maximum of 6 providers were interviewed weekly through convenience sampling. The interviews in the ward and clinic were conducted in the doctors' office and in the consultation rooms respectively. Health care providers were made aware that the survey was in no way a job performance review and all the results would remain confidential. Consent was given in a written form to the health providers. The consent form provided described the purpose of the study, the study procedure to be followed as well as the potential benefits and risks of participating in the study.

The investigator conducted the consent discussions and checked that the health care providers comprehended the information provided on the consent form. Any pertinent questions regarding the study were answered prior to signing the consent form. Consent obtained was voluntary and free from coercion.

Caregivers and providers who accepted to take part in the study signed the consent form and that was countersigned by the investigator. A copy of the consent form was given to the participants. For those caregivers who were illiterate, a neutral witness was present during the interviews to ensure that the caregiver was given the right information and his/her concerns were addressed, the caregiver's thumbprint was used as a signature and the witness countersigned. Data was collected from eligible caregivers and health providers by administration of a pre-tested structured questionnaire.

3.6 Study procedure and data collection procedure

3.6.1 Study tools

- 1) Pre- tested questionnaire for the caregivers
- 2) Pre- tested questionnaire for the health care providers
- 3) Focused group discussion (FGD) topic guides for caregivers
- 4) Key informant interviews (KI) guide for health care providers

3.6.2 Data collection procedures

The study was carried out by the researcher. During the study period the researcher reported to the haematology clinic every Monday and tried everyday of the week to include patients that may have been admitted in the paediatric wards.

The study was carried out in three consecutive stages: first the researcher interviewed caregivers and HCPs using pretested questionnaires, then conducted FGDs with the caregivers and finally key informant interviews was carried out among health care providers.

Respondents' interviews

The caregivers and health providers who gave consent were interviewed. Provider Communication subscale of the Consumer Assessment for Healthcare Plans and Systems Survey and the Picker Patient Experience Questionnaire are examples of some of the validated tools used in the formulation of the questionnaire (8, 75).

The awareness level of caregivers was assessed using a self-designed knowledge questionnaire. A 10 item tool was designed to assess the knowledge of care givers on SCD in the following areas: 1) pathophysiology, 2) physical manifestations, 3) treatment, 4) home based care, 5) health care delivery system. The knowledge questionnaire was founded on multiple choices. Higher scores on the knowledge questionnaire represent greater knowledge with a score of 10 being the total and 1 being the lowest possible point respectively.

Focus group discussions

Focus Group Discussions (FGDs) were conducted with the caregivers. The aim of the discussion was to explore the experiences, opinions and perceptions of the caregivers regarding facilitation and barriers to communication. All FGDs were conducted by the

primary investigator to ensure consistency of the responses. Each FGD had six to eight participants and lasted approximately one hour. The FGDs were conducted in the hematology clinic after 2.00pm in one of the consultation rooms located in the clinic. This ensured privacy was maintained during the discussions. The participants' chairs were arranged in a circle to facilitate easier discussion. A table put in the middle of the group was used to place the tape recorder. The researcher taped the proceedings during the FGDs. In addition, notes were taken verbatim including the participants' body language.

The FGD was conducted in four stages:-

Stage 1: Scene setting and ground rules: the research teams welcomed participants as they arrived for the FGD. Once the group was complete, the researcher formally started the FGD by introduction, stated the research topic and the purpose of the study. The participants were explained to by the researcher that they are all invited to give their own point of view during the discussion as there was no right or wrong answers. Participants were also requested to respect each other's opinions and allow one individual to speak at a time. The researcher informed the participants that the discussion was to be recorded. However, the records were to be kept confidential and only utilized for study purposes. The participants who agreed to the rules signed a consent form and took part in the FGD. The research assistant switched on the tape recorder.

Stage 2: The opening topic: the researcher engaged the participants by introducing the topic. She enquired about the participant's views and opinions on communication between caregivers and care providers.

Stage 3: Discussion: the participants were involved in in-depth discussion of the study topic using the questions obtained in the FGD topic guide. The researcher further explored the responses given by the participants and formulated follow up questions.

Stage 4: Ending the discussion, the researcher thanked the group for their participation.

A total of two FGDs were conducted with each comprising of eight caregivers. Those identified to participate were provided a detailed explanation of the study and verbally

invited to take part in the FGD before leaving the clinic. Those interested in taking part were informed of the time and location of the FGD. The questions for the FGD were obtained from the FGD topic guide containing open-ended questions. Formulation of further questions and comments were done based on the participants' responses. The researcher informed the respondents after taking part in the FGDs that their bus fare would be refunded.

From the 16 respondents expected to participate in the FGD, 8 were randomly picked from the haematology clinic and the remaining 8 were from the paediatric wards. A list was made from each recruitment location and every 6th respondent was picked from the 51 respondents interviewed from the haematology clinic to get 8 respondents. Every 5th respondent selected from the 10 respondents in each of the four paediatric wards to get a total of 8 respondents in all the wards. The respondents were randomly selected because the phenomena under investigation were homogeneously distributed.

Haematology clinic: $n = 51/6 = 8.5$ Paediatric wards: $n=10/5=2 \times 4=8$

Key informant interviews

In depth interviews were conducted with nursing officers in charge of the four wards and haematology clinic. These were done after the survey with the caregivers. The key informant interviews were scheduled according to the respondent's availability, when they were not attending to any patient, so as not to interrupt their undertakings. The interviews were conducted in the doctors' room so as to maintain privacy.

3.7 Data management and analysis

Data were collected using structured questionnaires and entered into a password protected database. The hard copy data forms were stored in a lockable cabinet in the Principal Investigator's office during collection and after analysis. These were moved to a lockable cabinet in the statistician's office during data entry and analysis. Upon completion of data entry, hard copy forms were compared with the entered data to identify errors and corrections made appropriately. Descriptive statistics were carried out where discrete variables were summarized with frequencies and percentages while continuous variables were summarized using measures of central tendency and dispersion such as mean, median, mode, standard deviation and inter-quartile ranges. The interviews were audio recorded, transcribed and translated accordingly. The word document was imported into *ATLAS .ti* version 8.0. The scripts were coded into emerging themes and codes. A code book was developed from the emerging themes after validation from the supervisor. The key concepts derived from the codes were grouped to form categories and from the various categories themes were identified. Quotes were identified which were used to describe the perceptions and experiences of caregivers and the health care providers towards their perception on communication with regards to SCD.

3.8 Quality assurance procedure

The research proposal was reviewed by the University of Nairobi Department of Paediatrics and Child Health, Kenyatta National Hospital and University of Nairobi Ethics and research committee before being allowed to carry out the study. Pre-testing of 10% of questionnaires was done by the researcher at KNH before the actual study was carried out to ensure validity and completeness of the questionnaires and make any adjustments on the questionnaires accordingly. This included 9 care givers of SCD patients and 7 health care providers who work in the paediatric wards and haematology clinic. The purpose of the pilot test was to refine the questionnaire so that respondents did not have problems answering the questions and there was no problem in recording the data. In addition, it enabled assessment of the question's validity and the likely reliability of the data that was collected. Preliminary analysis using the pilot test data was undertaken to ensure the data collected would answer the research questions. During the study, the questionnaires filled and the audiorecorder were stored by the researcher in a lockable cabinet. The questionnaires were moved to a lockable cabinet

in the where data entry and analysis was done using a Microsoft database with a protected password known by the researcher.

3.9 Ethical considerations

3.9.1 Ethical approval

Ethical clearance was sought from Kenyatta National Hospital and University of Nairobi Ethics and Research Committee. The researcher explained to the study participant the purpose of the study and stressed that it was fully voluntary and that the study participant had a right to withdraw from the study even after signing the consent form with no repercussions. Additionally, the researcher informed the study participants that there were no rewards or monetary gain for participating in the study. The researcher strived to maintain a relationship of honesty, openness, trust and respect with the study participants. The phone number of the researcher was made available in the event that they wanted clarification with regards to the study. The phone numbers and email addresses of the supervisors and Ethics and regulatory committee were also availed to the participant in case he/she has any concerns or reservations with regards to the study.

3.9.2 Consent

There was a signed informed consent by the study participants after an explanation about the study in simple and clear language that the study participants understand and any questions they have addressed. This was done in either the haematology clinic or the paediatric wards. After the consent has been signed, the researcher began a face-to-face questionnaire guided interview.

3.9.3 Privacy and confidentiality

Privacy and confidentiality was guaranteed to the study participants as the names of the participant was omitted from the questionnaire and instead of their names, number codes were used in the consent forms and questionnaires.

When going through the patient files, the researcher was only interested in the patient's diagnosis and no other additional information was taken from the files. This was done in the records office and the files were left in the records office once the researcher was done.

The questionnaires and audio recorders used for data collection was stored in the office of the researcher in a locked cabinet only accessed by the researcher. The questionnaires were then transferred to the statistician office where data entry and analysis was undertaken in a password secured Microsoft database, and the password was known by the researcher and statistician only. The supervisors were allowed by the researcher to access the research on request.

3.9.4 Study risk

Minimal risk was involved, and the management of the patients in the wards was uninterfered with throughout the study.

3.9.5 Benefits to study participants

After an interview with a caregiver, the researcher ensured that the caregiver was educated on the pathophysiology, complications and management of SCD. After the interview, the researcher availed her contacts for further consultation.

3.10 Control of errors and biases

The following measures were taken to reduce different forms of bias and errors:-

- Measurement bias was reduced as the questionnaire was pretested to ensure the questions were sensitive enough to detect the differences in the variables detected
- Information bias was reduced by assessment of the responses given to the questionnaires daily during data entry to ensure validity of collected data.
- All FGDs were conducted by the principle investigator to ensure consistency of responses and the data was transcribed daily to ensure accuracy.

4. RESULTS

4.1: Characteristics of respondents

4.1.1 Caregivers

A total of 91 caregivers participated in this study. The characteristics of the caregivers are as presented in Table 1 below. Majority (74.7%) of the caregivers were female and 25.3% were male. With respect to age, 15.4% of the respondents were within the age group 18-25, 45.1% were in the 26-35 age group, 27.5% were in the 36-45 age group, 7.7% in the 46-55 age group and 4.4% were 55 years and above.

Most (79.1%) of the participants in the study were married. Fourteen percent of the caregivers reported that they were single. Almost one quarter (41.8%) of the caregivers reported that they had attained secondary level of education while 37.4% had primary education. Caregivers who had gone to tertiary colleges accounted for 8.8% of the total population while 9.9% had university education. Only 2.2% had no formal education.

Out of the 91 respondents, 22% were casual labourers, 13.2% were formally employed, and 29.7% were self employed. About a third (34.1%) were unemployed. A majority (95.6%) of the respondents were the children's parents. More than half (69.2%) had lived with the children for more than 10 years.

Table 5 : Profile of caregivers

Variable	Frequency(n=91)	Percent
Age		
18-25	14	15.4
26-35	41	45.1
36-45	25	27.5
46-55	7	7.7
Above 55	4	4.4
Gender		
Male	23	25.3
Female	68	74.7
Marital status		
Married	72	79.1
Single	13	14.3
Divorced/Separated	5	5.5
Widow/Widowed	1	1.1
Duration of living with patient		
5 years and below	27	29.7
6-10 years	36	39.6
11 years and above	28	30.8
Relationship of primary caregiver to child		
Parent	87	95.6
Aunt/Uncle	2	2.2
Sibling	2	2.2
Occupation of caregiver		
Unemployed	31	34.1
Casual employment	20	22.0
Formal employment	12	13.2
Self-employment	27	29.7
Other	1	1.1
Education of care giver		
Primary	34	37.4
Secondary level	38	41.8
Tertiary level	8	8.8
Bachelor degree or higher	9	9.9
No formal education	2	2.2
Care givers religion		
Christian	91	100.0

4.1.2 Health care providers

A total of 72 HCPs participated in this study. Their characteristics of the caregivers are as presented in Table 6 below. Females constituted the majority (77.8%) of respondents. With respect to age, most (88.9 %) of the respondents were within the 26-35 age group. More than half (56.95 %) had worked for over ten years.

