PSYCHOSOCIAL ECONOMIC VULNERABILITY OF FAMILY CAREGIVERS OF PERSONS LIVING WITH SICKLE CELL DISEASE IN NAIROBI CITY COUNTY, KENYA

KWENA FOULATA TABITHA
(B.ED ARTS; MBA MARKETING)
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A THESIS SUBMITTED TO THE SCHOOL OF HUMANITIES AND SOCIAL SCIENCES IN FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF DOCTOR OF PHILOSOPHY (GENDER AND DEVELOPMENT STUDIES) OF KENYATTA UNIVERSITY

MAY, 2022
DECLARATION

I confirm that this thesis is my original work and has not been presented for a degree in any other university/Institution for certification or any other award. The Thesis has been complimented by referenced works duly acknowledged in accordance with anti-plagiarism regulations.

Signature: ______________________________  Date: __________________

Foulata Tabitha KWENA
Reg. No. C82/23443/2013
Department of Gender and Development Studies

Supervisors

This Thesis has been submitted for examination with our approval as university supervisors.

Signature: ______________________________  Date: __________________

Dr. Mildred Lodiaga
Department of Sociology, Gender and Development Studies
Kenyatta University

Signature: ______________________________  Date: __________________

Dr. Grace Okong’o
Department of Sociology, Gender and Development Studies
Kenyatta University

Signature: ______________________________  Date: __________________

Prof Joash R. Aluoch
Department of Internal Medicine and Therapeutics
College of Health Sciences
Jomo Kenyatta University of Agriculture and Technology
DEDICATION

To my children, the late Ray Shilisia, Tara Shilisia, the late Samuel Shilisia and Sonia Shilisia whose lives inspired me to do this study. I am grateful for their perseverance and their supportive big loving hearts. To my husband the late Eng. Patrick M’mbolo Shilisia who bore the loneliness and emotional distance when I got engrossed in this work. I wish they were all here to see the end…

To all sickle cell patients thriving or departed, the most valiant warriors I know.
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I acknowledge Kenyatta University and the Department of Sociology, Gender and Development Studies for having provided the opportunity for me to pursue this research. I thank everyone in this department who interacted with my work to enrich it especially Dr. F. Kere, Dr. Henry Rono, Dr. George Owino, Dr. Paul Kizito, Dr. Casper Masiga. Last but not least, Dr. Marygoretty Akinyi of the University of Nairobi, Department of Gender and Development Studies.

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I recognize the phenomenally brave women and men who dedicate their lives to loving and caring for their children or people born with sickle cell disease each day of their lives from diagnosis walking with them day by day never tiring, to whatever end. The caregiving journey is such that only those who have undertaken it can appreciate the magnitude of its joys and sorrows. I honour anyone who has been down this road.

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<td>Acute Chest Syndrome</td>
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<td>AMPATH</td>
<td>Academic Model Providing Access to Healthcare</td>
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<td>AON</td>
<td>A Gaelic word meaning &quot;one&quot;. The company was rebranded to Minet</td>
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<td>NHIF</td>
<td>National Health Insurance Fund</td>
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<tr>
<td>PLWSCD</td>
<td>Person(s) Living with Sickle Cell Disease</td>
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<tr>
<td>RBC</td>
<td>Red Blood Cell</td>
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<tr>
<td>SACCO</td>
<td>Savings and Credit Company</td>
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<tr>
<td>SCA</td>
<td>Sickle Cell Anaemia</td>
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<tr>
<td>SCD</td>
<td>Sickle Cell Disease</td>
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<td>SCT</td>
<td>Sickle Cell Trait</td>
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<tr>
<td>SDGs</td>
<td>Sustainable Development Goals</td>
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<tr>
<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>SEC</td>
<td>Socio-economic capacity</td>
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<td>SEV</td>
<td>Socio-economic vulnerability</td>
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<td>SEE</td>
<td>Socio- Economic Endowment</td>
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<td>UAP</td>
<td>UAP Old Mutual Holdings</td>
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<tr>
<td>U5M</td>
<td>under-5 mortality</td>
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<td>UN</td>
<td>United Nations</td>
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<td>VOC</td>
<td>Vaso Occlusive Crisis</td>
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<tr>
<td>WAR</td>
<td>West Africa region</td>
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<td>WBCs</td>
<td>White Blood Cells</td>
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<td>WCGs</td>
<td>Women Caregivers</td>
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<td>WHA</td>
<td>World Health Assembly</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WHOA</td>
<td>World Health Organization - Africa</td>
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<td>WHOQOL</td>
<td>World Health Organization Quality of Life</td>
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</table>
OPERATIONAL DEFINITION OF TERMS

For the purpose of this study, the following concepts will be used with the following understanding and/or indicators

**Anaemia**: A condition of a person clinically established to be characterized by a deficiency of red cells with symptoms that include fatigue, weakness, drowsiness, shortness of breath and episodes of pain

**Caregiver**: Any involuntary, informal person at home providing assistance to another person who is incapacitated to some degree and needs help. In this study, one supporting a person with Sickle Cell Disease.

**Caregiving**: Coordinating and supporting activities to support (manage) incapacitated persons; particularly persons with SCD

**Disability**: Infirmity, impairment or incapacitation

**Nursing Care**: Giving medications, dressing ulcers, monitoring vital signs and working with medical equipment

**Community**: A group of people with common interests (location, culture and socio-economic development)

**Chira/Ishira**: Any unexplained or an understood occurrence in form of illness among the Luo/Luhya communities in Kenya

**Extended Family**: Refers to people with a common ancestry such as brothers, sisters, uncles, uncles, cousins, nieces, nephews, grandparents, grandchildren and in-laws who live in one household or nearby.

**Economic vulnerability**: Refers to the woman caregiver’s inability to manage her life and resources to cater for the child’s needs and also engage in developmental activities like investments, education/career growth for herself and her dependents. It involves loss of money, jobs, lives and incapacitation to participate in events.

**Family**: Nuclear family is a social unit comprising of father, mother and their children.
Jaundice: Yellowing of eyes due to excess bilirubin in the blood signaling excessive breakdown of the Red Blood Cells (RBCs).

Involuntary Family Caregivers: Refers to family members who are transformed by an impairment (incapacitation) of a family member into caregivers.

Mental Health Vulnerability: Refers a likely prevalence of mental disorders following exposure to an SCD patient (or adverse situation) and may include likely reduction of the ability to concentrate, excessive worries, anxiety, slippage to depression, dementia, and developmental disorders such as autism.

Psychosocial: Refers to interaction (convergence) of the mental processes of a person and the social-cultural processes that include aging, education and competencies, occupation or employment, social endowment and incomes, and social capital among others.

Psychosocial Vulnerability: Refers to possible (likely) erosion (depletion) of the mental and social wellbeing as a result of exposure to the PLWSCD; including likely reduction of the ability to concentrate, excessive worries, anxiety, slippage to depression, social deprivation, exclusion and marginalization.

Psychosocial Economic Vulnerability: Refers to possible (likely) erosion (depletion) of the mental, social and economic wellbeing following an exposure to SCD patient; including likely reduction of the ability to concentrate, excessive worries, anxiety, slippage to depression, social deprivation, exclusion, reduced or loss of occupation, financial assets and income.

Psychosocial Economic Wellbeing: Refers acceptable standard of mental, social and economic experience even during an exposure to SCD patient; and include ability to concentrate, minimize worries, anxiety, depression, reduce social deprivation, exclusion, minimize loss of occupation, financial assets and income.
<table>
<thead>
<tr>
<th><strong>Quality of Life</strong></th>
<th>Refers to an experience of sustainable socio-economic wellbeing where a person or a household have adequate food security and able to meet basic needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reproductive Roles</strong></td>
<td>Refers to responsibilities of child care and domestic tasks required to ensure the maintenance and reproduction of labor related to the continuity of the family</td>
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<tr>
<td><strong>Resilience</strong></td>
<td>Resilience is the ability, capacity or strength to withstand, overcome and to recover from an adversity</td>
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<tr>
<td><strong>Sickle Cell Disease</strong></td>
<td>Also known as Sickle cell anemia is a clinically established chronic-inherited condition characterized by sickle cells breaking apart easily and dying, leaving the body with a deficiency (reduction) of red blood cells (anemia).</td>
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<tr>
<td><strong>Sickle cell Trait</strong></td>
<td>Refers to a person clinically established to have inherited one sickle haemoglobin HbS; who is a potential carrier, no symptoms but can pass the sickle gene to their offspring.</td>
</tr>
<tr>
<td><strong>Socio-economic resilience</strong></td>
<td>Refers to ability, capacity or strength of a person, a household or a group of people to withstand, overcome and to recover from an adversity in terms of the socio-economic capacity</td>
</tr>
<tr>
<td><strong>Socio-economic capacity</strong></td>
<td>Refers to education, occupation and accumulated assets to mitigate adversity; to withstand, overcome and to recover from an adversity</td>
</tr>
<tr>
<td><strong>Socio-economic vulnerability</strong></td>
<td>Refers to exposure to a process (disease) that increases the risk of erosion (depletion) of socio-economic assets including education, occupation and accumulated assets</td>
</tr>
<tr>
<td><strong>Vaso-Occlusive Crisis</strong></td>
<td>Refers to pain episodes characterized by varied levels of severity usually caused by blockage of veins and capillaries by sickled red blood cells that hinder free flow of blood.</td>
</tr>
<tr>
<td><strong>Vulnerability</strong></td>
<td>Exposure to a condition (adversity) that increases the risk (possibility, propensity) of harmful, catastrophic or disaster situation.</td>
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</tbody>
</table>
Vulnerability to Impoverishment: Increased possibility (propensity) of eroded (depleted) socio-economic capacity of a person, household, or a group of people.

Women Caregivers: Women taking care of people with SCD at home. These include mothers, aunties, step-mothers, sisters, daughters, grandmothers, granddaughters, daughters-in-laws, wives, cousins or nieces who step in to give support to a person with SCD.
ABSTRACT

Nearly 90% of the burden of the sickle cell disease (SCD) has been in Sub Saharan Africa (SSA) and a greater proportion of the burden of the disease usually fall on the involuntary family caregivers. Some form of impairment and related caregiving vary in duration, intensity, dependency and impoverishment with the type of the chronic health condition. Persons Living with Sickle Cell Disease (PLWSCDs) have typically been accompanied by prolonged, intensive, dependency and impoverished caregivers. Accordingly, this study was intended to identify the psychosocial economic vulnerability of Involuntary Family Caregivers (IFCGs) of PLWSCDs in an urban center of LMIC, the effects on the psychosocial economic wellbeing and the necessary interventions. The objectives of the study were 1) to identify the nature of the SCD in the urban centers of the LMIC, 2) to assess the characteristics of the IFCGs 3) to assess related psychosocial economic vulnerability 4) to assess coping strategies and 5) to identify necessary intervention measures. The study was based on three key theories namely the psychosocial-economic vulnerability, the psychosocial-economic resilience and the gender empowerment to address the capacity of the IFCGs to build their psychosocial-economic resilience. The study was principally a survey with in-depth interviews. The target population was IFCGs living in Nairobi in 2016. From a population of 510, a sample of 226 IFCGs was determined through Yamane (1967). Data was collected through interview guides. Results indicated that average age of IFCGs was 43 years, 81% were married, 60% had secondary or higher education. and 56% were knowledgeable about SCD. In addition, 58% of IFCGs lived in informal settlements, 60% of IFCGs earned less than KES 35,520 ($320) which was the average income for urban low income households in Kenya per month. The IFCGs spent an average of KES 31,746 ($286) which was higher compared to the household average of KES 16,983 ($153). Overall, 60% of IFCGs had provided caregiving for a period of 6 to 20 years. The effects of the caregiving ranged from ill physical and mental health 26%, social deprivation and exclusion 24% and socio-economic deprivation 50%. The study recommends developing and implementing a SCD policy including the management of family caregivers, enhancing medical insurance policy for the PLWSCDs and incorporating family caregivers in social protection schemes in order to mitigate some of the psychosocial economic challenges.
CHAPTER ONE

INTRODUCTION AND BACKGROUND OF THE STUDY

1.0 Introduction

From the time Sickle Cell Disease (SCD) was declared as a public health challenge (WHA 2006, WHO 2006; WHO Africa, 2010), the management of the SCD has remained a major challenge characterized by adverse effects on the parents and the caregivers. The burden of the disease has remained substantially high and devastating in Lower-Middle Income Countries (LMICs), Sub-Saharan Africa (SSA) and among the low income population. The latest estimates indicated that 90% of the burden of the disease and related effects were in SSA (DeBaun et al. 2020; Wastnedge et al., 2018; Madani et al., 2018). Beyond the patients, the caregivers shouldered a greater proportion of the burden of the disease; accompanied by a wide range of vulnerabilities and impoverishment.

In view of the foregoing, this study addressed the nature of the SCD among the PLWCSD in Nairobi - an urban center of a Low-to-Medium Income Country (LMIC), the nature of the caregiving and the vulnerability to psychosocial economic wellbeing. It was expected that advances made in the clinical care of SCD and in the policy framework would have mitigated some of the burden and related effects.

Caregiving service remains an essential service to people experiencing some disability to lengthen their life expectancy, improve the quality of life and to participate in social and economic life (Reinhard et al 2015, 2017; WDR, 2011). Accordingly, caregiving is essential to enable the disabled person to function and to meet the basic needs. Available reports indicate that approximately 44 million caregivers provide caregiving services to estimated 97 million disabled persons i.e. approximately one in every five adults is a caregiver.
Caregiving of persons living with Sickle Cell Disease (PLWSCD) has typically been accompanied by high dependency and demand (Madani, Al Raddadi, Al Jaouni, Omer, & Al Awa, 2018; Welkom, 2012; den Tweel et al 2008). Indeed, PLWSCD maintain essential, life-supporting and emotional dependency with the caregivers, who have in most of the cases been women. On average over 87% of the SCD caregivers have either been mothers or grandmothers (Carter 2019, Madani et al., 2018; Fowora 2016; Adegoke & Kuteyi, 2012; den Tweel et al 2008). Accordingly, the caregiving of PLWSCD has been accompanied typically by a large disproportional gender burden (DGB), large vulnerabilities and impoverishment.

1.1 Background

About 14% (1 billion people) globally live with some form of disability and require some form of caregiving (WRD 2017, 2011). Reports indicate that the prevalence of people with some form of disability is projected to increase because of the dynamics in the demographics and increase of chronic health conditions among others (WRD 2017, 2011).

In principle, a person experiencing some disability (impairment, infirmity or incapacitation) would require assistance of a caregiver; a person who provides support which ranges from the physical, basic clinical/nursing and emotional care (Alspach 2009; Frey 2009). Informal caregiving is usually involuntary and is provided in a wide range of situations - ‘diseases or circumstances’. Caregivers have existed historically within a family to support an impaired person including the elderly patients. Outside the professional clinical care, there are family (informal) caregivers, usually family members, friends or neighbors who provide care to an individual with an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, taking medications, tube feeding and ventilator care (Reinhard et al., 2015).
Essentially, caregiving is associated with chronic disability and intensive demands, responsibilities, events and tasks which constitute stressors that challenge the homeostasis of the caregivers with devastating effects on the psychosocial-economic life of the caregivers (Losada-Baltar, 2017; Bekhet & Avery, 2018). It is estimated that one patient or impaired persons is attended by at least one caregiver; and in some cases a caregiver may take care of more than 2-3 patients (Adegoke & Kuteyi, 2012). As survival rates increase due to medical advances, caring for PLWSCD involves caring for people of all ages. The level of care however depends on the complication (Mitchell et al., 2009).

Globally over 70% of the children with SCD die before adulthood and approximately 50% of adults die before their 5th decade (Wastnedge et al., 2018; Madani et al., 2018, Sharp & Spiegel, 2011, 1985). The disease is common in Malaria endemic areas. By 2018, the prevalence of homozygous babies at birth was 112 per 100,000 newborns globally and 1125 per 100,000 newborns in SSA based on the global meta-estimate (Odame & Jain 2020; Wastnedge et al., 2018). The difference indicated that a greater proportion of the burden of SCD was in SSA where 60 to 80% of the newborns with SCD are expected to die before adulthood (Odame & Jain 2020; DeBaun et al 2020; Wastnedge et al., 2018; Makani et al., 2011).

About 75 – 85% of children born with SCD globally are born in Africa (Modell & Darlison, 2008). There was one SCD child in every 150 new-births in 2010; and projected to increase to one SCD child in every 100 by 2050 in line with the population (Amendah et al., 2013). More specifically, the prevalence of SCD in Sub-Saharan Africa ranges between 2 and 30% of the population, resulting in greater morbidities and mortalities related to SCD mostly in children under five years, adolescents and pregnant women (WHO Africa, 2010; Grosse et al., 2011). Between 50–80% of the estimated 300,000 – 400,000 infants born yearly with SCD in SSA die before the age of five years. This is common in resource-
limited nations where most children born with SCD usually die undiagnosed due to inadequate programmes for early detection and treatment (Chakravorty & Williams, 2015; WHO, 2017). The median survival rate in SSA is five years and below. The end-organ damage caused by SCD also shortens their lifespan. (Grosse et al., 2011; WHO Africa, 2010). In Kenya SCD patients rarely live past 20 years (Ojwang et al., 1987).

The 59th World Health Assembly (WHA) in 2006 identified SCD as a significant public health problem in Africa that contributes to up to 16% of under-5 mortality (U5M) in some countries. In addition, the 63rd meeting of the UN General Assembly in 2008 accepted a declaration on the “recognition of sickle-cell anemia as a public health problem” and urged other Member States to raise awareness of SCD (Grosse et al., 2011).

Most of the manifestations of SCD are readily amenable to treatment and sound management. Available reports indicate that up to 70% of the mortalities in SCD are preventable (DeBaun et al 2020, Wastnedge et al., 2018; Makani et al., 2011; WHO Africa, 2010). The clinical treatment and management consist of 1) early or newborn screening (NBS), 2) early treatment and prevention of secondary risks including infections and likely damages of essential organs, 3) training of medical and paramedical personnel, 4) education and building resilience for the parents and the caregivers. In 2006, SCD was recognized as a global health problem by the World Health Organization (WHO) through the World Health Assembly (WHA, 2006) and recommended early identification (screening) and implementation of comprehensive healthcare management (CHCM).

Overall the survival period has increased from 42 to 48 years in patients with haemoglobin “SS” - HbSS and 60 and 68 years in patients with haemoglobin SC (HbSC) males and females respectively in the US and Jamaica. Those reaching 70 years have access to Comprehensive Health Care Management (CHCM), found in developed countries (Sergeant, 2009, Mitchell et al., 2009, Thomas & Taylor, 2002). In addition, inadequate
treatment and management has been associated with 1) limited or severely inadequate facilities for accurate diagnosis, 2) limited medical and paramedical personnel and socioeconomic implications to the affected persons, families, communities and the nation (Wastnedge et al., 2018; Madani et al., 2018, Sharp & Spiegel, 2011, 1985). Recurrent sickle-cell crises interfere with life cycle development of the affected person particularly physical growth, education, work and family.

Women’s and men’s roles are different in many societies based on cultural practices. Globally, studies point to the fact that most caregivers at home are women because of their perceived gender roles as caregivers (Mauro et al., 2006; Burnes et al., 2008). It is usually a woman who is attached emotionally to the person in need of care. Other factors include attitudes, belief systems, learning, parent’s occupation and social status. Available reports indicate that an average of 85% of the caregivers of the SCD patients are mothers (Kuerten et al., 2020; Rodríguez-Madrid et al., 2019; Adzika et al., 2017; Reinhard et al 2015; Adegoke & Kuteyi, 2012; DeSilva et al., 2008). In addition, studies have reported that 97.1% of the Women Caregivers (WCGs) do not get adequate support from their spouses (Karadağ et al., 2018). Men’s minimal involvement affect women’s ability to plan their future due to the erratic nature of the painful crisis (Burnes et al., 2008). Available reports indicate also that while WCGs have been handling the most difficult caregiving tasks that include toileting, dressing, and bathing, the male caregivers (MCGs) have typically addressed arrangements for care and finances which have been considered to be less intensive and vulnerable (IACO, 2015).

A descriptive study of 114 caregivers of children with intellectual disability in Gachie, Kenya, reported that 79% of WCGs were at risk of clinical depression and anxiety (Mbugua et al., 2011). Another study in Kilifi, Kenya, reported that WCGs of SCD experienced stigmatization, anxiety and varied forms of depression Marsh et al., 2011).
From the studies above, the psychosocial issues experienced by IFCGs may differ in different parts of the world, regions or by the type of illness hence the need to study issues specific to IFCGs in Nairobi.

Reports indicate that caregiving has remained undervalued both socially and economically; a private invisible task carried-out at within the family without reward, compensation or any remuneration because it is a reproductive process that has no market dimension (Rodríguez-Madrid et al., 2019; Reinhard et al., 2015; Mauro, Medel, & Diaz, 2006). On the other hand, Caregiving for SCD has particularly been more intensive. Persistent pains limit the functional capabilities of the patients, traumatize the caregivers and interfere with ability to attend key activities such as education and the occupation to support livelihoods (Brandow et al., 2009).

While some of the caregivers have been overwhelmed, others have been able to withstand the burden associated with greater demands and responsibilities (Petriwskyj et al., 2016). Those that have been able to withstand greater demands and responsibilities have been considered to have a relatively greater psychosocial-economic resilience (Petriwskyj et al., 2016). Reports indicated that in West Africa region (WAR) 60% of the caregivers had completed basic education, 35% tertiary education and 5% university education. Similarly, in WAR, an average of 58% of the caregivers held vulnerable occupations that included petty traders, artisans or full-time housewives and 42% were employed in public and private sector. While considerable attention has been given to SCD, limited attention has been given to the nature of the SCD in urban centers of the LMICs, the effects of disease on the psychosocial-economic wellbeing of the caregivers and necessary mitigation. A few donors have funded SCD programs like the Academic Model Providing Access to Healthcare (AMPATH), Kenya Medical Research Institute, KEMRI and the German Doctors but these resources remain very inadequate. Patient support groups have sprouted
in Kenya and serve as lobby and advocacy groups like the Children Sickle Cell Foundation (CSCF) that provided the list of respondents as seen in appendix v.

1.2 Statement of the problem

Despite, the progress that has been made in clinical-care, and related policy framework, the prevalence of SCD and the resulting caregiving remains high in lower-middle income countries (LMICs), particularly in sub-Saharan Africa (SSA) with limited intervention. Out of approximately 350,000 children born with SCD globally every year, 75% of them continue to be located in SSA with inadequate interventions to mitigate the adverse effects. In addition, the disease contributes to 30 - 50% incidence of disability, reduced productivity, unemployment, and a leading cause of stroke among children and adolescents. Beyond the patient, the caregivers bear a greater proportion of the burden, particularly in respect to erosion of the psychosocial economic wellbeing leading to severe mental disturbance, socio-economic deprivation and impoverishment.

Despite the progress that has been made in clinical-care, and related policy framework, the prevalence of SCD and related involuntary family caregiving (IFCG) remains high in lower-middle income countries (LMICs), particularly in sub-Saharan Africa. Out 300,000 children born with SCD every year globally, 75% of them have been located in Sub-Saharan Africa with inadequate interventions to mitigate the adverse effects. The disease contributes 30–50% of the disability, reduced productivity, unemployment, and a leading cause of stroke among children and adolescents. Beyond the patient, the IFCGs bear the largest burden of the disability related to SCD, particularly in respect to depletion of the psychosocial economic wellbeing leading to severe mental disturbance, socio-economic deprivation and impoverishment.

This study was intended therefore to identify the nature of the SCD in urban centers of LMICs, the effects on psychosocial economic vulnerability and the necessary
intervention. Available reports indicated that 60% of the urban population in SSA lived in areas classified as slums (WB 2019, 2016, Lall et al., 2017). This reflected the vulnerability of the urban population and the capacity to address a chronic disease such as SCD. In addition, it was envisaged that urban centers in LMICs would have capacity to address SCD and to mitigate adverse effects on the psychosocial economic wellbeing of the caregivers and the parents. More specifically, it was expected that the concentration of the health facilities and services in an urban center in LMIC would improve capacity to address the clinical care of the SCD and to mitigate adverse effects on the psychosocial economic wellbeing of the caregivers and the parents.

1.3 Objectives of Study

1. To assess the characteristics of the caregivers of PLWSCD.
2. To identify the characteristics of SCD in an urban center of a LMIC.
3. To assess psychosocial economic vulnerability of the caregivers of PLWSCD.
4. To assess coping/adaptive strategies by the IFCGs of PLWSCD.
5. To identify necessary measures to reduce IFCGs vulnerability.
6. To make recommendations

1.4 Research Questions

In order to enhance the clarity of the research objectives, the following research questions were adopted:

1. What are the typical characteristics of the IFCGs?
2. What are the key characteristics of the SCD in an urban center of a LMIC?
3. What are the key psychosocial economic vulnerabilities of the IFCGs of PLWSCD?
4. What measures have IFCGs adopted to mitigate the vulnerability?
5. What would be sustainable intervention measures?
1.5 Assumptions of the Study

The study was carried out with four (4) main assumptions. First, the study assumed that urban centers in LMIC had adequate infrastructure in terms of health facilities and services to address SCD and to mitigate adverse effects of related involuntary family caregiving on the psychosocial economic wellbeing or erosion of the psychosocial economic wellbeing. Secondly, the study assumed that persons constituting membership of the Children Sickle Cell Foundation (CSCF) in Nairobi had been screened and identified correctly to have SCD. Thirdly, the study assumed that PLWSCD and their respective caregivers at the CSCF would represent typical features of PLWSCD and their caregivers in urban centers of LMIC. Lastly, the study assumed also that the typical features of the PLWSCD and their respective IFCGs at the Foundation would reflect vulnerability or indeed eroded psychosocial economic wellbeing of other caregivers.

1.6 Justification and significance

Whereas there has been a reasonable progress on the clinical care and the policy framework in respect to SCD, limited attention has been given to the adverse effects of related involuntary family caregiving (IFCG) on the psychosocial economic wellbeing or erosion of the psychosocial economic wellbeing. Accordingly, the findings of the study were expected to guide the way involuntary family caregiving should be addressed and the IFCGs would be managed to mitigate adverse effects of the caregiving of PLWSCD.

More specifically, the findings of this study were intended to provide insight on three key areas. First, the findings were expected to enhance the understanding of the characteristics of the SCD in LMICs and the nature of the clinical care. Secondly, the findings were expected to enhance the understanding of the impact (effects) of related IFCG on the psychosocial economic wellbeing, the coping mechanisms and promising mitigation measures. Thirdly, the findings were expected to provide insight on the policy gaps in the
management of the SCD and the need to enhance the psychosocial economic safety net which would in turn maintain or improve the psychosocial economic capacity (resilience) of the caregivers and PLWSCD.

The governments in SSA including Kenya have remained blind to the prevalence of the SCD, ways to address the PLWSCD and the burden to the caregivers who most of them happen to be women caregivers and therefore disproportional gender burden. The study added to existing social research on SCD increasing the knowledge in Kenya.

1.7 Scope and limitations

The study examined the characteristics of the SCD in urban centers of the LMICs and the effects of related IFCG on the psychosocial economic wellbeing. More specifically, the study focused on the experiences of the caregivers, key informants and experts to identify characteristics of the SCD in urban centers of the LMICs and the effects of related IFCG on the psychosocial economic vulnerability of the caregivers. The study was carried-out in Nairobi as a typical urban center in SSA; ranked 9th based on the population density and related demographics (World Bank 2019, 2016).

Although urban centers in SSA have expanded with enhanced capacity to address chronic disabilities, a considerably large population remains vulnerable with negative health outcomes which in turn erode psychosocial economic wellbeing. The study specifically used registered members of the Children Sickle Cell Foundation (CSCF) located in Nairobi and which provided an opportunity for in-depth assessment of the characteristics of the SCD in urban centers of the LMICs and the effects on the psychosocial economic vulnerability of the caregivers. The study took place between 2010 and 2016 after the enactment of the 2010 constitution that promised access to healthcare by all.

Accordingly, the study did not address the psychosocial economic vulnerability of the parents and the extended household or family. In addition, the study did not address
directly the characteristics of the SCD in rural areas of the LMICs and the effects of SCD on the psychosocial economic vulnerability.
CHAPTER TWO
REVIEW OF RELATED LITERATURE

2.0 Introduction

In this chapter, the study reviewed literature in respect to 1) disability and caregiving, 2) the nature of the caregiving, 3) the nature of the SCD in urban centers, 4) psychosocial economic vulnerability of the caregivers, 5) the characteristics of the caregivers, 6) coping or adaptive strategies and 7) identify necessary measures to reduce IFCGs vulnerability. The study also identified gaps in the previous studies, reformulated theoretical perspectives and the conceptual framework.

2.1 Caregiving and Disability

2.1.1 Disability

In 1948, WHO defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Accordingly, disability (infirmity or impairment) is a form of deficiency in physical, mental and social well-being accompanied by inability to meet basic needs and inability to sustain quality life without assistance. Disability has typically been considered as an interaction of health conditions, personal and environmental factors. It is characterized by diversity and heterogeneity.

The disability due to health conditions may be visible or invisible; temporary or long term; static, episodic, or degenerating; painful or inconsequential. Available data indicate that people with disabilities (and their families) tend to experience economic and social disadvantages than those without disability (WRD 2017, 2011). Available reports indicated also that disability may increase the risk of poverty and poverty may also increase the risk of disability (Banks, 2017; Pinilla-Roncancio, 2015; Yeo, 2019).
According to the World Disability Report (WRD 2017, 2011), by 2017, about 14% or 1 billion people globally lived with some form of disability and required some form of caregiving. The same report projected that the prevalence of people with some form of disability will increase in the next three to five decades because of the dynamics in the demographics and increase of chronic health conditions among others (WRD 2017, 2011). The same report emphasized that nearly everyone is likely to experience some form of disability (temporary or permanent) at some point in their life-time. Finally, the same report indicated also that people with disabilities have had lower education achievements, less participation in socio-economic life, greater rate of socio-economic deprivation and poorer health outcome.