Table 6: Profile of health care providers

Characteristics	Frequency(n=72)	Percent
Age		
26-35	64	88.9
36-45	7	9.7
46-55	1	1.4
Gender		
Male	16	22.2
Female	56	77.8
Cadre		
Pediatrics registrar	41	56.9
Nursing officer	24	33.3
CO Pediatric	7	9.7
Number of years in medical practice		
<5	31	43.05
6-10	38	52.78
>10	3	4.17

4.2 Perceived communication barriers

4.2.1 Caregivers' perceived communication barriers

i. Sociodemographic characteristics of HCPs

As shown in the figure below 5.5% of the caregivers' perceived that HCPs culture was a barrier, followed by gender at 25.3% and lastly age at 29.7%. Hence, a majority were of the opinion that the sociodemographic characteristics of HCPs does not affect communication. (Figure 2)

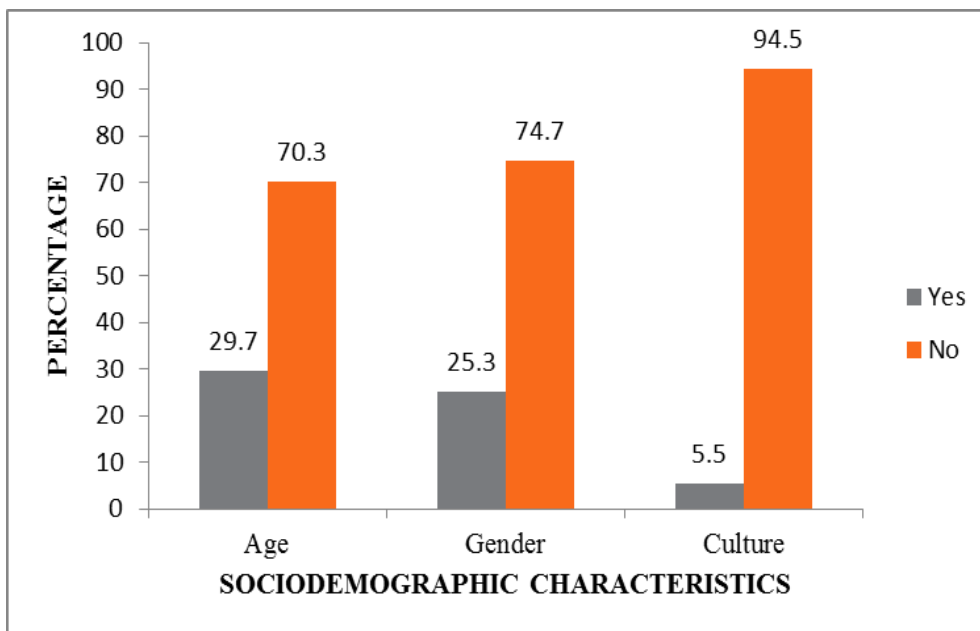


Figure 2 Sociodemographic characteristics of HCPs (n=91)

ii. Consultation time

A likert scale was used to rate the caregivers perception on the adequacy of consultation time, approximately 42% of the respondents felt the consultation time was inadequate. (Table 7)

Table 7: Adequacy of consultation time

The consultation time is adequate	Frequency (n=91)	Percent
Strongly Disagree	3	3.3
Disagree	9	9.9
Unsure	26	28.6
Agree	17	18.7
Strongly Agree	36	39.6
Total	91	100.0

iii. Language barrier

Majority (96.7%) of the caregivers reported that language used by the healthcare providers was understandable. Very few (3.3%) caregivers stated that they do not understand the language health care providers' use during consultation.

iv. Use of medical jargon

Most (70.4%) of caregivers reported that health care providers explain things in a simplified way while 29.6% stated otherwise.

v. Health care providers' communication behavior

Generally caregivers gave high ratings on health care providers' communication behaviors. The highest rated item was 'pays attention to my explanation' while the lowest rated item was 'explain things in a way that I understand'. (Table 8)

Table 8: Caregivers perception on health care providers communication behavior (n=91)

Communication behavior	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
The HCPs greet me warmly at every visit	39 (42.9)	28 (30.8)	14 (15.4)	10 (11.0)	0
The HCPs pays attention to my explanations	51 (56.0)	28 (30.8)	8 (8.8)	4 (4.4)	0
The HCPs treats me with courtesy and respect	55 (60.4)	20 (22.0)	9 (9.9)	7 (7.7)	0
The HCPs uses a friendly tone during consultation	55 (60.4)	17 (18.7)	9 (9.9)	8 (8.8)	2 (2.2)
The HCPs takes my questions kindly	46 (50.5)	23 (25.3)	16 (17.6)	4 (4.4)	2 (2.2)

vi. Main communication barriers

The three main reasons cited by caregivers for ineffective communication were, insufficient time for consultation (41.2%), use of technical terms (18.3%) and lack of privacy during consultation at (10.7%). (Table 9)

Table 9: Main communication barriers reported by caregivers (n=91)

Communication barriers	%
Short consultation time	41.2
Use of technical terms by the health care providers	18.3
Lack of privacy during consultation	10.7
Cultural differences	4.6
Age differences	7.6
Gender difference	3.1
Others	2.1

4.2.2 Health care providers perceived communication barrier

i. Sociodemographic characteristics of caregivers

Most (90.3%) of the HCPs stated that the caregivers socioeconomic factors, age (72.2%), and education (90.3%) had an effect on how caregivers communicate. When asked how the caregivers' education affected communication, a majority responded that it was easier to communicate to the more educated caregiver as they were able to have a better comprehension of the disease and they played an active role in seeking information. (Table 10)

Table 10: Sociodemographics characteristics of caregivers

Perceived barriers	Frequency (n=72)	
	Yes	No
Do you think patients' socio-economic background affects communication?	65(90.3)	7(9.7)
Does the caregiver's age affect how they communicate?	52(72.2)	20(27.8)
Does the education have a role on how they communicate?	65(90.3)	7(9.7)
Does the caregiver's gender affect how they communicate?	32(44.4)	40(55.6)
Does culture play any part on how you communicate with caregivers?	35(48.6)	37(51.4)

ii. Work environment

Almost all (98.6%) of health care providers felt that the work environment can act as a barrier to effective communication with shortage (69.4%) of health care providers being cited as the major limitation. Some of the reasons that were cited as making the work environment unfavourable include long working hours and excessive workload.

(Table 11)

Work environmental limitations among health care providers (n=72)

Table 11: Distribution of work limitation barriers among health care providers

<i>Work limitation</i>	Frequency	Percentage (%)
Lack of enough consultation space	20	27.8
Lack of rules and regulations	1	1.4
Shortage of health care providers	50	69.4
Lack of diagnostic and monitoring equipment	29	40.3
Unfavorable work environment	20	27.8
Other	2	2.8

iii. Training on communication skills

More than a half (56.9%) of health care providers had no training on communication skills. (Figure 3)

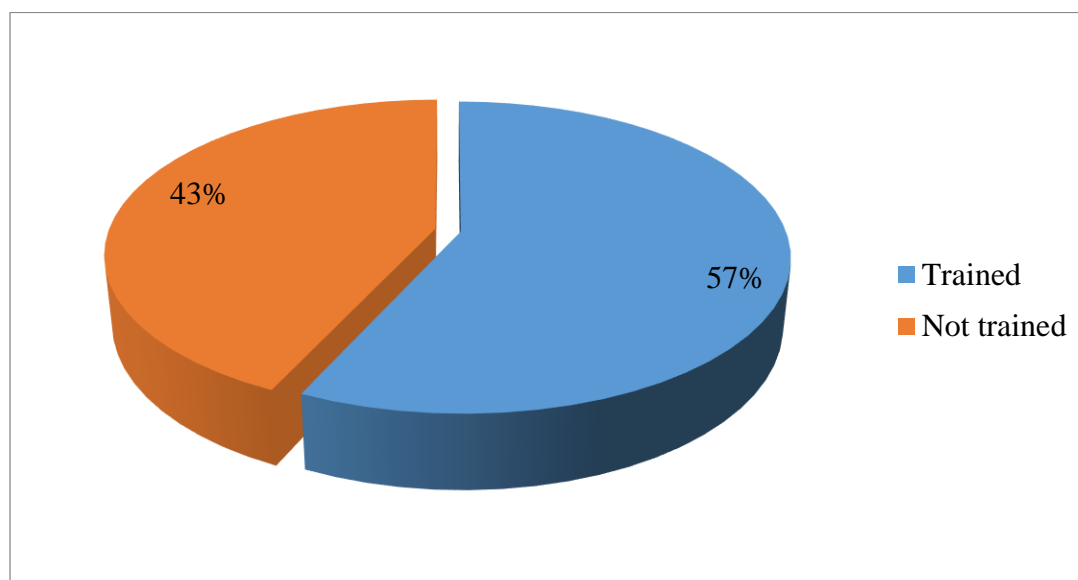


Figure 3 Training on communication skills

Training period

Approximately half (54.8%) of the health care providers were trained on communication skills during their undergraduate program, 48.4% in seminars and conferences, while 19.4% were trained during their postgraduate program. (Table 12)

Table 12: Distribution of training period among HCPs trained in communication skills

Variable	n= 31	Percent
During my undergraduate/diploma/certificate training	17	54.8%
During my postgraduate/higher-diploma training	6	19.4%
In a seminar/conference/in service training	15	48.4%
Through E-learning (internet)	2	6.5%

iv. Main communication barriers

High workload was the main (86.8%) barrier to effective communication cited by HCPs. It was followed by lack of sufficient time (55.9%) and lack of medical training on communication skills (27.9%). (Table 13)

Table 13: Communication barriers (n=72)

Communication barriers	%
High workload	86.8
Lack of sufficient time	55.9
Lack of medical training on communication skills	27.9
Poor health care systems	27.9
Low medical literacy of care givers	14.7
Others	2.9

4.2.3 Proportion of health care providers who experience challenges when communicating with caregivers

Almost three quarters (76.4%) of the health reported that they sometimes faced challenges when communicating with caregivers. Very few (8.3%) never experienced any challenge in communication. (Figure 4)

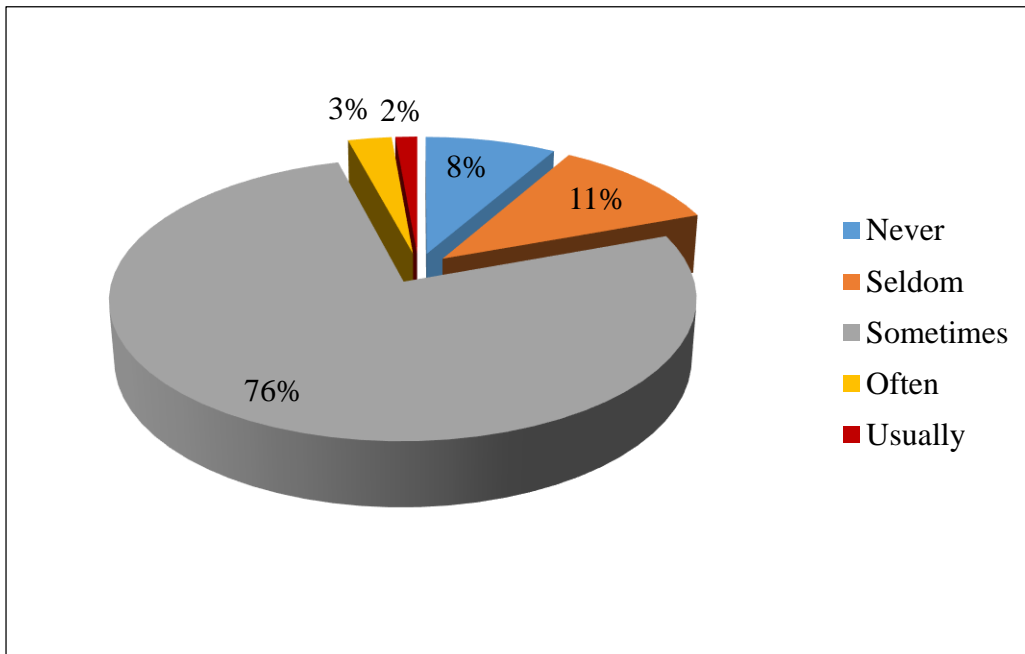


Figure 4 Proportion of HCPs who have had challenges disclosing SCD information to caregivers

4.3 Caregivers' perceptions on communication with HCPs

A Likert scale was used to assess communication based on the seven tenets used by Barnlund to define effective communication. The highest rated tenet was that the information caregivers received was helpful while the lowest rated tenet was the information was complete and understandable. (Table 14)

Table 14: Caregivers' perceptions on communication with HCPs

Tenets of Effective Communication	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The information I receive during consultations with health care providers is helpful	6 (6.6)	3 (3.3)	7 (7.7)	25 (27.5)	50 (54.9)
The information I receive during consultations with health care providers is specific to caregivers	2 (2.2)	11 (12.1)	11 (12.1)	15 (16.5)	52 (57.1)
The information I receive during consultations with health care providers is clear and precise	5 (5.5)	9 (9.9)	21 (23.1)	19 (20.9)	37 (40.7)
The information I receive during consultations with health care providers is complete and understandable	6 (6.6)	14 (15.4)	28 (30.8)	15 (16.5)	28 (30.8)
Health care providers present information with courtesy and consideration with health care providers is appropriate	6 (6.6)	13 (14.3)	9 (9.9)	26 (28.6)	37 (40.7)
The information I receive during consultations with health care providers is appropriate	3 (3.3)	11 (12.1)	14 (15.4)	20 (22.0)	43 (47.3)
The information I receive during consultations with health care providers is brief and correct	2 (2.2)	9 (9.9)	10 (11.0)	20 (22.0)	50 (54.9)