Caregiving has been a long-established tradition to assist people with some disability to meet basic needs, access necessary clinical-care, to improve the quality of life and to lengthen the life expectancy. Most extended families have a disabled member where therefore one of the non-disable members is involuntarily transformed into a caregiver; to assume the responsibility of caring and supporting the disable member (WRD 2017, 2011). Persons with disabilities need assistance and support to maintain quality of life and to be able to participate in social and economic life. In view of the increasing need for the caregiving, various reports have called for disability inclusion in the health sector and scaling-up the disability services in primary healthcare, particularly in rehabilitation interventions. Part of the effort include the UN Disability Inclusion Strategy (UNDIS, 2019) to promote ‘sustainable and transformative progress on disability inclusion through all pillars of the work of the United Nations.

2.1.2 The Caregiving of Disabled Persons

Caregiving is a process of assisting persons with some disability to meet the basic needs; access needed clinical-care, to improve quality of life and to increase the life
expectancy. Where a "person attends to the needs of a dependent person" (UN, 2008; Hunt, 2003; Thomasma, 1993). These are particularly people with some chronic biomedical vulnerability. In other words, caregiving is essentially necessary to enable the disabled person to function and to meet the basic needs. Caregiving involves more than caring as the caregiver enters into a mutual change process with the person being cared for the benefit of both (McGee J., 2016).

The responsibilities of the caregiver may vary in duration, intensity, dependency and the quality of the services (Reinhard et al., 2015). The private invisible task of caregiving is done at home, is undervalued both socially and economically and not remunerated (Rodríguez-Madrid et al., 2019). The practice of caregiving has been sustained on the basis of the moral principle to care for those who are disabled and dependent. The degree of the disability and/or vulnerability of the patient determine the nature and the quality of the caregiving (Hunt, 2003; Thomasma, 1993).

The caregiving of a person with chronic illness or disability has typically been characterized by the duration of care, intensity of care, access to healthcare services and varied levels of social support and protection (Schulz, 2016; Evans, 2010). Caregiving has naturally been characterized by various dimensions including the caregiving to the children, caregiving of the elderly persons, caregiving of the disabled persons and the caregiving of the people experiencing various types of diseases (Ghazawy et al., 2020; Schulz 2016; Talley & Crews 2012). Caregiving for persons with spinal cord injuries dementia and SCD have been reported consistently to be one of most demanding types of caregiving (Schulz & Sherwood, 2018; Pinquart & Sorenson, 2007; Ory et al., 1999).

In this respect, caregiving services (CGS) have evolved and expanded over the centuries from family care to institutional care; creating series of possibilities and combinations to caregiving. Expansion has therefore been characterized by a range of
providers from family (household) caregiving to professional caregiving including
paramedical and medical or institutional care with related challenges (UN, 2008; Hunt,
2003). On one end of the continuum is informal (involuntary) family care and on the other
end is formal (medical-institutional) care; with a middle position of formal (medical-institutional and informal (family) care.

Medical-institutional care has been characterized by advantages and limitations. While it is supported by professional and para-professional personnel, medical-institutional care has remained relatively expensive and not affordable to the majority of the population. Outside the professional and/or clinical care, are family (informal) caregivers who usually may be family members, friends or neighbors who provide care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard et al., 2015). Of course in most situations a family-centered care is preferred for many reasons including the supply of emotional support and a wide range of socio-economic considerations (Brooks, 1997)

A chronic and progressive disability of a family member usually transforms an immediate relative (spouse, mother or father, daughter or son) to an involuntary caregiver; with women taking the primary caregiving role (Swinkels et al 2019; Sharma et al., 2016; Kipp et al 2007). These reports indicate that about 77% of the impairments globally have been attended within the family framework. Accordingly, by definition the involuntary family caregivers are members of the family who have been transformed by a disability of a family member into caregivers. It is not so much of their willingness or readiness but an obligation to care for a disabled (impaired) family member. In addition, family care has remained largely “informal care” where caregivers have not been given appropriate recognition, reward or any payment (UN, 2008; Hunt, 2003).
By 2017, it was estimated that there were globally 44 million informal-family caregivers over the age of 18 years; approximately one in every five adults (Reinhard et al., 2015). Available reports indicate that about 90% of persons with chronic diseases has been cared for by relatives; particularly those who live with the patient (Blanes et al., 2007). Caregiving also has potential to increase the risk (vulnerability) of psychosocial economic wellbeing of the disabled person, the caregiver and the family (Reinhard et al., 2015). Indeed, caregiving has been associated with considerable costs in terms of socio-economic opportunities; or trading (forfeiting) socio-economic activities by caregivers. By 2017, it was estimated that the unpaid economic value of the family caregiving stood at $257 billion based on the 2000 USA dollars.

2.1.3 The Nature of the Caregiving of Persons with SCD

The caregiving of a person with chronic illness or disability has typically been characterized by the duration of care, intensity of care, access to healthcare services and varied levels of social support and protection (Schulz, 2016; Evans, 2010).

2.2 Caregivers

Caregivers of patients with Alzheimer’s disease, HIV and critically ill patients in the US, see caregiving as a difficult 24-hour job requiring long term commitment that could expand to take over much of one’s life with a substantial toll on the caregiver that require re-organizing activities in one’s life to survive the unpredictable consequences (Center, 2008; Mullan, 1998; Alspach, 2009; Northington, 2000). In Spain, a ratio of 40%: 24% women to men caregivers reported impaired health while 35:20% of women to men felt depressed (Rodríguez-Madrid et al., 2019).

In Kenya SCD IFCGs have not been well researched, documented nor well understood as a majority of studies on SCD were medical ignoring the social aspects. There are social studies on caregiver’s HIV, Alzheimer’s, Dementia, Mental disability but SCD
caregivers have not been amply researched (Mbugua et al., 2011). There is only one study in Kilifi, Kenya illustrating illness stigma and women’s inability to work (Marsh et al., 2011). Studies on SCD have been done in different contexts but women caring for SCD patients may not have similar experiences because of the differing environments they operate in. Some developed countries have CHCM while most countries in Africa do not (Serjeant et al., 2009; WHO Africa, 2010). The experiences of SCD WCGs in Kilifi County could differ from experiences of caregivers in Nairobi or any other county. Even at the individual level, the caregiving experience may be totally personal.

Studies have shown psychological, social and economic challenges resulting from fear of untimely deaths, social isolation, stigma and inadequate healthcare (Burnes et al., 2008; Marsh et al., 2011). Caregiver’s quality of life has been affected (Da Silva et al., 2012). This study sought to establish experiences of SCD caregivers in Nairobi as a result of their unsupported caregiving positions due to lack of a sickle cell policy and inadequate medical care, as IFCGs try to engage in other productive activities outside the home and how this impacted on them from psychosocial economic perspectives. Most studies on various aspects of this study targeted other illnesses or contexts, hence the need to collect and document data relevant to SCD IFCGs in Nairobi. On an individual level, SCD may affect caregivers differently depending on their occupation, attitudes, beliefs, motivation, learning, socialization and social status as well as how families, ethnic groups and society at large interpret SCD as this in turn translates to the social support offered to IFCGs.

2.2.1 Characteristics of the Involuntary Family Caregivers

We have indicated that caregiving is a process of supporting disabled persons to meet the basic needs, access needed clinical-care and to increase the life expectancy (UN, 2008; Hunt, 2003; Thomasma, 1993). Accordingly, chronic and progressive disability of a family member typically transforms an immediate relative (a spouse or partner, mother or father,
daughter or son) to an involuntary caregiver (Swinkels et al., 2019; Sharma et al., 2016; Kipp et al., 2007). In this section, we examine the typical characteristics of the involuntary family caregivers (IFCGs) and their capacity to provide caregiving services (CGS) to disabled people. Among the key characteristics include the age of the IFCGs, the duration in caregiving role, their needs and skills, and their socio-economic capacity (Addo et al., 2018; Nortey et al., 2017; Schulz, 2016).

Studies have estimated that the average age of the IFCGs has been 47 years (Reinhard, 2008); which indicate that most of the caregivers are at the prime phase of their adulthood as well as their careers. Accordingly, the concern has revolved around the risk of caregiving subverting the trajectories of adulthood and related careers, or life transitions (Sharma, · 2016; Zuurmond et al., 2019). Other estimates have reported that 48% of the IFCGs have been between 18-49 years old and 34% have been 65 and above years (Nortey et al., 2017, Reinhard, 2008).

Studies have also reported that the average duration of the IFCGs in caregiving role has been approximately 4-5 years. More specifically, 30% of the IFCGs have provided care for less than a year, 24% for more than 5 years and 15% for 10 or more years (Nortey et al 2017, Schulz 2016). In addition, these studies reported that caregivers have tended to spend an average of four hours per day; or an average of 28 hours per week giving care. Caregivers attending to patients with severe disability, high demands and dependence have been estimated to spend an average of 8 hours per day or equivalent to an average of 56 hours per week giving care. This is characterized by fatigue and intensive stress. Other reports indicate that caregivers have spent an average of 11.3 hours per day (79.1 per week) to caring for persons with severe disabilities such as spinal cord injuries (SCI) and also be responsible for related housekeeping tasks and the care of other dependent family members (De Vivo and Fine 1985).
Patients with severe paralysis, spinal cord injuries (SCI), dementia and SCD have been reported to be accompanied by high demands and dependence, related fatigue and intensive stress (Nortey et al., 2017, Schulz, 2016). In nearly all situations, IFCGs are thrust into caregiving role without adequate experience, competencies and skills (Muller-Kluits & Slabbert, 2018). Although, they operate as an extension of the professional clinical personnel, typically, IFCGs have not been prepared to assume the caregiving role particularly those of the severe and delicate patients. Studies have continued to report a general absence of caregiving knowledge and skills (WHO, 2017; Schumacher et al. 2000). In most cases, IFCGs operate with limited knowledge, experience and no guidance on how to address complex issues particularly those related to severe paralysis, spinal cord injuries, dementia and SCD. Accordingly, studies have also emphasized the principle of developing skill and competencies to support the transition of the IFCGs to the role of caregiver (Leocadie et al 2020; WHO, 2017). Such would enhance adaptability and self-confidence on the role of the caregiver.

Besides their productive capacity and the level of input into the care of the patients, IFCG has remained largely unpaid, socialized, confounded by low socio-economic endowment (SEE), poverty, vulnerable employment and related resource constraints (Addo et al., 2018; Nortey 2017, WHO, 2017). In most parts of the SSA, involuntary family caregiving has been socialized into a social responsibility with limited economic compensation. In addition to lack of payment and low SEE, IFCGs forfeit a wide range of socio-economic opportunities including education, career development and employment among others (Addo et al., 2018; Nortey 2017; WHO, 2017).

In principle, we have noted that most of the IFCGs have been at the prime of their age and career, provide care to nearly 60% of their time, usually with limited experience, competence and knowledge with no or limited remuneration; and forfeit a wide range of
socio-economic opportunities including education, career development and employment among others.

2.2.2 Gender Dimension of the Caregivers

Women are key actors in development individually or collectively but are often left out as 80% of the role they play in the economy is invisible i.e. bearing children, domestic management, subsistence agriculture, taking care of children, representing families in church and other social functions and caring for relatives and nurturing and solving family disputes (Costa et al., 2016). Societal expectations are women’s’ main motivation to accept this role in line with Albert Bandura’s social learning theory (Bandura, Ross & Ross, 1961). Societal gender role stereotyping worldwide predisposes women to take on caregiving work with minimal help from fathers (Mauro et al., 2006; Burnes et al., 2008).

The involuntary caregiving and the IFCGs have been confounded by the gender dimension of the disability caregiving (GDDCG). It is well acknowledged that women have been at the frontline and largely represented in the caregiving for the disabled people (Sharma, 2016; WDR 2011; UN, 1993). At the mid-life (ages 40-69) globally, women have been more likely than men to provide care whereas men have been more likely than women to provide care above age 80 (WHO, 2017; Schulz & Eden, 2016).

Women have assumed a large role in the IFCG; particularly in low income countries and specifically in SSA. In other words, informal family caregivers (IFCGs) have remained predominantly women caregivers (WCGs) based on their other roles as spouses (partners), mothers and the grandmothers. Available reports indicate that over 85% of the IFCGs have been women (Swinkels et al., 2019. Madani et al., 2018; Reinhard et al., 2015; WHO, 2017; Sharma et al., 2016, Kipp et al., 2007; DeSilva et al., 2008). In Turkey 97.1% of caregivers of SCD were women who did not get any help from spouses (Karadağ et al., 2018). By definition, IFCG represent women members of the families who have been
transformed by a disability into caregivers. Indeed, early studies highlighted the gendered nature of informal care of the dependent people (Ginn & Arber 1991).

Studies have reported consistently that over 85% of the caregivers for PLWSCD have been Women, usually housewives and mothers. Reports have also indicated that 59.5% were married, 82.5% used the family house as the place of care, 77% of the WCGs have had low primary education, 81% have had low or vulnerable occupations, over 51% lived with less than USD 120 per month and 80% had no insurance and limited support. (Swinkels et al., 2019; Madani et al., 2018; Reinhard et al., 2015, Sharma et al., 2016, Kipp et al., 2007; Da Silva et al., 2012). This puts them under substantial pressure to meet the needs of the SCD patients (Madani et al., 2018). Rattler, Walder, Feng, & Raphael, 2016; Wonkam et al., 2014; Adegoke & Kuteyi, 2012).

The total average duration of care of SCD patients in Brazil was 16.08 years (± 9.9 years); and 89.2% reported providing 24-hour care per day (Da Silva et al., 2012). Primary caregivers provide care due to moral obligation (75%) and absentee caregivers tend to be males (73.3%) residing long distances from the relative (Rodríguez-Madrid et al., 2019). In KwaZulu-Natal, South Africa, Caregivers of all orphaned children (OVCs) because of HIV/AIDS were overwhelmingly women at 87% (DeSilva et al., 2008). In Kenya women have been socialized to take on caregiving work as societal expectations of the feminine roles (Muchangi, 2014). In Kenya nearly 90% of OVC caregivers were a females, usually mothers or grandmothers and ½ of these were widowed, 1/5 had a chronic illness and over 1/3 were members of support groups (Thurman et al., 2012). In principle, we can conclude that women are predominantly represented in involuntary family caregivers, subjected to intensive and lengthy duration of care and characterized by limited socio-economic endowment, limited support and social protection (Madani et al., 2018; Rattler, Walder, Feng, & Raphael, 2016; Wonkam et al., 2014; Adegoke & Kuteyi, 2012).
2.3 The Nature of the Sickle Cell Disease

2.3.1 Prevalence of Sickle Cell Disease

Sickle cell disease (SCD) is one of the most prevalent genetic blood diseases in the world affecting over 5% of the global population in 2008 but it is biased towards people of African descent (WHO Africa, 2010; Mitchell et al., 2009; Modell & Darlison, 2008). Other estimates indicate that by 2012, SCD affected 20 – 25 million people globally and of these, 12 - 15 million lived in Africa (Mulumba & Wilson, 2015). SCD is also found in people from Asia, Caribbean, Mediterranean and Middle East (Fixler & Styles, 2002; Burnes et al., 2008; Mitchell et al., 2009). SCD is also documented in Brazil, UK, USA, Canada, Jamaica, Yemen, Greece, Italy and India (Ankre et al., 2013; Claire Laurent, 2012; Foy H. and Kendall A.G., 1974).

Developed countries have less than 1% of the global burden and over 90% of people born with SCD survive into adulthood because of new born screening, support and CHCM (Mburu & Odame, 2019; DeBaun & Galadanci, 2019). In contrast, more than 2/3 (75 - 85%) of people with SCD globally are born in Africa where 80% of them go undiagnosed and more than half die before their 5th birthday (Pate & Giroir, 2019; Wastnedge et al., 2018; WHO, 2017). Globally, 70% of PLWSCD die before adulthood and approximately 50% of adults die before their 5th decade (Wastnedge et al, 2018; Madani et al., 2018; Sharp & Spiegel 2011, 1985).

Estimated prevalence in 40 African countries is 2% for SCD and 10 – 45% for SCT (WHO Africa, 2010; Mulumba & Wilson, 2015). The condition originated from malaria zones in the tropics between latitudes of 15° North and 20° south of the equator where carriers (SCT) are protected against death from malaria and enjoy an evolutionary advantage (Chakravorty & Williams, 2015; Mulumba & Wilson, 2015). SCD therefore favors places with strong natural selection for morbidity and mortality from malaria.
When these surviving carriers marry one another, they bring two recessive genes together birthing a SCD patient (Ojwang et al., 1987; Aluoch, 1997; Kifunde C. M., 2008). By 2018, the prevalence of homozygous at birth was 112 per 100,000 newborns globally and 1125 per 100,000 newborns in SSA based on the global meta-estimate. (Odame & Jain 2020; DeBaun et al 2020; Makani et al., 2011; Wastnedge et al, 2018).

This prevalence results in greater morbidities and mortalities. Mortalities related to SCD complications occur mostly in children under five years, adolescents and pregnant women (WHO Africa, 2010). Between 50%–80% of the estimated 400 000 infants born yearly with SCD in SSA die before the age of five years. The survivors suffer end-organ damage which shortens their lifespan (WHO Africa, 2010).

The 2010 African Strategy does not highlight SCD occurrence in Kenya. but other reports indicate also that out of the 240,000 children born with SCD each year in SSA by 2010, 6,000 were in Kenya alone (Amendah et al., 2013, WHO Africa, 2010). This was equivalent one SCD child in every 150 new-births; and projected to increase to one SCD child in every 100 by 2050 in line with the population. There are considerable differences in SCD prevalence among communities in Kenya with the Luo having the highest prevalence of 58.4%, Luhya 23.9% and Kambe ‘Mijikenda’ 8.5%. Other Bantu and Nilotic groups are affected but to a very small scale (Aluoch, J. R.; Aluoch, 1993; Foy H. and Kendall A.G., 1974). In Kenya, SCD is a widespread hereditary problem at a national level but resources to address it are limited (Aluoch, J. R. & Aluoch, 1993).

The 59th World Health Assembly (WHA) in 2006 identified SCD as a significant public health problem in Africa that contributes to up to 16% of under-5 mortality (U5M) in some countries. In addition, the 63rd meeting of the UN General Assembly in 2008 accepted a declaration on the “recognition of sickle-cell anemia as a public health problem”
and urged other Member States to raise awareness of SCD (Grosse et al., 2011). Although the African SCD Strategy provides a set of interventions to reduce the SCD burden through awareness, prevention and early detection, SCD remains an ignored public health disorder that dodges health experts (Wambebe, 2001; WHO Africa, 2010; Grosse et al., 2011). At the time of this study, Kenya neither recognized nor planned for SCD. Lack of a SCD policy exacerbated caregiver vulnerability as they operated in an environment without relevant support, information and tools.

2.3.2 Sickle Cell Disease

Sickle cell disease (SCD) is a life threatening recessively inherited blood condition with a myriad of severe symptoms (Thomas & Taylor, 2002). In East Africa, HbSS disease, Sickle Cell Anaemia comprises 99% of SCD. SCD affects the functioning of the Red Blood Cells (RBCs) by reducing the quantity of healthy RBCs necessary for carrying oxygen throughout the body. The RBCs of a people living with sickle cell disease (PLWSP) contain an abnormal kind of haemoglobin called Sickle Haemoglobin (HbS) - an abnormal form of the oxygen-carrying protein. Deficiency of oxygen causes HbS to crystallize, distorting the RBCs into sickle shape making them fragile and easily destroyed, leading to anaemia. Accordingly, SCD is a chronic condition (Madani et al., 2018; Adegoke & Kuteyi, 2012; Rees et al., 2010; WHO Africa, 2010; Tweel et al., 2008, Sharp & Andrew Spiegel, 2011, 1985).

One gets SCD by genetically inheriting a recessive gene from each parent, making two recessive genes in their DNA responsible for making faulty homozygous - HbSS. People who inherit one recessive gene from only one parent are heterozygous – HbAS are Carriers or Sickle Cell Trait (SCT). The HbAS genotype is usually asymptomatic but can pass on the S gene to their offspring. Each parent of a SCD patient has at least one defective β-globin gene HbAS (Thomas & Taylor, 2002; Burnes et al., 2008). Repeated
polymerization reduces the lifespan of RBCs by $\geq 75\%$, resulting in hemolytic anemia. The polymerized cells cannot move easily in the small blood vessels, resulting in vaso-occlusion (Rees et al., 2010; WHO Africa, 2010; Tweel et al., 2008). The hallmark of SCD is anaemia is vascular occlusion (VOC) that is erratic and presents in extremely painful episodes referred to as crisis. VOC is a major cause of hospitalization and death among PLWSCD due to long term tissue and organ damage. These complications co-exist and impact the quality of life for PLWSCD (Foy H. and Kendall A.G., 1974; Mulumba & Wilson, 2015).

The episodes of pain vary in severity and duration. Some of the affected people may experience a few pain episodes in a year while others may experience greater and more severe re-occurrence in a given year. SCD is also associated with high mortality, particularly under five-year category (U5M). The contribution of haemoglobin disorders to U5M has been 3.4% globally and 6.4% in Sub Sahara Africa (Modell & Darlison, 2008). Recurrent crises interfere with life cycle development of the PLWSCD particularly education, work and family development.

Symptoms of SCD occur when the body gets stressed due to infections, dehydration, reduced oxygen concentrations, extreme temperatures and over-exertion including pregnancy or psychological stress. Chronic anaemia caused by abnormal rate of RBCs breakdown causes PLWSCD to sometimes exhibit pallor, fatigue, jaundice, susceptibility to infections, shortness of breath, chronic leg ulcers and delayed growth and development. Other symptoms include painful swelling of hands and feet, priapism, abdominal crisis, Acute Chest Syndrome (ACS), central nervous system disease, cardiovascular manifestations, splenic sequestration, acute pulmonary sequestration; pulmonary hypertension; stroke and cerebral vascular accidents; painful episodes especially in the long bones, renal and retinal failure or gallstones and liver problems. Repeated crises lead to other complications such as avascular necrosis, swelling of flat bones, osteomyelitis and
aplastic crisis. SCD’s acute and chronic aspects lead to a condition requiring sustained medical attention for prevention and treatment of complications (Serjeant, 2001; Chen, Lathrop, & Shevkoplyas, 2012; Graff et al., 2010) Acute chronic disorders like priapism, organ damage, ACS and stroke evolve to become worse with time (Mitchell et al., 2009). Children have high resting energy consumption rates, low bone density, late skeletal and bone maturation, experience poor growth and chronic pain. PLWSCD who are over 40 years’ experience decline in Hb levels, greater bone pains or kidney failure. Over 60 years PLWSCD mostly die from chronic kidney failure, stroke, ACS, liver failure, congestive cardiac failure or infections (Serjeant et al., 2009).

2.3.3 Determination of Sickle Cell Disease

SCD is characterized by the presence of dense, sickled cells that causes hemolysis of the red blood cells, anemia, episodes of severe pains, organ damage, and in some cases death. Early detection of the disease can improve treatment and management of the disease, reduce severity of the pain episodes and mortality (Arishi et al., 2020; Madani et al., 2018; Amendah et al., 2013, WHO Africa, 2010). At the practical level, clinical determination is recommended through newborn screening (NBS), series of screening for infections and chronic damage of vital organs (Arishi et al., 2020, Madani et al., 2017; WHO Africa, 2010).

Specific clinical approaches include 1) screening tests that include complete blood count, peripheral blood smears, and sickling test, 2) confirmatory tests that include hemoglobin separation techniques and genetic tests, and 3) emergence of portable techniques that include coupling solubility tests, image processing techniques, rapid immunoassays, and sensor-based platforms, most of which have tended to be simple low cost approaches to the detection of the SCD (Arishi et al., 2020, WHO Africa, 2010).
Equipped clinical laboratories are critical for the detection of hemoglobin S and diagnosis of SCD. Within such laboratories, biochemical and molecular tests are carried-out to detect and to confirm presence of hemoglobin S and related SCD. The most popular methods for detecting these disease is the full count of blood cells, Hb electrophoresis and high-performance liquid chromatography (Arishi et al., 2020; WHO Africa, 2010).

2.3.4 Treatment and Management of Sickle Cell Disease

Most of the manifestations of SCD are readily amenable to treatment and sound management. Reports indicate that up to 70% of the mortalities in SCD are preventable (DeBaun et al., 2020; Wastnedge et al., 2018; Makani et al., 2011; WHO Africa, 2010). The reports indicate that Hydroxycarbamide (Hydroxyurea) has been used to manage SCD largely to reduce pain episodes. In addition, Penicillin V prophylaxis has been advocated as a preventive measure against severe pneumococcal infections in children with sickle cell anemia. Envisaged treatment has potential to generate positive outcomes subject to management consisting of 1) early or newborn screening (NBS), 2) early treatment and prevention of secondary risks including infections and likely damages of essential organs, 3) training of medical and paramedical personnel, 4) education and building resilience for the parents and the caregivers.

In 2006, SCD was recognized as a global health problem by the World Health Organization (WHO) through the World Health Assembly (WHA 2006) and recommended early identification (screening) and implementation of comprehensive healthcare management (CHCM). More specifically, resolution 59.20 of WHA 2006 urged African nations with high burdens of SCD to design and implement national policies on SCD with a focus on four (4) key components; namely 1) early detection through newborn screening (NBS), 2) early treatment and prevention of secondary risks including infections and likely damages of essential organs, 3) training of medical and para-medical personnel, and 4)
education and building resilience of the parents and caregivers. In addition, it has been demonstrated that comprehensive treatment and management have reduced significantly morbidities and mortalities related to SCD (Vichinsky, 1991; Rahimy et al., 2003). The Recommended treatment and management model may be summarized as follows:

![Components of Comprehensive Care Model](image)

Figure 2.1: Components of Comprehensive Model

However, the management of SCD has been characterized by increased vulnerabilities to PLWSCD, parents and caregivers. Most countries have inadequate national health policies and plans, scarce facilities, diagnostic tools, treatment services and trained personnel. There is hence a need for urgent interventions to address this public health problem (WHO Africa, 2010).

2.3.5 Inadequate Treatment and Management

I have indicated above that by 2018, a greater proportion of the burden of SCD was in SSA where 60 – 80% of the newborns with SCD die before adulthood alongside impoverishment of the parents and the caregivers (Odame & Jain, 2020; DeBaun et al., 2020, Wastnedge et al, 2018; Makani et al., 2011). Available reports indicate that 94% of
PLWSCD in High Income Countries (HIC) are expected to survive to adulthood compared to around 40% in SSA. The wide disparity has been associated with inadequate or negligible implementation of WHO based care of the SCD patients; particularly in respect to early detection through NBS, early and timely treatment including Penicillin-V prophylaxis, pneumococcal vaccinations, training of medical personnel and paramedical personnel, education and social protection for the parents and the caregivers.

Available reports indicate that majority of PLWSCD, particularly those from vulnerable socio-economic backgrounds have not had adequate assess to 1) early detection or newborn screening (NBS), 2) early treatment and prevention of secondary risks including infections and likely damages of essential organs, 3) adequately trained medical and para-medical personnel and 4) education and building resilience for the parents and caregivers (Madani et al., 2017, Amendah et al., 2013, Adegoke & Kuteyi, 2012; WHO Africa, 2010). These studies emphasized the need to give greater attention to the vulnerable segments of the population, particularly children under five years, adolescents and pregnant women. In addition, inadequate treatment and management has been associated with 1) limited or severely inadequate facilities for accurate diagnosis, 2) limited medical and paramedical personnel, and socioeconomic implications to the affected persons, families, communities and the nation (Wastnedge et al., 2018; Madani et al., 2017; Sharp & Spiegel, 2011, 1985).

The experience of Jamaica indicates that even before interventions such as penicillin-V and pneumococcal vaccine became recognized or available, identification of SCD resulted in substantial decline in childhood mortality and increase in the number of individuals with SCD requiring care (Grosse et al., 2011). Many African countries such as Benin, Ghana, Cameroon, DRC, Tanzania and Nigeria have established SCD centres (Rahimy et al., 2003, Makani et al., 2011). Although the SCD birth prevalence in Tanzania
stood at 6 per 1000, Tanzania strategically integrates SCD into the NCD programme for purposes of optimizing resources (GOT, 2009). The estimated annual cost for care is more than US$ 1000 per patient (WHO Africa, 2010). The annual economic cost per PLWSCD for outpatient care attending a SCD clinic in Kenya was estimated at USD 138 in 2010 with a range of USD 94 to USD 229 in Kilifi, a rural area of a LMIC (Amendah et al., 2013; Marsh et al., 2011).

In SSA, the SCD burden is confounded by inadequate health services, poor nutrition and infectious co-morbidities like malaria, tuberculosis and Human Immunodeficiency Virus (HIV) (Mburu & Odame, 2019; DeBaun & Galadanci, 2019; Makani et al., 2011). This is because of limited resources in settings where majority of patients continue to be born. PLWSCD therefore continue to die in childhood usually undiagnosed due to insufficient programs to detect and treat SCD (Chakravorty & Williams, 2015). In Kenya, SCD is a widespread hereditary problem at a national level but resources to address it are limited (Aluoch, J. R. & Aluoch, 1993). At the time of the study, although the constitution promised access to healthcare to all citizens, the government neither recognized nor planned for SCD. Lack of a SCD policy exacerbated caregiver vulnerability as caregivers operated in an environment without relevant support, information and tools.

2.4 The Psychosocial Economic Vulnerability

In this section, we review the link between the involuntary family caregiving and the psychosocial-economic vulnerability; i.e. risk (likelihood or possibility) of eroding psychosocial-economic wellbeing of the IFCGs. Studies have reported that caregiving has all the features of an experience of a chronic stress, social deprivation and erosion of the socio-economic endowment (Kumagai, 2017; Sallim et al., 2015; Pottie et al., 2014; Borbon 2014; WHO, 2012; Schulz & Sherwood, 2018). It has also been considered in terms of IFCG burnout or burden.
The challenges experienced by the caregivers have been designated collectively as the burden of the caregivers; covering key dimensions such as the mental, emotional, physical, social and economic challenges (Muller-Kluits & Slabbert, 2018; Irfan et al., 2017; Reinhard, 2015; Carmagnani and Ferreira, 2007). While caregiving continues to be an important and essential service, it has also been characterized by the burden of the disability. The more severe the disability, the greater the dependency and the burden. Responsibilities of the caregivers may vary in respect to severity of the disability, duration of the exposure, intensity, dependency and the quality of the services (Reinhard et al., 2015). Accordingly, caregivers have been characterized by a potential of increased risk (vulnerability) of psychosocial economic well-being (Reinhard et al., 2015). Caregivers experience psychological, social and economic strain with little opportunity for adaption and potential to generate secondary stressors in multiple life domains (Schulz et al., 2017; Irfan et al., 2017; Reinhard et al., 2015; De Vivo and Fine, 1985).

2.4.1 Vulnerability of IFCGs to Mental and Physical Health Outcomes

Studies have reported that the extended and intense role of IFCG creates physical and psychological strain, accompanied by high levels of unpredictability (Schulz & Eden, 2016; Borbon, 2014; Schulz & Sherwood, 2018). Studies have reported that caregiving fits the formula for chronic stress so well that it is used as a model for studying the health effects of chronic stress. These studies reported that IFCG of chronic disabilities such as paralysis, dementia and SCD has been associated with negative mental health outcomes including loss of self-identity, lower levels of self-esteem, constant worry, or feelings of uncertainty.

IFCGS are usually exposed to intense pressure accompanied by the risk of developing psychological problems; which in turn affect their ability to take care of the patients (Adegoke & Kuteyi, 2012). A study of the quality of life of caregivers of SCD patients in Brazil revealed that 13.5% reported having emotional problems (Da Silva et al., 2012).
study in the USA on needs assessment of 34 caregivers of HIV and critically ill reported that caregivers experienced frustration, social isolation, stress from duties, longing to return to normalcy, depression over opportunities lost, lowered life satisfaction, disillusionment over lack of understanding by the non-caregivers, anger, psychological distress, emotional exhaustion, stigma, fear of contagion and uncertainty about the direction of the disease (Alspach, 2009; Theis et al., 1997).

Bearing in mind the key role in the patient’s life, it is vital that the caregivers maintain their well-being and lead a healthy lifestyle procuring health care and guidance, so that they are able to provide proper care to the family member in need (Costa et al., 2016). In this context, the Health-Related Quality of Life (HRQL) is fundamental regarding the context of health status or variation of the impact caused by a disease on an individual’s life, according to one’s perception (Costa et al., 2016). The HRQL of IFCGs is presented as compromised in almost all domains and caregivers of patients with higher degree of disability obtained lower scores in mental health.

2.4.1.1 Stress in Caregiver

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published by the American Psychiatric Association (APA), acute stress disorder is the development of definite fear behaviors that last from three days to one month following a traumatic event. The symptoms always arise after the patient witnesses or experiences sexual assault, physical attack, physical abuse, active combat, a natural disaster, serious injury, death or threat of death. The acute stress disorder can result from hearing about the violent or accidental trauma of a loved one, or repeated exposure to traumatic events (APA, 2017).

Symptoms of acute stress disorder may include general sleep disturbances, intrusive thoughts or memories of the traumatic event, flash backs or distressing dreams about the
trauma. Conversely, one may “block out” and be unable to remember the event or parts of it. Patients may experience negative moods of depression, anxiety, anger, guilt or inability to be happy. If the patient has unrealistic feelings or beliefs about the event like the event could have been avoidable, they become hyper vigilant, have problems with concentration and exaggerated startle response. Physical symptoms, such as headaches, dizziness and sensitivity to light or sound may occur, even without injury (APA, 2017).

The sickle cell strategy for Africa revealed that caregivers of SCD experienced stress out of fear of recurrence of painful vaso occlusive crisis or fear of early death (WHO Africa, 2010). A cross-sectional sociological survey on the psychosocial burden of SCD on Parents in Cameroon evaluated general perceptions of stress and reported five main stressors like clinical severity, hospital, financial, family and SCD-child factors. The study revealed that chronicity of SCD might impair the quality of life of caregivers; that unemployment affected all the stressors’ categories; that stressors scores went up with parents who were female, single, with low education level as well as with the more children with SCD in a household (Wonkam et al., 2014).

A longitudinal study of 642 caregivers of HIV patients in the US measuring how capable they felt as a caregivers revealed that Caregivers experience two types of stress: Primary/proximal stress caused by feelings of overload, being caged, guilt and incompetence, loss prior to death and Secondary/distal stress including stress proliferation and stigma that extend to caregivers (Mullan, 1998; Rose & Clark-alexander, 1998). In the studies above, Stress in SCD caregivers was triggered by the chronicity of the SCD and tended to intensify in females who were unmarried with low education levels. The studies on stress in caregivers had focus on other illnesses and were also not done in Kenya. This study sought to establish if IFCGs in Nairobi experienced stress and the factors that provoked the stress in IFCGs of PLWSCD.
2.4.1.2 Depressive Disorder Symptoms in Caregivers (DDS)

Studies have demonstrated that depressive disorders have been common among IFCGS as the outcome of the erratic occurrence of symptoms and resultant social and economic implications. IFCGS of PLWSCD are likely to manifest depressive disorders because they have been involved in the daily management of preventive behaviors, treatment and pain most especially during the vaso-occlusive crises. Caregivers of people with conditions such as Alzheimer’s in the US and of SCD in UK could get sick from stress and get hospitalized for depression (Anie 2005; Center 2008). A cross-sectional descriptive survey of 114 caregivers in Gachie, Kenya to determine the threat of depression in caregivers of children with intellectual disability indicated that 79% of caregivers had a risk of mild, moderate and severe clinical depression (Mbugua et al., 2011).

In the DSM-5, depressive symptoms include subjective feelings of sadness, irritability, emptiness, markedly diminished interest or pleasure in almost all activities, anger, significant weight loss or weight gain due to change in feeding habits, insomnia or hypersomnia, weariness, feelings of worthlessness or excessive or incongruous guilt and lack of concentration or indecisiveness. The above symptoms lead to impairment in social, occupational and other important areas of functioning (APA, 2017). Moreover, primary caregivers who often report a lack of support from family and friends during the painful crises experience feelings of hopelessness, helplessness and frustration (Welkom, 2012).

A grounded theory approach used to evaluate chronic sorrow in caregivers revealed that caregivers pass through three overlapping stages: They learn about the illness, incorporate it in their daily lives, experience sorrow and do what it takes to move on. Diagnosis triggers initial feelings, including sorrow but as time passes; other triggers also begin to arouse sorrow that in the long run becomes chronic (Northington, 2000). Hope for normalcy fades with daily nursing care required and high levels of stress (Alspach, 2009).
In Mississippi and Nigeria chronic sorrow was described in caregivers of adult populations with Cancer, Multiple sclerosis, Parkinson’s, Infertile couples, mentally disturbed husbands and HIV. Chronic sorrow was also seen in caregivers of developmental disabilities like mental retardation, Spina bifida, premature infants, physical and mental disabilities, Schizophrenia, bipolar disorders and neural tube defects (Northington, 2000). Depressive disorders in caregivers are an outcome of the erratic occurrence of symptoms and resultant social and economic implications. Since the caregivers of SCD patients are involved in the daily management of preventive behaviors, treatment and pain most especially during the vaso-occlusive crises, they are likely to manifest depressive disorders.

A study on gender differences in social support received by informal caregivers in Spain indicated that a ratio of 35:20% of women to men felt depressed (Rodríguez-Madrid et al., 2019). Caregivers of people with conditions like Alzheimer’s in the US and those of SCD in UK could get sick from stress and be hospitalized for depression (Anie, 2005; Center, 2008). An integrative review to identify families with SCD in Brazil found that the stress of disease management has ramifications on family dynamics ‘family bonds, social interactions in which family influence that is more structured and hierarchical roles’ and may precipitate depression in parents (Gesteira et al., 2016).

An examination of patterns of caregiving and associated psychological impact of maternal caregivers of children with SCD in San Francisco revealed that caregivers of children with SCD had considerably higher depressive mood scores than those caregivers of healthy children (Moskowitz et al., 2007). Most studies reviewed on depressive disorders were not done in Kenya and the focus of was not SCD. The only study reviewed on DDS among caregivers in Kenya focused on children with intellectual disability while this study focuses on SCD.
2.4.1.3 Generalized Anxiety Disorder Symptoms (GADs)

According to DSM-5, Generalized Anxiety Disorder Symptoms (GADs) include excessive anxiety and worry, apprehension which makes it difficult for the individual to control the worry. The worry or fear leads to irritability, restlessness or feeling keyed up or on edge, fatigue, difficulty concentrating or mind going blank, sleep disturbances and clinically significant distress or impairment in social, occupational, or other important areas of functioning (APA, 2017). In a survey on psychosocial burden of SCD on parents in Cameroon, mothers expressed constant fear of premature death, having more children with SCD, infections, erratic crises, hospitalizations and bills (Wonkam et al., 2014). Similarly, in a study in Kilifi, Kenya on gendered experiences of stigma in families, one caregiver indicated that when her child with SCD leaves for school, she does not leave the house or go far until he comes back for fear that the son might get a crisis while she is away (Marsh et al., 2011). Moreover, these caregivers stressed the disruption in developmental milestones that contribute to feelings of uncertainty (Welkom, 2012).

The psychosocial effects of caring for children with SCD can be ignited by guilt at having gestated a sick child. The risk of conceiving another child with SCD may also have a negative effect on the mood of these mothers (Gesteira et al., 2016). An electronic review of published works in the United Kingdom to establish the psychological complications SCD revealed that mental disabilities and behavior change in SCD result from major strokes in babies or hemorrhages in adults (Anie, 2005). These complications traumatize caregivers leading to reduced quality of life, anxiety, depression; cognitive impairment, high stress levels, overprotection, excessive feelings of responsibility and guilt (Anie, 2005). Persistent SCD post discharge pains limit ones functional capabilities and traumatize caregivers as revealed by a prospective cohort study in the US on post discharge pain after a painful vaso-occlusive crisis (Brandow et al., 2009). In Netherlands, Cameroon...
and Nigeria, parents to SCD children have been reported to have worse Health Related Quality of Life (HRQL) (Wonkam et al., 2014; Brown et al., 2010). Fathers being trivially involved in Canada aggravated mothers’ challenges in an environment where children need 24 hour supervision (Burnes et al., 2008). The studies above reveal that caregivers endure a lifetime of anxiety disorders for varying reasons being physical, sociocultural, environmental and psychological as well as the nature of the illness. This study sought to highlight GAD symptoms exhibited by IFCGs of PLWSCD in Nairobi and related triggers under the psychological vulnerability.

2.4.1.4 Vulnerability of SCD Women Caregivers to Physical Challenges

Studies have established that caregiving has negative physical health effects. The factors that control these effects include the level of dependency, the type and intensity of care needed. Unlike non-caregivers, IFCGs have worse health-related quality of life, greater physical and mental health problems and less healthy life habits. These challenges vary from individual to individual but the physical and mental health deterioration are greatest in women, older caregivers, caregivers from a low socio-economic backgrounds, caregivers of poor previous health and caregivers with little social support (Rodríguez-Madrid et al., 2019). Caregiving of a SCD patient has been associated with daily restructuring of routine activities, reduced economic status, change in the family life, anxiety, fatigue, depression, fear and awareness of the possibility of death; which removes any control of the health status (Da Silva et al., 2012).

There were 27% of the caregivers reported having physical problems (Da Silva et al., 2012). In this study, 37.8% of caregivers had been primary caregivers as an occupation for 2 - 10 years and 10.8% for over 30 years. The longer the duration of care, the worse the quality of life of caregivers and the caregivers burden scale scores indicator showed that caregivers with a greater burden had a worse quality of life (Da Silva et al., 2012). A ratio
of 40:24% women to men caregivers reported impaired health. Women caregivers also experienced greater mental illness and worse self-perceived health (Rodríguez-Madrid et al., 2019).

A Descriptive needs assessment survey of 34 caregivers of HIV and critically ill in the US to establish caregivers perceived needs revealed that caregivers experience declining physical health ‘fatigue, weight loss, change of physic etc’, higher mortality, sleep disturbances, development of chronic conditions themselves, chronic fatigue and diminished work performance (Alspach, 2009; Theis et al., 1997). A guide for seniors and their caregivers in in Detroit indicated that, some caregivers stop exercising and develop unhealthy eating habits that lead to hypertension, heart disease, migraines and low immunity (Frey, 2009). From the reviews above, caregiving sometimes affects the caregiver’s physical and clinical health as well as the ability or function properly reducing their perceived quality of life. Most studies were done on caregivers of other illnesses or of the aged persons in the developed nations where people are more individualistic and employing helpers is very costly. This study sought to establish how SCD IFCGs’ physical health in Kenya is affected by challenges induced by their caregiving positions.

2.4.2 Vulnerability of IFCGs to Social Deprivation

Similarly, extended and intense IFCG has been associated with the likelihood of reduced capacity (deficiency) to address basic needs and rights and/or to address unequal access to basic needs and rights. In other words, extended and intense IFCG induces inability to address culturally accepted and encouraged rights and obligations including interaction, stability of the family association, standards of education, standard of work and productivity among others (WHO, 2012; Walker & Pettigrew, 2011).

Severe and chronic diseases have been associated with extended IFCG and social deprivation of the IFCGS; i.e. forfeiting socio-economic endeavors, socio-economic
opportunities and lose of socio-economic assets (Maresova et al., 2019; Piran et al., 2017; Golics et al., 2013). The psychosocial perspective on the IFCGS incorporates personal, family and sociocultural factors associated with adjustment, and adaptation to the chronic disease and caregiving. A study on the quality of life of SCD caregivers in Saudi Arabia indicated that the average time spent at home for the caregivers was $20.4 \pm 3.3$ hours per day and 34.4% were concerned about not finding enough time for themselves (Madani et al., 2018).

### 2.4.2.1 Support in Caring for the Child

Caregiving appears to be involving as illustrated by these studies. In a descriptive survey in the US, caregivers of the critically ill, HIV and Alzheimer’s rated caregiving as a difficult 24 hour job requiring long term commitment that could expand and take over much of one's life with a substantial toll on the caregiver that required re-organizing activities in one’s life (Center, 2008; Mullan, 1998). The SCD burden related to suddenness of the diagnosis, severity and changes in the affected person (Alspach, 2009). A study in Memphis on communication in families with SCD concluded that relatives who witnessed a crisis appreciated SCD more and respected parent’s concerns (Graff et al., 2010). A qualitative study of SCD at the Intersection of race, gender, and stigma in Canada using long interview method of 8 mothers revealed that fathers distanced themselves from children's pain making women to impulsively take on most caregiving duties. These women portrayed stressful routines consumed by the child's illness and neglected their own wellbeing (Burnes et al., 2008).

Reports have shown that IFCGs especially women had little or no support from their spouses (Karadağ et al., 2018). A study of quality of life of SCD caregivers showed that the most supportive people were partners 73% of cases, followed by children 38.1%; and then grandparents in 25.4% of the cases. Social support is one of the main predictors of
caregiver health and it is mostly important for relieving the burden as it gives caregivers a greater sense of control over their lives (Rodríguez-Madrid et al., 2019). There are 65% of caregivers who reported having undergone difficult trials during their life such that 35% needed support to overcome it while only 21% received a financial support (Madani et al., 2018).

A study on gender differences in social support received by informal SCD caregivers in Spain revealed that women sought less help than men and relied more on support from relatives than from formal support systems or paid help. They therefore got help from other women of similar profiles as theirs. Men's networks on the other hand were broader and more diverse enabling them to get more help from outside family circles confirming the need to develop strategies that do not reinforce traditional gender roles and encourage a greater sharing of responsibility (Rodríguez-Madrid et al., 2019). In Nigeria, an interview on culture relevant disease revealed that caregivers could not get excited about future events due to the volatility of crises and generally faced enormous financial, interpersonal and psychological problems (Adegoke & Kuteyi, 2012).

### 2.4.2.2 Stigma and Social Isolation

According to the DSM-5, stigma is occasioned by lack of information on the condition, denial or refusal of acceptance that the disease exists (APA, 2017). A longitudinal survey of 8 Canadian mothers of Caribbean and African decent through gender and racial oppression to understand the experience of raising a child with SCD revealed that stigma came from uneducated views. Fathers resisted negative events in children’s life while mothers experienced a culture of silence surrounding SCD or got blamed for knowingly bearing a sick child. Stigma worked with racism to create social isolation (Burnes et al., 2008). In UK SCD stigma affected African women and black people from other races (Gallo et al., 2010). Non-directive, focus group discussions led by patients
focusing on how SCD affects life revealed that association with black or minority groups increased stigma because the population in UK is predominantly white (Thomas & Taylor, 2002). The Igbo in Nigeria saw children with SCD as malign and some relatives stayed away to avoid being stigmatized alongside. Stigma affected the psychological, financial and social status of victims, caregivers and their families (Adegoke & Kuteyi, 2012). A qualitative study on gendered experiences of stigma in 13 families with SCD using in-depth interviews in Kilifi, Kenya revealed that mothers were blamed for misaligned paternity leading non-support by their husbands who distanced themselves from the SCD.

SCD is often confused with HIV or other infectious afflictions. The above study in Kilifi, revealed that in patrilineal societies where power is mainly ascribed to the male gender, the rate of stigma on SCD women caregivers’ increases rendering them helplessness. The only options available to mothers of PLWSCD were to protect their livelihoods and that of their children (Marsh et al., 2011). This relates to their roles in the family structure and the impact of poverty on mothers’ resilience in meeting extra childcare costs and responsibilities (Marsh et al., 2011). Lack of information and insufficient attention in hospitals led the Giriama to interpret SCD as normal with clarifications drawn from bio-medical traditions and seen as a form of Malaria, supernatural, ancestral curses, spirits or devils. Additionally, the father’s tendency to deny of paternity was very high thus blaming SCD squarely on their wives (Marsh et al., 2011). There is a void in literature on illness stigma associated with SCD. Stigma strengthens and breeds existing inequalities (Burnes et al., 2008). Caregivers of SCD children experience stigma ranging from self-perception of the disease, relatives, the community and cultural beliefs, practices and attitudes.

From the above studies, some features that make caregiving tough and heavy necessitating social support systems are consistent across different illnesses but may differ
in relation to other determinants like contexts, making the results not applicable to the Kenyan setting. For instance, results from developed countries with CHCM and social welfare systems vise vies developing countries. The study sought to find out experiences of IFCGs of PLWSCD in Nairobi owing to differing socio-cultural and socio-economic contexts as well as differing SCD haplotypes. To learn how caregivers interpreted SCD, if they experienced stigma and what triggered and strengthened it and relate it to what happens in other cultures.

2.4.2.3 Severity and Dependency Relation Theory

Severity and dependency relation refers to the degree of the severity of the disability (disease) and related caregiving, as well as the degree of the dependency of the patient on the caregiver. The more severe the disability, the greater the dependency on the caregiver and the greater the vulnerability of negative impact to psychosocial-economic wellbeing to the caregiver. The more intense the needs of the patient, the more intense the dependence and therefore the burden to the caregiver (Kavuran & Turkoglu, 2018; Garre-Olmo et al, 2016; Cantar, 1983). Accordingly, a wide range of studies have used the nature of the patient-caregiving dependence to assess the nature of the burden to the caregivers.

2.4.3 Vulnerability of IFCGs to Eroded Socio-Economic Wellbeing

Caregiving saves families and governments a lot of money (Frey, 2009). Caregiving services in the US were worth $470 billion annually in 2013 (Hounsell et al., 2019). This is the opportunity cost by people who give up Income Generating Activities (IGAs) to give care involuntarily. In 2013, the National Alliance of Caregiving in the US estimated that 65.7 million Americans forming 29% of the adult population were informal caregivers of an ill or disabled relative, involving 31% households (Hounsell et al., 2019).

Women and men’s roles are different and are based on cultural practices that have been there for ages. In line with the Harvard Analytical Framework, in a family setting,
women are expected to perform reproductive roles that are repeated on a daily basis like preparing food, childcare, health care, fetching water and fuel, repair works, cleaning, and occasionally selling things in the market. Most of these socio-economic activities are neither quantified nor remunerated at a household level. Men on the other hand spend time doing productive activities like Agriculture which is usually mechanized, employment and other IGAs that are remunerated giving them an upper hand as they end up having control of family resources.

While reproductive roles are done on a day to day basis, productive roles are only done seasonally leaving men with much more time than women who are bogged down by drudgery. This already creates a disadvantage for women even before the caregiving of sickle cell comes in. The men also tend to have an upper hand when it comes to accessing and controlling resources like land, equipment, and capital. The Harvard Analytical Framework also highlights community roles in which women caregiver’s participation is limited by her caregiving responsibilities shrinking her social capital. Other factors that influence gender differences are societal norms, social hierarchies, training, education, political, economic and cultural factors (Berg, 2020).

SCD is characterized by erratic painful events that sometimes force caregivers to leave work to support the sick in pain interfering with their opportunities to make the much needed money. One study in Saudi Arabia revealed that only 21% of SCD women caregivers received financial support. Notable financial and emotional burdens on these caregivers affected various aspects of their quality of life and their levels of social and professional achievement with the financial situation, free time activity and life environment being rated the lowest satisfaction scores (Madani et al., 2018). Given its prevalence, the SCD burden in Africa has increased and led to major public health and socio-economic implications (WHO Africa, 2010). From the evidence above, if women’s
work was quantified and properly remunerated, they would be more empowered financially than their male counterparts owing to the number of hours spent daily performing these reproductive roles. This study looked for the IFCGs financial vulnerability occasioned by their caregiving positions given that their caregiving work as a reproductive role at the time of the study remained unquantified and unremunerated.

2.4.3.1 Expenditure Levels

In Canada, insurance plans refused to cover prescribed medication for SCD forcing parents to pay cash and increasing family expenses (Burnes et al., 2008). Lack of insurance makes caregivers lose income, benefits or take out loans to care for the sick (Adegoke & Kuteyi, 2012). In Kenya, only a small population has insurance cover from commercial health insurance companies. The National Health Insurance Fund (NHIF) covers only 20-35% of the population. The rest can’t qualify for traditional insurance (Anangwe, 2008). Financial stress was positively linked to two or more hospitalizations in studies done in Nigeria and Cameroon as caregivers were faced with huge bills (Adegoke & Kuteyi, 2012; Wonkam et al., 2014). The median cost of care expenses in Saudi Arabia ranged from USD 12.8–384.6 per child per month; with an average of 102.5 USD per child per month (Madani et al., 2018). In DRC, estimated annual budget for care per patient in hospital was more than US$ 1,000 (Tshilolo et al., 2009). In Nigeria funding SCD treatment was a challenge to many households because of high cost of drugs and foods (Muoghalu, 2016).

The study in Kilifi, Kenya revealed that SCD patients required high level of care, increased costs of running homes and treatment (Marsh et al., 2011; Amendah et al., 2013). It is evident that SCD requires substantial finances to keep up with bills and maintenance of the patients at home yet most patients do not have an insurance cover due to unreasonable exclusions in available insurance policies rendering the policies useless to patients. Caregivers are therefore forced to pay cash which impacts negatively on family finances.
Resources diverted to SCD lead to sickness–poverty traps (Adegoke & Kuteyi, 2012). This study compared the expenditure on SCD in Nairobi to those in other LMCs and to expenditures in Kilifi. It also presented data on experiences of IFCGs with insurance companies.

2.4.3.2 Income Levels

Lingering post discharge crisis pains interferes with the caregiver’s ability to work or attend school (Brandow et al., 2009; Panepinto et al., 2009). One study in Brazil revealed that of the 37 caregivers in that study, 81.1% were women, 73% were mothers, 59.5% were married, 54.1% were mulattos, 48.6% were housewives, 54.1% had family incomes of up to one minimum wage and 75.7% had only completed elementary education. The mean duration of care provided was 16.08 ± 9.88 years and 89.2% reported that they provided 24-hour care (Da Silva et al., 2012). This means they were not able to work to earn a living at all. Women struggle to keep jobs; balance work, childcare with other duties as unpredictability of crises increase the chances of rushing away from work always pending leading to feelings of being out of control. Very few employers are supportive (Graff et al., 2010). Financial implications of handling critically ill patients in the US include reduced work hours and wages; reduced pay, benefits, profits, retirement income; out of pocket expenses, financial strain, benefit loses, and unpaid leave. This occurs due to arriving to work late, taking leave of absence, switching to part-time work, giving up work, losing work benefits and turning down promotions (Alspach, 2009; Frey, 2009).

In India, terminal illnesses let some caregivers to make harmful decisions like taking hazardous jobs or resort to illegal activities (Emanuel et al., 2010). In Kilifi - Kenya, mothers had difficulty setting up or maintaining IGAs hence losing income (Marsh et al., 2011). Work cultures in various settings predispose women to be treated differently at work like being paid less for the same job done by a man or being segregated due to their reproductive
role pressures at home. Inability to work in Kenya may also not have similar consequences like in places with social welfare systems. This study sought to establish how SCD caregiver’s income level is affected by caregiving responsibilities and factors contributing to the implications on the affected income.

2.4.3.3 Ability to Work

A survey on 252 households in Chile to highlight costs of health care at home and how it affects women’s work revealed that health related caregiving tasks at home are done mostly by women through their lives as adolescents and as adults regardless of economic or social status. That while upper income groups may hire help at home to allow them to work, low and middle income earners have to take on caregiving duties and paid work themselves (Mauro et al., 2006). A prospective cohort study in the US on post discharge pain indicated that SCD caregiver’s most likely had jobs without sick leave or flexible work hours making caregiving a barrier to employment and that multiple absences from work sometimes led to job losses (Brandow et al., 2009). Another US study on lifting the burden of women’s care work highlighted the cultural socialization that in most societies it is a woman’s role to care for the sick for free or minimal remunerations as aides and personal attendants. Thus, dependency work impacts their status as equal citizens when burdens are unequally shouldered (Parks, 2010). A survey on the psychosocial burden of SCD on parents in Cameroon revealed that unemployment affects all the stress categories. These are fear of admissions, of crises at the wrong time, of having another child with SCD, of infections in the child and hospital bills (Wonkam et al., 2014).

Studies show that in spite of various efforts undertaken like enactment of gender-based laws and policies, gender differences persist in various dimensions of industrial occupations both in Kenya and other parts of the world. Women representation in wage employment remains very low forming less than 30% of wage employment in Kenya.
Muchangi, 2014). This is a gender bias affecting women economically even before they become caregivers. In Kenya, caring for children is a woman’s gender role (Marsh et al., 2011; Muchangi, 2014). Expecting women to be the ones giving up opportunities to care for the sick, weak or old in the homestead without remuneration as seems to be custom in many nationalities is also a gender bias. Where the child develops frequent complications, the women have been forced to give up their productive engagements. They are left executing mostly reproductive roles rendering them completely dependent of the man who controls over family resources. This study sought to establish if SCD IFCGs in Kenya have been unable to work or engage in IGA’s due to caregiving positions.

2.4.4 The Psychosocial Economic Resilience

We have indicated that psychosocial-economic resilience refers to ability of the IFCGs to withstand, recover from and/or to transform vulnerabilities (shocks or risks) related to mental deficiencies, social deprivations, socio-economic wellbeing (endowment). In other words, psychosocial-economic resilience refers to resilience that would address mental health and capacity; social deprivation resilience (SDR) to address capacity or minimize (offset) the likely social deprivation, and the socio-economic resilience to address capacity to minimize (offset) erosion (depletion) of the socio-economic assets including education, occupation or employment, income or financial loses (Joling et al 2016; Su et al 2010). The theory of resilience in caregiving refers to the capacity of the caregivers to overcome challenges and risks; including those related to diseases and caregiving, ranging from mental stress to socio-economic aspects. It also refers to building resilience in respect to treatment and counselling of the IFCGs, and providing support in form of the social protection of the IFCGs
Resilience is the ability, power, strength and capacity to transcend adversity positively to resume the original shape or position. It is the capacity to adapt successfully in adversity and ability to bounce back after encountering the difficulties, negative events or tough times. Caregivers must therefore not only bounce back, but must bounce forward too, transcend difficulties, reintegrate into society and move on with life in a positive way (Lin et al., 2013). It is a positive outcome despite exposure to adversity or risk and focuses on strengths rather than weaknesses. It is the ability to have high levels of psychological well-being ‘self-esteem and mastery’ despite different types of high caregiving demands. It is the process of negotiating, managing and adapting to significant sources of stress or trauma. Having resources and powers that control stress to enable one achieve positive results and restore life satisfaction, self-esteem and self-respect (Joling et al., 2016; Lin et al., 2013).

A concept analysis of resilience among caregivers of children with chronic conditions in Taipei defined resilience within four main dimensions being, disposition patterns, situational patterns, relational patterns, cultural patterns and sometimes philosophical patterns. A caregiver under severe stress may experience cognitive, social, emotional or instrumental imbalances that disrupt family functioning (Lin et al., 2013). Problem-solving functions within the cognitive construct that enable resilience of the caregiver include intelligence, optimism, creativity, humor and a belief in oneself. The required competencies include coping strategies, social skills, above average memory and educational abilities. The internal strength of beliefs is also a source of resilience (Lin et al., 2013). Resilience addresses the dynamics and development of complex social–ecological systems with three aspects that are central being resilience, adaptability and transformability. These interrelate within multiple scales making use of crises as windows
of opportunity for novelty and innovation, recombining sources of knowledge and experience to navigate social–ecological transitions (Folke et al., 2010).

Caregivers draw on individual resources, but also interact with environment they live in by drawing on communal and societal resources that facilitate or hinder resilience. Resilience is supported by social and cultural factors, psychological characteristics and properties of the caring relationships. The sociodemographic factors that affect resilience in caregivers of dementia include: caregiver’s employment status, age, gender, education level and the patients age and gender. The caregiver’s inner psychological attributes were sense of competence and mastery, copying styles and guilt. The context of care was affected by the quality and type of relationships, the care burden, duration of care and type of dementia. The social and community resources included loneliness, regular help from friends, social support and use of services. Using downward comparisons with others, staying positive, actively seeking knowledge, use of respite care and strong social relationships facilitated their resilience (Joling et al., 2016).