4.3.1 Proportion of caregivers satisfied with communication (n=91)

Almost a third (28.6%) of the caregivers were dissatisfied with how the HCPs communicated during consultation. (Figure 5)

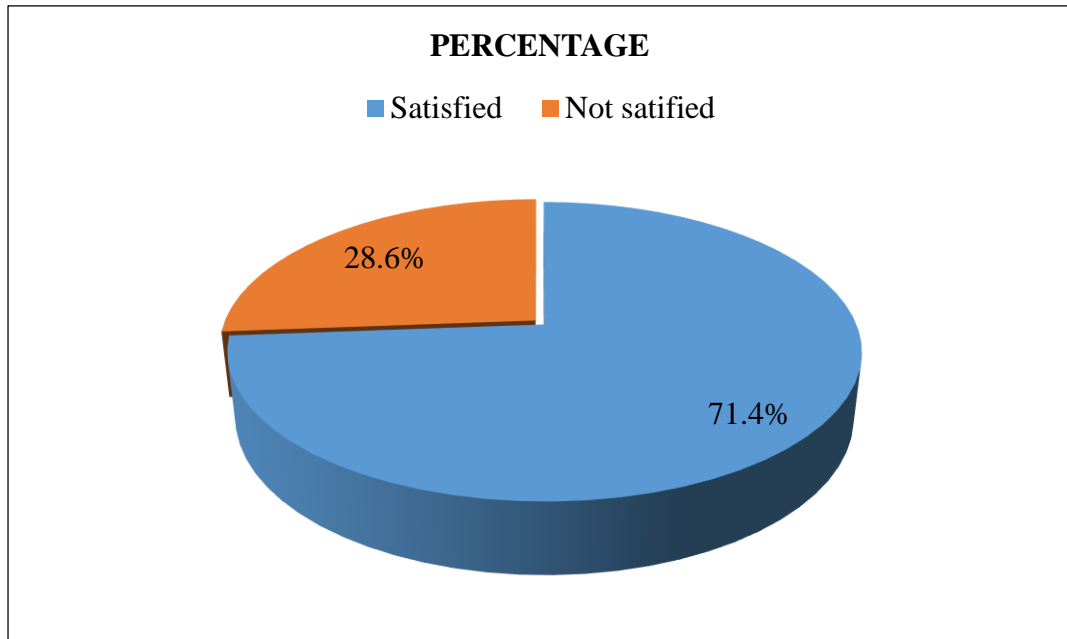


Figure 5 Proportion of caregivers satisfied with communication

Some of the reasons that brought about dissatisfaction are shown in the figure below. Most of the caregivers cited 'incomplete information' as the main reason for their dissatisfaction. (Figure 6)

Reasons for dissatisfaction of information given by HCP (n=27)

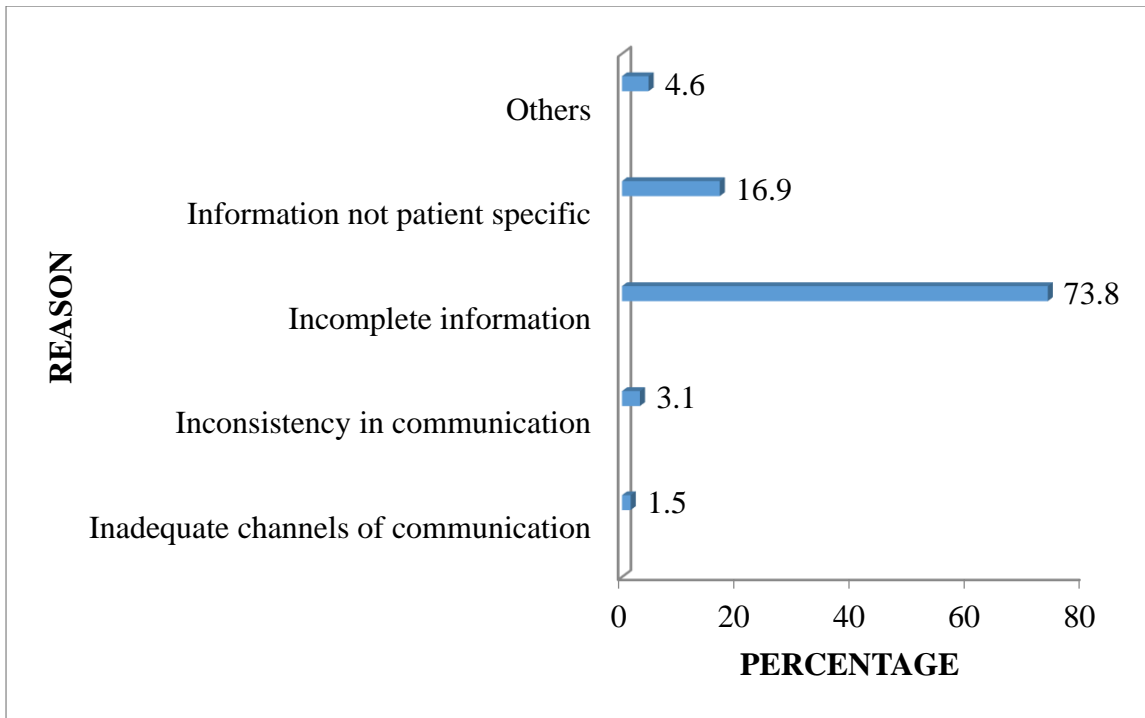


Figure 6: Caregivers' reasons for dissatisfaction

4.3.2 Caregivers' knowledge about SCD

With regards to information on the origin and causes of the illness, most of the respondents (70.3%) were aware that SCD affects red blood cells. Majority (87.9%) knew that the disease was inherited while 72.5% were aware that the cells become sickle shaped and hard. On information on ways of preventing crises, 65.9% knew that drinking plenty of fluids helped when having a painful crisis, with almost all (96.7%) reporting that it is good practice for children to wear warm clothes when it gets cold. More than half (57.2%) were knowledgeable on the complications of SCD. On information regarding medications used in SCD, less than half (40.7%) knew the use of penicillin while 69.2% were aware that hydroxyurea is a medication used in the treatment of SCD. (Table 15)

Table 15: Caregivers' knowledge about SCD

Variable	Frequency (n=91)	Percent
Sickle cell disease is a condition that mainly affects _____		
White blood cells	5	5.5
Red blood cells	64	70.3
All of the above	3	3.3
I don't know	19	20.9
Red blood cells in sickle cell disease cause problems because they can become _____		
Too soft	2	2.2
Sickle shaped and hard	66	72.5
Round and hard	4	4.4
I don't know	19	20.9
Sickle cell disease is _____		
Infectious disease	3	3.3
Inherited blood disorder	80	87.9
I don't know	8	8.8
sickle cell disease is diagnosed by-----		
Blood test	88	96.7
I don't know	3	3.3

When having sickle cell pain, a patient should ____		
Drink plenty of fluids	60	65.9
Go to the emergency room right away	24	26.4
I don't know	7	7.7
Reason for taking penicillin every day among children sickle cell disease is		
To treat infections	11	12.1
To increase appetite	1	1.1
To prevent painful episodes	16	17.6
To decrease risk of serious infections	37	40.7
I don't know	26	28.6
The following are complication of sickle cell disease except		
Frequent infections	2	2.2
Leg ulcers	9	9.9
Cancer	53	58.2
I don't know	27	29.7
In cold weather, a person with sickle cell should		
Wear warm clothes	88	96.7
Never go outside	3	3.3
Knowledge Hydroxyurea		
Chemical found in urine	3	3.3
Medication used to treat sickle cell disease	63	69.2
A part of normal red blood cells	1	1.1
Lack of water in the body	2	2.2
I don't know	22	24.2
Most common symptoms of sickle cell disease		
High levels of sugar in the body	2	2.2
Bleeding that is difficult to stop	9	9.9
Pain episodes	74	81.3
I don't know	6	6.6

4.3.4 Source of information about SCD

Health care providers were cited by caregivers as the main (85.7%) source of information according to the caregivers. Few (3.3%) obtained most of the information from the media. (Figure 7)

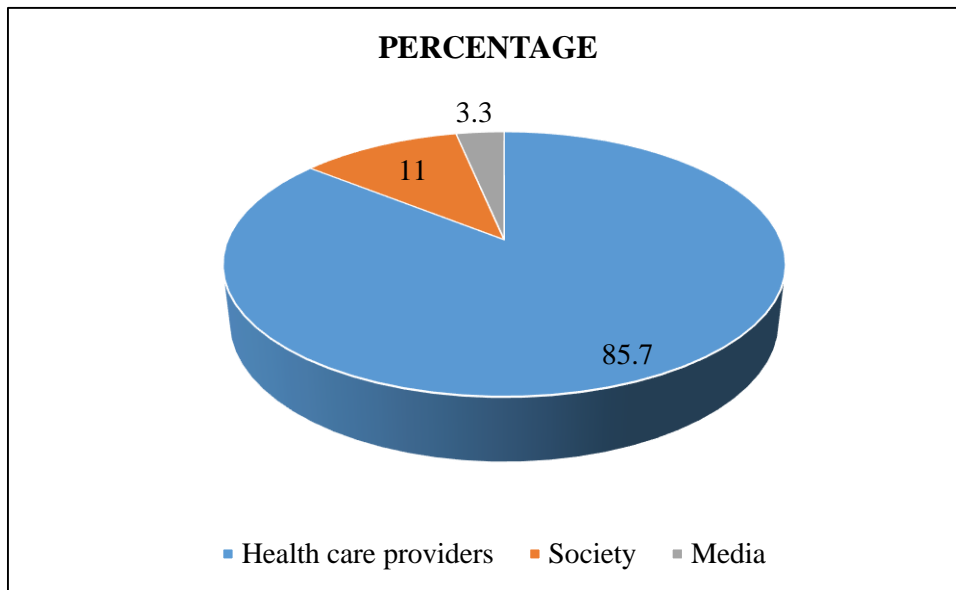


Figure 7: Source of information

4.3.5 Use of written materials during communication

Approximately three quarters (74.7%) of the caregivers reported that they were not given written information on what symptom or health problems to look out for when at home. (Figure 8)

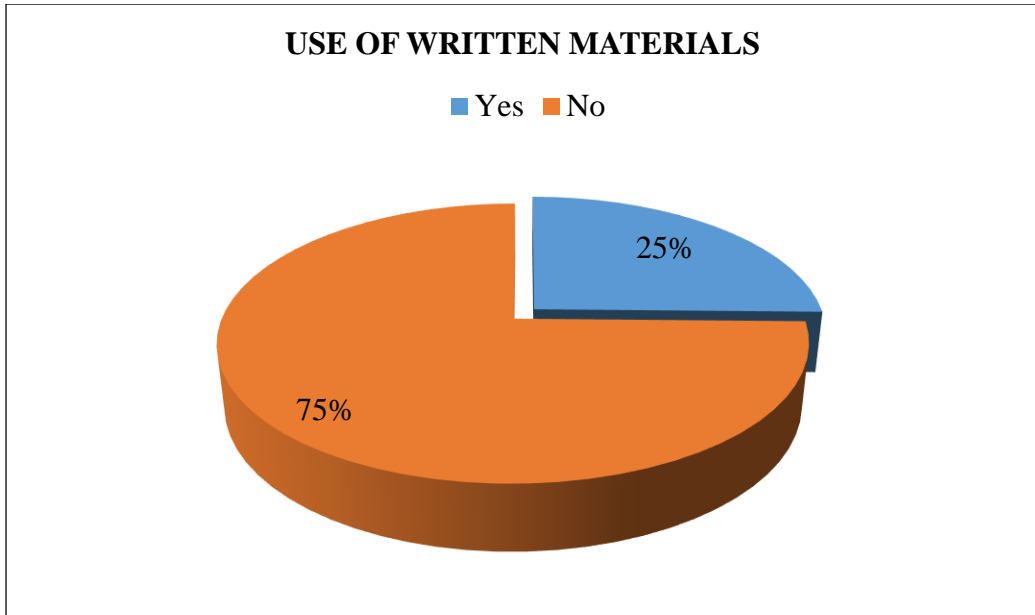


Figure 8: Use of written materials during consultation

4.4 Suggestions on ways to improve communication

i. Caregivers

The three main reasons suggested by caregivers were: i) to offer a more detailed explanation on SCD, ii) increase the number of health care providers and, iii) spend more time with caregivers. (Table 16)