Personal attributes were strongly related to caregivers’ response to major stressors in life and in maintaining external relationships. The key attributes of individual resilience are maturity, empowerment, creativity and sense of belonging. On the other hand, distinctive attributes of caregivers’ resilience are responsiveness to stress, the desire to maintain normal states, self-understanding, the ability to take responsibility for causing trouble, readiness to accept critical situations, patience in attaining goals, being content with things as they are, and remaining adaptable. Resilience is therefore a property, or characteristic, that causes changes in a person’s ability to function according to their own value system when facing major life stressors thus becoming one of the properties of family functioning (Lin et al., 2013). An article on factors of resilience in informal caregivers of dementia in
the Netherlands and UK revealed that the prevalence of resilience varied from 35% to 43% depending on the demands for high care, caring for a female, being a male caregiver, low caregiver burden and living apart from the patient were positively related to caregiver resilience (Joling et al., 2016). Caregivers with resilience in response to major life stressors also had strong individual strength and a positive view of children with chronic conditions and their families (Lin et al., 2013). On the other hand, perceived loss of social relationships, having a negative outlook and feeling isolated hinders resilience. Resilience therefore becomes an important predictor of life satisfaction, change in burden and perceived stress (Joling et al., 2016).

2.5 Women Caregivers Needs

Generally, caregivers face enormous financial, interpersonal and psychological problems (Adegoke & Kuteyi, 2012). HIV Caregivers in Oklahoma however revealed some positive aspects of caregiving being self-satisfaction, increased self-respect and reduced costs of caregiving (Theis et al., 1997). Caregivers of critically ill patients in the US identified the need for general information, emotional support and respite (Alspach, 2009). Lack of research and information on SCD appears to be a global problem as revealed by studies in Canada, Cameroon and Kenya (Burnes et al., 2008; Wonkam et al., 2014; Marsh et al., 2011). In Canada, women desired public awareness to dispel misconceptions and myths about SCD (Burnes et al., 2008). In a survey in Cameroon, affected mothers who were informed the foetus had SCD chose elective medical abortions to stem more births of babies with SCD (Wonkam et al., 2014). Alzheimer’s Caregivers in the US needed to learn symptoms of caregiver stress and the importance of maintaining adequate relationships with doctors to help them manage emotional and social consequences of the illness (Center, 2008). They felt a need to re-model their lives to survive or adapt to unpredictable consequences that cause chronic sorrow (Northington, 2000).
In SCD, more than parent support groups and fathers’ involvement were desired (Slaughter & Dilworth-Anderson, 1988). Most African countries lack basic facilities, diagnostic tools and qualified medical personnel to manage SCD leading to misinformed, misdiagnosed or mismanaged patients with detrimental results (WHO Africa, 2010). There is a general belief that caregiving has only negative implications but one study above although not related to SCD, has revealed that caregiving had some derived benefits for the caregivers. This study sought to establish if there are any positive aspects of SCD caregiving and the caregivers’ needs in Nairobi as described by caregivers themselves owing to the non-existence of a sickle cell policy and budgetary allocations for management of the disease in the country.

2.6 Coping Strategies of Caregivers

The degree to which stressors impact on the caregivers’ life depends, on how she responds, manages or acts to resolve the associated challenges which depends on the caregivers’ coping strategies (Losada-Baltar, 2017). An empirical study of family caregiving and chronic illness like SCD and β Thalassemia in the UK revealed that there were things that make coping a bit easier for caregivers. These included early diagnosis, appropriate information, family dynamics and availability of material and social support (Atkin & Ahmad, 2000). In Tennessee, mothers who learned physical assessment skills, how to navigate medical systems and keep health records for emergencies managed better (Graff et al., 2010). Caregivers in Canada desired to form groups to escalate awareness (Burnes et al., 2008). In Nigeria when appropriate professional support was given, it reduced caregiver frustrations and enabled coping through awareness, psychological and financial support (Brown et al., 2010).

On the other hand, some experiences make coping difficult for the caregiver. For instance, in Canada, doctor’s ignorance was frustrating and SCD caregivers were forced to
play gurus and teach medics (Burnes et al., 2008). This meant that caregivers who did not know about SCD experienced a lot of difficulties. Insurance companies refusing to pay for prescribed drugs precipitated financial stress complicating coping. Consequently, caregivers avoided revealing their child's condition so that the insurance pays. Some fathers’ attitudes undermined the mothers’ ability to cope while pain made coping strategies vulnerable (Burnes et al., 2008). In Nigeria, ineptitude and unsympathetic reactions from medics undermined ability to cope and worsened feelings of isolation, inadequacy and helplessness (Brown et al., 2010).

In Mississippi SCD caregivers coped with chronic sorrow by praying, religion, information seeking, relying on family and friends for support (Northington, 2000). Self-directed online information-seeking is used by highly stressed Caregivers as a way of coping in order to gain a sense of control over the situation (Meyer, Gassoumis, Kelly, & Benton, 2019). Spending a lot of hours giving care per week however reduced the likelihood of seeking health information related to caregiving online (Meyer et al., 2019). HIV caregivers in the US revealed that problem-solving strategies like planning and taking direct action are linked to positive outcomes, but emotion-focused approaches like escapism, discharging emotions, and blaming oneself were linked to poor outcomes (Mullan, 1998). Prayer followed by confrontive approach was used to maintain control. Counseling was emphasized to help caregivers survive emotional turmoil (Rose & Clark-alexander, 1998). A UK study revealed that some caregivers are initially engulfed but later develop a balance while others still lapse back to engulfment mode. Mothers accepted their husbands’ avoidance and took caring as their duty. Some chose a good cry, a shouting match with their partners or chose a network of people to talk to (Atkin & Ahmad, 2000). Life presents people with situations in life. When things get complicated and unbearable, women employ coping mechanisms to survive challenges that come with SCD caregiving
because life must go on. There are no studies on coping of SCD caregivers in Kenya. This study sought to establish strategies IFCGs use cope and what enhanced or undermined their coping with SCD in Nairobi.

2.7 Research Gaps on Involuntary Family Caregiving

The literature has highlighted the need for caregiving among people with some disability including sickle cell disease. The literature has also highlighted the duration and intensity of the caregiving. However, limited attention has been given to psychosocial economic wellbeing in urban areas of low and middle income countries. More specifically limited attention has been given to capacity to diagnose and treat the disease, the capacity to equip and support the caregiver including psychosocial support and socioeconomic support including social safety net.

2.8 Theoretical Framework:

The study was guided by three theoretical perspectives namely the psychosocial-economic vulnerability to address the effects of the IFCG on the mental, social and economic wellbeing, the psychosocial-economic resilience to address the ability of the IFCGs to sustain mental, social and economic wellbeing; and the gender empowerment to address the capacity of the women caregivers (WCGs) to sustain equity in socio-economic life.

Psychosocial-economic vulnerability referred to disability IFCG processes and related shocks that deplete the capacities of the caregivers; and psychosocial-economic resilience referred to abilities of the caregivers to withstand and/or recover from the vulnerabilities (shocks) and even transform to better psychosocial-economic wellbeing. More specifically, vulnerability has typically been used to refer to disability IFCG risk to deplete psychosocial-economic wellbeing and resilience has been used to refer to psychosocial-economic ability of the caregivers to withstand, recover and even transform
into better psychosocial-economic wellbeing (Farla, 202; Kumar, 2017, Thomson & Schmied, 2017; Lacoviello & Charney, 2014; Lechat, 1990). The relation between the two theoretical perspective has usually been summarized as follows

\[
\text{Disease (SCD) Risk} = \frac{\text{Exposure + Vulnerability}}{\text{Resilience Capacity}}
\]

Where the degree of exposure to disability (any disease including SCD) increases vulnerability to deplete psychosocial-economic wellbeing; which may then be mitigated by existing, enhanced or built resilience. In other words, the greater the exposure (in duration, intensity or severity) to the caregiving of increasingly severe disability (any disease including SCD) increases vulnerability which may only be mitigated by existing or enhanced psychosocial-economic resilience.

2.8.1 Dependency Relation Theory

Severity and dependency relation refers to degree of the severity of the disability (disease) and related caregiving, as well as the degree of the dependence of the patient on the caregiver. The more severe the the disability (disease) the greater the dependency on the caregiver and the greater the vulnerability of negative impact to psychosocial-economic wellbeing to the caregiver.

The more intense the needs of the patient, the more intense the dependence and therefore the burden to the caregiver (Kavuran & Turkoglu, 2018; Garre-Olmo et al., 2016; Cantar, 1983). Accordingly, a wide range of studies have used the nature of the patient-caretaking dependence to assess the nature of the burden to the caregivers.

2.8.2 IFCG Psychosocial-Economic Vulnerability

IFCG psychosocial-economic vulnerability encompasses three sub-perspectives: namely IFCG induced psychological vulnerability which addresses the risk (likelihood or possibility) of the caregivers to recede (forced) into negative mental health outcomes; IFCG
induced vulnerability to social deprivation which also addresses the possibility (the likelihood) of the inability of the caregivers to sustain culturally accepted, essential and encouraged rights and obligations including interaction, standard of living and aspirations to improve their wellbeing; and ; IFCG socio-economic vulnerability which addresses possibility (the likelihood) of eroded assets including education, work, productivity, occupation, accumulated assets and income

2.8.2.1 IFCG Psychological vulnerability

The IFCG induced psychological vulnerability refers to the exposure of the caregivers to a person with a disability such as paralysis, dementia and SCD which subsequently induces, (drives) the likelihood of negative mental health outcomes; including likely reduction of the ability to concentrate, excessive worries, anxiety, and slippage to depression among others which in turn would affect behavior and productivity of the person (Nogueira et al., 2017; Kinser & Lyon 2014; WHO, 2012; Dadomo et al., 2011; Sinclair & Wallston, 1999, 2010; Riskind & Alloy 2006; Aday 1994). One of the One of the common example include stress-vulnerability model of depression (Ormel & Neeleman, 2000; Rodgers 1991). Accordingly, it was predicted that SCD would increase psychological vulnerability leading to reduction of the ability to concentrate, excessive worries, anxiety, and varied forms of depression.

2.8.2.2 Vulnerability to Social Deprivation

The IFCG induced vulnerability to social deprivation refers to exposure of the caregivers to a person with a disability such as paralysis, dementia and SCD which subsequently induces (drives) the likelihood of reduced capacity (deficiency) to address basic needs and rights; and/or to address unequal access to basic needs and rights. In other words, exposure of the caregivers to a person with a disability such as paralysis, dementia and SCD have been associated with the inability to maintain culturally accepted and
encouraged rights and obligations including interaction, stability of the family association, standards of education, standard of work and productivity among others (WHO, 2012; Walker & Pettigrew, 2011). In principle, most of the chronic diseases have been associated with increased inability to maintain or to meet basic needs, rights and obligations (Ochola et al., 2020; Soors et al., 2013; Singh & Singh, 2008).

Some of the key indicators include sliding to severe forms of poverty, deprivation to pursue education, occupation and/or employment. Some of the authors have asserted a vicious cycle of a chronic disease, vulnerability to social deprivation and poverty (Sapkota et al., 2020; Ochola et al., 2020; Thorne et al., 2015; WHO, 2014). Diseases of poverty have been considered to be more prevalent in low income countries (LIC) and low-income populations (LIP) and where such diseases include SCD, HIV-Aids, Tuberculosis (TB).

2.8.3 Socio-Economic Vulnerability and Resilience

IFCG socio-economic vulnerability (SEV), refers to risk, possibility or experienced erosion of the socio-economic wellbeing (endowment) related to caregiving to persons with some disability; and the situation becomes more severe with severe disability (disease), intense and extended caregiving. We have indicated that exposure of the caregivers to the patients with SCD will increase the possibility (likelihood) or eroded socio-economic wellbeing that may include loss of productivity, occupation or employment, accumulated socio-economic assets (endowments), and/or income among others. Caregiving consists of both the losses and expenditure to support the patient.

The three sub-theoretical framework of psychosocial-economic vulnerability were consistent with the definition of health by (WHO, 1948) that health was “state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. This fundamental definition has reiterated the need for an integrated theoretical perspective
to diseases; particularly on aspects related to chronic diseases including SCD which consists of the primary patients, caregivers and the parents

In other words, psychosocial-economic resilience refers to mental resilience that would address mental health and capacity; social deprivation resilience (SDR) to address capacity or minimize (offset) the likely social deprivation, and the socio-economic resilience to address capacity or to minimize (offset) erosion (depletion) of the socio-economic assets including education, occupation or employment, income or financial loses (Joling et al 2016; Su et al., 2010). The theory of resilience in caregiving refers to the capacity of the caregivers to overcome challenges and risks; including those related to diseases and caregiving, ranging from mental stress to socio-economic aspects. It also refers to building resilience in respect to treatment and counselling of the IFCGs, and providing support in form of the social protection of the IFCGs

2.8.4 Gender Empowerment Theory

Gender empowerment (GE) theory was used in the study to address ways in which women caregivers have been enabled to develop capacities to main equity in socio-economic life. Gender empowerment (GE) has typically been considered a process to strengthen the capacities of women and girls with a view to gender equity in various domains of social life (Sharma et al., 2016; UN Women 2016, 2011) defined gender empowerment as a process to enable women to acquire or develop ability to make strategic life choices and consisted of three interrelated elements; namely resources, agency, and achievements. In this respect, resources referred to material, human, and social expectations and allocations and agency referred to the ability or sense of ability to prioritize goals, act upon them, and decide on their own strategic life outcomes.
2.9 Theoretical Framework

A theory is a system of ideas intended to explain something. It contains reasoning and logical connections built on one or more hypothesis and based upon evidence. Whereas many theories can be applied and be relevant to this study, some lacked the conclusiveness required in developing a theoretical framework because the perspectives of this study are multiple in nature as the study focused on vulnerability and behaviour of IFCGs.

2.9.1 Severity and Dependency Relation Theory

Severity and dependency relation refers to degree of the severity of the disability (disease) and related caregiving, as well as the degree of the dependence of the patient on the caregiver. The more severe the the disability (disease) the greater the dependency on the caregiver and the greater the vulnerability of negative impact to psychosocial-economic wellbeing to the caregiver. The more intense the needs of the patient, the more intense the dependence and therefore the burden to the caregiver (Kavuran & Turkoglu, 2018; Garre-Olmo et al., 2016; Cantar, 1983). Accordingly, a wide range of studies have used the nature of the patient-caregiving dependence to assess the nature of the burden to the caregivers.

2.9.2 Psychosocial-Economic Resilience

We have indicated that psychosocial-economic resilience refers to ability of the IFCGS to withstand, recover and/or to transform vulnerabilities (shocks, or risks) related to mental deficiencies, social deprivations, socio-economic wellbeing (endowment). In other words, psychosocial-economic resilience refers to mental resilience that would address mental health and capacity; social deprivation resilience (SDR) to address capacity or minimize (offset) the likely social deprivation, and the socio-economic resilience to address capacity or to minimize (offset) erosion (depletion) of the socio-economic assets including education, occupation or employment, income or financial loses (Joling et al., 2016; Diaz, 2015; Su et al., 2010). The theory of resilience in caregiving refers to the
capacity of the caregivers to overcome challenges and risks; including those related to diseases and caregiving, ranging from mental stress to socio-economic aspects. It also refers to building resilience in respect to treatment and counselling of the IFCGs, and providing support in form of the social protection of the IFCGs.

2.9.3 The Gender Empowerment (GE) Theory

The Gender empowerment (GE) theory was used in the study to address ways in which women caregivers have been enabled to develop capacities to maintain equity in socio-economic life. Gender empowerment (GE) has typically been considered a process to strengthen the capacities of women and girls with a view to gender equity in various domains of social life (Sharma et al., 2016; UN Women 2016, 2011; Kabeer, 1999). Gender empowerment is defined as a process that enables women to acquire or develop ability to make strategic life choices and consisted of three interrelated elements; namely resources, agency, and achievements. In this respect, resources referred to material, human, and social expectations. The agency referred (mental capacity of the caregiver) to the ability or sense of ability to prioritize goals, act upon them, and decide on their own strategic life outcomes. The achievement refers to the reduction of the adversity (psychosocial economic vulnerability) of adversity.

2.10 Conceptual Framework

The conceptual framework is an outline of the relation among the key variables in the study; based on the time-causal sequence. Accordingly, in this study, key variables included psychosocial economic wellbeing as the dependent variable; psychosocial economic vulnerability, psychosocial economic resilience and interventions as the intervening variables; and disability (disease), demographics of the patient and the caregiver and socio-economic characteristics as the independent variables. Each with indicators as summarized below.
What triggers IFCGs vulnerability is the discovery of the disease, its severity and the caregiver experience with the disease; caregivers’ demographic and socioeconomic characteristics to SCD is caused by perpetual caregiving responsibilities that overburdened them. Stigma and social isolation occasioned by insufficient knowledge, Poverty caused by inequality of gender roles, inability to work, hospital bills and lack of support in different spheres of the WCGs lives.

The intervening variables include availability of research, information and awareness on SCD; Developing SCD policies and guidelines; supporting WCGs socio-economic capability, social and technical support in various spheres of the woman’s life. These variables if implemented could lessen the burden of SCD on WCGs and contribute to reduction in resultant vulnerability, which might contribute to reduction in gender disparities. If not implemented could aggravate the gender inequalities as well as vulnerabilities.
**INDEPENDENT VARIABLE**

Disease:
1. Discovery, severity of SCD and Experience
2. Demographic Characteristics of the patient and the caregiver (Gender)
3. Socio-Economic Characteristics of the caregiver
4. Support given to Caregivers (Medical, social and financial)

**DEPENDENT VARIABLE**

Psychosocial Economic Outcomes
1. Decreased or Improved HRQL: Experience of Mental Health Outcomes i.e. anxiety, stress, depression (the level of severity)
2. Experience of Social Deprivation i.e. reduced capacity (deficiency) in addressing key aspects of social life (the level of severity)
3. Vulnerability to poverty or Resilience to maintain socio-economic wellbeing. (i.e. Severity of the impoverishment or resilience (expenditure & financial loses).

Indicators included

a) The Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI)

b) The quality of life index,

c) Socio-economic resilience index (SERI)
   (Kuerten et al., 2020; Adzika et al., 2017; Adegoke & Kuteyi, 2012)

**INTERVENING VARIABLES**

1. Social and Technical Support: (Medical, Research, Information) to reduce vulnerability (risk to depleted or negative impact on psychosocial economic wellbeing)
2. Resilience: Build existing capacities to withstand the risk of depletion or negative impact on psychosocial economic wellbeing.
3. Interventions: Policies and guidelines to enhance resilience of IFCGs including social safety net.
4. Gender Empowerment: Special Support to Women Caregivers
CHAPTER THREE
RESEARCH METHODOLOGY

3.0 Introduction

These chapter presents approaches used to assess the characteristics of the caregivers and the households, gender dimension in the family caregiving, the nature of the psychosocial economic vulnerability of the caregivers, coping or adaptive strategies to minimize the psychosocial economic vulnerability of the caregivers, and necessary intervention measures to mitigate the psychosocial economic vulnerability. Approaches included the design and methodology of the study, description of the study site, the study population and the unit of analysis, sample and sampling methods, the validity and reliability of research instruments, the data collection methods, procedures of data analysis and presentation as well as the ethical considerations.

3.1 Research Design

The study adopted a survey design to secure quantitative data and in-depth interviews alongside participant observation to solicit qualitative data. The study used a survey design, basically one-time collection of data from a target population, to solicit both quantitative and qualitative data. The survey design was adopted because it allowed the study to collect data from a relatively large area and reasonably large number of IFCGs at a relatively short-time. The disadvantages of the survey design included the inability to assess historical changes in the nature of SCD, involuntary family caregiving and the involuntary family caregivers (Babbie 2016; Glasow, 2005; Owens, 2002).

3.2 Site of the Study

The study was carried in Nairobi City County; selected purposely as a typical urban center in SSA, East Africa and Kenya. Indeed, Nairobi City County is one of the largest urban centers in Kenya with 4.397 million people and a population density of 6,317.6/km2.
by 2019. According to the World Bank (2019, 2016), Nairobi city was the 9th city in SSA based on the population density and related demographics. In 2019, Nairobi had a human development index of 0.653, a GDP of US$14.9 billion, a poverty rate of 22.5% and a fully immunized population of 86.8% below one year. It had a nurse-patient ratio of 1:2,797 and doctor-patient ratio of 1:23,000 (Kenya County Fact Sheets, 2011).

Whereas urban centres are expected to have reasonable capacity to address chronic disabilities, related family caregiving and vulnerabilities, 60% of the urban population in SSA live in vulnerable settlements (WB, 2019, 2016, Lall et al., 2017). This reflects their limited capacity to address chronic diseases such as paralysis, dementia and SCD. More specifically, the site of study was the Children Sickle Cell Foundation (CSCF) in Nairobi City County; which was also selected purposely as a single point of the large concentration of PLWSCD and their respective IFCGs. The Foundation is run on voluntary basis by patients, IFCGs and doctors. By 2016, the Foundation had 510 PLWSCD registered and their respective IFCGs.

The Foundation has a board and an executive office comprising of the Chair, Vice Chair, a Treasurer and a Secretary. Additional members are usually co-opted to support the Foundation in various capacities. Among the responsibilities of the Foundation include formation of support groups, empowering members through sharing of information and knowledge, awareness, outreach, forums for guests and experts, communication platforms, consultation and treatment, linking patients to information or services and commemoration of World Sickle Cell Days. In addition, the Foundation also engages with the government to develop frameworks to address SCD and related challenges, lobbying for SCD policies and collaborating with organizations targeting SCD. The map of Nairobi is in appendix vii.
3.3 Target Population and Unit of Analysis

The target population of the study was the entire Family Caregivers (FCGs) of PLWSCD registered by the CSCF and living in Nairobi City County in 2016. The unit of analysis was therefore an FCG who were 18 years and above. Accordingly, the FCGs were identified from the register of PLWSCD at the Foundation; where the register had the names of the patients and their caregivers. The study also collected in-depth-qualitative data from selected IFCGs, Key Informants (KI) and the Focus Group Discussions (FGD) for validation and greater insight on the nature of the caregiving, the nature of the SCD in urban centers, the psychosocial economic vulnerability of the caregivers, the characteristics of the caregivers and their households.

In addition to IFCGs as the primary population, the study also collected in-depth-qualitative data from selected IFCGs, Key Informants (KI) and Focus Group Discussions (FGDs) for validation and greater insight on the nature of the caregiving, the nature of the SCD in urban centers, the psychosocial economic vulnerability of the IFCGs, the characteristics of the IFCGs and their HHs.

3.4 The Sample and Sample Size

In addition to the survey design, the study collected both quantitative and qualitative data for the in-depth understanding of the challenges of the family caregivers (Akhtar & Narayan, 2017; Babbie 2013; Bhattacherjee, 2012; Weber, 1949)

3.4.1 Quantitative Sample Data

Quantitative data usually requires a representative sample; a sample that represents the target population a 100% in every aspect (Smith, 2013; Israel 1992; Kalton, 1983). Accordingly, the sample size required ought to (should) increase probability of the representativeness by either 95% or even better by 99% degree of confidence that the sample would be representative. In view of the 510 registered persons living with SCD and
their respective involuntary family caregivers (IFCGs), a sample 226 IFCGs was therefore required to provide valid statistical understanding of the nature of the SCD in urban centers, the psychosocial economic vulnerability of the IFCGs, the characteristics of IFCGs and the households and the coping strategies (Israel, 2003; Cohen, 1977, 1992; Krejcie & Morgan, 1970; Yamane, 1967; Madow, 1968; Penyelidikan, 2006). More specifically, the formula by (Yamane, 1967) was used to determine required sample size given a population of 510 PLWSCD.

\[
n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}
\]

The formula by (Yamane, 1967) has been used to determine the sample sizes for small or finite populations such as those of the CSCF in Nairobi City County in Kenya. In addition, required sample of 226 IFCGs was also determined and verified with the table of 95% confidence by (Krejcie & Morgan, 1970).

### 3.4.2 Qualitative In-depth Data

The requirement for the qualitative data is to have limited typical examples of involuntary family caregivers (IFCGs), not exceeding fifteen (15) to provide insight understanding of the nature of the SCD in urban centers, the psychosocial economic vulnerability of the IFCGs, the characteristics of the caregivers and the households and the coping strategies (Bhandari, 2020; Haradhan, 2018; Miller et al., 2008; Ospina, 2004). Accordingly, the study examined in detail fifteen (15) IFCGS to solicit insight understanding of the nature of the SCD in urban centers, the psychosocial economic vulnerability of the IFCGs, the characteristics of the caregivers and the households and the coping strategies.
3.5 Sampling Approach and Selection of Informants

3.5.1 Quantitative Sampling Approach

For the purpose of the quantitative data and necessary procedure, the register maintained by the CSCF was used to draw the required sample of 226 IFCGs. With the population of 510 persons living with SCD, each with a family caregiver, systematic sampling method was used to draw an individual sample of IFCGs at interval of every two persons until required sample of 226 IFCGs was realized. Systematic sampling method is one of the approaches recommended as part of the procedures to secure a representative sample.

3.5.2 Qualitative Selection of Family Caregivers

For the purpose of the qualitative data and necessary procedure, fifteen (15) typical FCGs were identified for in-depth interviews and insight understanding of the nature of the SCD in urban centers, the psychosocial economic vulnerability of the FCGs, the characteristics of the caregivers and the households and the coping strategies. The key challenge was to be able to identify typical FCGs such as those that had cared for most severe cases of PLWSCD, those that had provided caregiving for longer duration (extended period) and those that had experienced severe psychosocial economic vulnerability.

3.5.3 Key Informants and Focused Group Discussion

In addition, 12 key informants were selected based on their experience with persons living with SCD and the challenges of the family caregivers. The key informants for the study consisted of 1 official from the Ministry of Health, 2 doctors, 2 nurses, 2 representatives of the advocacy agencies, 3 persons living with SCD and 3 family caregivers. The study also identified a panel of 12 members for the focused group discussion (FGD) and which also consisted of 1 official from the Ministry of Health, 2
doctors, 2 nurses, 2 representatives of the advocacy agencies, 3 persons living with SCD and 3 family caregivers.

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involuntary Family Caregivers (IFCGs) i.e. the sample and respondents</td>
<td>226</td>
</tr>
<tr>
<td>Key Informants (information, knowledge and experience)</td>
<td>12</td>
</tr>
<tr>
<td>One FGD with a panel of 12 people (also based on information, knowledge and experience)</td>
<td>12</td>
</tr>
</tbody>
</table>

### 3.6 Research Instruments

In order to solicit quantitative and qualitative data three data collection instruments were used, namely the interview guide which was administered to the primary respondents, interview schedule which was used to solicit qualitative data from the key informants and the guide for the focused group discussion (FGD).

#### 3.6.1 Interview Guide (Questionnaire)

The interview guide (questionnaire) was used to collect data from the primary respondents which included the characteristics of the IFCGs, the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions. The guide incorporated key indicators of the psychosocial economic vulnerability. Accordingly, the psychosocial economic vulnerability was assessed with three components. First the psychological or negative mental health outcomes were assessed with a 3-scale indicator of anxiety which was an adaptation of the Beck Anxiety Inventory (BAI) (Beck et al., 1988); and a 3-scale indicator of depression which was also an adaption of the Beck Depression Inventory (BDI) (Beck et al., 1979). Secondly, reduced capacity (or deficiency) to address basic needs and rights and/or to address unequal access to basic needs and rights as a result of the caregiving to SCD person were assessed with social deprivation, specifically a 3-scale social deprivation index (Suppa et al., 2017; Myck
et al., 2015; Butler, 2013). Thirdly, deterioration in socio-economic wellbeing (SEW) as a result of the caregiving to SCD person was assessed with expenditure and financial losses.

The summary of the indicators for the three components were summarized as follows:

<table>
<thead>
<tr>
<th>Table 3.2: Measurement Scales for the Psychosocial Economic Deprivation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological vulnerability or negative mental health outcome</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Social vulnerability or reduced capacity (deficiency) to address basic needs, social rights and social life</td>
</tr>
<tr>
<td>Socio-economic vulnerability</td>
</tr>
</tbody>
</table>

### 3.6.2 Key Informants Guide

The key informant guide was used to identify and to verify key (typical) characteristics of the characteristics of the IFCGs, the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions. The primary objective was to solicit typical examples of characteristics of the characteristics of the IFCGs, the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions.

### 3.6.3 Guide for FGD

The guide for the FGD was used to build consensus on aspects related to characteristics of the characteristics of the IFCGs, the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions. The objective was to enable the panel review a given aspect and arrive as some conclusion or agreement on the real position in respect to characteristics of the IFCGs,
the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions.

3.7 Pre-Testing Research Instruments

Pilot study was carried-out to assess the relevance, acceptability, reliability and validity of the data collection instruments. Although the three (3) instruments were important, the relevance, acceptability, reliability of the interview guide (the questionnaire) was the most critical. Accordingly, the interview guide (the questionnaire) was administered to 15 pilot respondents who were members of the CSCF from Busia and Kisumu Counties (their contacts were obtained from the CSCF Leadership in those counties), key informant guide to 3 pilot key informants and the guide for FGD was administered to 3 pilot panel group members. The people who participated in the pilot study did not form part of the main sample. Following the pilot study, necessary adjustments (improvements) were made to the data collection instruments.

3.8 Validity and Reliability of Research Instruments

Reliability refers to the ability of the instruments to generate consistent responses. On the other hand, validity refers to the ability to assess the intended objects i.e. the intended challenges of the caregivers. Accordingly, the pilot was used to ensure the data collection instruments had ability to generate consistent results to maintain reliability. The instruments also had the ability to reflect the correct challenges of the caregivers.