Table 16: Caregiver suggested ways of improving communication

SUGGESTIONS ON IMPROVING COMMUNICATION Responses from caregivers	Frequency (n=91)	%
1. Doctors should explain more about the cause, treatment, investigations and results	30	33
2. Increase the number of health care providers	20	21.9
3. Health care providers should spend more time with patients/caregivers	19	20.9
4. Health care providers should be more sensitive to the patient's condition;be more friendly/kind	10	10.9
5. Provide enough rooms for privacy during consultation	7	7.7
6. Health care providers speak in a language caregivers understand	6	6.6
7. Use simple terms,listen more, train on SCD , public awareness among public	11	12.1

ii. Health care providers

The three main suggestions proffered by health care providers were: i) conduct seminars and trainings on communication, ii) increase the number of health care providers and, iii) give more time for caregivers to ask more questions and express themselves. (Table 17)

Table 17: HCP suggested ways of improving communication

SUGGESTIONS ON IMPROVING COMMUNICATION Responses from health care providers	Frequency n=72	%
1. Conduct seminars, and training in communication	26	36.1
2. Increase the number of health care providers	24	33.3
3. Allow time for caregivers to sk questions and express themselves	15	20.8
4. Have translators in the wards and clinic	8	11.1
5. Health care providers should use visual aids, charts, models, and literature material	8	11.1
6. Organize health talks and seminars for caregivers	7	9.7
7. Provide enough rooms for privacy during consultation	6	8.3
8. Public education on SCD	6	8.3
9. Reducing the number of patients booked in the clinic	2	2.7

4.5 Qualitative data analysis

The interviews were audio recorded, transcribed and translated accordingly. The word document was imported into *ATLAS .ti* version 8.0. The scripts were coded into emerging themes and codes. A code book was developed from the emerging themes after validation from the supervisor. The key concepts derived from the codes were grouped to form categories and from the various categories themes were identified. Quotes were indentified which were used to describe the perceptions and experiences of caregivers and the health care providers towards their perception on communication with regards to SCD.

4.6 Key informants interviews

4.6.1 Demographics of key informant interview participants

There were 4 key informant interviews conducted with nurses who have worked at Kenyatta referral hospital for over 10 years.

4.6.2 Finding from the key informant interview

The main themes which were indentified from the Key Informant interview were

Theme 1: Workload barrier

Theme 2: Literacy level

Theme 3: Culture

Theme 1: Workload barrier

Workload was mentioned as one of the major challenges which hinders effective communication between the caregiver and the HCPs. The health workers interviewed noted that they have to manage many patients and are therefore not able to communicate effectively.

‘KII 2...Communication is a problem because of the workload that we have, you find that we do not have enough time to effectively talk to the patients. Currently the work load is overwhelming because all clients are admitted as compared to receiving only referral clients’

‘KIII ...We receive any patient in whichever condition because this is a hospital but if they were purely referrals we would have more time for them. We need to also have specialized sickle cell paediatric clinic to enable us have health talks that are specifically based on SCD’

‘KII2...The work load is too much and we are few, we may not get enough time to communicate with the caregivers, the nurses have so much to do and they may not get time to talk to patients, we need counsellors whose responsibility would be to counsel and educate the patients’

'KII3...There is need to increase staff because of the work load, imagine during admissions, the providers are all in a hurry, and do you expect them to explain everything the mothers might wish to know? The caregivers also fear asking questions when they see how busy the providers are'

Theme 2: Literacy level

The level of education was considered a communication barrier. Some of the caregivers are not literate and therefore it takes long to explain details. Some medical terms are too technical for the caregivers to comprehend. This can at times intimidate caregivers and some may not be confident enough to seek further clarification. Generally the perception was that it was easier to communicate to the educated caregivers, however some felt that the less educated are more attentive.

'KII2...Yes,the level of education affects communication since it is easier to communicate to those with higher literacy levels and educated caregivers will even probe so as to get a better understanding of what is happening''

'KII4...Those who are not "very learned" they are more attentive than those who are, the learned caregivers might feel like they are knowledgeable and are able to google information but the other group purely trusts in you for information'

'KII3...The learned ones can google or search for information and they might even question you'

Theme 3: Cultural barriers

Culture was another barrier to effective communication. Some male caregivers feel that it's not culturally right when a woman address a man. Others still believe in witchcraft and curses.

'KIII ... Cultural issues especially a lady addressing a man, in some communities men are not supposed to be addressed by ladies and when the men are being addressed by female health providers you find that they are not keen '

'KII2...In some cultures, men are chauvinistic and they would be like "why would I listen to a woman?" let me put it that way'

'KII4....In some communities they believe that chronic diseases are brought about by witchcraft and they might be in denial with regards to the disease'

4.7 Focus group discussions

Focus group discussions were conducted with caregivers of paediatric patients with SCD.

4.7.1 Key findings from focus group discussions

The main themes identified from the qualitative interviews were as follows:

Theme 1: Workload

Theme 2: Health provider attitude

Theme 3: Level of education

Theme 4: Lack of sufficient information

Theme 1: Workload

Majority of the participants noted that workload was the main barrier to effective communication. HCPs are over burdened by the high numbers of patients they have to attend to daily resulting in fatigue which negatively affects the HCPs performance, subsequently affecting their communication. The caregivers reported that health care providers are in a hurry and do not offer clear and complete information. The participants also felt that there was lack of sufficient time for consultation.

R1....Again when in a hurry they don't have time to give information on care and management of the condition'

'R2...Information was not given to me regarding the disease, you are being discharged and yet you don't have any information on the condition your child is suffering from'

'R4...Some health care providers are in a hurry and in such a state they don't have time to communicate, doctors are always in a hurry! Where are they rushing to, I don't understand, they never have time to explain to us what is happening to our children, when they come to see patients, are they given ten minutes to see each patient or do they like have a hundred to cover within an hour? Why are they in a hurry! They should talk to us before rushing to do other things'

'R6...I think they are busy, we are very many and they are very few especially the doctors'

'R5...I came with my child when he had a swollen face and he had no blood, I was in shock and was worried but the doctor was not telling me anything, the doctors were not telling me anything concerning the sickness of my child!'

R3...They did not explain to me, even the one who told me my baby has sickle cell did not explain to me how I will handle and take care of her or what kind of food she should eat. So I don't know'

'R2...I was just told that your child has sickle cell and would be admitted into the ward but I was not told what sickle cell is and I had not seen or heard of this disease. So as I got admitted into the ward I was wondering and asking myself what this sickle cell disease is?'

'R7...Some time it's good to collect information from these doctors because they might be facing their own challenges like they are tired because of workload or poor payments so because of all these issues, by the time the doctors comes to the ward he or she is too tired or is too bored to attend to my needs '

Theme 2: Health care providers' attitude

Caregivers felt that some of the HCPs were not friendly hence they found it difficult to communicate. This unfriendly attitude made it difficult for the caregivers to ask questions pertaining the progress of their children. Some participants felt that some health care providers were rude. The caregivers feared that if they expressed themselves they would annoy the HCPs and this would inturn compromise the treatment of their children. For this reason, for the purpose of maintaining a cordial relationship with the health care providers the thought the best option was to remain silent.

'R3...Some of the health care providers are not friendly and it's very difficult to approach them, some are very rude'

'R1...They are so arrogant and I think the nurses are taught to fix lines during their training 'why can't they fix a line when there is an emergency? There was a time I felt like my child had a fever and when I went to tell the nurse, she asked me why I was saying that and yet I did not have a thermometer, and when she came to check, my child actually had a fever, and the nurse asked why I don't have paracetamol..''

'R3...You know doctors are like teachers, parents don't know a lot. If I ask you a question and you are rude to me, I might get very annoyed and if my spirits got up I might find myself shouting back at the doctor, and thereafter I will hate that doctor'

'R7...He told me I am discharging you because your child's haemoglobin is okay and he doesn't need transfusion but you do not want to go home" but I informed him "I have called my people and they have donated blood which the other doctor had told me would save my child's life", I begged him to let my child get the transfusion before being discharged. The doctor's remarks made me furious as no one would want to be in hospital unless they had to'

'R6...I have a problem with the nurses, when you come to the wards they harass you, sometimes you have a problem but they talk back in a rude manner, and they tell you if you are not comfortable with the public hospital, you should go to the private hospital, however with this disease you cannot manage a private hospital, you will end up being poor. But they should not frustrate us as it is not our wish neither is it our children's wish to have this disease'

Theme 3: Language barrier

Language was thought to hinder effective communication when the caregivers spoke a language the HCPs did not understand. Some of the participants complained about the use of technical terms. The participants felt that it was crucial to have the knowledge and the needed information on SCD to help curb and minimize the spread.

'R4...We should have a translator within the ward who we can deal with directly because again we have communication barrier when we talk in Swahili and the doctor can't understand what we are saying'

'R5...The older doctors explain, they tell us more about this condition even though for us it's a bit hard to understand because it's something very technical. The young doctors will come and tell you, 'the boy is anemic' and you don't understand what anemia is, most of us never went to school, some of us we are illiterate'

Theme 4: Lack of sufficient information

A number of caregivers noted that HCPs did not give sufficient information on SCD. They had negative experiences due to the fact that the HCPs do not give them information. They felt that professionalism was lacking and were of the opinion that before being admitted it was necessary to be educated on the child's illness. They also noted instances where HCPs gave contradicting information. The other concern was that they were not involved in the management of their children. The caregivers expressed the need to be educated on key issues like treatment, investigations and complications of SCD.

'R1....There are those doctors who do not give enough information, they just tell you that your child has SCD but they don't tell you what to expect. The first time I was just told that your child has SCD and is going to be admitted, I went to the ward asking myself what SCD is, later I was told it's a disease that leads to low levels of blood in the body. It's only after I was discharged that my husband had to google to find out about SCD, so that information is missing, you are just informed that your child has this and will take these drugs. It took me a long time to understand how to manage the disease'

'R4...Some other times you might find a doctor who gives you instructions on what to do but then you find that when you go back to a different doctor he will ask you, 'who told you to do that' so doctors are giving contradicting information'

'R3...They did not explain to me even the one who told me my baby has sickle cell did not explain to me how I will handle and take care of her, or the kind of food she should or should not eat. So I don't know and I am also scared of asking the doctor to take my child's file and explain to me what is happening, upto now I look at my child and I want to cry because I don't know how to handle him, we are in hospital every month and I am wondering if this is going to be a routine, I am a single mother and I have to look

for ways of providing for my child and with this frequent admissions, will I really manage? What should someone do? I have not been told.'

'R5...Doctors are always in a hurry! Where are they rushing to, I don't understand, they never have time to explain to us what is happening to our children, they should talk to us before rushing to do other things'

5. DISCUSSION

Barriers to communication between physicians and patients have been previously described in China (88), Jamaica (78) and America (86). To the best of our knowledge, this is the first study in Kenya, conducted in a tertiary facility that explores barriers to communication among caregivers and HCPs of children with SCD. This study reveals that the three top barriers to communication identified by caregivers of children with SCD are short consultation time (41.2%), use of technical terms by HCPs (18.3%) and lack of privacy during consultation (10.7%). Similar findings were reported in a study done by Sabherwal et al where 93% of the respondents cited insufficient time as the main communication barrier (88). In a different study done by Ochuodho at a private hospital in Kenya, use of technical terms and medical jargon was reported as the main communication barrier (96). This difference may be due to the high patient provider ratio in public hospitals compared to private hospitals.

High workload (86.8%), insufficient time (55.9%) and lack of training on communication skills (27.9%) were the top three barriers to communication reported by HCPs. This is in keeping with the results in a study done by Sun et al (72). Inadequate consultation time could be as a result of high workload and poor healthcare systems. Health care providers appreciate the importance of communication skills on improving communication, however, most attribute medical conflicts to their high workload or to patients' low medical literacy. The demand for primary care services in public hospitals has increased and at the same time, the supply of HCPs in public hospitals is constrained. Health care providers have limited time for each patient and sometimes it is impossible to deliver satisfactory service during consultations. This may further be compounded by the low medical literacy of caregivers as more time may be spent in trying to educate them.