3.9 Data Collection Procedures

Respondents were informed about the study in CSCF’s monthly meetings and on social media platforms alerting them that some of them would be contacted to participate. Arrangements were made with selected respondents on venue and time. The researcher collected data in line with objectives. Boundaries for the study was set as well as rules for recording information through semi structured interviews and observations. The researcher
made field notes on behavior and activities of people as she conducted face to face interviews. The FGD had 12 people only and was conducted during sickle cell clinics. An observation checklist helped get data describing the physical setting at home or accounts of particular events or activities for example speculations, feelings, ideas, hunches, problems, prejudices and impressions. The interview guide had a heading, guidelines, questions, space to record responses, probes, and a thank you note for respondent’s time. Recorders and note books were used to collect data which was later transcribed verbatim.

3.10 Data Analysis and Presentation

The data were analyzed with two approaches, quantitative and qualitative approach in order to assess statistical aspects of the characteristics of the IFCGs, the nature and severity of the SCD, the effects on the psychosocial economic wellbeing, coping strategies and necessary interventions and also to assess the typical examples of the same issues.

Quantitative approach included use of the frequencies, percentages, average, tables and charts to assess the quantitative structures and generalizations. Quantitative data that included economic variables such as amount of money spent in hospitals, Age was analyzed using Excel and N-Vivo and presented in form of percentages in tables, charts and graphs. Quantitative analysis was followed immediately by qualitative analysis to assess typical examples and verbatim reports. Qualitative data presented in verbatim reports was reviewed, made sense of and classified into themes that cut across all data sources. Data was analyzed for materials that address codes on expected topics, surprising and anticipated, unusual but of conceptual interest and those that address a larger conceptual interest (Creswell J. W. 2009).

3.11 Ethical Considerations

The rights, needs, values and desires of informants were respected because sensitive information was to be revealed. Informants’ rights, wishes and interests were considered
first when deciding where to meet and deciding to report the data. Numbers were used on questionnaires and recordings to musk respondents from exposure. Objectives were articulated to be understood by the informants. Respondents were informed of all data collection devices, activities and transcribed reports. The researcher used information provided for the purpose of this study only. Participation was voluntary as those willing to take part in the study signed consent forms (Appendix ix) before interviews. The completed questionnaires were kept under lock and key. Before carrying out research, the researcher sought permission from Kenyatta University Graduate School and Ethics Office, The National Council for Science, Technology and Innovation (NACOSTI), CSCF and relevant Government Administration Offices. The works of other authors were referenced using APA 7th edition. There was no fabrication, falsification nor misinterpretation of data. Any possible conflict of interest was declared and any communication regarding this research done in a transparent manner.

Respondents were protected from any emotional, psychological or physical harm through signing of consent forms where confidentiality was assured and freedom to withdraw communicated to them. The information gathered in this research was communicated to patients as feedback during clinic days and the benefit clearly outlined. Results were disseminated by giving copies of the work to the University, NACOSTI. The copy given to NACOSTI may be used by the government for policy formulation and implementation. The researcher gave a copy to the Ministry of Health respondents who are directly responsible for policy review and implementation as well as the CSCF.
CHAPTER FOUR
FINDINGS, INTERPRETATIONS AND DISCUSSIONS

4.0 Introduction

The purpose of this study was to investigate the psychosocial economic vulnerability of involuntary family caregivers (IFCGs) of people living with sickle cell disease (PLWSCD) in Nairobi, Kenya. In this chapter, we present findings of the study, interpretations and discussions organized in order of the five study objectives namely: (i) To assess the characteristics of the involuntary family caregivers of PLWSCD in urban centers in Sub Sahara Africa (SSA); (ii) To identify the characteristics of the SCD in urban centers in SSA; (iii) To assess psychosocial economic vulnerability of the caregivers in urban centers in SSA; (iv) To assess coping/adaptive strategies by the IFCGs and (v) To identify necessary measures to reduce IFCGs vulnerability. The study revealed psychological, social, socio-economic and physical vulnerability among caregivers of PLWSCDs. It will be noted that the findings were based on 226 caregivers, key informants and the focused group discussion.

4.1 Characteristics of the Involuntary Family Caregivers (IFCGs)

The study assessed the socio-economic characteristics of the informal caregivers of the PLWSCD; particularly in respect to the age, gender, marital status, the size of the household, levels of education, type of occupation or employment, experience and preparedness to caregiving.

4.1.1 Age of the Caregivers

The age of a person is usually associated with socio-economic responsibilities and expectations. In view of these responsibilities and expectations, the study assessed the age of the caregivers. Responses indicated that majority of the caregivers (25%) were between
45 and 49 years of age (Table 4.1) below. Responses indicated also that 84% of the
caregivers were between 30 and 59 years of age. The youngest IFCG was 20 years old and
the oldest was 60 years. More precisely, the average age was 43 years of age.

<table>
<thead>
<tr>
<th>Years</th>
<th>Caregivers</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 - 19</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>20 - 24</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>25 - 29</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>30 - 34</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td>35 - 39</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>40 – 44</td>
<td>29</td>
<td>13</td>
</tr>
<tr>
<td>45 – 49</td>
<td>56</td>
<td>25</td>
</tr>
<tr>
<td>50 – 54</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>55 - 59</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>60 - 65</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>43</td>
</tr>
<tr>
<td>Median</td>
<td>45</td>
</tr>
<tr>
<td>Mode</td>
<td>45-49</td>
</tr>
</tbody>
</table>

This is in agreement with the general age of caregivers elsewhere, in SSA and in
Kenya (MetLife, 2020). In view of the fact that 84% of the caregivers were 30 to 59 years
of age, the study concluded that involuntary caregiving occurs at the prime age.
Accordingly, a greater proportion of the caregivers have to compromise their prime age,
productive years, to attend a vulnerable person including persons with SCD. Depending
on the intensity of the caregiving, most of the caregivers would not be able to engage on
productive activities to support their livelihoods and wellbeing. Indeed, most of the
caregivers would not be able to work; and therefore get disadvantaged.

Most people start building their careers at about the age of 20 years as they complete
school and college. Starting to give care that requires 24-hour commitment at this age can
derail ones’ career especially when the caregiver has more than one PLWSCD to care for
with little help. The career may never take off incapacitating the caregiver entirely or if the caregiver has a job, the caregiver may lose the job and never pick up. By the time they raise children, they are likely to be too old to rebuild themselves. Some other times, the children never really ever become independent such that she has to continue supporting them even in adulthood. Caregivers yet to be married may lose relationships compounding their situation making coping even more difficult.

4.1.2 Gender of the Involuntary Family Caregivers

The gender of a person has been associated with varied responsibilities and expectations in typical life cycle of people. Caregiving has been characterized by substantial gender difference on the responsibilities and expectations; particularly in the case of the SCD. Accordingly, the study assessed the gender of the caregivers; where 81% were females and 19% were males (table 4.2).

<table>
<thead>
<tr>
<th>Sex</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women Caregivers</td>
<td>183</td>
<td>43</td>
<td>226</td>
</tr>
<tr>
<td>Percentage (%)</td>
<td>81 %</td>
<td>19%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Available reports indicate that the proportion of the female caregivers globally range from 57% to 87% and usually the wives, mothers or daughters (Akpan-Idiok et al., 2020; Patil, 2018, Asuquo, 2017; Rodríguez-Madrid et al., 2019; DeSilva et al., 2008). Various studies have reported that women, all over the world, have been predominant providers of informal care for family members with chronic medical conditions (disabilities) including the weak, the elderly and adults with mental illnesses (Sharma et al., 2016). It has been argued that caregiving is a role expected of family members and one which has been predominated by women (Patil 2018; Asuquo, 2017, Sharma et al., 2016).
Over-representation of women in caregiving, particularly in respect to SCD, suggest unequal distribution of responsibility of caregiving between women and men (Parks, 2010; Marsh et al., 2011; Muchangi, 2014). This is because in most societies including Kenya, women are socialized to play the role of caring for the sick for free. It has been considered that the normative role of women extends from reproduction, to nurturing infant and sick family members. Others have argued that caregiving has been feminized and women socialized into nurturing roles.

In view of the foregoing data and observations, the study concluded that the caregiving of PLWSCD in Kenya and SSA have been largely females. The data and observations indicate that women tended to be absorbed immediately into involuntary family caregiving; to attend a vulnerable family member. The study concluded also that over-representation of women in the caregiving of PLWSCD in Kenya and SSA has implications on the socio-economic wellbeing of women. The unequal share of care responsibilities between women and men worsens with the disadvantages of over-representation of women in caregiving; particularly of PLWSCD.

4.1.3 Marital Status of the Involuntary Caregivers

In typical situations, marriage is accompanied by additional responsibilities and expectations; particularly those related to establishing a family and livelihoods. In view of the envisaged responsibilities, the study assessed the marital status of the IFCGs. Most (81%) of the caregivers were married and 11% were widowed (table 4.3) below. The rest were either separated or divorced. Of those married, 2% had remarried and were in their 2nd marriages while 2% were living in polygamous unions.
Table 4.3: Marital Status of IFCGs, Nairobi 2016

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Caregivers</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>179</td>
<td>79</td>
</tr>
<tr>
<td>Separated</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Divorced</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Remarried</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

These findings reflect what other studies found that majority of caregivers are women. A study in Brazil revealed that 73% of caregivers were mothers, 57.35% - 59.5% were married and 48.6% were housewives (Da Silva et al., 2012; Costa et al., 2016). Hence once separation or divorce occurs, the burden of raising children is left to the woman who usually the mother is putting her at a disadvantage when it comes to personal growth. Caregiving impacts single women even more severely because they have neither moral nor financial support which affects their ability to build resilience against shocks (Joling et al., 2016). SCD therefore increased their vulnerability to mental, physical, social and economic well-being. The burden women are left to carry as the man walks free causes gender inequality.

4.1.4 Number of Children for Caregivers

It is usually considered that an increase in the number of children in a household (family) increases responsibilities to the parents and the caregivers. Increase of children for caregivers with a PLWSCD has also been demonstrated to increase challenges and complications. In view of the demonstrated increase of challenges and complications, the study assessed the number of children for the caregivers and the outcomes were summarized in table 4.4 below. Majority (23%) of the caregivers had 3 children; and 59% of the caregivers had between 2 and 4 children.
Table 4.4: Number of Children for IFCGs, Nairobi 2016

<table>
<thead>
<tr>
<th>Children</th>
<th>Caregivers</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>47</td>
<td>21</td>
</tr>
<tr>
<td>3</td>
<td>53</td>
<td>23</td>
</tr>
<tr>
<td>4</td>
<td>34</td>
<td>15</td>
</tr>
<tr>
<td>5</td>
<td>30</td>
<td>13</td>
</tr>
<tr>
<td>6</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>8</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>226</td>
<td>100</td>
</tr>
</tbody>
</table>

It will be noted that the national average number of children in Kenya stands at around 4 children (KNBS 2019) and therefore the modal category of the study is consistent with the national average. This shows that apart from the PLWSCD, there are other children, likely siblings to the PLWSCD in the household who require the caregiver’s attention. The caregiver’s responsibility doesn’t therefore end with the PLWSCD.

4.1.5 Formal Education of Caregivers

Education has been considered an important characteristic and capacity to understand, management and to develop livelihood. In view of the importance of this characteristic, the study assessed the level of education for the involuntary family caregivers and responses were summarized in table 4.5 below. Majority (36%) of the caregivers had primary education; followed by 28% of the caregivers who had secondary education. In principle, 60% of the caregivers were literate and had at least secondary or higher education.
Table 4.5: Formal Education for the Caregivers, Nairobi 2016

<table>
<thead>
<tr>
<th>Level of Formal Education</th>
<th>Caregivers</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Education</td>
<td>9</td>
<td>4%</td>
</tr>
<tr>
<td>Primary Education</td>
<td>81</td>
<td>36%</td>
</tr>
<tr>
<td>Secondary Education</td>
<td>63</td>
<td>28%</td>
</tr>
<tr>
<td>Tertiary Education</td>
<td>25</td>
<td>11%</td>
</tr>
<tr>
<td>University Graduate</td>
<td>43</td>
<td>19%</td>
</tr>
<tr>
<td>Post Graduate</td>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The education level is one of the sociodemographic factors that affect resilience of IFCGs (Joling et al., 2016). A study on SCD caregivers in Brazil revealed that 75.7% had only completed elementary education while 51.47% of caregivers of stroke patients had formal educational level of 5-9 years (Da Silva et al., 2012; Costa et al., 2016). In this study, literacy levels correlated with the knowledge IFCGs had of SCD. This is in line with the Alspach’s findings that the literacy correlated with interest in learning and the ability to read and ask questions, follow guidelines like giving prescriptions, observing routines and proper diet (Alspach, 2009).

Literacy also helps in understanding the condition and following instructions on the care of the child with probable better outcomes. Understanding the condition and knowing where to get help triggered positive cognitions. In other studies, positive thoughts had mediating and partially moderating impact on the relationship between caregiver burden and resourcefulness (Zauszniewski et al., 2009). Educated IFCGs had better chances of having better paying jobs that enabled them to hire help while they worked and reduce stress levels (Mauro et al., 2006). The ability to understand the scenario one is operating can also ease the anxiety experienced while ignorance could augment it. The level of education disproportionately affected illiterate women more due to their ignorance. This further aggravated their ability to adapt and develop resilience.
4.1.6 Income of the Caregivers

Income of a caregiver is usually considered as a key indicator of the socio-economic capacity (SEC). Accordingly, the study assessed the monthly income of the caregivers as a key indicator of the SEC including capacity to address vulnerability. Responses were summarized in figure 4.1 below. The study established that the average income for the IFCGs was KES 35,900 ($323) in which 60% earned less than KES 35,520 ($320) which was the average income in Kenya per month for urban low income households (KIHBS, 2015/2016).

![Figure 4.1: Family Income per Month in Kenya Shillings (Caregivers=226), Nairobi 2016](image)

In 2008, the World Bank came out with a revised figure of $1.25 at 2005 purchasing power parity. By 2020, the average low income in Kenya stood at KES 23,670 (US $ 209) per month (KNBS 2020). Other projections ranged from KES 12,072 (US $ 107) to KES 24,144 (US $ 214). Accordingly, 60% of the caregivers had low average income. Lingering post discharge crisis pains interferes with the caregiver’s ability to work or attend school (Brandow et al., 2009; Panepinto et al., 2009). In Brazil, most caregivers of persons with SCD (45.59%) were unemployed with 58.09% having income of 1-3 minimum wages (Costa et al., 2016).
4.1.7 Residential Areas of the Caregivers in Nairobi City

The area of residence has typically been used as an indicator of socio-economic characteristic of people (Darin-Mattsson et al., 2017; Galobardes et al., 2007; Blakely, 2004). In addition, pain crises (episodes) in PLWSCD can be severe and vary in duration, location, type, and severity (Fuggle et al., 1996). In view of such importance, the study assessed the residential area of caregivers. Responses indicated that 58% of the caregivers lived in informal settlements (slums) (table 4.6 below). Responses also indicated that 34% lived in middle class areas and therefore reflected their middle class socio-economic status.

<table>
<thead>
<tr>
<th>Residential Location</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower Class/Slums</td>
<td>131</td>
<td>58</td>
</tr>
<tr>
<td>Mathare, Kariobangi, Umoja, Kibra, Dandora, Huruma, Ngomongo, Kiambiu</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle Class</td>
<td>77</td>
<td>34</td>
</tr>
<tr>
<td>Donholm, Kayole, Tasia, Buruburu, Kahawa, Embakasi, Park Road, Langata, Saika, Jamuhuri, Ziwani, Komarock, Limuru, Lucky Summer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affluent</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Harlingham, Kileleshwa, Karen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>226</td>
<td>100%</td>
</tr>
</tbody>
</table>

This clearly indicates the socio-economic capacity of the households in terms of the capacity to pay rent for their shelter or where they are able to find work. We conclude that most of the respondents were low income earners who spend the better part of their income on medical bills. What was left could only afford them housing in these low class areas.

4.1.8 Type of Housing for the family

The type of housing is also used as an indicator of socio-economic characteristic of a population especially in determining the poverty line (World Bank, 2008). The poverty line is usually determined by finding the total cost of all the essential resources that an
average human adult consumes in one year. The largest of these expenses is typically the rent required to live in an apartment. Economists use real estate market and housing prices as strong poverty line affecter. Figure 4.2 below indicates that 57% of the respondents lived in either one room or one-bedroom stone houses. The main motivation for a stone house was warmth since the cold precipitates crisis. 15% however lived in houses made of iron sheets ‘mabati’ as they probably could not afford the rent for stone houses. Only 9% lived in bungalows a few of them being owned by IFCGs, 9% lived in Maisonettes and 9% in 2-3 bedroom flats. Many struggled to pay rent and occasionally needed assistance. One caregiver who was not interviewed informed the researcher that she had relocated to the village because she could not keep up with the rent obligations because she couldn’t keep a job.

To determine the poverty line, the World Bank used the total cost of essential resources that an average human adult consumes in one year. The largest of these expense is typically the rent required to live in an apartment. This study therefore illustrated that most of the caregivers could not afford to live in an apartment hence lived generally below the poverty line. Their income and expenditure per HH had a bearing on the type of house.
rented due to financial considerations. In figure 4.6 depicting expenditure on PLWSCD below, IFGS reported that SCD depleted money meant for rent. Most of these IFCGs lived in squalor in various slums in Nairobi and would chose better houses if they could afford.

4.1.9 Comfort in the Home

The infrastructure in the houses was varied. The type of seats, beddings and clothing were used to gauge the level of comfort in the HHs. In this study, 32% of houses were warm with good seats and warm beddings. They even had a TV, a wall unit or sewing machines as extras. In 19% of the houses the comfort would be described as fair while in 23% had scanty uncomfortable seats and poor dressing that were not very warm. One 24-year-old boy adorned the sister’s sweater. Only 11% of HHs could be rated as comfortable. This group lived in stone houses that were warm, had comfortable seats and dressed well and warmly with extras as internet, technology gadgets and carpets indicating they could afford extras. There were 15% of caregivers who avoided having the interviews at their homes and opted to meet in the street or elsewhere. Majority of families at 57% therefore lived uncomfortably.

4.2 Characteristics of Sickle Cell Disease

The study assessed the socio-economic characteristics of the involuntary caregivers of the PLWSCD; particularly in respect to the age, gender, marital status, the size of the household, levels of education, type of occupation or employment, experience and preparedness to caregiving.
4.2.1 Symptoms, Severity and Complications of Sickle Cell Disease

The study assessed experiences of the caregivers with the symptoms and complications of the SCD in respect to their respective patients. The symptoms with the greatest occurrences (commonly reported) included swelling of hands and feet ‘dactilytis’ (68%), joint and bone pain (57%), low blood levels (anaemia) (49%), acute chest syndrome (45%), frequent infections (42%), stomach crisis (38%) and painful events in different parts of the body (38%) (table 4.7) below.

Table 4. 7: Reported SCD Symptoms, Nairobi 2016

<table>
<thead>
<tr>
<th></th>
<th>Experienced Symptoms</th>
<th>Responses N=226</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Vascular Occlusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dactilytis - Swelling hands &amp; feet in babies</td>
<td>157</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Acute Chest Syndrome</td>
<td>102</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Stomach crisis</td>
<td>92</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Painful events (different locations)</td>
<td>86</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Headaches</td>
<td>63</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Backaches</td>
<td>57</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Priapism</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>Anaemia</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Low Hb (Paleness)</td>
<td>111</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td>Weakness/Fatigue</td>
<td>86</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Nose bleeding</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>End Organ Damage</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Joint and bone leg pain swelling</td>
<td>129</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td>Leg ulcers/Rushes</td>
<td>68</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Splenic sequestration/big Tummy</td>
<td>52</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Avascular Necrosis/Hip pain</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Retinal failure/Eye problems</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Stroke/slowness/numbness</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>High heart rate/pulmonary hypertension</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Renal/Kidney failure</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Frequent infections</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Upper Respiratory Tract Infections (URTIs)</td>
<td>95</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>Urinary Tract Infections(UTIs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Body image issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor Body posture</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Extended Jaw bones</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Long legs/distinct shape of legs</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Change in behaviour patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor appetite</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Loss of Self Confidence</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Sweating on top of the head</td>
<td>9</td>
<td>4</td>
</tr>
</tbody>
</table>
Caregivers were requested to indicate selected symptoms within a framework of six (6) key broad symptoms of the SCD. Overall 32% of the caregivers reported Vaso Occlusive Crisis (VOC) as the most common symptom with indicators that included Dactilytis, Acute Chest Syndrome, Stomach crisis and general painful events among others. Anaemia was the second most common symptom with indicators of low Hb/Paleness and body weakness/fatigue. End Organ Damage was seen in patients who presented Joint & bone leg pain swelling, Leg ulcers, splenic sequestration, avascular necrosis, renal and retinal failure, stroke and pulmonary hypertension. The most frequent infections included Upper Respiratory Tract Infections (URTIs) and Urinary Tract Infections (UTIs). Change in behavior patterns included having poor appetite and loss of self-confidence. Responses were summarized in table 4.8 below.

**Table 4.8: Reported SCD Symptoms, Nairobi 2016**

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaso - occlusion /Painful crisis</td>
<td>172</td>
<td>32</td>
</tr>
<tr>
<td>Anaemia</td>
<td>57</td>
<td>25</td>
</tr>
<tr>
<td>End organ damage</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>Frequent infections</td>
<td>27</td>
<td>12</td>
</tr>
<tr>
<td>Body image issues</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Behaviour patterns</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

These symptoms related to studies which revealed that the hallmark of SCD is anaemia and vascular occlusion that is erratic and presents in extremely painful episodes referred to as crisis. Studies reported that vascular occlusion caused long-term tissue and organ damage to multiple body organs and sometimes caused death in the long run. (Foy H. and Kendall A.G., 1974; Mulumba & Wilson, 2015). The symptoms and outcomes of SCD increased vulnerability. The most difficult experience in IFCGs journey was dealing
with painful crises (26%) followed by fear of losing the child (15%). It was reported that pain in PLWSCD occurred erratically destabilizing the caregivers’ plans and this always caused anxiety as they wondered when next the crisis will reoccur. Crises sometimes caused death; hence the painful episodes and death are intertwined. Where there was adequate medical support, the painful episodes reduced and functionality increased in patients (Mitchell et al., 2009). When this happens, the IFCG also relaxes. This is not however the case in Kenya because most facilities are ill equipped to manage SCD’s painful crises and complications which lead to early mortality.

4.2.2 Age of Persons Living with SCD

The study assessed the age of PLWSCDs at the Children Sickle Cell Foundation and responses were summarized in (Table 4.9) below. Responses indicated that majority (58%) were less than 15 years of age, 77% were less than 20 years of age, 85% were less than 25 years old and 90% were less than 30 years old. It will be noted that only 10% were more than 30 years old.

<table>
<thead>
<tr>
<th>Years of PLWSCD</th>
<th>Frequency</th>
<th>Percentage (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 5</td>
<td>31</td>
<td>14</td>
</tr>
<tr>
<td>6 - 10</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>11 - 15</td>
<td>61</td>
<td>27</td>
</tr>
<tr>
<td>16 - 20</td>
<td>42</td>
<td>18</td>
</tr>
<tr>
<td>21 - 25</td>
<td>19</td>
<td>15</td>
</tr>
<tr>
<td>26 - 30</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>31 - 35</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>36 - 40</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>41 - 45</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>46 - 50</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>51 - 55</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
The table 4.9 above implies that 58% of PLWSCD were deceased by age of 15 Years, 77% by age 20 years and 92% by the age of 30 years. The median age of people with SCD in this group was 14 years; the mean was 16 years while the mode was 13 years. The mean age of 16 years is in line with findings that PLWSCD in Kenya rarely lived past 20 years (Aluoch & Aluoch, 1993; Ojwang, 1987). The median age of 14 years is an improvement of the general median survival rate of 5 years in Africa where 50 – 90% of patients die before their 5\textsuperscript{th} birthday (WHO Africa, 2010; Grosse et al., 2011). The discrepancy in life expectancy could be due to availability of clinics that serve these patients and the efforts of the Foundation which educates informal caregivers. These clinics were not operational to serve patients at the time when Ojwang’ and Aluoch carried out their studies.

Painful episodes and deaths of their relatives occurring make IFCGs to continue living on tenterhooks wondering when the pain or death will strike. This makes them to lack peace. The age of patients serves to encourage or discourage caregivers (Joling et al., 2016). IFCGs get encouraged when they see a PLWSCD who is in great health or grown up whether it’s their own child or not. The context of care i.e. the caregiver - patient relationship, duration of care, the burden of care and the type of diabetes affects caregivers (Joling et al., 2016). Similarly, in SCD, the burden, duration, complications and haplotype could affect IFCGs differently. Constantly being in a state of anxiety inhibits caregivers’ ability to be proactive and some lose hope increasing their vulnerability.

4.2.3 Prevalence of PLWSCDs at the Children Sickle Cell Foundation

The study assessed the prevalence of SCD at the Foundation and the ethnic representation. In a sample of 226, 54% were from the Luo Ethnic Community, 38% were from the Luhya Ethnic community and 8% were distributed among several ethnic communities namely Kuria, Mijikenda, Kisii and Kamba (Table 4.10) below.
Table 4.10: Prevalence of SCD and Ethnic Representation in CSCF, Nairobi 2016

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luo</td>
<td>122</td>
<td>54</td>
</tr>
<tr>
<td>Luhya</td>
<td>86</td>
<td>38</td>
</tr>
<tr>
<td>Kuria</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Kamba</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Kisii</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Mijikenda</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>226</td>
<td>100%</td>
</tr>
</tbody>
</table>

It will be noted that the communities with high prevalence were from the Lake Victoria basin and the coastal region of Kenya. Available reports indicate that prevalence of SCD tend to be high in malaria endemic zones (Ojwang et al., 1987; Aluoch, 1997; Kifunde C. M., 2008). Key informants reported lack of proper documentation to avail statistics hence were not aware of the studies done in 1971 and 1997. The prevalence may also have changed over time. The key informants were also not able to relate the prevalence of SCD in Kenya with other countries as they were not aware of the existing statistics. Below are their assertions.

“SCD is found along the Lake Victoria basin and the Indian Ocean.” KI8 on 5.11.2016
“Not well documented. There are no official statistics of patients.” KI2 on 7.11.2016
“There is significant prevalence but no data to quantify the numbers.” KI5 on 6.11.2016
“Those counties along the ocean also have sickle cell disease.” KI1 on 4.11.2016
“There is no local data for comparison.” KI8 on 5.11.2016

The disease occurring in these areas with high prevalence for malaria is in line with studies done that showed prevalence of Luo 58.4% leading followed by Luhya 23.9% and Kambe ‘Mijikenda’ 8.5%. Other Bantu and Nilotic groups are affected but to a very small scale (Aluoch, J. R. & Aluoch, 1993; Foy H. & Kendall A.G., 1974; Kifunde 2008; Ojwang et al., 1987; Aluoch, 1997). This is because SCD came about as a result of gene mutation
to protect people from malaria. The carriers with one sickle cell gene were protected and malaria to marry other carriers and produce children with SCD. Currently, there is no widespread genetic counselling to sensitize these populations to test and choose spouses wisely to prevent more births of children with SCD. These figures may not give the exact position on the ground because the study was done in Nairobi where some affected people may not have had a chance to come. It however gives us the distribution of people that the researcher spoke to CSCF.

4.2.4 Knowledge of Sickle Cell Disease among IFCGs

The study sought to establish the knowledge of SCD among IFCGs. Figure 4.3 below shows that 56% of caregivers understood SCD and said it’s a genetic blood related disorder that is tough, serious, chronic and incurable characterized by sickling processes that cause anaemia and predisposes affected people to getting other illnesses as opined below.

SCD has no proper local name among affected caregivers’ communities which indicates how unfamiliar the disease is to them. They use the English name ‘sickle cell disease’ or the Swahili name acquired from Tanzania - ‘Maradhi ya Selimundu’. They shared the following.

“It’s a condition one is born with inherited from both parents” WC4, 12.1.2016 at Tasia
“It’s chronic and incurable needing attention all the time.” WC3, 15.1.2016 in Mathare
“SCD predisposes one to getting other illnesses.” WC8 on 10.1.2016 in Kamulu;
“It’s an inherited blood disorder characterized by chronic anaemia” WC24, 4.6.2016, Karen

There were 38% of IFCGs who were totally ignorant and gave responses reflecting lack of knowledge confusing SCD with other illnesses like leukemia or saying that it’s not a disease. Some think it is related to the effects of the parent’s behaviour like extra marital affairs which often result in a condition commonly known as ‘ofuyu’.

“It’s an abnormality in the blood where White Blood Cells are more than Red Blood Cells -that’s why they sickle” WC25 on 8.6.2016 in Limuru
“There are bones where blood doesn’t reach.” WC22 on 3.6.2016 in Mathare N/A
“My Dad’s side thinks it’s ‘ofuyu’ - as a result of dad having extra-marital affairs” P9B on 7.8.2016 at Huruma - John Saga

In spite of the education given during SCD clinics, 6% of IFCGs still lacked knowledge and believed in misconceptions and myths. They likened SCD to other conditions like Kwashakor, HIV, Cancer; called patients pretenders or weaklings; likened patients to dead people ‘marehemu”; blamed doctors for transfusing the child with bad blood or blamed demons as seen below.

“I was told it’s a demonic disease. I tried treating traditionally but it didn’t work. Others said the baby had been given bad blood which brought SCD.” WC21 on 3.4.2016 at Umoja
“Ni ugonjwa wa shetani. Sio ugonjwa ya kawaida” It is demonic, not a normal ailment. When the child is in crisis and I pray, the pain reduces” WC27, 5.4.2016 at Ngomongo
“They said it was ‘Ishira/Chira’” WC14 on 6.8.2016 at Kayole
“‘Kwashakor’ or ‘Liima’ – big tummy” WC19 on 9.8.2016 at Kiambiu
“Some think its AIDS, cancer or ‘Lacina’ – spell or cultic demons” M2 on 5.7.2016 at Baraka

Lack of information is a global problem as revealed by a studies in Canada, Cameroon and Kilifi, Kenya (Marsh et al., 2011; Burnes et al., 2008; Wonkam et al., 2014). The knowledgeable caregivers in this cohort is credited to the efforts of the Foundation to give education and counselling services to patients and their caregivers. The 56% who retained information correlate with caregivers within literacy levels of 60%. Illiteracy contributed
to lack of understanding or retaining of knowledge imparted making them remain ignorant and operating with myths.