Most of the caregivers stated that they were comfortable communicating with the HCPs regardless of their age or gender. However, a majority of HCPs felt that the sociodemographic characteristics of the caregivers affected communication with a majority (90.3%) stating that it is easier to communicate with educated caregivers. Education has been reported as a predictor of doctors' tendency to give information where college-educated patients tend to receive more information than those who did not go to college (93). In this study, less than a quarter (18.7%) of the caregivers were

college educated. The HCPs may have a misperception that the less educated caregivers may not wish to know so much about the disease or they may not be able to understand, and this may explain why ‘completeness of information’ was the lowest rated tenet by the caregivers. However, it is important to note that there was no difference between the less educated and better educated caregivers in their desire for information. The HCPs ought to assess the patient’s knowledge and understanding about SCD, establish what the caregivers want to know and explain the illness using simplified terms. The caregivers should also be able to voice their concerns and gather as much information as possible.

There are reported observations of doctors avoiding discussion of the emotional and social impact of patients' problems because it distressed them when they could not handle these issues or they did not have the time to do so adequately. This situation negatively affected doctors emotionally and tended to increase patients' distress (8). Less than half (43.1%) of the HCPs reported that they were trained on communication skills, out of this, 54.8% were trained during their undergraduate program, 48.4% in seminars and 19.4% during their post graduate program. Approximately three quarters (76.4%) stated that they had challenges when disclosing information to caregivers. These findings are supported by several other studies where it was observed that many medical schools are yet to incorporate communication skills training in their curricula (7,52,53). Training on communication skills was the main suggestion preferred by HCPs when they were asked what they felt would improve communication. Communication skills training has been shown to improve doctor-patient communication (7). Health care providers can also improve their communication skills in workshops or seminars focusing on physician-patient communication.

Generally, participants gave high ratings on physician communication behaviors, suggesting that HCPs in this study engaged in a high number of good communication behaviors. The highest rated item was ‘listened carefully to what you had to say’ while the lowest rated item was ‘takes my questions kindly’. This was consistent with findings from other studies (28,29). However, from the FGDs, the HCPs attitude was seen as one of the communication barriers with some caregivers stating that a negative attitude from the HCPs deterred them from asking questions or seek clarification about the

illness. This negative attitude could be attributed to the high workload and the frustrations that come with being overworked.

Informative communication is one of the key elements of physician-parent-child consultation. The level of satisfaction has been found to be proportional to the behavior of the HCPs and the amount of information provided (7). Most (72.3%) of the caregivers' were knowledgeable on the cause, diagnosis (96.7%) and what to do to prevent crises, (96.7%), however less than half (40.7%) had knowledge on why penicillin was given on daily basis and 31.8% did not know that hydroxyurea was used in the treatment of SCD. Other studies have reported low level of awareness of SCD among patients (52,53,86). Improving the knowledge of caregivers on SCD has been shown to improve adherence to treatment, create positive health beliefs, foster positive family relations and improve their quality of life. Caregivers stated that HCPs were their main (85.7%) source of information on SCD. This shows that health workers are a vital source of information on SCD and they need to ensure that the caregivers are educated on SCD and are further involved in the day to day management of their children.

Effective communication has been shown to improve health outcomes by improving compliance to treatment in patients and decreasing the risk of malpractice (57). The dissatisfaction (28.6%) reported by caregivers concerning the communication they were receiving from HCPs is comparable to that in a study done in Jamaica where 27% of the patients were dissatisfied. This could have resulted from the communication barriers that have been mentioned.

The health care providers' contact with patients and caregivers, the volume of patients to be seen in a given time and the need for doctors to spend more time explaining to their patients have been seen as the barriers to communication. Some of the participants' responses suggested that the health authority had the responsibility to provide more health care providers or reduce the number of patients to be seen. As it takes time to communicate, the issue of time to communicate effectively would appear to bear directly on the provider's ability to communicate effectively.

Despite the positive rating of doctors' attitude by the caregivers, it is clear that a doctor's disposition, the effect of provider patient ratio on provider-caregiver interaction and conditions under which they work all have an effect on the provider-caregiver communication of paediatric patients with SCD at KNH.

5.1 Study strengths

One of the strengths of this study is that both qualitative and quantitative methods were used to determine the communication barriers among HCPs and the caregivers of children with SCD.

5.2 Study limitations

The study was based on reported rather than observed communication practice. Therefore, there is a risk that participants may report what is expected of them instead of their actual practice.

The study was carried out in Kenyatta National Hospital paediatric wards and haematology clinic, a tertiary health facility, and the findings may not be generalized to the other wards and hospitals in the country.

5.3 Conclusion

The main communication barriers cited by caregivers were: insufficient time, use of technical terms and, lack of privacy during consultation.

High workload, insufficient time and, lack of medical training on communication skills were the main barriers cited by health care providers.

Training on communication skills was low with less than half of the health care providers stating that they had been trained on communication skills.

5.4 Recommendations

Several barriers have been shown to affect caregiver-provider communication and measures need to be taken to try and improve communication. Health care providers need to be sensitized on the importance of effective communication.

Efforts should be made to reduce the workload placed on health care providers which will ultimately provide them with more time to sensitize the caregivers and address any of their queries or concerns. Health education should be a continuous process. This can further be improved by the use of written materials and visual aids.

Kenyatta Hospital requires an expansion of health infrastructure and human resources. SCD training manuals should be developed and incorporated as a tool to be used during every clinic visit. Health care providers need ongoing on the job training on communication skills.

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APPENDICES

Appendix I: Caregiver consent form in English

Title of Study:

ASSESSING COMMUNICATION BARRIERS BETWEEN HEALTH CARE PROVIDERS AND CAREGIVERS OF PAEDIATRIC PATIENTS WITH SICKLE CELL DISEASE AT KENYATTA NATIONAL HOSPITAL

Principal Investigator\and institutional affiliation:

Dr Shiundu Jackline Mukolwe

Paediatric Resident, University of Nairobi

Tel Number:-0721302133

Supervisor:

Prof. Jessie Githanga

Professor Department of Human Pathology

University of Nairobi

Tel Number:-0721245721

Introduction:

I would like to tell you about a study that I am conducting. My name is Jackline Shiundu Mukolwe and I am a post graduate student undertaking a degree in Master of Medicine in Paediatrics and Child Health at the University of Nairobi. This study is on Communication barriers between health care providers and caregivers of paediatric patients with sickle cell disease at Kenyatta National Hospital and is part of the requirement to be fulfilled for the award of the degree. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research:

- i) Your decision to participate is entirely voluntary
- ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal
- iii) Refusal

to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue? **YES** / **NO**

This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No. _____

Purpose of the study

The purpose of this study is to assess the barriers to communication between caregivers and health care providers of paediatric Sickle cell disease patients at Kenyatta National Hospital. Participants in this research study will be assessed on their level of awareness on sickle cell disease, the factors that affect communication and the communication barriers between caregivers and health care providers. I will be interviewing caregivers of sickle cell patients on follow up at the haematology clinic and those admitted in the paediatric wards. You may be called upon at a later date to take part in a focused group discussion to further explore the barriers to communication and what can be done to improve communication between caregivers and health care providers. There will be approximately ninety nine participants in this study randomly chosen. I am asking for your consent to consider participating in this study. If you agree to participate in this study, the following things will happen:

I will be interview you in a private area where you feel comfortable answering questions. The interview will last approximately twenty minutes.

Benefits

Your participation in this study will help us identify communication barriers that exist between caregivers and health care providers. This will help in developing measures to improve communication, knowledge of caregivers and the overall management of children with sickle cell disease. You will also benefit by receiving free counselling on how to take better care of children with sickle cell disease. This will involve being educated on what causes sickle cell disease, the possible complications and management.

There are no monetary reward for agreeing to participate in the study however those who are called to attend the focus group discussions will be compensated for transport.

Voluntariness of participation

This study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point. Refusal to participate will not compromise your child's care in any way.

Confidentiality

The information obtained about you or your child will be kept in strict confidence. No specific information regarding you or your child will be released to any person without your written permission. We will, however, discuss general overall findings regarding all caregivers interviewed but nothing specific will be discussed regarding you or your child. We will also not reveal your identity in these discussions. During the focus group discussions, an audiotape will be used to record the discussions. This is to ensure that the researcher does not forget any point that was discussed during the meeting. These audiotapes will be kept in a secure place and only the researcher will be able to access and use them. The tapes will only be used during data analysis and the information in the tapes will be deleted once the research is complete.

Risks

Medical research has the potential to introduce psychological, social, emotional and physical risks. One potential risk of being in the study is loss of privacy. We will keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.

Problems or Questions

If you have further questions or concerns about participating in this study, please call or send a text message to the researcher on 0721302133 or the research supervisors Prof Githanga on 0721245721, Dr Mungai on 0724654135, Dr. Kariuki on 0722679119. For more information about your rights as a research participant you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and

Research Committee Telephone No. 2726300 Ext. 44102 email
uonknh_erc@uonbi.ac.ke.

Right of withdrawal

Your decision to participate in research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of any benefits.

STATEMENT OF CONSENT

Participant's statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counsellor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study: Yes / No

Participant printed name: _____

Participant signature / Thumb stamp _____ **Date** _____

Witness signature _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher's Name: _____ **Date:** _____

Signature _____

Appendix II: Fomu la idhini – Kiswahili

Anwani ya utafiti

VIKWAZO YA MAWASILIANO KATI YA WALEZI NA WATOA HUDUMA ZA KIAFYA WA WATOTO WENYE UGONJWA WA SELI YA DAMU KATIKA HOSPITALI YA KITAIFA YA KENYATTA.

Mchunguzi mkuu

Dr. Jackline Shiundu Mukolwe

Mwanafunzi wa uzamili, idara ya daktari wa watoto pamoja na afya ya watoto, chuo kikuu cha Nairobi.

Nambari ya simu:-0721302133

Msimamizi:

Prof. Jessie Githanga

Profesa Idara ya Magonjwa ya binadamu

University of Nairobi

Tel Number:-0721245721

Utangulizi

Ningependa kuwaelezeni kuhusu utafiti ninautekeleza. Kwa majina ni Jackline Shiundu Mukolwe na mimi ni mwanafunzi wa uzamili anayechukulia shahada ya uzamili wa daktari wa watoto na afya ya watoto katika chuo kikuu cha Nairobi. Utafiti huu unahusu Vikwazo katika mawasiliano kati ya walezi na watoa huduma wa watoto wenye ugonjwa wa seli ya damu katika hospitali ya kitaifa ya Kenyatta kama mojawapo ya mahitaji ya kutimiza kwa tuzo ya shahada. Azimio la nakala ya ridhaa hii ni kukupa habari utakayohitaji ili kuamua iwapo utashiriki au hautashiriki kwenye utafiti huu. Jihisi huru kuuliza swali lolote kuhusu kusudio la utafiti huu, kitachofanyika ukishiriki utafiti, uwezekano wa hasara na faida, haki zako kama mwenye hiari na kitu chochote kuhusu utafiti kisichowazi. Wakati tutakapomaliza kujibu maswali yako yote hadi ukaridhika, una nafasi ya kuamua kubaki au kuacha kushiriki katika utafiti. Huu mchakoto huitwa “ridhaa julishi”. Pindi utakapoelewa na kukubali kuwa kwenye utafiti, nita kuhitaji utie sahihi ya jina lako kwenye nakala hii. Unahitajika kuelezwa sharia kijumla zinazounganisha washiriki wa utafiti wa udaktari. i)Uamuzi wako wa kushiriki ni wenye hiari kwa ujumla ii) Unaweza kujiondoa kwenye utafiti bila kutoa sababu yako ya kujiondoaiii) Kukataa kushiriki kwa utafiti hakutaathiri huduma zinazostabilishwa kwenye kituo hiki cha afya au kituo kingine. Tutakupa nakala ya hii fomu kama kumbukumbu.

Naweza endelea? Ndio / La

Huu utafiti umeidhinishwa na Hospitali ya Kitaifa ya Kenyatta-Kamati ya utafiti na maadili chuo kikuu cha Nairobi.

Nambari ya itifaki_____

Azimio ya utafiti

Azimio la utafiti huu ni kutathmini Vikwazo katika mawasiliano kati ya watoa huduma za kiafya na walezi wa wagonjwa wa seli ya damu katika hospitali ya kitaifa ya Kenyatta. Washiriki kwa huu utafiti watatathminiwa juu ya kiwango chao cha ufahamu wa ugonjwa wa seli ya damu unaosababisha ukosefu wa damu, vigezo vinavyoathiri mawasiliano na Vikwazo vinavyoathiri mawasiliano kati ya watoa huduma za afya. Nitawahoji walezi wa watoto wa ugonjwa wa seli ya damu wanaofuatiliwa kwenye kliniki ya hamatolojia na waliolazwa kwenye wadi. Baadaye, huenda ikawa utahitajika wakati mwingine kushiriki mjadala na kundi lenye malengo mahususi ili kuzidi kuchunguza Vikwazo vya mawasiliano na kile kinachoweza kufanywa ili kuboresha mawasiliano kati ya watoa hudumaza kiafya na watunzaji.