Knowledgeable caregivers are better at observing routines to minimize occurrence of stressors, monitoring vital signs, and working with medical equipment (Alspach, 2009). This is in line with findings in this study which noted better outcomes in the management of patients among knowledgeable caregivers than ignorant ones. The study also reveals that IFCGs defended themselves better when their womanhood was attacked by patriarchal stereotypes that apportioned blame for the existence of a sickle cell child to them alone because they knew that they contributed only 50% of the SCD genes and the husband was responsible for the other 50% of the genes. IFCGs reported that men with knowledge, who realized that they contributed to the problem, if they did not suffer denial, became more supportive of WCGs lessening the burden of care. These men learnt to ignore the community’s views about gender roles as they realize they have a special problem unique to their family. Ignorant men continued to be unsupportive and blamed their wives compounding Woman caregiver’s vulnerability.

4.2.5 Reaction to Diagnosis and Knowledge

The study assessed the initial reactions of the caregivers on the outcomes of the diagnosis; particularly confirmation of the SCD, severity and complications. The key initial reactions included shock 19%, lack of understanding 17%, pain 15% and worry 13% (table 4.11) below. Others experienced denial and sought help while others treated it as a normal ailment. These four reactions will be discussed further in section 4.3 under vulnerability to psychosocial challenges.
Table 4.11: Initial Reaction to Outcomes of the Diagnosis in CSCF, Nairobi 2016

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Frequency (N=226)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Shocked</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td>2 Did not understand</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>3 Experienced pain</td>
<td>34</td>
<td>15</td>
</tr>
<tr>
<td>4 Experienced worries</td>
<td>29</td>
<td>13</td>
</tr>
<tr>
<td>5 Considered normal disease</td>
<td>29</td>
<td>13</td>
</tr>
<tr>
<td>6 Experienced denial</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>7 Sought Help</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>8 No comment</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Ignorance in affected populations can be seen in cultures that perpetrate the gene through intermarriage but remain very unsupportive to affected caregivers. Those who lacked understanding were also not hit hard by the news as seen below.

“I didn’t understand it. I had been told that by 5 years, the baby might die if SCD is not reduced.” M7 on 4.7.2016 at Mathare N/4A
“I didn’t understand even after the doctor explained” WC15 on 19.1.2016 at Umoja.
“The family just said ok and told me to see what to do.” WC19 on 9.8.2016 at Kiambiu

There were 6% of IFCGs who took on SCD by the horns and proactively sought to find solutions to their children’s problems by learning or taking the child to hospital when need arose as stated in the assertions below.

“She embraced it. I got admitted for 3 months when I was only 2 months old. My mother had known because she was a carrier.” WC33 on 10.3.2016 at Hurlingham
“I followed to see a way out. We sought medical support. Came to clinics and learnt. Now I am on top of things.” WC23 on 9.2.2016 at Mathare

The study also assessed the reaction after IFCGs gained knowledge of the SCD and their responses summarized in (table 4.11) below. Responses indicated the majority (34%) became relaxed, 17% struggled to accept and 15% accepted what had befallen them. Of the remaining, some still worried about the future, some felt stronger, others felt tied down and others developed a medical condition. Being stronger, feeling tied down, worrying
about the future, struggling to accept and worrying has been discussed under mental health challenges in table 4.12 below.

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Frequency (N=226)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 More relaxed</td>
<td>77</td>
<td>34%</td>
</tr>
<tr>
<td>2 Struggled to Accept</td>
<td>38</td>
<td>17%</td>
</tr>
<tr>
<td>3 Accepted</td>
<td>34</td>
<td>15%</td>
</tr>
<tr>
<td>4 Worried about future</td>
<td>29</td>
<td>13%</td>
</tr>
<tr>
<td>5 Felt stronger</td>
<td>18</td>
<td>8%</td>
</tr>
<tr>
<td>6 Blank</td>
<td>16</td>
<td>7%</td>
</tr>
<tr>
<td>7 Felt tied down</td>
<td>9</td>
<td>4%</td>
</tr>
<tr>
<td>8 Developed medical conditions</td>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>226</td>
<td>100%</td>
</tr>
</tbody>
</table>

The 34% of IFCGs felt more relaxed about having a child with SCD felt so because they had acquired information and knowledge on caring for a PLWSCD, having grown-up children with SCD, PLWSCD growing up and being able to take care of themselves or they just got used to the condition which creates some semblance of normalcy. Being stronger has been discussed further under emotional benefits in section 4.3. They shared below.

“Knowing how to control SCD helps me develop peace. I am not worried ‘roho inatulia, sina wasi wasi’. I give medication and pray for him” WC2 on 7.1.2016 Huruma
“I am more positive with knowledge. I have hope that the children can grow because I have seen grandparents with SCD” WC24 on 4.6.2016 at Karen
“She is a bit calm. She knows I can care for myself although still worries when I am down.” P7G on 22.7.2016 at Dandora
“Now She’s happy and not frightened because am 30 years old with a child.” They didn’t expect me to reach this age. P8G on 25.7.2016 at Dandora

IFCGs accepted the caregiving role and took what came in stride and sought proactive solutions. They also saw themselves to be in a better place compared to mothers whose children had conditions they considered worse. They did what they needed to do to prevent crises and helped the PLWSCD to be alive.
“She has accepted and thinking of treatment. We realized SCD is better and easier than some other illnesses like disability, retardation, blindness” M6, 9.6.2016 at Strathmore

“I treat him the way we have been taught. At some point, I used to wish God takes him when he had a lot of pain.” WC6 on 16.1.2016 at Lucky Summer

“I have accepted it and often ask ‘if not me, then who?’ I feel privileged to care for a person with SCD and God has given me resources to do so.” WC26 on 10.2.2016, Jamuhuri

“I am proud mother. It has taught me another side of life I would never have learnt.” WC29 on 15.5.2016 at Buruburu

Some of the caregivers suggested the possibility of avoiding a spouse with the SCD trait (HbAS) (81%) and others emphasized the need to screen pregnancy with a view to terminating if the foetus has the homozygous HbSS (sickle cell disease) (34%).

Other studies reviewed also highlighted lack of understanding by caregivers of HIV and critically ill people (Alspach, 2009; Theis et al., 1997). Most initial reactions of IFCGs towards the news of SCD were negative. These reactions were triggered by past experiences or information the person had prior to diagnosis. Caregivers without prior knowledge were not initially as frightened or worried about SCD as those who had some information or negative experiences with it. They went on as though everything was normal and were unaffected emotionally. Those with information felt pained, worried or made decision to find solutions.

When IFCGs got some knowledge of SCD, some changed their reaction from initial shock, denial, pain, fear, to being more relaxed, accepting and feeling stronger. Some however still struggled to accept, worried about the future, felt tied down or developed medical conditions. Those who worried more were those without information hence operated on myths and misconceptions as well as those who had lost other children to SCD. Even with the information provided to IFCGs, a few still struggled to accept; felt tied down or got sickly. Caregivers’ getting sick is in line with the Needs Assessment study for HIV Caregivers which revealed that caregivers sometimes developed chronic conditions
themselves (Alspach, 2009; Theis et al., 1997). IFCGs therefore need economic and psychosocial support while caring for their sick children to prevent them from getting sickly, feeling tied down and overburdened.

4.2.6 Preparadness of Caregivers

The study assessed ways in which caregivers who are members of the CSCF could have been prepared to provide caregiving; particularly to SCD patients. In figure 4.4 below shows that 70% reported that they were prepared, 28% were not prepared at all while 2% did not give any indication of whether they were prepared or not.

![Figure 4.4: Preparation of IFCGs for Caregiving Responsibilities, Nairobi 2016](image)

The preparation was done by either doctor in hospitals, by the caregiver’s previous experience with the disease and by their personal research in an effort to understand the disease. They indicated that the information given and preparation done by doctors in hospitals was crucial for them. After diagnosis, some hospitals gave caregivers pamphlets with information and taught them about diet and opportunistic infections. Others were prepared by consultant doctors or by other patients and their caregivers in the foundation. Some researched on the internet or from peers who were also caregivers. They shared below.
“Yes, at Mradi/Baraka. After they discovered it was SCD, they gave us drugs, taught us and advised us to make sure I attend the clinics.” WC2 on 7.1.2016 at Huruma

“Yes. She was counselled by the doctor who diagnosed the child. I also looked for more information.” M3 on 22.3.2016 at Strathmore

“Yes. We were told to give lots of water, keep warm, take medications, provide a balanced diet and cleanliness. If in pain, to rush to hospital.” WC5, 15.1.2016 Mathare

“Yes. From the CSCF, testimonies from other patients and parents were very educative.” WC16 on 7.6.2016 at Kitengela

“Yes. They tried to explain to us but at that time we were not listening. We were just seeing death.” M6 on 9.6.2016 at Strathmore

“Yes. The doctor counseled me but was I listening? I tried to read but I didn’t know what to focus on. After my 1st born died, I started to learn seriously.” WC24 on 4.6.2016 at Karen

“I didn’t listen to anyone. I googled … then I initially looked for people who had experience – another mother - she explained to me.” WC4 on 12.1.2016 at Tasia

Those not prepared at the point of diagnosis likely had the diagnosis done in other institutions not associated with the foundation. They suffered a lot groping in darkness for answers. They visited witchdoctors, herbalists, pastors for prayers. One caregiver looked for information to help her child live after hearing people describe her child as ‘kufdead’ saying the medicine to SCD is a hoe ‘grave’ as shared below. They got information after joining the foundation.

“No. We had lots of crisis because we did not know how to care for the child.” WC9 on 12.1.2016 at Huruma

“Had been in KNH, St. Mary’s but only got educated at Baraka.” WC18, 6.8.2016 Park

“No. ‘Tulizunguka Saana’ - we went around a lot because I had never seen anyone. We went everywhere ‘waganga, dawa ya kienyeji’ - to witchdoctors for traditional herbs and for prayers to no avail.” WC3 on 8.1.2016 at Huruma

There were 70% of IFCGs who indicated that the information from doctors or hospitals was crucial for them. After diagnosis, some hospitals gave IFCGs pamphlets and taught them about diet and opportunistic infections. Other IFCGs were prepared by consultant doctors, other patients and their caregivers. Other IFCGs were informed but due to their emotional states at the time did not retain the information. They shared below.

“Yes, at Mradi/Baraka. After they discovered it was SCD, they gave us drugs, taught us and advised us to make sure I attend the clinics.” WC2 on 7.1.2016 at Huruma
“Yes. She was counselled by the doctor who diagnosed the child. I also looked for more information.” M3 on 22.3.2016 at Strathmore

“Yes. We were told to give lots of water, keep warm, take medications, provide a balanced diet and cleanliness. If in pain, to rush to hospital.” WC5, 15.1.2016 Mathare

“Yes. From the CSCF, testimonies from other patients and parents were very educative.” WC16 on 7.6.2016 at Kitengela

“Yes. They tried to explain to us but at that time we were not listening. We were just seeing death.” WCM6 on 9.6.2016 at Strathmore

“Yes. The doctor counseled me but was I listening? I tried to read but I didn’t know what to focus on. After my 1st born died, I started to learn seriously.” WC24 on 4.6.2016 at Karen

Some IFCGs were given information but were too preoccupied with possible negative outcomes. These preoccupations involved experiences they had with other children with SCD in the past or neighbours/relatives’ children with SCD. These created fear that served as a distraction. Those who had had intimate experience with SCD used this experience and knowledge to know how to deal with the situation that faced them. Other IFCGs researched for information from the internet or from other people. There are also IFCGs who were given inaccurate information by medical teams that led to IFCGs making wrong decisions or taking wrong steps. The wrong information made myths seem true as illustrated below.

“Nurses explained & told me it was like cancer.” WC8 on 10.1.2016, Kamulu

“A doctor in KNH told me not to worry now but after age 14.” WC, 11.2.2016 at Umoja

“No. I had lots of experience with a friend who lost a son at 32 and a sister who had a 30-year-old daughter. M9 on 19.7.2016 in Nairobi – CBD.

“I didn’t listen to anyone. I googled ... then I initially looked for people who had experience – another mother - she explained to me.” WC4 on 12.1.2016 at Tasia

There were 70% of IFCGs who were prepared when their children were diagnosed with SCD was attributed to the fact that caregivers in this study were members of the Foundation and attended the sickle cell clinics in Baraka, Strathmore medical Centre or Oasis clinic in Nairobi where education and counselling is done. This education by the foundation has therefore been very useful these IFCGs. IFCGs who had previous exposure to SCD by helping relatives had more hands on experience of caregiving in terms of what to
expect or do incase symptoms occurred. The IFCGs who sought information online had either not been informed, been misinformed or had not been paying attention when the doctors tried to explain to them about SCD. The researcher however noted that before they came to the foundation, some had been given inaccurate information or no information at all by medical staff. Misinformation or lack of information is in line with the assertion in the SCD African Regional Strategy 2010 which highlighted scarcity of trained personnel to manage SCD (WHO Africa, 2010). Uninformed or misinformed IFCGs had heightened vulnerability to anxiety and stress than informed ones.

4.2.7 Years of experience in Caregiving

The study assessed the years of the experience of the caregivers in the caregiving and responses were summarized in (table 4.13) below. Responses indicated that majority (32%) had an experience of 11 to 15 years of the caregiving. Overall, 60% of the caregivers had an experience of between 6 and 20 years. Those IFCGs who have given care for more than 20 years were only 28% and those above the age of 30 years only 12%. The highest number of years in experience was 45 years.

Table 4. 13: Years of Experience with Caregiving of PLWSCD, Nairobi 2016

<table>
<thead>
<tr>
<th>Years</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>1 - 5</td>
<td>29</td>
<td>13</td>
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<tr>
<td>6 - 10</td>
<td>30</td>
<td>13</td>
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<tr>
<td>11 - 15</td>
<td>72</td>
<td>32</td>
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<td>16 - 20</td>
<td>34</td>
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<td>21 - 25</td>
<td>18</td>
<td>8</td>
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<tr>
<td>26 - 30</td>
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<td>31 - 35</td>
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<td>36 - 40</td>
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<tr>
<td>46 - 50</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>226</td>
<td>100%</td>
</tr>
</tbody>
</table>
The caregiver experience correlates to the age of the patients. However there is a slight difference attributed to the fact that some caregivers have more than one child while others have lost children and given birth others with SCD. The total average duration of care of SCD patients in Brazil was 16.08 years (± 9.9 years); and 89.2% reported providing 24-hour care per day (Da Silva et al., 2012).

4.2.8 The SCD Burden

The study assessed immediate challenges that were associated with the outcomes of the diagnosis. Immediate challenges (burden) to the caregivers included living through the pain episodes referred to as painful crisis (26%), day to day caregiving responsibilities (17%), worries of losing the child (15%), financial challenges (13%) and loosing hope (11%). Being mishandled by medical staff and broken relationships (table 4.14) below. Given the expenditures on a PLWSCD per month, the number of PLWCD in a household increased the burden.

<table>
<thead>
<tr>
<th>Challenges Related to Diagnosis Outcomes</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with pain episodes</td>
<td>59</td>
<td>26%</td>
</tr>
<tr>
<td>Experience of anxiety</td>
<td>38</td>
<td>17%</td>
</tr>
<tr>
<td>Worries of losing the child</td>
<td>34</td>
<td>15%</td>
</tr>
<tr>
<td>Challenge of finances</td>
<td>29</td>
<td>13%</td>
</tr>
<tr>
<td>Worry of Loosing Hope</td>
<td>25</td>
<td>11%</td>
</tr>
<tr>
<td>Blank</td>
<td>14</td>
<td>6%</td>
</tr>
<tr>
<td>Discouraging remarks</td>
<td>9</td>
<td>4%</td>
</tr>
<tr>
<td>Balancing with work</td>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td>Others</td>
<td>14</td>
<td>6%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Living with episodes of pain was the most difficult experience for the majority of IFCGs at 26%. This group shared statements relating to the fact that they experience the
pain too, that they get upset when things are not done in the expected way, that their inability to help with alleviating the pain, that watching one’s baby become incapacitated or having delayed developmental milestones is very frustrating. Dealing with pain made them develop fear, anxiety and sorrow. It also affected their finances consequently impacting other family decisions. They avowed below.

4.2.8.1 The Intensity of Caregiving

PLWSCDs experience frequent and intense pain that occur erratically. Living through episodes of pain was the most difficult experience for the majority of IFCDs at 26% (table 4.9). Caregivers reported that they experienced the pain of the person they cared for too. That they got upset when things were not done in the expected way in hospitals, their inabilities to help with alleviating the pain, watching one’s baby become incapacitated or having delayed developmental milestones was very frustrating for them. Dealing with pain made them develop fear, anxiety and sometimes sorrow. Painful episodes also affected their finances negatively consequently impacting other family decisions as avowed below.

“When the child got operated on because of some suspicions, I was upset they didn’t wait for me.” M8 on 12.7.2016 at Rongai
“When the child is in crisis, I feel the pain the child is feeling.” M4 on 4.4.2016, at Gikomba
“When the child got boils and we did not know the cause. He was sick for a long time until he lost developmental milestones.” WC5 on 15.1.2016 at Mathare
“The pain that doesn’t respond to drugs and the baby is hurting. I never saw such pains before. I wish I could take the pain to relieve the child.” WC27 on 5.4.2016, Ngomongo
“When a child looks up to you to give a solution and you are unable to solve the problem” WC29 on 15.5.2016 at Buruburu

Nature of support required by the PLWCD demanded a lot of time from the caregiver and was highlighted as the second most difficult experience by 17% of them. The erratic nature of the PLWCD’s needs required a caregiver to spend a lot of hours per day or per month to care for them. It was impossible for caregivers to stick to planned schedules
as they were obligated to find solutions at whatever hour of the day or night. Debilitating complications like stroke or brain hemorrhage incapacitated PLWSCDs and forced caregivers to stay with them putting more demands on their time. Transfusions frighten some caregivers as they believed that it made the PLWSCD weak. Anxiety from day to day caregiving responsibilities led to physical health challenges like fatigue, stomach ulcers and pain. It also precipitated apprehension about possible negative outcomes. They shared the following.

“Watching my son go through the effects of stroke was terrifying. Also when he got blood and the body rejected it and started changing colour. It was frightening. I worry because his age mates are doing things for themselves but he can’t” WC26 on 10.2.2016 at Jamuhuri

“When a crisis comes at night, no means to go to the hospital and sometimes no money” P12G on 9.8.2016 at Dandora Phase 2

“Adding blood frightens me.” WC2 on 7.1.2016, Huruma

“Lack of peace and a life thinking of the uncertainty in future.” WC8, 10.1.2016 Kamulu

Most caregivers have found themselves in precarious situations at one time or another: Table 4.9 above highlights this as one of the most difficult experiences IFCGs have is constantly found themselves in. One caregiver had two children admitted with painful crises in different wards and both needed her support. Another caregiver shared an experience where one child was sick at home and another admitted in hospital yet she needed to care for both of them. One-woman caregiver had to care for her child admitted in a male ward which she found very cumbersome. This calls for flexibility, quick thinking and action while at the same time becoming innovative to survive the circumstances.

“There was a time one child was admitted in the men’s ward in KNH and I had to take care of the child there. Another time the 3 of my children were sick and admitted at the same time in crisis in different wards. When one died, it was hard and yet another time two babies were sick, one at home and one in hospital.” P2B on 14.7.2016 at Kayole

“When I went to KNH and they put 4 children who were 8 years and above on one bed. One was having a running stomach, the other had HIV and the ward was flooding. I had to discharge the baby myself the next day although the child was still in pain. Sometimes at Mbagathi, I would leave the ward to go to sleep with the baby in the car with the drip after the drugs have been given and the nurses have gone away for the
night. *Sometimes I carried my own painkillers to supplement hospital drugs because chasing after the nurses is more draining. Too many injectable drugs (Pethidine and tramadol) till my son’s legs were getting lame. Lack of knowledgeable medical staff to manage the condition at Shalom. Since then we have always gone to Gertrudes.*” WC16 on 7.6.2016 at Kitengela.

Caregivers have had to balance work and children. Choosing between work and children, the PLWSCD/children always wins but this often lead to job loses as we shall see in 4.3.3 below. On the other hand, caregivers dealt with some medical teams who are not supportive who mishandled them. This will further be discussed under social challenges in 4.3.2 below. As discussed under determinants of choice of hospitals, 38% of IFCGs in table 4.13 below, IFCGs appreciated hospitals with knowledgeable medical teams while 9% appreciated empathetic medial teams. Some of these IFCGs experiences acted as triggers for the psychological, economic and social vulnerability. They shared below.

“She had to go to work and live a small child in hospital when he was less than one year.” M6 on 9.6.2016 at Strathmore
“When my marriage broke.” WC31 on 7.8.2016 at Huruma, John Saga

Reports in other studies have indicated that caregiving burden related to suddenness of the diagnosis, severity of symptoms and changes in the PLWSCD (Alspach, 2009). A study on caregivers in Brazil revealed that. The mean duration of care provided was 16.08 ± 9.88 years and 89.2% reported that they provided 24-hour care (Da Silva et al., 2012). Caregivers of patients with Alzheimer’s, HIV and critically ill patients in the US also saw caregiving as a difficult 24-hour job requiring long term commitment that could expand to take over much of one's life with a substantial toll on the caregiver. This required re-organizing activities in the caregivers life to survive the unpredictable consequences (Center, 2008; Mullan, 1998; Alspach, 2009; Northington, 2000).

### 4.2.8.2 Number of PLWSCDs per Caregiver

In most cases, caregivers have also been the mothers of PLWSCD and therefore carriers of the SCD. In view of this biological-inheritance, the study assessed the number
of PLWSCDs per caregiver. Accordingly, the study established that there were 329 persons with SCD, 151 (46%) girls and 178 (54%) boys.

The study found that there was at least one PLWSCD per caregiver. However, some caregivers had more than 2 to 3 PLWSCD as we saw in table 4.15 below. One caregiver had five children with SCD and three were deceased at the time of the study. Having more than 2-3 children with SCD greatly increases the demand on the caregivers’ time, resources and energy. Some of the households had an average of 3 persons with SCD. A part from the children who had SCD, there are other family members with their own general and unique needs the IFCG needed to attend to as well. If attending to one PLWSCD is one full time job, attending to three required her to spread so thin leading to some things or children being left unattended.

Table 4.15: Number and Gender of PLWSCDs per Household, Nairobi 2016

<table>
<thead>
<tr>
<th>No of PLWSCD/HH</th>
<th>Frequency (N=226)</th>
<th>Percentage (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>226</td>
<td>100</td>
</tr>
<tr>
<td>2</td>
<td>90</td>
<td>40</td>
</tr>
<tr>
<td>3</td>
<td>13</td>
<td>06</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>329</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender of PLWSCD/HH</th>
<th>Frequency (N=226)</th>
<th>Percentage (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls</td>
<td>151</td>
<td>46</td>
</tr>
<tr>
<td>Boys</td>
<td>178</td>
<td>54</td>
</tr>
</tbody>
</table>

The number of PLWSCD in this study are consistent with other studies which indicated that financial stress worsened where there is more than one or two children with SCD in a household, more admissions/hospitalizations and lack of insurance (Adegoke & Kuteyi, 2012; Wonkam et al., 2014; Burnes et al., 2008).
4.2.8.3 Life expectancy in PLWSCD

Morbidity, mortality and life expectancy formed part of the burden for the caregivers. PLWSCDs were predisposed to getting infections that lead to VOCs and frequent hospitalizations. Their life expectancy was unpredictable and most died prematurely. The reality that one can lose their PLWSCD anytime was very frightening and discouraging to caregivers. This constant fear was ranked 3rd among the difficult experiences by 15% of caregivers. In this cohort, 51 (23%) of families had lost one, two or three PLWSCD to SCD complications. Each loss triggered traumatic experiences which affected the emotional wellbeing of the caregivers like the generalized anxiety and stress as will be discussed in section 4.3. Those who have not lost someone lived day by day wondering if their PLWSCD will be next. The fear came from stories of other families who had lost someone, from deaths of other PLWSCDs, within the family or community, from myths or from the personal near death experiences due to various VOC crises or hemolysis. Watching a baby who was struggling to breathe, who was unconscious, with a stroke, with very low blood levels and the hospital is not responsive really put mothers on edge as seen below.

“The day he had fever, convulsed, then got quiet and weak. He could not eat but drunk a little. He stretched. His HB was 2.0. He got emergency transfusion but could not respond. I feared he was dying” WC9 on 12.1.2016 at huruma
“I collapsed and got admitted to ICU. Mother gave up and thought I was dead. The next day I woke. I went out crying after her and collapsed after one minute.” P3, 15.7.2016 at Ziwani
“In July 2011, I’ll never forget. She’d an acute chest syndrome. The heart rate was crazy under 20. She was on oxygen over a week. Antibiotics didn’t seem to change anything. After 1 week, we got another doctor who said there was water in her lungs & required an operation. She was only 4 years at the time. I thank God she managed.” WC4, 12.1.2016, Tasia
“When the baby is sick on oxygen and blood. It frightens me a lot. I imagine he is dying with closed eyes and difficulty in breathing.” WC18 on 6.8.2016at Park Rd
“Once I went to a wedding and returned to find him vomiting badly. He had no blood and his HB was 2.5. He started kicking. That scared me but they managed to transfuse him. I was sure my son was dying.” WC13 on 18.1.2016at Kibra Olympic
4.2.8.4 Increased Caregiving Expenditure

PLWSCDs have additional expenses that the IFCGs had to deal with that they would otherwise not have considered at all if they were not giving care to a PLWSCD. The main additional expense was medication and hospital bills, extra dietary needs, warm clothing and sundry. PLWSCD are required to take different medications on a daily basis when they are in good health to support various body functions for their well-being. These are Hydroxyreaah, Folic, Zinc, Palludrine as anti-malaria prophylaxis and Peniciline-V as prophylaxis against pneumococcal infections. To increase immunity, they require booster vaccinations (Pneumoccal, Typhoid, Meningoccal) to boost their immunity. IFCGs reported that when PLWSCD became ill, they required treatments like analgesics, inhalers, stabilizers, antibiotics and infusions as well as laboratory testing, X-rays and nutrition advice. Other care options included dressing leg ulcers.

Caregivers therefore reported that they incurred expenses that non-caregivers do not worry about. Nairobi having temperatures of 15°C to 30°C, IFCGs aware that the cold is a trigger for painful events bought warm clothes as well as heaters to keep them warm. To stem infections, IFCGs bought water filters to ensure availability of clean drinking water while others boiled their water for drinking, bathing and for hot water bottles which increased the amount paid for utilities, rent and general running costs of the home. Some caregivers shared the statements below.

PLWSCD tended to get sick or in painful crisis erratically necessitating medical attention. They visit hospitals many times both outpatient and inpatient care to treat infections, manage pain and complications and sometimes for routine clinic appointments. When they got sick, they require more medication to treat the infections like antibiotics, antihystamines, inhalers, stabilizers, analgesics as well as other treatments like intra venous fluids, infusions, blood transfusions, X-rays, chellation, and respiratory support, dressing
wounds and operations like hip replacements and splenectomy to name but a few. Being with the patient robbed the IFCGs time to participate in productive economic and social activities.

“I can’t go a day without buying some special thing cocoa, milk, fruits at least 100 per day out of a salary of Kshs 200. I had planned to save 20 bob per day but can’t manage because of pressure.” WC7 on 5.1.2016 at Mathare

“My husband feared children going to hospital because of frequent infections and many drugs to take.” WC19 on 9.8.2016 at Kiambiu

“Meeting other dietary requirements that could not be necessary if the child didn’t have SCD” M3 on 22.3.2016 at Strathmore

“Balanced/special diet for blood like (beetroot, fruits for cleaning blood, healthy foods, finger millet, green vegetables, milk)” WC4 on 12.1.2016 at Tasia

PLWSCD required additional nutritional support and a good balanced diet with additional nutrients like folic to help in the production of blood. Caregivers struggled to buy foods rich in these minerals and fruits to support the health of the child. They also required comforts at home like warm clothing. Some caregivers rented stone houses to accord the patient warmth. IFCGs were willing to pay more for warmer more comfortable houses.

“‘Hii ugonjwa inachukua pesa’ - this disease takes money. One needs money for X-rays, bills; Fruits – nutrition as recommended in hospital not like other kids; warm clothes so he doesn’t get cold; you can’t sit with this child in the cold to do business. It necessitates a warm business premises.” WC21 on 3.4.2016 at Umoja

The average expenditure for urban low income households in the Kenya was KES 16,983 ($153) per month and the expenditure for the caregivers of PLWSCD was KES 31,746 ($286) (KIHBS, 2015/2016). The study assessed the monthly expenditure on one PLWSCD and established that the average expenditure was higher by KES 14,750 ($129) per month. There were 72% of caregivers who spent Kshs 1 – 10,000, 11% spent 10,001 - 20,000, 6% spent 30,001 – 40,000, 2% spent 40,001 – 50,000, 2% spent 110,001 – 120,000 and 2% spent 130,001 – 140,000. The mean expenditure was KES 14,750 which was more than the KES 10,000 that 34% of caregivers earned in one month in figure 4.5 below. The
modal expenditure was Kshs 1-10,000 and the median Kshs 1,458. Majority being 96% of IFCGs did not have medical insurance and paid cash. The 4% who are paid above Kshs. 110,000 had a good medical cover usually paid for by their employers and minimally used their income on the medical expenses.