Kutakuwa na takribani washiriki tisini na moja katika utafiti huu watakoachaguliwa kinasibu. Naomba ridhaa yako ya kukadiria kushiriki utafiti huu. Iwapo utakubali kushiriki utafiti huu, mambo yafuatayo yatafanyika, nitakuhoji faraghani ambapo utahisi faraja ukijibu maswali. Mahojiano yatachukuwa takribani dakika ishirini.

Manufaa

Kushiriki kwa huu uchunguzi utatusaidia kutambua Vikwazo vya mawasiliano kati ya watunzaji na wahudumu wa kiafya. Hii itasaidia kuchangia mbinu za maendeleo na kuboresha mawasiliano na ujuzi wa watunzaji na jumla ya usimamizi wa watoto wenye ugonjwa wa seli ya damu unaosababisha upungufu wa damu mwilini. Hii itashinikisha elimu kuhusu vigezo vinavyochangia migogoro papa hapo na jinsi ya kuzuia. Iwapo kutakuwa na changamoto, nitanukuu nambari zako na nikualike kwa kikao cha mafunzo nitakaoandaa muda utakaofuata. Hakuna zawadi inayoendana na pesa unapokubali kushiriki katika uchunguzi. Hata hivyo, wale ambao wamealikwa kuhudhuria mjadala wa makundi yenye malengo mahususi watafidiwa nauli.

Hiari

Uamuzi wako wa kushiriki utafiti ni hiari yako. Una uhuru wa kukata kushirikia katika utafiti wakati wowote bila haki zako kukiukwa au kupoteza faida yoyote.

Usiri

Maneno utakaochukuliwa kuhusu wewe na mtoto wako hautapatiwa kwa mtu mwingine na utawekwa mahali siri. Ingawaje, tutazungumza juu ya yale matokeo tutayoyapata kwenye huu utafiti. Utambulisho wako utabaki siri. Wakati wa mjadala wa makundi, mazungumzo itarekodiwa kwenye kifaa cha kurekodi sauti. Hii ni kuhakikisha ya kwamba mchunguzaji hatasahau jambo lolote lililozungumziwa kwenye mjadala. Hiki kifaa cha kurekodi sauti kitawekwa pahala pa usiri na ni mchunguzaji tu atayeweza kuzitumia. Hiki kifaa kitatumika tu wakati wa uchambuzi na rekodi yenyewe utafutwa wakati utafiti utakamilika.

Hasara

Utafiti wa kimatibabu una uwezo wa kuchangia hasara kisaikolojia, kisosholojia, kihisia na kimwili. Mijawapo ya upungufu wa utafiti huu ni kukosa usiri. Tutahakikisha kuhifadhi usiri katika kila jambo utakalo tuambia. Tutatumia kodi ya nambari ili kukutambulisha kupitia tarakilishi iliyolindwa na nywila na kuweka kodi za kazi iliyo kwenye karatasi kwenye kabati iliyofungwa. Hata hivyo, hakuna mfumo wa ulinzi wa usiri unaowezakuwa salama kabisa, kuna uwezo mtu kupata kuwa ulikuwa kwa utafiti na kupata mambo kukuhusu. Aidha kujibu maswali kwa mahojiano kunaweza kukukosesha faraja. Iwapo kuna maswali huhisi kujibu, unawezaruka. Una haki ya Kukataa kuhojiwa ama kukataaswali kwenye mchakato wa mahojiano.

Maswali na Matatizo

Ikiwa una swali la ziada au wasiwasi kuhusu kushiriki katika utafiti huu, tafadhali piga simu au tuma ujumbe kwa mtafiti kwa 0721302133 au msimamizi wa utafiti Professor Githanga kwa 0721245721, Daktari Mungai kwa 0724654135 au Daktari Kariuki kwa 0722679119. Kwa ujumbe Zaidi kuhusu haki yako kama mshiriki wa utafiti, Unaweza kuwasiliana na katibu au mwenyekiti, hospitali ya kitaifa ya Kenyatta - chuo kikuu cha Nairobi cha mmadili na utafiti wa kamati kwa nambari ya simu 2726300ext44102. Barua pepe uonknh-erc@uonbi.ac.ke.

TAARIFA YA RIDHAA

Taarifa ya washiriki

Nimesoma hii ridhaa au nikasikia ujumbe nikisomewa. Nimekuwa na nafasi ya kujadili huu utafiti na mshauri wa utafiti. Maswali yangu yamejibiwa kwa lugha ninayoielewa. Nimeelezwa hasara na manufaa. Ninaelewa kuwa, kushiriki kwangu kwa huu utafiti ni wa hiari na hivyo naweza kuchagua kujitoa wakati wowote. Nina uhuru wa kukubali kushiriki utafiti huu. Naelewa kuwa kila juhudi zitafanya ili kuweka ujumbe wangu binafsi. Kwa kutia sahihi hii ridhaa, sijakata tamaa haki za sharia zozote ambazo niko nazo kama mshiriki wa utafiti. Nakubali kushiriki katika huu utafiti.

Ndio/Hapana**Jina la mshiriki** _____**Sahihi ya mshiriki/Alama ya kidole** _____**Sahihi ya shahidi** _____**Taarifa ya mtafiti**

Mimi nitakapotia sahihi, nimeeleza ujumbe wa utafiti kwa undani kwa washiriki waliotajwa hapo juu na kuamini kuwa washiriki wameelezwa na wana hiari na uhuru wa kupewa ridhaa

Jina la mtafiti _____ **Tarehe** _____**Sahihi** _____

Appendix III: Health care provider consent form

Title of Study

ASSESSING COMMUNICATION BARRIERS BETWEEN HEALTH CARE PROVIDERS AND CAREGIVERS OF PAEDIATRIC PATIENTS WITH SICKLE CELL DISEASE AT KENYATTA NATIONAL HOSPITAL

Principal Investigator\and institutional affiliation:

Dr Shiundu Jackline Mukolwe

Paediatric Resident, University of Nairobi

Tel Number:-0721302133

Supervisor:

Prof. Jessie Githanga

Professor Department of Human Pathology

University of Nairobi

Tel Number:-0721245721

Introduction

I would like to tell you about a study that I am conducting. My name is Jackline Shiundu Mukolwe and I am a post graduate student undertaking a degree in Master of Medicine in Paediatrics and Child Health at the University of Nairobi. This study is on communication barriers between health care providers and caregivers of paediatric patients with sickle cell disease At Kenyatta National Hospital and is part of the requirement to be fulfilled for the award of the degree. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent'. Once you understand and agree to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research: i) Your decision to participate is entirely voluntary ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

May I continue? YES / NO

This study has approval by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No. _____

Purpose of the study

The purpose of this study is to assess the barriers to communication between caregivers and health care providers of sickle cell disease patients at Kenyatta National Hospital. Participants in this research study will be assessed on the factors that affect communication and associated communication barriers between caregivers and health care providers. I will be interviewing health care providers of sickle cell patients on follow up at the haematology clinic and those admitted in the paediatric wards.

There will be approximately seventy two participants in this study randomly chosen. I am asking for your consent to consider participating in this study. If you agree to participate in this study, the following things will happen: I will be interview you in a private area where you feel comfortable answering questions. The interview will last approximately twenty minutes.

Benefits

Your participation in this study will help us identify the factors that affect communication between caregivers and health care providers and identify the barriers to communication with an aim of improving communication between caregivers and health care providers.

Voluntariness of participation

This study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point. Refusal to participate will not compromise your child's care in any way.

Confidentiality

The information obtained about you or your child will be kept in strict confidence. No specific information regarding you or your child will be released to any person without your written permission. We will, however, discuss general overall findings regarding all caregivers interviewed but nothing specific will be discussed regarding you or your child. We will also not reveal your identity in these discussions.

Problems or Questions

If you have further questions or concerns about participating in this study, please call or send a text message to the researcher on 0721302133 or the research supervisors Prof Githanga on 0721245721, Dr Mungai on 0724654135, Dr. Kariuki on 0722679119. For more information about your rights as a research participant you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. 2726300 Ext. 44102 email uonknh_erc@uonbi.ac.ke.

Risks

Medical research has the potential to introduce psychological, social, emotional and physical risks. One potential risk of being in the study is loss of privacy. We will keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview. There are no monetary reward for agreeing to participate in the study.

STATEMENT OF CONSENT

Participant's statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counsellor. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts will be made to keep information regarding my personal identity confidential. By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study: Yes / No

Participant printed name: _____

Participant signature _____ **Date** _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

Researcher's Name: _____ **Date:** _____

Signature _____

Appendix IV: Caregivers questionnaire

ASSESSING COMMUNICATION BARRIERS BETWEEN HEALTH CARE PROVIDERS AND CAREGIVERS OF PAEDIATRIC PATIENTS WITH SICKLE CELL DISEASE AT KENYATTA NATIONAL HOSPITAL

Questionnaire No. _____ Initials _____ Age _____ Date _____

Instructions

Please Circle the letter with the appropriate answer.

Section A: Socio-economic background of caregivers

1. Gender of primary caregiver
 - a) Male
 - b) Female

2. Marital status of primary caregiver
 - a) Married
 - b) Single
 - c) Divorced/separated
 - d) Widow/Widowed

3. Duration of living with patient
 - a) 5 years and below
 - b) 6-10 years
 - c) 11 years and above

4. Relationship of primary caregiver to child:
 - a) Parent
 - b) Aunt/uncle
 - c) Grandparents
 - d) Sibling
 - e) Non relative adult

5. Occupation of Caregiver
 - a) Unemployed
 - b) Casual employment
 - c) Formal employment

- d) Self-employment
 - e) Other
6. Education of Care giver
- a) Primary
 - b) Secondary level
 - c) Tertiary level
 - d) Bachelor degree or higher
7. Care givers religion
- a) Christian
 - b) Muslim
 - c) Hindu
 - d) Other (specify)

Section B: Assessment of Caregivers' Knowledge on Sickle Cell Disease

8. Which is your source of information on sickle cell disease?
- a) Health care providers (Doctor/Nurse/Clinical Officer etc.)
 - b) Society (Family/ friends etc.)
 - c) Media (Internet/ TV/ Radio/ Magazines etc.)
 - d) Other (specify).....
9. Sickle cell disease is a condition that mainly affects?
- a) White blood cells
 - b) Red blood cells
 - c) Platelets
 - d) All of the above
 - e) I do not know
10. Red blood cells in sickle cell disease cause problems because they can become?
- a) Too large
 - b) Too soft
 - c) Sickle shaped and hard
 - d) Round and hard
 - e) I do not know

11. Sickle cell disease is?
- a) Infectious disease(can be caught like a cold)
 - b) Inherited blood disorder(passed down from parent to child)
 - c) A bleeding problem
 - d) Caused by poor diet
 - e) I do not know
12. How is sickle cell disease diagnosed?
- a) Blood test
 - b) Urine test
 - c) Stool test
 - d) I do not know
13. When having sickle cell pain, a patient should?
- a) Drink plenty of fluids
 - b) Always stay home from work or school
 - c) Go to the emergency room right away
 - d) Limit intake of food
 - e) I do not know
14. Why do children with sickle cell disease take penicillin every day?
- a) To treat infections
 - b) To increase appetite
 - c) To prevent painful episodes
 - d) To decrease risk of serious infections
 - e) I do not know
15. One of the following is not a complication of sickle cell disease?
- a) Frequent infections
 - b) Leg ulcers
 - c) Acute chest pain
 - d) Cancer
 - e) I do not know

16. In cold weather, it is good practice for a person with sickle cell to do the following?

- a) Wear warm clothes
- b) Never go outside
- c) Stay home from school or work
- d) Cancel doctor's appointment
- e) I do not know

17. Hydroxyurea is?

- a) Chemical found in urine
- b) Medication used to treat sickle cell disease
- c) A part of normal red blood cells
- d) Lack of water in the body
- e) I do not know

18. One of the most common symptoms of sickle cell disease is?

- a) High levels of sugar in the body
- b) Bleeding that is difficult to stop
- c) Pain episodes
- d) Frequent seizures
- e) I do not know

19. Does the knowledge you get influence your attitude and behavior towards the management of sickle cell disease?

- a) Yes
- b) No

20. Do doctors and nurses check whether you understand the information they give you on sickle cell disease?

- a) Yes
- b) No

21. If no to question 18, did you ask for clarification?
- a) Yes
 - b) No
22. Do the doctors and nurses give you information in writing about what symptom or health problems to look out for at home?
- a) Yes
 - b) No
23. Overall, how well do you think your child's sickle cell disorder is looked after by health care providers?
- a) Very well
 - b) Quite well
 - c) Not very well
24. Would you like to receive further information on sickle cell disease?
- a) Yes
 - b) No
25. If yes to question 24, what is your preferred contact? _____

Section C: Caregivers Attitude towards Communication with Health Care Providers

26. Please tick the number that best describes your feelings about your communication with the health care provider.

	Statement	Strongly Agree 5	Agree 4	Unsure 3	Disagree 2	Strongly Disagree 1
1	The HCPs greet me warmly at every visit					
2	The HCPs pays attention to my explanations					
3	The HCPs treats me with courtesy and respect					
4	The HCPs uses a friendly tone during consultation					
5	The consultation time is sufficient					
6	There is privacy during consultation					
7	The HCPs takes my questions kindly					
8	The HCPs explain things in a way that I understand					

Section D: Factor Affecting Communication with Health Care Providers

27. Does the health providers' age affect how they communicate?

- a) Yes
- b) No

If yes, how?

28. Does the health provider's gender affect how they communicate?

- a) Yes
- b) No

If yes, how?

29. Does culture play any part on how you communicate with health care providers?

a) Yes

b) No

If yes, how?

30. Which groups of care providers do you find it difficult to communicate with?

a) Younger care providers

b) Older care providers

c) Male care providers

d) Female care providers

(Explain why you are making that choice)

Section D: Assessment of Effective Communication

31. Please tick the number that best describes your feelings about your communication with the health care provider

	Statement	Strongly Agree 5	Agree 4	Neutral 3	Disagree 4	Strongly disagree 5
A.	The information I receive during consultations with health care providers is helpful					
B.	The information I receive during consultations with health care providers is specific to caregivers					
C.	The information I receive during consultations with health care providers is clear and precise					
D.	The information I receive during consultations with health care providers is					

	complete and understandable					
E.	Health care providers present information with courtesy and consideration during consultation					
F.	The information I receive during consultations with health care providers is appropriate					
G.	The information I receive during consultations with health care providers is brief and correct					

Section E: Barriers to Caregiver-Provider Communication

32. Do you understand the language the care providers uses?

- a) Yes
- b) No

33. Do you feel comfortable communicating with the care providers?

- a) Yes
- b) No

34. What would you say are the three main barriers to effective communication with health care providers?

- a) Poor articulation by the care provider
- b) Use of technical terms by the health care providers
- c) Different cultural perspectives between care givers and health care providers
- d) Age difference between care providers and care givers
- e) Gender difference between care givers and health care providers
- f) Short consultation time
- g) Lack of privacy during consultation
- h) Other (specify)

35. Are you satisfied with the communication you are receiving?

- a) Yes
- b) No

36. If the answer is no, why are you not satisfied?

- a) Inadequate channels of communication
- b) Inconsistency in communication
- c) Incomplete and inaccurate
- d) Communication not patient specific
- e) Other (specify)

37. What is your suggestion to improving communication with health care providers?

- a)
- b)

Appendix V: Dodoso za watunzaji

VIKWAZO YA MAWASILIANO KATI YA WALEZI NA WATOA HUDUMA ZA KIAFYA WA WATOTO WENYE UGONJWA WA SELI YA DAMU KATIKA HOSPITALI YA KITAIFA YA KENYATTA

Dodoso No ___ Herufi ya kwanza ya majina _____ Umri _____ Tarehe _____

Maagizo

Tafadhali weka mzunguko kwenye jibu sahihi

Sehemu A: Sehemu ya asili ya jamii na uchumi wa watunzaji

- 1) Msingi wa jinsiam ya mtuuza
 - a) Kiume
 - b) Kike

- 2) Msingi wa hali ya ndoa ya mtunzaji
 - a) Kwenye ndoa
 - b) Wasio kwenye ndoa
 - c) Waliotalikiana

- 3) Muda wa kuishi na mgonjwa
 - a) Miaka tano na chini ya miaka tano
 - b) Miaka 6-10
 - c) Miaka kumi na moja na Zaidi

- 4) Uhusiano kati mtoto na mtunzaji
 - a) Mzazi
 - b) Shangazi/Mjomba
 - c) Babu/Nyanya
 - d) Mandugu
 - e) Watu wazima wasio na ukoo

- 5) Kazi ya mtunzaji
 - a) Asiye na ajira
 - b) Ajira ya kawaida
 - c) Ajira ya rasmi
 - d) Ajira ya kibinafsi

- e) Nyingineo
- 6) Elimu ya mtunzaji
 - a) Shule ya msingi
 - b) Shule ya sekondari
 - c) Elimu ya juu
 - d) Elimu ya chuo kikuu
- 7) Dini ya mtunzaji
 - a) Mkristo
 - b) Mwislamu
 - c) Mhindu
 - d) Nyingine(eleza bayana)

Sehemu B: Maswali ya kutathmini elimu ya watunzaji kuhusu ugonjwa wa seli ya damu unaosababisha upungufu wa damu mwilini

- 8) Ni nini chanzo cha ujumbe kuhusu ugonjwa wa huu ugonjwa?
 - a) Watoa huduma za afya (daktari, nesi, afisa wa kliniki,na kadhalika)
 - b) Jamii(familia/marafiki/na kadhalika)
 - c) Vyombo vya habari(mtandao,televisheni,redio,magazeti, na kadhalika)
- 9) Ugonjwa wa seli ya damu inaathiri nini haswa?
 - a) Seli nyeupe ya damu
 - b) Seli nyekundu ya damu
 - c) Damu platelet
 - d) Majibu yote ni sahihi
 - e) Sijui
- 10) Seli nyekundu ya damu kwa ugonjwa wa seli ya damu inaleta matatizo kwa sababu gani?
 - a) Ni kubwa sana
 - b) Ni laini
 - c) Ni umbo la mundu na ni ngumu
 - d) Sifahamu
 - e) Sijui

11) Ugonjwa wa seli ya damu ni?

- a) Ugonjwa wa kuambukiza (unaezapatwa kama homa)
- b) Ugonjwa wa kurithi (mzazi anaupitisha kwa mtoto)
- c) Ugonjwa wa kuvuja damu
- d) Unasababishwa na kutokula vyakula mbaya
- e) Sijui

12) Ni vipi ugonjwa wa seli ya damu hutambulishwa?

- a) Uchunguzi wa damu
- b) Uchunguzi wa mkojo
- c) Uchunguzi wa kinyesi
- d) Sijui

13) Wakati mtu anapopata uchungu unaosababishwa na ugonjwa wa seli ya damu, mgonjwa apaswa?

- a) Kunywa maji nyingi
- b) Lazima asiende shuleni au kazini
- c) Lazima aende kwa chumba cha dharura mara moja
- d) Apunguze kukula chakula
- e) Sijui

14) Ni kwa nini mtoto wa ugonjwa ya seli ya damu anameza penicillin kila siku?

- a) Ili kutibu magonjwa
- b) Kuongeza hamu ya kula
- c) Kujikinga na uchungu unaosababishwa na ugonjwa wa seli ya damu
- d) Kuzuia kutopata maambukizi kubwa
- e) Sijui

15) Moja ya haya majibu si tatizo inayosababishwa na ugonjwa wa seli ya damu?

- a) Kupata maambukizi mara kwa mara
- b) Vidonda vya miguu
- c) Kupata uchungu wa kifua papo hapo
- d) Kansa
- e) Sijui

16) Je, wakati wa msimu wa baridi, ni vizuri mtu aliye na ugonjwa wa seli ya damu kufanya?

- a) Kuvaa mavazi yanaleta joto
- b) Kutoenda nje kabisa
- c) Kukaa nyumbani na kutoenda shuleni au kazini
- d) Kuvuta uteuzi wake na daktari
- e) Sijui

17) Hydroxyurea

- a) Ni kemikali inayopatikana kwa mkojo
- b) Dawa inayotumiwa kutibu ugonjwa wa seli ya damu
- c) Sehemu ya seli nyekundu ya damu
- d) Upungufu wa maji mwilini
- e) Sijui

18) Wagonjwa wa seli ya damu wanapata dalili gani mara kwa mara?

- a) Kiwango ya sukari mwilini kuwa juu
- b) Kuvujadamu iliyongumu kusmamisha
- c) Kuwa na uchungu mwilini mara kwa mara
- d) Kupata kifafa mara kwa mara
- e) Sijui

19) Je, ujuzi unaopata unathiri tabia na mienendo kuhusu kumudu ugonjwa wa seli ya damu?

- a) Ndio
- b) La

20) Je, madaktari na waaguzi wanakagua iwapo umeelewa maelezo wanayokupa iwapo umeelewa maelezo wanayokupa kuhusu ugonjwa wa seli ya damu mwilini?

- a) Ndio
- b) La

- 21) Ikiwa la kwa 18, uliuliza kuhusu ufafanuzi zaidi?
- a) Ndio
 - b) La
- 22) Je, madaktari na wauguzi hukupatia ujumbe kwa maandishi kuhusu dalili au shida kwa maandishi kuhusu dalili au shida za kiafya za kuchunguzwa nyumbani?
- a) Ndio
 - b) La
- 23) Kwa ujumla, unafikiria watoa huduma za kiafya kwa watoto wenye ugonjwa wa seli ya damu mwilini hutoa huduma vizuri?
- a) Vizuri sana
 - b) Vizuri kabisa
 - c) Si vizuri sana
- 24) Je, ungependa kujua mambo Zaidi kuhusu ugonjwa wa seli ya damu?
- a) Ndio
 - b) Hapana
- 25) Kama ndio kwa swali nambari 24, ni nambari gani ya simu ungependa kuwasiliana nayo? _____

Sehemu ya C: Mtazamo ya watunzi kuhusu mawasiliano na watoa huduma za kiafya

26) Tafadhali sahihisha nambari bora inayoeleza hisia zako kuhusu mawasiliano na watoa huduma za kiafya:

	Taarifa	Nakubali sana5	Nakubali 4	Sina uhakika 3	Sikubali 2	Sikubali kabisa 1
1.	Watoa huduma za kiafya hunijulia hali vizuri ninapowatembelea					
2.	Watoa huduma huwa makini kusikiliza maelezo yangu					
3.	Watoa huduma hunitibu kwa kusikiliza fadhila na heshima					
4.	Watoa huduma hutumia toni ya kirafiki					
5.	Wakati wa maswasiliano huwa wa kutosha					
6.	Kuna faragha wakati wa mawasiliano					
7.	Watoa huduma huchukulia maswali yangu kiukarimu					
8.	Watoa huduma hueleza mambo kwa njia ninayoelewa					

Sehemu ya D: Vigezo vinavyoathiri mawasiliano na watoa huduma za afya

27) Je, watoa huduma za afya huathiriwa na umri wao katika mawasiliano?

a) Ndio

b) La

Kama ndio, vipi?

28) Je, watoa huduma za afya huathiriwa na umri wao katika mawasiliano?

a) Ndio

b) La

Kama ndiyo, vipi?

29) Je, jinsia ya watoa huduma inaweza kuathiri jinsi wanavyowasiliana?

a) Ndio

b) La

Kama ndiyo, vipi?

30) Je, utamaduni Unaweza kukuathiri jinsi unavyowasiliana na watoa huduma za kiafya?

a) Ndio

b) La

Kama ndiyo, vipi?

31) Ni kundi lipi la watoa huduma za kiafya ni vigumu kuwasiliana nalo?

a) Watoa huduma za kiafya vijana

b) Watoa huduma za kiafya wazee

c) Watoa huduma ya kiafya ya jinsia ya kiume

d) Watoa huduma ya kiafya ya jinsia ya kike

(Eleza sababu inayokufanya utoe uamuzi huu)

Sehemu E: Kipimo cha ufanisi wa mawasiliano

32) Tafadhali sahihisha nambari bora inayoeleza hisia zako kuhusu mawasiliano na watoa huduma za kiafya:

	Taarifa	Nakubali kabisa 5	Nakubali 4	Pande zote sawa 3	Nakataa 2	Nakataa Kabisa 1
A.	Ujumbe ninaoupata wakati wa majadiliano na wataalam wa afya inamanufaa					
B.	Ujumbe ninaoupata wakati wa majadiliano na wataalam wa afya ni kipekee kwa wasaidizi wa wagonjwa					
C.	Ujumbe ninaoupata wakati wa majadiliano na wataalam wa afya ni rahisi kueleweka					
D.	Ujumbe ninaopata wakati wa majadiliano na wataalam wa afya imekamilika na kueleweka					
E.	Ujumbe ninaopata wakati wa majadiliano na wataalam wa afya ni ya kiungwana na inatujali					
F.	Ujumbe ninaopata wakati wa majadiliano na wataalam wa afya inafaa					
G.	Ujumbe ninaopata wakati wa majadiliano na wataalam wa afya ni kwa muhtasari na kwa usahii					

Sehemu F: Sehemu ya Vikwazo ya mawasiliano

33) Je, unaelewa lugha wanayotumia watoa huduma za kiafya?