![Monthly Expenditure on SCD Patient/Month](image)

Figure 4.5: Monthly expenditure on a PLWCS, Nairobi 2016

Figures 4.1 and 4.5 above demonstrated the impact of the medical expenses on household income. 75% of the households earned less than KES 50,000 a month while 72% spent at least 10,000 on SCD alone in a month. This impacts greatly on the HH income as 34% of these earned at most KES 10,000. This means that some HHs needed to pay more than they earned to sustain one dependent medically. Given that most Caregivers in this group did not have medical insurance cover, they basically worked and made money which ended up paying medical bills only. They were also obligated to care for the other children and relatives in the household. There could also be more children with SCD as seen in Table 4.4 above. This traps them into an existence where they feel hopeless and ineffective when the balance of time, finances and mental challenges do not add up rendering her unable to function the way non caregivers do.
4.2.8.5 Discouragement and exclusion

This study established that discouragement and inability to participate in social exchange activities affected the IFCGs mental and social wellbeing. Discouragement came in form of remarks that were disheartening. Some people around the caregiver called the PLWSCD ‘Jamidekre’ – the sick one, ‘Marehemu’ – the dead one or ‘Hi ni kaburi’- this is a grave. Usually the caregivers took this very hard. This was followed by lack of empathy and support

“The time she was told her baby was ‘marehemu’ a walking corpse, it really hurt her. With baby in crisis and the medical staff send her away and not helped. This was said in the worst way ‘hi ni kaburi’ this is a grave, we can’t help you” P7G on 22.7.2016 at Dandora

4.2.8.5 Livelihoods Deprivation

This study established that IFCGs experienced livelihoods deprivation which made them lose hope. This happened as a result of losing or reducing opportunities to participate in livelihood activities. They felt deprived when they experienced reduced chances to work, study or socialize. Other scenarios that caused deprivation included: A caregivers losing a child and when caregivers lacked of medical, social or psychological support. When Caregivers struggled with deaths in the family; when symptoms/complication developed and didn’t go away like leg ulcers or uncertainty over the child’s ability to be independent in future. It made IFCGs to lose hope. They shared the following:

“Mother was not eating well, fearing she would lose me. She also lost hope after I graduated with a 1st class honors and expected me to get a job or go for masters but instead, I got worse, getting sick more frequently. She ’d only peep at me and go, then acted like a confused woman. She asked if I had wronged any lady or if I had any debts ” P5B on 21.7.2016 at Kahawa Sukari

“I had a car accident at 6 years. I didn’t mend well with treatment at KNH. I had to go traditional.” P10 on 9.5.2016 at Kibra, Fort Jesus, Karanja

“I lost all faith and energy when I lost my first born son and when I lost my job after being in hospital HDU for over a month with 2 babies. Colleagues said that I used the babies to go do my private businesses so my contract was terminated.” WC24 on 4.6.2016 at Karen
Inability to work - a caregiver being called from work at any time is stressful and builds up pressure for them. A telephone call stopped them from anything they are doing because they understand the seriousness of the disease. This prevented them from working well as one might not stick to the schedules when they rushed to support the patient. As we will see in 4.3.3 below, colleagues and clients tagged them unreliable and lacking in seriousness at work or thought. IFCGs used the sick children as an excuse to get away from work to do other things creating stigma for the IFCG. It is very stressful for colleagues who know that one has a sickly child to not give support or understand. Inability to work resulted in reduced disposable income as well as reduced networks or relationships. Without income to hire help, the caregiver did all the caregiving by herself increasing the physical strain. Juggling work and care led to emotional challenges. Inability to work therefore exposed IFCGs to economic, social, physical and emotional vulnerabilities as seen below.

“When colleagues don’t help or understand when the child is sick” WC, 3.6.2016, Mathare
“When sick after a good day, it’s stressful and creates pressure. Being called erratically is stressful.” P8G on 25.7.2016 at Dandora

The fourth most difficult experience for IFCGs is finances (13%) as seen in figure 4.13 below. Finances were further discussed in section 4.3.3 below. Lack of adequate finances led to the inability to pay medical bills, afford an insurance cover, or subject the IFCGs to borrowing from all quarters which sometimes affected their self-esteem as they got tagged, stigmatized or socially isolated. The pain tends to come just when one has no money putting caregivers in precarious financial positions. They shared below.

“Financial challenges - We strain to look for money.” M1 on 10.3.2016 at Saïka
“When I was in hospital, money was needed. NHIF was not active. Life was hard. They surcharged me on the NHIF before they accepted to pay.” M5, 14.4.2016 at Mathare
“Being referred with a sick child to KNH & you don’t have money” WC17, 20.1.2016 Baraka
“Once I broke to the core when one child after another started ailing. Everyone said they had no money. I’d to go & borrow in church. It’s like being naked.” WC19 on 9.8.2016, Kiambiu

The socio-economic capacity of the Family played a role in their ability to build resilience towards socio-economic vulnerability. SCD is a very financially demanding condition. It got worse where there are more than one or two children with SCD or when there are two or more hospitalizations (Adegoke & Kuteyi, 2012; Wonkam et al., 2014). This study has shown that most insurance companies do not cover PLWSCD and most parents paid cash with 25% of IFCGs having no experience at all and 27% citing very bad experiences with medical insurance. When insurance is not tenable, the IFCG or their families required a good financial base to manage the frequent bills.

The IFCGs occupation affected their capacity to build resilience or not. Those with high income could hire help and continue working while low income earners had to balance between the job and caring for the child themselves (Mauro et al., 2006). Losing a job compounded their financial challenges. It helped if the IFCGs started giving care when they had some asset base that helped in offsetting the bills. Employment therefore became an important factor in building resilience (Joling et al., 2016). Where the family was supportive and were financially well, the caregiver could stay home to care for the child and still cope. Where the family was not supportive. When the caregiver was single, it worsened their vulnerability. For instance, we will see in this study that when a crisis occurred and there were no funds, caregivers took loans, sold household items, took salary advances or even engaged in illegal activities to raise funds to settle bills. When the caregiver was able to work and raise funds to cover the bills, it reduced their anxiety. On the other hand, material and social support increased her capacity to cope (Atkin & Ahmad, 2000).
4.2.9 Access to Healthcare Services

Accessibility to healthcare services can be viewed with the distance, affordability or availability lenses. Distance refers to proximity and convenience from one’s residence, affordability refers to cost of services provided in the facility while availability refers to whether or not there exists a hospital to go to or not.

4.2.9.1 Determinants for Choice of Hospital

The study assessed the important considerations for IFCGs’ choice of hospital for the PLWSCD. Figure 4.6 below shows the first determinant at 42% being affordability. This was followed by experienced medical staff at 38% and proximity by 28% of IFCGs then well-equipped facilities at 15%. Although the first consideration is affordability, IFCGs hoped that the facility is be accessible and has professional staff, diagnostic equipment and treatment to meet their needs. Affordability and knowledgeable staff and tools went hand in hand as sometimes a knowledgeable trained doctor could not help a patient without required facilities, equipment and medication. It became expensive when doctors kept guessing as time and money were wasted on unnecessary tests and treatments done before discovering the problem, many times with detrimental outcomes. Trained teams gave appropriate, well targeted assistance that ended up being cost effective in the long run. They shared below.

“Gertrudes. I get immediate attention when the child is in a crisis. They are faster in handling Sickle cell patients” WC4 on 12.1.2016 at Tasia
“I had 3 children and I couldn’t afford KNH because of conflicting financial priorities. I needed Kshs 3,000 per clinic and more money for medications and X-rays. Baraka is cheaper as I pay Kshs 300 per child totaling Kshs 900 for 3 children.” WC3 on 8.1.2016 at Huruma
“Mradi/Baraka – they were able to help people with SCD. Here we pay a little and we are given medications.” WC5 on 15.1.2016 at Mathare
“Free medication and ambulance services to KNH” M7 on 4.7.2016 at Mathare NA4A
“Baraka, Tests and treatment are free for children > 5 years.” WC20 on 10.8.2016 at Baraka
“It’s handy, available, near and their services are good.” M9 on 19.7.2016, Nairobi.
The facility might have been in close proximity to the caregiver but if the service fee was unaffordable, they chose hospitals that were further away but less costly. Other considerations included the medical insurance and ability to handle serious admissions. Insurance removed the worry regarding cost implications. However, lack of flexibility of an insurance cover tied a caregiver to a particular facility whether the facility served them well or no. For instance, patients were tied hospitals by NHIF even if the hospitals did not have requisite facilities or medication.

The last consideration was the ability to admit when a PLWSCD who needed inpatient care. IFCGs might would prefer other facility for outpatient management but if it did not have inpatient services, they chose another facility with in-patient care facilities. The hospital could have been accessible, affordable with trained medical teams but the caregiver would choose another facility for inpatient care if the usual facility did not offer these services as shared below.

“I go for specialized treatment (Hematology).”  M2 on 5.7.2016 at Baraka
“When I had good medical cover by an international insurance company, I went to any high end hospitals of my choice. When I lost my job, I went to Mater where my husband’s company paid or Strathmore medical Centre because they are specialists and I am willing to pay cash for faster well targeted service. Strathmore had discounts for SCD patients on Tuesdays at the time of the study and we paid only Kshs 300 then.” WC24 on 4.6.2016 at Karen

“Nairobi or Agakhan. I had a good medical cover that works for both inpatient and outpatient. Nairobi was near where I used to stay” WC26 on 10.2.2016 at Jamuhuri

“Gertrudes. The payments are covered by Britam Insurance for the company where my husband works.” WC on 8.6.2016 at Limuru

“Shalom or Gertrudes in Kitengela Proximity and accessibility.” WC16 on 7.6.2016, Kitengela
Studies have shown that most African countries lack basic facilities, diagnostic tools and qualified medical personnel to manage SCD leading to misinformed, misdiagnosed or mismanaged patients with detrimental results (WHO Africa, 2010). Availability, accessibility and affordability of medical care affect caregiver’s vulnerability. Kenya like most African countries lack trained medical personnel, diagnostic tools and treatment for SCD leading to 50 – 90% under five mortality rates (WHO Africa, 2010; Grosse et al., 2011).

In this study, caregivers took into consideration affordability, accessibility, trained empathetic medical teams, availability of diagnostic tools and treatment as well as medical insurance and inpatient facilities while choosing hospitals. Hence, there is need for the cost of healthcare to be affordable or free so as encourage IFCGs to take their children to scheduled clinics and to hospital for treatment when need arises. As we have seen above, trained medical teams are more humane while handling patients and caregivers. There is therefore need for all-inclusive, well equipped but affordable medical facilities close to the affected people with trained empathetic medical teams. The insurance companies need to give flexibility in the choice of hospitals to be useful to patients.
Premature deaths cause anxiety as do painful events that are not be managed professionally and with compassion. IFCGs having to give direction to the doctors who are not familiar with treatment of SCD is very frustrating (Burnes et al., 2008). Other caregivers may not know how to articulate what they need. Trained medical personnel are able to provide support, useful information and counselling to caregivers reducing their frustrations and enabling coping through awareness, psychological and financial support (Brown et al., 2010). To caregiver’s vulnerability, there is need for comprehensive SCD management centres that are affordable or subsidized.

4.2.9.2 Distance to the Nearest Preferred Hospital

The study assessed the distance that IFCGs covered to access healthcare services for the PLWSCD. The mean distance covered by patients is to hospital is 6.2kms (Figure 4.7).

Proximity had cost implications in terms of transport and accessibility. A hospital that was near someone’s home was convenient as it could be reached faster. The level of stress and anxiety experienced in traffic was reduced as well as well complications that arose in choosing the mode of transport or route. During extreme emergencies, the patient had a better chance of survival if the hospital is easily accessible. Convenience was important as a mother might have needed to care for the child in hospital and also check on
the children at home when need arise. In the event that one needed to send for something back home when admitted, it was easier to do so if the facility was not too far from home. It was also easy to ask a neighbor to take one’s child to hospital if it was close by. Comprehensive management centers therefore needed to be in close proximity with caregivers. A hospital might have been near but if it was not affordable and did not offer desired services or had diagnostic tools and treatment, the caregiver opted for a facility that was further but which offered the care they needed at affordable cost.

4.2.10 Gender Equality in Caregivers of PLWSCD

The caregivers of the persons with SCD were assessed in respect to primary caregivers, gender representation and responsibilities,

4.2.10.1 Primary Caregivers of Persons with SCD

In this section, the study assessed the primary provider of the PLWSCD in Nairobi, Kenya. Outcomes indicated that 71% of the primary caregivers were mothers, 19% shared roles and 10% included fathers, sisters and grandmothers (Figure 4.8). Most of these women happened to be mothers and the men also happened to be fathers to the PLWSCD. Other caregivers were spouses.
From the figure 4.8 above, the majority of caregivers of PLWSCD were women. The women were not able to avoid caregiving responsibilities since they felt it was their prescribed gender role. Working women caregivers provided both the financial support and also did all the physical work especially if they were not able to hire help. The WCGs reported that their husbands removed themselves from the center of care claiming psychological intolerance to the child’s challenges which they expected the women to weather alone. That sometimes fathers hide behind the formal work or work outside the home to avoid the caregiving work. These dads gave only financial support but left the bulk of the physical care work to the mother. The WCGs had no luxury of escapism as their male counterparts did. For 24 hours, seven days a week, they were available when the PLWSCD called.

“Mother - Dad is affected psychologically and is sad because of not knowing what to do.” P1B on 13.7.2016 at Saika

“When younger, mother provided the main support.” WCG26; 10.2.2016 at Jamuhuri

“Mother - Dad lived in Nairobi because he worked there and mother lived in the village with me.” P3B on 15.7.2016 at Ziwani

“Mother - but dad supports financially. Buys food and pays bills. He is never hands on.” WCG21 on 3.4.2016 at Umoja
Women caregivers reported that their husbands slept through the painful crisis or asked the mothers to move to other rooms or go outside with the ‘noisy’ child. Some WCGs reported that their husbands took other wives as a ‘sanctuary’ to run to when they wanted peace. These WCGs also reported that their husbands would not stay in hospital with the child when admitted. On the other hand, WCGs would give up their work and social commitments to stay in hospital and all the husbands did was to drop them off at the hospital. That some fathers did not even visit in hospital when the PLWSCD was admitted. Some WCGs reported that their husbands blamed them for the errant gene to avoid responsibility or used it as a reason to leave the marriage entirely leaving WCGs to be single parents. There was only one mother who left the child with the husband and got married elsewhere. They shared below.

“Mother hee! Even if I am far, I am the one to be called.” WCG8; 10.1.2016 at Kamulu

“Mother, my husband left; I do everything, school and all. He left when the 1st born was in class 7” WC8 on 11.1.2016 at Baraka

“Mother, when the child cries, the dad asks me to go outside or downstairs.” WCG12 on 13.1.2016 at Komarock

“Mother, women sit up all night and the men sleep.” WCG32 on 14.2.2016 at Mathare

“Mostly mother but both cared for me except when dad was at work. He would wake up and even take us to hospital.” P3B on 22.3.2016 at Ziwnani

“Mother, dad never cared unless it was critical.” WC30 on 13.2.2016 at Mathare

Where mothers were not present, the grandmothers or sisters to the PLWSCD took on the caregiving responsibility and became the main caregiver. This happened only when there was some unfavorable situation at home like when the mother was incapacitated or absent. In this study one grandmother took responsibility when the daughter abandoned her child with SCD and got married because she could not deal with SCD as shared below.

“Sister when sick because the mother is incapacitated.” M9 on 19.7.2016 in Nairobi

“Big sister, when my mother went to the village and the climate at home was too harsh for me. I was brought to my sister’s house in Nairobi. My mother however keeps checking in” P7G on 22.7.2016 at Dandora.

“The mother, my daughter doesn’t care so I take care of my grandson.” WC22 on 3.6.2016 at Mathare
In this study, the men (father) and women (mother) shared the caregiving responsibilities equally in 19% of households. They took turns in caring for the child physically at home as well as taking the PLWSCD to hospitals. They shared the following.

“When my husband was alive, he was very supportive. He even went to hospital with us and took leave to care for the child” WC10 on 14.2.2016 at Komarock

“We help each other equally but mother takes her to clinics.” M7; 4.7.2016 at Mathare

“50/50 both mother and dad equally. Dad was very busy but would come. He was equally concerned.” P4G on 20.7.2016 at Karen IPR.

“I do ‘Jua Kali’ and sometimes she’s not around and I may have time. I call, she calls.” M1 on 10.3.2016 at Kariobangi South

This study established that only 4% of IFCGs were fathers as the primary caregivers. This occurred when there was some special reason. One father opted to live with the child/PLWSCD in Nairobi to access medical facilities because the rest of the family lived in the village and he couldn’t afford to bring the whole family to Nairobi. The 2nd father was the main caregiver because of the wife’s work demands. The wife had a better job and brought home more money so he decided to support her.

“Mostly the father because I was working. When I stopped working, I took over. We stopped finding house helps long ago. WC14 on 6.8.2016 at Kayole

These outcomes were consistent with previous reports (Kuerten et al., 2020; Madani et al., 2018). Indeed, Madani et al reported that out of 277 caregivers, 87% were women mostly mothers and 13% were men, mostly fathers. We have indicated that women, all over the world, have been predominant providers of informal care for members of the family with chronic medical conditions (disabilities) including the elderly and adults with mental illnesses (Sharma et al., 2016). While caregiving is expected to be carried-out by the family members, women have largely been over-represented (Patil 2018; Asuquo, 2017; Sharma et al., 2016).

Women are expected to give care to children, weak or sick members in the home as a prescribed societal gender role which they perform due to their socialization (Bandura,
Mothers accepted their husbands’ avoidance and took caregiving as their duty or prescribed gender role (Atkin & Ahmad, 2000). In Kenya too, caring for children is a woman’s gender role which they perform without demanding for support from their spouses (Marsh et al., 2011; Muchangi, 2014). Over 75% of caregivers are women (Rodríguez-Madrid et al., 2019; DeSilva et al., 2008). In Turkey, 97% of women did not get any support from spouses (Karadağ et al., 2018). In Chile, health related caregiving tasks at home are done mostly by women throughout their lives regardless of their economic or social status (Mauro et al., 2006).

In most cultural practices, a family is usually considered as a social unit of production, consumption, reproduction and accumulation governed by a given set of cultural and socio-economic practices. The prevailing cultural and socio-economic system has delineated division of labor to members of the family (households) including caregiving to the vulnerable (or sick) member of the family. Accordingly, the normative role of women extends from production, consumption, reproduction, to nurturing of infant and sick members of the family (Kuerten et al., 2020; Kalomo et al., 2018; Evans & Thomas, 2009; Bigombe & Khadiagala, 2004).

Other sources have maintained a view that in most of the African societies, care work has remained highly gendered, with women and girls considered as the primary providers of caregiving because of their assumed natural ‘roles as nurturers’ (Evans & Thomas, 2009; Robson, 2004). Caregiving has therefore been conceptualized as a moral duty, founded on love, emotional attachments, reproduction-relation and reciprocal kinship responsibilities, rather than monetary exchange (Becker, 2007). Still others maintain a view that mothers have a special relation to the PLWSCD creating an involuntary compulsion to provide care including seeking for treatment, providing required support and meeting necessary socio-economic wellbeing (Ali et al., 2017).
Similarly, prevailing cultural and socio-economic system has delineated division of labor to members of the family (households) including caregiving to the vulnerable (or sick) member of the family. The role of the men has tended to emphasize production, consumption, reproduction and socio-economic security (Kuerten et al., 2020; Kalomo et al., 2018; Evans & Thomas, 2009; Bigombe & Khadiagala, 2004). However, this role needs to be expanded to include equal nurturing of infant and sick members of the family.

4.2.10.2 Type of Support Given by Men

The study assessed the support women caregivers received from their husbands particularly when the child was ill in crisis. Table 4.16 below shows that 45% reported that the husbands mostly gave financial and occasionally moral support, 32% reported sharing responsibilities, 17% of respondents did not receive any support from their husbands even when there was a crisis.

<table>
<thead>
<tr>
<th>Support given by husbands when the PLWSCD is sick</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial and moral support only</td>
<td>102</td>
<td>45</td>
</tr>
<tr>
<td>Shared responsibilities equally</td>
<td>72</td>
<td>32</td>
</tr>
<tr>
<td>No support given</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>No response</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

There were 17% of women caregivers who did not get any support from their husbands at all even when their child got sick. The men did not get involved with the child to provide either physical or financial support. They shared the statements below.

Zero, Father does not even visit in the ward to just see the child. He has a car but can’t even carry us to hospital.” WC12 on 13.1.2016 at Komarocks
“Nothing, he visits once and disappears. Sometimes he helps financially and sometimes not. Depends, once in a while he can take me and help carry the child.” WC3 on 8.1.2016 Huruma

“If he gave any financial support, it was very little; he would not sleep with the child in hospital.” WC9 on 12.1.2016 - Huruma

Majority of men (husbands) at 45% mostly gave financial and moral (emotional/psychological) support. The men were not physically involved with caring for their children even when they were sick and in a crisis. The finances they provided went towards supporting purchase of food, drugs and paying hospital bills. The moral support involved praying together, visiting in hospital, encouragement and advice. Some fathers gave only moral support. This still left the gruesome job of lifting, bedpans, soothing, administering medication, reminding of routines and staying in hospital to the woman. They share the following statements.

“Mother takes front line and pays all bills. When he visits in hospital he sits in the car. During the last admission, he discharged me for the very first time.” P5, 21.7.2016 Kahawa

“Financial support; advice and prayer – he is obsessed with prayer.” P1 on 13.7.2016 - Saika

“Laughs” ... maybe money. Sometimes he complains “kila saa ugonjwa, ugonjwa” - all the time sickness, sickness and only helps when it’s too critical. WC30 at Mathare

“Paid hospital bills, bought food, paid for drugs, took me for trips to just hang out.” P3 on 15.7.2016 - Ziwani

“Ensures we get to hospital. He visits like once in two weeks.” P2, 14.7.2016 – Kayole

The respondent reported that during a crisis, both the man and the woman shared responsibilities equally in 32% of the homes. They shared in the caregiving work which included fully participating physically in the care, assisting with hospitalizations as well as financial and moral support as seen below.

“When he was alive, he was very supportive, we went to hospital and stayed in the ward together till the child was stable. At home he woke up to check on the child.” WC4 on 12.1.2016 at Tasia

“My husband gives much support to his son as he stays with us in hospital when he is admitted” WC1 on 5.1.2016 at Donholm
"My husband has always been there in all ways. He provides and participates." WC29 on 15.5.2016 at Buruburu

4.2.10.1 Secondary Caregivers of Persons with SCD

The study assessed who the secondary caregivers were and responses indicated that they included teachers, paid house helps and clinical officers. Hired helps were useful especially when the mothers were away from home. They gave care because they were paid to do so. Caregivers who hire help highlighted the value of getting a good and reliable person to stay with the baby while they worked. Teachers are also very helpful when the child is in school. When teachers are caring, it makes the mothers more at ease and very grateful. Caregivers whose children got support from teachers or other social spheres did better than those who did not as seen below.

"Teachers were very supportive. He finished school even college. He got stroke at age six but has gone through school because of that support." WC26 on 10.2.2016 at Jamuhuri.

Parents with children who have SCD wished for their children to be in schools where people are more caring to be sure their children were being watched. This is usually a challenge in public schools with many learners. Parents preferred private schools with a few children to guarantee the attention but many were not able to afford the fee since it is usually higher especially when resources were exhausted taking care of medical expenses for the PLWSCD.

"One may use up funds for other children’s school fees to pay medical expenses." P1B on 13.7.2016 at Saika

The family structure and support systems affects resilience in IFCGs. In this study, the 17% of women caregivers who got help in paying medical bills and 19% who got support from their husbands and family members were not overburdened by the caregiving work. On the other hand, the 71% who did not get any help at all from spouses or family
members felt more burdened. There are families who worked together and supported one another while other family structures were such that everyone was on their own. Some husbands attitudes even undermined the wives ability to cope (Burnes et al., 2008). For instance, husbands who saw the woman as wasting money on a child that will just die were not supportive especially when the women were not working. When the WCG had income, she commanded some respect from the husband. WCGs in families that worked together seemed to be more resilient than those in families that did not. Among caregivers of dementia, social and community resources like social support and regular help from family members and friends helped women caregivers to remove the feeling of loneliness (Joling et al., 2016). It is vital to sensitize families on SCD and the importance of supporting affected family members. Caregiving therefore impacted women’s status as equal citizens when burdens are unequally shouldered (Parks, 2010).

4.3 Psychosocial Economic Vulnerability of IFCGs of PLWSCD

In this section, the study assessed the psychosocial economic vulnerability of the IFCGs specifically, the way characteristics of the SCD and related caregiving had influenced the psychosocial and economic vulnerability of the IFCGs. The psychosocial and economic vulnerability were assessed in terms of negative mental outcomes, physical health outcomes, social deprivation and exclusion and socio-economic deprivation. Caregivers responded to the three dimensions of the psychosocial economic vulnerability as follows.

<table>
<thead>
<tr>
<th>Dimensions of the psychosocial economic vulnerability</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health vulnerability</td>
<td>59</td>
<td>26%</td>
</tr>
<tr>
<td>Social deprivation vulnerability</td>
<td>54</td>
<td>24%</td>
</tr>
<tr>
<td>Socioeconomic vulnerability</td>
<td>113</td>
<td>50%</td>
</tr>
<tr>
<td>Total (N=226)</td>
<td>226</td>
<td>100%</td>
</tr>
</tbody>
</table>
4.3.1 Mental and Physical Health Outcomes

The literature and theoretical perspectives indicated that caregivers of persons with chronic disabilities have been associated with mental illnesses; largely because of prolonged and intensive caregiving (Schulz & Eden 2016; Borbon, 2014; Adegoke & Kuteyi, 2012; Alspach, 2009). The 1st component of the third objective namely to assess the psychosocial economic vulnerability of caregivers was to assess mental and physical health outcomes. In conventional practice, three dimensions of mental illness have been identified namely depressive disorders, anxiety disorders and stress all of which have been considered to be conceptually distinct ‘separate and different’ (Kuerten et al., 2020; APA, 2017; Adzika et al., 2017; Adegoke & Kuteyi, 2012). Accordingly, the indicators of the three dimensions were pre-categorized to make it easier for respondents.

Caregivers reported that they experienced mental health challenges. Out of the 59 (26%) caregivers with mental health challenges, 47% of them experienced Depressive Disorder Symptoms (DDS), 36% experienced Generalized Anxiety Disorders (GADs) and 17% had stressful dispositions as summarized in the (table 4.16) below.

<table>
<thead>
<tr>
<th>Types of Mental Health Challenges</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depressive Disorders (DDS)</td>
<td>28</td>
<td>47</td>
</tr>
<tr>
<td>Generalized Anxiety Disorders (GAD)</td>
<td>21</td>
<td>36</td>
</tr>
<tr>
<td>Stressful Dispositions</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>59</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

These findings were consistent with studies that have reported that the extended and intense role of informal caregiving created physical and psychological strain, accompanied by high levels of unpredictability (Schulz & Eden, 2016; Borbon, 2014; Schulz & Sherwood, 2018). The mental health challenges were discussed further below.
4.3.1.1 Depressive Disorder Symptoms (DDS)

Caregivers reported depressive disorders that included (i) exhaustion, (ii) discouragement, (iii) self-pity, (iv) bitterness/anger, (v) lack of peace, (vi) withdrawal, (vii) sorrow, (viii) helplessness and (ix) struggle to accept the existence of SCD itself in the family.

The caregivers reported that various aspects of caregiving of PLWSCD led to exhaustion. Key aspects included long hours of caregiving, severity and frequency of episodes, distance to hospitals and dependency. Specifically, caregivers reported that the inability to do something useful to ease pain during a crisis triggered helplessness. Helplessness came with depression, sympathy, empathy, getting emotional and losing faith. Many IFCGs got emotional and just cried in situations that were out of their control like being in a hospital where medical personnel were not helpful, when caregivers lacked funds and the PLWSCD could not be treated without money or when a PLWSCD screamed relentlessly and they couldn’t alleviate that pain. They also reported feeling helplessness when denied permission at work to go to a child in crisis. They shared the following statements.

“I was 35 years but I changed one would think I was much older. It bothered me. That time we did not even have motor bikes. I used to carry the baby every week 5kms to hospital. I changed. I wished I didn’t live.” WC25 on 8.6.2016 in Limuru
“Depressed and down. There is misery in the family.” P2B on 14.7.2016 at Kayole “Desperate, angry, frustrated. I think of the last time it happened and now it’s happening again. “When I am told he’ll die early, it affects me. I lack peace.” WC32 on 14.2.2016 at Mathare
“I’m hardened when situations require emotional exhibition.” WC26 on 10.2.2016 at Jamuhuri
“I fear being locked up/confined in hospital during admission for 2-3 weeks. I feel frustrated, caged and desperate.” WC24 on 4.6.2016 at Karen
“Apathy - I feel completely helpless. WC16 on 7.6.2016 at Kitengela”
4.3.1.2 Generalized Anxiety Disorders GADs

Caregivers reported that they endured a lifetime of anxiety disorder symptoms which reflected in form of (i) constant apprehension (ii) worry and panic attacks (iii) impaired social and occupational areas of functioning (iv) feeling tied down (v) irritability (vi) sleep disturbances and (vii) difficulty concentrating.

The caregivers reported that various aspects of caregiving of PLWSCD led to various dimensions of Generalized Anxiety Disorders (GADs). Among the key aspects that were associated GADs included long hours of caregiving, severity and frequency of episodes, distance to hospitals and dependency. Caregivers feared the vaso-occlusive crises or premature deaths, infections, their children marrying other carriers to perpetuate the SCD gene, getting another child with SCD, stigma, their children’s’ growing into maturity, non-achievement developmental milestones and independence. Some of the caregivers said the following.