- a) Ndio
- b) La

34) Je, unahisi vizuri unapowasiliana na watoa huduma za kiafya?

- a) Ndio
- b) La

35) Kwa maoni yako, ni sababu gani tatu inasababisha kuwepo kwa vikwazo ya mawasiliano kati ya walezi na watoa huduma za kiafya?

- a) Maelezo duni ya watoa huduma ya kiafya
- b) Matumizi ya misamiati ya kiufundi na watoa huduma za kiafya
- c) Tofauti za kitamaduni kati ya wafunzi na watoa huduma za kiafya
- d) Muda mchache wa mashauriano
- e) Tofauti za kijinsia kati ya mtuunzi na watoa huduma za kiafya
- f) Tofauti ya kiumri kati ya mtunzi na watoa huduma ya kiafya
- g) Ukosefu wa usiri wakati wa mashauriano
- h) Nyingine (bainisha)

36) Je, umetosheka na mawasiliano unayopokea?

- a) Ndio
- b) La

37) Kama la, mbona hujatosheka?

- a) Upungufu wa njia za mawasiliano
- b) Mawasiliano hayaendani
- c) Mawasiliano hayajakamilika na si sahihi
- d) Mawasiliano hayamshauri na si sahihi
- e) Nyingine(bainisha)

38) Je, unapendekezo gani la kuboresha mawasiliano ya watoa huduma?

- a) _____
- b) _____

Appendix VI: Health care providers questionnaire

ASSESSING COMMUNICATION BARRIERS BETWEEN HEALTH CARE PROVIDERS AND CAREGIVERS OF PAEDIATRIC PATIENTS WITH SICKLE CELL DISEASE AT KENYATTA NATIONAL HOSPITAL

Questionnaire No. _____ Initials _____ Age _____ Date _____

Instructions

Please Circle the letter with the appropriate answer/s.

Section A: Care providers' socio-demographic characteristics

1. Gender
 - a) Male
 - b) Female

2. Cadre
 - a) Pediatrician
 - b) Pediatrics registrar
 - c) Nursing officer
 - d) Other (specify)

3. Number of years in medical practice_____

Section B: Factors Affecting Communication with Caregivers

4. Do care givers explain their problems clearly?
 - a) Yes
 - b) No

(Explain why you are making that choice)

5. Do you explain things in a way caregivers can understand?
 - a) Yes
 - b) No

6. Do you think the patients' socio-economic background affects communication?
 - a) Yes
 - b) No

7. Does the caregiver's age affect how they communicate?
- a) Yes
 - b) No
- If yes, how?
8. Does education have a role on how they communicate?
- a) Yes
 - b) No
- If yes, how?
9. Does the caregiver's gender affect how they communicate?
- a) Yes
 - b) No
- If yes, how?
10. Does culture play any part on how you communicate with caregivers?
- a) Yes
 - b) No
- If yes, how?
11. Which groups of caregivers do you find it difficult to communicate with?
- a) Younger caregivers
 - b) Older caregivers
 - c) Uneducated
 - d) Educated
 - e) Male
 - f) Female
- (Explain why you are making that choice)
12. Do patients play an active role in obtaining information regarding their illness?
- a) Yes
 - b) No

13. Do you think caregivers follow your instructions faithfully?
- a) Yes
 - b) No
- (Explain why you are making that choice)
14. What do you do when patients do not follow proper medical instructions?
- a) Convince the patient
 - b) Refer the patient to another doctor
 - c) Go along with the patients choice
 - d) Refer the patient to another doctor
 - e) Other(specify)
15. Patients have grievances that health care providers are not available and that they do not tell the truth regarding their condition, do you agree?
- a) Agree
 - b) Disagree
 - c) Unsure
16. Have you ever had challenges disclosing to a caregiver information about his or her condition?
- a) Never
 - b) Seldom
 - c) Sometimes
 - d) Often
 - e) Usually
17. Do you tell the caregivers of every known risk involved in a treatment of his or her child that you recommended?
- a) Every risk I can think of
 - b) Only major risks
 - c) Only if I am asked
 - d) Only if I judge it to be in the patients interest to know
 - e) No

Section C: Assessing Communication Barriers Between Caregivers and Health providers

18. Do you think the hospital and the work environment has some limitation to creating effective health service delivery?
- a) Yes
 - b) No
19. If yes, what are the limitations?
- a) Lack of enough consultation space
 - b) Lack of rules and regulations
 - c) Shortage of health care providers
 - d) Lack of diagnostic and monitoring equipment
 - e) Unfavorable work environment
 - f) Other (specify)
20. Do you have any hesitance when communicating with the caregiver?
- a) Yes
 - b) No
21. If yes, what are the three main problems when communicating with caregivers?
- a) Lack of sufficient time
 - b) High workload
 - c) Language barrier
 - d) Low medical literacy of care givers
 - e) Lack of medical training on communication skills
 - f) Poor health care systems
 - g) Other
22. Have you had any training on how to communicate with patients/caregivers?
- a) Yes
 - b) No

23. If yes when?

- a) During my undergraduate/diploma/certificate training
- b) During my postgraduate/Higher-diploma training
- c) In a seminar/conference/in service training
- d) Through E-learning(internet)
- e) Other (specify)

24. Do you wish to receive training on communicating with patients and caregivers in the future?

- a) Yes
- b) No

25. What are your recommendations to improving communication between health care providers and caregivers?

- a)
- b)

Appendix VII: Focus group discussion topic guide for caregivers

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate in this group as your point of view is important to us.

Introduction

The aim of this discussion will be to explore your experiences, opinions and perceptions of communication with care providers so as to determine factors that enhance or act as barriers to communication. The information obtained from this study will be used to provide information to the hospital in order to improve your future experiences. The focused group discussion will take about an hour.

Anonymity

Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely in a locked facility until they are transcribed, word for word then they will be destroyed. The notes taken during the focus group will not record individuals' names. Try to answer and comment as accurately and truthfully as possible. Kindly refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so, however please try to answer and be involved as possible.

Ground rules

Only one person speaks at a time. If someone is speaking please wait until they have finished before you start.

There are no right or wrong answers

You do not have to speak in any particular order

When you do have something to say, please do so, regardless of other group members' opinions.

You do not have to agree with the views of others in the group.

Does anyone have questions?

Then let's begin

Questions

- a) What factors affect how you communicate with health care providers?
- b) How do these factors affect how you communicate with health care providers?
- c) What are your thoughts on how care providers communicate with you?
- d) What experiences have you heard when communicating with care providers?
- e) How do you evaluate the communication with care providers?
- f) How does communication with care providers influence your knowledge, attitude and practice?
- g) What do think are the reasons for medical disputes?
- h) What do you think hinders communication with health care providers?
- i) What can be done to improve communication with care providers?

Conclusion

Thank you for participating. This has been a very informative discussion. Your opinions are a valuable asset to this study. We hope the discussion was interesting.

Appendix VIII: Mada ya mwongozo wa mjadala wa makundi yenye malengo ya watunzaji

Karibu na asante kwa kuhiari kushiriki kwa kundi hili la malengo. Umetakikana kushiriki kwa hili kundi kwa kuwa ufasiri wako ni wenye umuhimu kwetu.

Utangilizi

Lengo la mjadala huu litakua kuchunguza uzoefu, maoni na mtazamo wako kuhusu mawasiliano na watoa huduma za kiafya ili kuthatmini vigezo vinavyoathiri au kuwa Vikwazo katika mawasiliano. Ujumbe utakaopatikana katika huu uchunguzi utatumika kupeana ujumbe hospitalini ili kuboresha uzoefu wako wa baadaya. Mjadala wa kundi lenye malengo utachukua takriban saa moja.

Kutojulikana

Licha ya kuchukuliwa kwenye kanda, Ningependa kukuhakikishia kuwa mjadala huu utakuwa usio na majina. Kanda zitahifadhiwa kwa usalama kwenye sehemu iliyofungwa hadi wakati zitakaponakiliwa neon kwa neon, kisha ziharibiwe. Maelezo yatakayotolewa wakati wa mjadala wa kundi lenye malengo hayatataja jina la mtu binafsi. Jaribu kujibu na kutoa maoni kwa usahihi na ukweli uwezavyo. Nakusihi usijadili maoni ya wanachama wengine kando na kundi lenyu lenye mjadala. Iwapo kuna maswali au mjadala hautaki kujibu ama kushiriki kwayo, usifanye hivyo, hata hivyo jaribu kujibu maswali na kushirikishwa uwezavyo.

Sheria za kimsingi

Ni mtu mmoja anazungumza kwa wakati mmoja. Ikiwa mtu anazungumza, tafadhali subiri amalize ndio uanze.

Hakuna majibu sawa wala yasiyo sahihi.

Hauhitaji kuzungumza hasa kwa utaratibu Fulani.

Unapokosa cha kusema, tafadhali usitegeme maoni ya wanachama wengine.

Hauhitaji kukubaliana na maoni ya wanachama wengine.

Kuna mtu ana swali? Basi tuanze.

Maswali

- a) Ni vigezo vipi vinavyokuathiri unapowasiliana na watoa huduma za kiafya?
- b) Vigezo hivi vinakuathiri vipi jinsi unavyowasiliana na watoa huduma za kiafya?
- c) Mawaazo yako ni yapi kuhusu jinsi watoa huduma za kiafya wanavyowasiliana na nyinyi?
- d) Umepitia mambo yepi ukiwasiliana na watoa huduma za kiafya?
- e) Toa tathmini yako kuhusu mawasiliano na watoa huduma za kiafya.
- f) Ni vipi mawasiliano yako na watoa huduma za kiafya huathiri elimu, tabia na vitendo vyako?
- g) Unafikiria ni sababu zipi zinazochangia kuwepo na mgogoro wa kimatibabu?
- h) Unafikiri nini kinachosababisha Vikwazo vya mawasiliano na watoa huduma za kiafya?
- i) Nini kinawezafanywa ili kuboresha mawasiliano na watoa huduma za kiafya?

Hitimisho

Ahsante kwa kushiriki. Huu umekuwa mjadala wa upimaji. Maoni yako ni mali muhimu kwa utafiti huu. Umekuwa wa kuvutia.

Appendix IX: Focus group discussion participants form (caregivers)

	Age (Yrs.)	Child's Age	Age at diagnosis	Duration of follow up at clinic
1.				
2.				
3.				
4.				
5.				
6.				
7.				

Appendix X: Key informant interview guide

Good Morning/ Afternoon,

My name is Jackline Shiundu. I am a graduate student at Nairobi University. As a requirement for partial fulfilment of a Masters in Paediatrics and Child Health, I am Assessing Communication Barriers between Health Care Providers and Caregivers of Paediatric Patients with Sickle Cell Disease at Kenyatta National Hospital". The aim of this study is to explore your experiences, opinions and perceptions of communication with care givers so as to establish factors that enhance or act as barriers to communication.

The research is purely for academic purposes and the responses provided will be treated with utmost confidentiality. The findings will be fundamental to help both health care providers and care givers communicate more effectively and achieve improved medical outcomes

I am requesting for your permission to record this interview. This will help me remember everything accurately and avoid unnecessary mistakes during data analysis and presentation. Therefore, please just relax and if you are uncomfortable with any question treat it as optional and do not answer it. If need be, I shall arrange to give you a copy of my research once it is completed.

Thank you for your time.

1. How long have you worked as a doctor/nurse at KNH?
2. Averagely, how long do you take with one patient?
3. Please outline how you conduct the consultation.
4. Do the caregivers explain their problems clearly? Why?
5. Do you feel that they listen to you attentively? Why?
6. Do they communicate with you clearly?
7. Do you think they follow your instructions carefully? Why?
8. Which factors do you think hinder communication between you and caregivers?
9. Which patients are easier to communicate with; the younger ones or the older ones? Why
10. Does education have any role on how they communicate? How?
11. Does the patient's gender affect how they communicate? How?
12. Does culture influence how you communicate with your patient? How?
13. Give suggestions on how this communication can be made more effective.

14. Any other comments or additional concerns?

Thank you very much for your valuable time. Hope you will be willing to co-operate with me should need arise.

Once again, thank you very much.