“When she’s in pain, I worry for the worst – death. I sleep with her when in a crisis so I can keep checking heart beats, pulse etc.” P7G on 22.7.2016 at Dandora
“Thinking of her early passing makes me withdrawn and disoriented” M3 on 22.3.2016 at Strathmore
“I think a lot... Myths about how they die young makes me fear. I would like her to give birth.” M4 on 4.4.2016 at Gikomba
“I fear him being away. That I may make a mistake & he dies.” WC29; 15.5.2016 Buru
“I am pained. I’ve only one child and fear he may not reach 17 years. My 2nd child died. I don’t see a future. I lose hope because I am not conceiving.” WC13; 18.1.2016, Kibra
“With 3 out of 5 children dead and 2 with SCD remaining, I feel I am alone. When any of them gets sick, I fear she might die too. I wonder when these two will die. People also discourage me with comments.” (Weeps) WC3 on 8.1.2016 at Huruma

The study established that 23% of IFCGs had lost a loved one to SCD with some caregivers having lost two or three PLWSCDs. According to verbatim reports, women caregivers especially worried about where to bury their PLWSCDs disowned by fathers when they died. In addition, verbatim reports indicate that caregivers who had lost children worried more than those who had not. Further the verbatim reports indicated that mothers
who were not able to conceive other babies worried that the one they had might die leaving them childless. They also reported worrying about running errands with a calm mind fearing something bad might happen when they were away. Caregivers reported going through life thoughtful, discouraged, feeling low and fearful that they may never see their children get married to give them grandchildren. These experiences made them to take desperate measures like visiting witchdoctors, traditional healers or people of different religions for help. They reported that they would abort if they had an opportunity to do so. Caregivers reported that they worried about their children getting infections when they mixed with others. Some of the caregivers stated that.

“No, I will abort even if it’s against the law, even if it kills me!” WC19; 9.8.2016 Kiambiu
“No, I can’t bring him to the world to suffer. Why can’t this ‘abortion’ be possible here in Kenya?” WC32 on 14.2.2016 in Mathare
“I got babies after many miscarriages and desperation. I would hold onto any baby however they are.” WC24 on 4.6.2016 at Karen
“I would not link up with another carrier” M6 on 9.6.2016 at Strathmore
“Even if they put a million shillings on the table, I can’t carry a carrier. I’ve even told my daughter to ensure she checks her genotype before marriage.” WC3 on 8.1.2016 at Huruma

Caregivers reported that they worried about the children’s puberty, periods, beards and child birth especially girls. That they worried about major symptoms like stroke which impaired their mental and physical functioning permanently. Caregivers reported worrying for lack of knowledge about SCD which triggered stress, depression, loss of appetite, restlessness, misery, confusion, helplessness, confusion, terror and feeling that life is not fair. They reported reacting with desperation and anxiety when they lacked of resources for recurrent medical bills, for transport, medications, nutrition and a comfortable living environment wished SCD was a physical blemish like a disfigured body part, not requiring hospitalization all the time. Some caregivers shared the following.

“She is terrified, worried & confused what will happen next.” PWC212G on 9.8.2016 on Dandora
“The crisis pain that doesn’t respond to drugs and the baby is hurting. I never saw such pains before. I wish I could take the pain to relieve the child.” WC27 on 5.4.2016, Ngomongo

“Sometimes when she is sick, I feel so low especially when I have no money. I worry because she needs immediate attention.” M9 on 19.7.2016 at Nairobi CBD

“She worries about his inability to do things his age mates are doing like going to college, marrying and working because of the stroke.” WC26 on 10.2.2016 at Jamuhuri

“She worries about my virility, my employment, where I’ll live and wishes for me to marry a caring woman preferably a medic or a teacher.” P5B; 21.7.2016 Kahawa S

This study revealed that caregivers experienced stigma that proliferated from PLWSCD when they were stigmatized evoking negative emotions. Caregivers also reported feeling irritable to insensitive comments or when systems like hospitals failed to handle a crisis. They reported experiencing sleep disturbances during a crisis while supporting patients rubbing to soothe pain, monitoring medical equipment or treatments. Prolonged crises badly affected their sleep cycles leading to exhaustion and difficulty concentrating. They stated below.

“I feel frustrated, disoriented and desperate. WC24 on 4.6.2016 at Karen

“It pains; I can’t concentrate nor go to work.” WC12 on 13.1.2016 at Komarocks

“I Felt bad when my boss told me to pay nannies better to improve care to prevent their wellbeing. He asked me to stop having babies if they would have SCD and take up organizations valuable time and to better take charge of my home” WC24 on 4.6.2016 at Karen

4.3.1.3 Stressful Dispositions

Caregivers reported that they experienced stress in form of (i) stressful routines, (ii) self-negligence, (iii) shock, (iv) denial, (v) physical pain like stomach ulcers, (vi) restlessness, (vii) indecisiveness, (viii) regrets and (ix) feelings of guilt.

The caregivers reported that various aspects of caregiving of PLWSCD led to stressful situations key aspects included long hours of caregiving, severity and frequency of episodes, distance to hospitals and dependency. That the IFCGs not only neglected themselves but also their spouses and other children in the household. More specifically, caregivers indicated that stress was triggered by awareness of the caregiving responsibilities that
awaited them, reports of the deceased PLWSCDs, lack of support in caring for the child at home, traumatic events, inadequate finances for perpetual bills, inability to work to generate the much needed income, stigma and social isolation, lack of adequate medical support, dealing with erratic painful events and being in a perpetual state of hypervigilance as they tended to be overprotective of the PLWSCD.

“When my son of form 4 died, I came home and found my daughter sick too. I was thinking a lot, I had lots of tension after the funeral. I left one child in the house as I took the other to hospital. I lost it, I got into shock, I had no energy, and I was disoriented. I was diagnosed with stress. I blacked out from 2.00 pm – 10 pm. The stress continued. The Baraka team counseled me for quite a while. Time to time, I still go for counseling whenever stress comes. It’s not anything anyone can help with, even a sister.” WC3 on 8.1.2016 at Huruma

“When I was in HDU and needed deposit of Kshs 400,000, I shed tears. I really became emotional.” WC17 at 20.1.2016 at Baraka

“Total devastation, I had lost a sister in form two and believed people with SCD died. I held my son but cried for him as if he were not there already” WC24; 24.6.2016 at Karen.

Verbatim reports also indicated that IFCGs struggled to trust other people to care for the child because of their ignorance or their thinking that the child is pampered. They also reported that dealing with untrained medical teams who needed to be told by the caregiver how to assist or when turned away with the PLWSCD in pain was stressful. IFCGs especially women caregivers reported experiencing stress when blamed for the child’s condition. Others reported that they regretted marrying their spouses who were carriers and felt guilty when they wished their PLWSCD died to end the painful cycles. Some caregivers reported experiencing denial and calling SCD witchcraft, took the PLWSCD to witchdoctors or moved from one hospital to another hoping for different results. They shared below.

“‘Ni uchungu saana na ni vigumu!’ - It is very painful and it is hard. It is even hard to explain. You don’t know how to start. It’s as though you have reached the end. There is no help and no one can change the situation. There is no break. One has no surety of getting a child without SCD after getting five. Children just dying...When my son in form four died, I lost it. ‘Ni uchungu, ni uchungu sana watoto Kukatika tu!’ – It’s very painful. Children just dying... He was big and he just died!” WC3; 8.1.2016 at Huruma
“I was shocked, scared and angry. I cried a lot when the doctor said there’s no cure and explained the risks. I thought he would die immediately.” WC26; 10.2.2016 at Jamuhuri
“Shock, denial and refused to be part of the story.” WC31 on 7.8.2016 Huruma – JS
“We were in denial. We went to 3 hospitals before accepting.” WC412, 1.2016, Tasia.
“My husband’s side asked ‘which disease is that? It’s not in our place’” WC9 on 12.1.2016 at Huruma
“Mom regrets marrying my father! There is no peace” P1 on 13.7.2016 at Saika
“I wish the child didn’t have pain or I wish he just died.” WC23 on 9.2.2016 at Mathare

4.3.1.4 Physical Health Outcomes

During the assessment of the mental health outcomes, it emerged that a considerable proportion of the caregivers experienced physical health vulnerability as a result of their caregiving responsibilities. Indeed, out of the entire sample of 226 caregivers, 42% reported experiencing negative physical health outcomes.

Part of the physical health challenges reported by caregivers included weariness/fatigue; cardiovascular complications such as stroke, tension headaches and hypertension; sickness, pain and discomfort; stomach ulcers, muscle and bone pain; losing or gaining weight and general malaise. Caregivers reported that they physically they experienced weariness from prolonged and intensive caregiving of PLWSCDs. Specifically, caregivers reported that part of the physical health challenges arose from long hours of caregiving, overexertion, attending to strenuous situations or assisting the patient to move. Although some health challenges were reported to have occurred prior to caregiving, the responsibilities of caregiving compounded their effects for example, stress heightened stomach ulcers. Caregivers reported that the pressure of caregiving made them to have a tendency to ignore some of their own physical health problems. Caregivers reported that fatigue was sometimes accompanied by weight loss, nutrient deficiency and dehydration. Some informants stated the following.

“When the child is in crisis, I feel all the pain the child is feeling.” M4, 4.4.2016, Gikomba
“My mother is sickly herself. I used to stress her. She put aside her own illnesses to care for me.” P6G on 6.6.2016 at Tasia
“She developed hypertension after getting this child.” M8 on 12.7.2016 at Rongai
“The stress caused me to have a mild stroke which affected my health. I still have high BP and live on perpetual medication and therapy.” WC14 on 6.8.2016 at Kayole
“I had been in St. Mary’s hospital and had donated blood. I was hungry and I did not even have bus fare. I felt so lonely. I fainted on the road. WC19 on 9.8.2016 at Kiambiu
“My mother is forced to carry me on my back to hospital which is very far. This weight caused her back pains, hands, and legs because of trekking 5kms. When admitted, she carries me around to toilets which cumulatively impacted her.” P1B on 13.7.2016, Saika
“Sometimes they don’t sleep waiting for my admission.” P5B on 21.7.2016 at Kahawa
“I got stressed and I can’t even eat. I am tired emotionally, psychologically. I am now a size 10 down from size 16.” WC12 on 13.1.2016 at Komarocks
“I became sick and very tired living through their painful crisis. I have to be there rubbing them, holding them, giving them bed pans, screaming at medical staff who don’t seem keen to do the right things.” WC24 on 4.6.2016 at Karen
“I empathize.” “I actually go into labour pains. I cry.” WC4 on 12.1.2016 at Tasia
“I have ulcers which get worse when the child is sick. M7 on 4.7.2016 at Mathare N/A4B

The above results were consistent with the previous findings particularly in respect to mental health challenges characterized stress, anxiety disorders and depression disorders (Schulz & Eden 2016; Borbon 2014; Adegoke & Kuteyi, 2012; Mbugua et al., 2011; Alspach, 2009; Schulz & Sherwood, 2018; Center, 2008; Anie, 2005; Theis et al., 1997; Burnes et al., 2008). A study in Kenya reported that half of the women caring for children with intellectual disability were found to be at risk of clinical depression and anxiety (Mbugua et al., 2011). Some of the studies reported that caregivers experienced frustration, stress from duties, longing to return to normalcy, depression over lost opportunities, lowered life satisfaction, disillusionment over lack of understanding, sleep disturbances, anger, psychological distress, emotional exhaustion, stigma, fear of contagion and uncertainty about the direction of the disease (Alspach, 2009; Theis et al., 1997). Other reports indicated that caregivers became sick from stress and even got hospitalized for depression (Anie, 2005; Center, 2008).

Studies have reported that caregivers portrayed stressful routines consumed by the child's illness and neglected their own wellbeing (Burnes et al., 2008). The index of stress increased with the caregivers who had limited support such as the single, female, with low
education level or if the number of children cared for were more than three (Adegoke & Kuteyi, 2012). Reports indicated that incidences of stigma triggered psychological health challenges (Adegoke & Kuteyi, 2012). Other reports indicated that exposure to jarring traumatic events, such as watching a loved one die suddenly or witnessing their struggle with excruciating pain made IFCGs to develop post-traumatic stress disorder whose symptoms could lead to impairment in social, occupational and other important areas of functioning of the caregiver (APA, 2017).

Observations in respect to physical vulnerability was consistent with other studies (Alspach, 2009; Theis et al., 1997; MetLife, 2020; Center, 2008; Mullan, 1998; Frey, 2009). A 1999 study in the US reported a 63% higher mortality rate in caregivers than non-caregivers (MetLife, 2020). Another study rated caregiving as a difficult 24 hour job requiring long term commitment that could take over one's life with a substantial toll on the caregiver (Center, 2008; Mullan, 1998). These studies have emphasized experience of declining physical health, higher mortality, sleep disturbances, development of chronic conditions themselves and chronic fatigue by the caregivers. Other studies reported that caregivers developed diseases such as hypertension, heart disease, migraines and low immunity because of lack of exercises, unhealthy eating habits among others (Frey, 2009).

In view of the above, the study concluded that there was association between the caregiving of PLWSCDs and the negative mental and physical health outcomes.
4.3.2 Social Deprivation and Exclusion

Studies have reported that severe and chronic diseases have been associated with extended caregiving and social deprivation of the IFCGs. Accordingly, the 2nd component of the third objective namely assessment of psychosocial economic vulnerability of caregivers was to assess the dimension of social deprivation and exclusion.

4.3.2.1 Dimensions of social exclusion and deprivation

Caregivers reported varied forms of social deprivation and social exclusion across various dimensions namely individual, spouse, family and the workplace and the responses were as summarized in the table 4.19 below.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work place</td>
<td>16</td>
<td>29</td>
</tr>
<tr>
<td>Family Level</td>
<td>12</td>
<td>22</td>
</tr>
<tr>
<td>Intimate Relations</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Individual Level</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Community</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td><strong>54</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Responses indicated that social economic deprivation and exclusion occurred at the workplace 29%, family level 22%, intimate relations 21%, level, individual level 17% and community level 11%. Key informants reported that the individual level, IFCGs lacked of time to socialize, missed functions and had to explain the PLWSCD’s body image issues leading to stigma and social isolation. Also, the key informants reported that at a family and community levels, IFCGs reported blaming, rejection, stigma, isolation, hatred and lack of support. Similarly, the key informants reported that at work, caregiver’s relationships with colleagues or clients were affected.
Caregivers reported various forms of social deprivation and exclusion that included:

(i) lack of support, (ii) stigma, (iii) social isolation, (iv) Blaming (v) Indifference (vi) Rejection (vii) broken relationships, (viii) being manipulated (table 20) below.

Table 4.20: Key indicators of social deprivation and Exclusion, Nairobi 2016

<table>
<thead>
<tr>
<th>Key indicator of social deprivation</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of support</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td>Stigma</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Blaming</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Indifference</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Rejection</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Broken relationships</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Feeling Manipulated by the PLWSCD</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>54</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The leading indicator of social deprivation was lack of support (30%) followed by stigma (23%) and social isolation (19%). This was consistent with other studies that have reported social deprivation of IFCGs (Madani et al., 2018).

Among the 30% who reported lack of support referred specifically to limited support at various dimensions. Specifically, the FGDs reported that some husbands supported the women caregivers financially but others did not and left them to carry the whole burden alone. IFCGs reported that they had challenges relating with colleagues at the workplace because of their lack of understanding of the nature of the caregiving of a person with SCD; which affected mostly women caregivers. It included the experience of WCGs being backbitten by colleagues who expected them to organize their schedules and to meet their obligations. The caregivers in businesses reported being judged by clients as unreliable due to their erratic absences. Some of the caregivers stated below.

“Dad supports financially, buys food, pays bills but is never hands on.” WCG21 on 3.4.2016, Umoja
“They say the excuses are monotonous and say ‘jipange’ that I should sort my own issues.” M5 on 14.4.2016 at Mathare
“I used to close business. Customers left thinking I’m unreliable.” P6G; 6.6.201, Tasia
“Work challenges - lack of understanding... ‘are you the only one with issues?’ This leads to stress so I just keep quiet.” M5 on 14.4.2016 at Mathare NA2

Among the 23% of those who reported stigma emphasized isolation related to mysterious or untreatable disease. Specifically, caregivers reported experiencing stigma when they were seen as bewitched or malign; cursed or having spirits; judged as one whose children do not grow well or are ever sick; as having HIV or cancer; when their PLWSCDs were treated differently; when answering disconcerting questions and when they found themselves as the focal point for gossip and branding as snobs. Some caregivers reported a form of stigma arising within themselves and others reported forms of stigma that arose from external sources primarily from immediate members of the household and the community. Caregivers reported that features that caused stigma included stunting or yellowness of the eyes which made PLWSCDs referred to as ‘Rwage’ or ‘Mbu’ because they are small or ‘Macho mayayi’ for the jaundice; remarks that affected both PLWSCDs and caregiver. Some caregivers shared the following.

“People believed he is enchanted. When they visit, he stays in the ‘simba’ to avoid their prying eyes.” P5B on 21.7.2016 Kahawa
“She was called ‘marehemu’ by doctors who refused to assist” P7G on 22.7.2016 Dandora
“Neighbours think we are victims of HIV and refuse to sell us groceries for fear of infection. M7 on 4.7.2016 at Mathare
“Some say they are curses from our homes.” WC8 on 10.1.2016 at Kamulu
“What is she suffering from? I never use the word Sickle Cell Disease. I just say malaria because they can’t understand SCD.” WC4 on 12.1.2016 at Tasia
“The age mates are bigger than her. When neighbours ask about age and size - This affects me because I also want him to grow well…” WC25 on 8.6.2016 at Limuru

Stigmatization of the disease vulnerability has been a fundamental driver of the social isolation. The 19% of caregivers who reported social isolation said it was a common occurrence associated with persistent vulnerability, disease vulnerability including the
conditions of SCD. Caregivers reported a form of isolation arising within themselves and other forms of isolation that arose from eternal sources primarily immediate members of the household and the community. Specifically, caregivers reported that they isolated themselves to avoid disclosure of SCD, to stem judgement or bad reactions. Caregivers reported inability to sustain membership to some social groups which included inability to attend other social gatherings such as weddings, funerals, church functions and parties. The caregivers reported reduced social interactions among relatives and friends as a way of minimizing chances of soliciting financial support to meet the bills.

In addition, the KI’s and FGDs reported that lack of time to socialize and missing social functions led to social isolation; canceling appointments or rushing off in the middle of events to attend to emergencies. The KIs and FDGs reported that in social groups, they reported not being given responsibilities, which sometimes caused them to lose self-esteem triggering feelings of timidity.

“They shut the door in my babies’ faces. We are isolated. Only one friend visits. Even church people don’t visit.” M7 on 4.7.2016 at Mathare

“Having time for other activities and socializing is rear.” P1 on 13.7.2016 at Saika

“I can’t get away with friends. I feel curtailed.” WC14 on 6.8.2016 at Kayole

“Wherever I am called that the baby is sick, I stop whatever I am doing.” WC4 on 12.1.2016, Tasia

“No evening functions. Events that require travelling far like upcountry to farm, for weddings, funerals, dowry negotiations etc. Whenever the babies get sick, I freeze all other interactions.” WC24 on 4.6.2016 at Karen

“They fear picking my calls as they fear that I am about to beg.” WC16 on 7.6.2016 at Kitengela

“Jumuiía Leadership: I failed to attend meetings a few times. People were not happy as I didn’t warn them about the emergency. I gave up leadership.” P7G on 22.7.2016 at Dandora

The remaining 28% of the caregivers that experienced social deprivation and exclusion reported other forms of isolation including blaming (9%), rejection (5%), Broken relationships (5%) and Feeling Manipulated (4%). Blaming involved considering (declaring) responsible for a fault, negative occurrence or experience. In the case of SCD,
blaming typically involved spouses trading accusations on who is responsible for the disease, subsequent caregiving and related challenges; blaming for aspects related to infidelity, misaligned paternity or bringing SCD; blame for actions precipitating crises; for the broken relationships; for missed opportunities to work or socialize; for witchcraft; for lack of quality time and intimacy; for wishing their PLWSCD dead to end the pain cycles; for non-participation in social events; for derailed developments, careers or studies and for wasting resources on the PLWSCD who will just die. Caregivers reported that women carried a greater burden of the blaming given their reproductive role and overwhelming representation in caregiving.

“Sometimes mothers are blamed for misaligned paternity” WC32; 14.2.2016, Mathare
“Without saying it, we blame each other for SCD gene. WC28 on 11.2.2016 at Jamuhuri
“They hate & blame me for bringing SCD. WC18 on 6.8.2016 at Park Rd
“My husband felt I give birth to sick or a bad breed of children” WC15 on 19.1.2016 at Umoja
“My brother blamed the doctor thinking it was HIV.” P7G on 22.7.2016 at Dandora
“Blaming women for actions that contributed to crisis. WC2, 14.7.2016 Kayole
“Mom blamed herself for not praying enough.” P5B on 21.7.2016 at Kahawa Sukari

Indifference was considered as lack of interest, concern or sympathy. Caregivers reported experiences of indifference from immediate members of the household, family, community and colleagues. Caregivers reported not to have bothered to know the IFCGs needs or their sick relatives' or the situation did not affect them directly. Women carried a greater burden of indifference given their reproductive role and a large representation in caregiving.

“Nobody bothers. Neighbours don’t even know anything because I don’t share. Some are harsh like the dad. Hence there is no happiness in the house.” WC15 on 19.1.2016 at Umoja
“They don’t help at all. Some feel happy. No empathy. I stay with strange relatives, mother in law, brothers in law and their wives.” WC18 on 6.8.2016 at Park Road
“My home, everyone is dead except 4 people who don’t care at all even if I shared the problem with them.” WC22 on 3.6.2016 at Mathare
“They gave up on the child to die but I hold on. I gave her porridge. They were tired and even stopped visiting.” WC 33 on 10.3.2016 at Hurlingham
Rejection is the act of pushing someone away. It hurts and resultant emotions can be painful. One may experience rejection from one's family, friends or a romantic partner. IFCGs reported that they experienced rejection at family level, community level and at the workplace. Rejection was often preceded by denial, stigma and could proliferate from the PLWSCD to their caregivers and siblings. They reported that blame was often accompanied by lack of support, increment in the caregiving burden and broken heartedness. This study reported that only two mothers rejected their PLWSCD entirely. The caregivers reported that some men compelled their wives to stop giving birth then proceeded to sire babies outside wedlock without confirming the genotype, consequently yielding more children with SCD. They reported that their participation rights in events were revoked when people considered them as unreliable. Some caregivers shared the following.

“My ‘in-laws’ say I have ‘Majiini’ demons. They don’t come to my house even when my son died. The demons apparently suck the children’s blood” WC3 on 8.1.2016, Huruma
“I hate my husband for being absent most times. I suspect he does not want to associate with me or the babies. We have no relationship with him at all.” WC24; 4.6.2016, Karen
“My husband’s elder brother never associates with us. He removed his children from a school when I took mine there. The wife comes and stands for a few minutes and leaves.” WC8 on 15.1.2016 at Mathare
My brother-in-law’s child with SCD was also thrown at me. His mother doesn’t care” WC18 on 6.8.2016 at Park Road

Broken relationships can be identified when one is not feeling happy with their spouses, arguing constantly, spending less time together or not sleeping in the same room together. However, broken relationships does not only refer to romantic couples but also important friendships that provide support and give life meaning. Caregivers reported that they experienced rejection at a romantic, family and community levels in form of tasteless relationships. This study reported that broken relationships presented in form of lack of quality time; emotional distance, lack of intimacy, lack of support and financial challenges. The verbatim reports revealed that SCD affected family unions because the reason for separation, divorce or polygamy was SCD (table 4.3).
“I divorced my husband believing he was the source of SCD.” M2 on 5.7.2016 at Baraka

“He took another wife and told me I give birth to lame children – ‘Watoto vivete’.” FGDe on 14.2.2017 at Baraka

“We discovered our 1st born had SCD at 6 months. My husband said it’s my problem. When the 2nd born also had SCD, he left and took another wife.” FGDi on 12.9.2017 at Baraka

“Men not wanting to be bothered make women bitter, so the relationship drifts apart.” WC9 Lucky Summer on 11.2.2016.

“I lost my marriage – we went different ways because we couldn’t understand each other.” WC31 on 7.8.2016 at Huruma, John Saga

Diminished sex drive was aggravated by loss of appetite, fear of getting another child with SCD, infidelity, the intensity of caregiving chores, minimum involvement of partners and financial challenges. Women caregivers were doubly affected by the caregiving position and felt impotent to act independently consequently being inhibited to participate on equal footing with men. Some caregivers shared below.

“My husband is confused - in between – he sired outside and wants to bring the child at home. disrespecting my marriage. If I could work, I would leave. He comes in at midnight - the love died.” WC3 on 8.1.2016, Huruma

“When babies are sick, one can’t think of sex.” M9 on 19.7.2016, Nairobi

“If I spend a lot of time in hospital, he becomes an enemy.” WC15 on 19.1.2016, Umoja

“We forget about each other. I don’t give attention. We all think about the child and easily become distant.” M6 on 9.6.2016 at Strathmore

“Wives’ not having time for husbands. This can make the man divert his time to ‘chips funga’ other women.” P1B on 13.7.2016 at Saika

Manipulation in relationships refers to actions taken by a person to try and control others usually in a deceptive or harmful way. Caregivers reported that they found themselves in a position where they got torn between accepting to be manipulated by the PLWSCD and showing tough love. Caregivers reported that some PLWSCD manifested painful crises when their requests were denied; pushing the caregiver to give against their wishes. They reported that this occurred because the PLWCD new that the caregivers were overprotective and would do anything to stem a crisis. Overprotection exhausted and contributed to IFCGs decisions to delay having more children or not having any other child.
“It delayed the mother’s decision to have other babies.” P4G, 20.7.2016 at Karen - IPR

Responses from the caregivers on social deprivation and exclusion were similar to those reported in other in other studies (Burnes et al., 2008; Adegoke & Kuteyi, 2012; Mullan, 1998; Rose & Clark-alexander, 1998; Marsh et al., 2011; Alspach, 2009; Theis et al., 1997). Reports indicate that fathers typically have been minimally involved in caring for PLWSCDs and that has affected the ability of WCGs to provide sustainable caregiving which in turn affects their ability to plan their future with confidence (Burnes et al., 2008). PLWSCDs have been reported as malign and people stayed away from them to avoid being stigmatized and which usually constituted part of secondary stress that extended to IFCGs from PLWSCD. In addition, stigma precipitated, strengthened and reproduced already existing inequalities of class, gender, sexuality and race (Adegoke & Kuteyi, 2012; Mullan, 1998; Rose & Clark-alexander, 1998; Burnes et al., 2008). Other studies have emphasized that caregiving of PLWSCDs have been characterized by gendered responsibilities; where women (mothers) take greater responsibilities and blame at the same time (Marsh et al., 2011). In summary, the study concluded that the caregivers of PLWSCDs have been characterized by varying forms of social deprivation and exclusion.
4.3.3 Socio-economic Deprivation

The 3rd component of the third objective namely to assess the psychosocial economic vulnerability of caregivers was to assess the dimension of socioeconomic deprivation. Studies have reported that severe and chronic diseases have been associated with socioeconomic deprivation of IFCGs. This component was assessed in terms of eroded capacity to meet the basic needs, reduced capacity to support livelihoods, eroded financial security and capacity to work. Among the 113 caregivers (table 4.15) above that indicated socioeconomic deprivation, 38% reported eroded capacity to meet basic needs, 30% eroded capacity to support livelihoods, 18% eroded financial security and 14% eroded ability to sustain work (table 4.21) below.

<table>
<thead>
<tr>
<th>Key indicator of socio-economic deprivation</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eroded capacity to meet basic needs</td>
<td>43</td>
<td>38</td>
</tr>
<tr>
<td>Eroded capacity to support livelihoods</td>
<td>34</td>
<td>30</td>
</tr>
<tr>
<td>Eroded financial security (capacity)</td>
<td>20</td>
<td>18</td>
</tr>
<tr>
<td>Ability to work (Employability/Ability to do Business)</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>113</td>
<td>100%</td>
</tr>
</tbody>
</table>

4.3.3.1 Eroded Capacity to Meet Basic Needs

The 38% of caregivers who experienced reduced ability to meet basic needs reported reduced ability to access adequate food and nutrition for the family; ability to secure or maintain adequate housing (shelter) and ability to meet the medical bills. Caregivers reported that they struggled to pay medical bills, buy medication and provide dietary requirements to bolster blood production and immunity. Caregivers reported that reduced inability also extended to the choice of healthcare providers and the schools. Some caregivers shared below.
“They need fruits – while one may not have money for fruits and he is crying. The baby needs proteins which are scarce because it is expensive.” WC27 on 5.4.2016 at Ngomogo

“So sometimes the money is not enough to buy medication.” WC9 on 12.1.2016 at Huruma

“Yes, when the person becomes sicker than expected, we end up spending a lot on them.” WC19 on 9.8.2016 at Kiambiu

“So much! The baby needs special diet. I can’t even buy fruits sometimes. Needs good beddings... Paying rent is hard because I have to stay in Nairobi to access treatment” WC7 on 5.1.2016 at Mathare

“In most cases, I don’t have money. So I run to Mama Lucy.” WC21; 3.4.2016, Umoja

“I had 3 children and I couldn’t afford KNH. I needed Kes 3,000 per clinic and more money for medications and X-rays. Baraka is cheaper as I pay Kes 300 per child totaling Kshs 900 for 3 children and we are given medications.” WC3 on 8.1.2016 at Huruma

“Baraka, Tests and treatment are free for children > 5 years.” WC20 on 10.8.2016 at Baraka

4.3.3.2 Eroded capacity to Support Livelihoods

In this category, 30% of those who experienced socioeconomic deprivation reported inability to continue with education, disruption of work and sustain the household socioeconomic endowment. Specifically, caregivers reported that this in turn disrupted their own developmental milestones (38%), rent and disposal family assets; affected relationships among their children (38%); affected their ability to save (28%; them to earn income (21%) and their ability to stick to schedules.

Caregivers reported that disrupted or inhibited careers presented in form of delay in career development including missed education opportunities, running businesses, denied promotions and forgoing opportunities. Increased burden of caregiving reduced the ability of the caregivers to meet their obligations including the ability to contribute to local social insurance (welfare) and/or to pay debts. Some caregivers shared below.

“I complain less when others are promoted because of being unable to pursue my studies, a master’s degree program.” WC26 on 10.2.2016 at Jamuhuri

“Fees is diverted to medical bills. The boys couldn’t go to high school because of SCD. The painful events always occur around exam time.” WC27 5.4.2016 at Ngomongo

“Construction of the family home in the village stopped. We can’t do this when the child is sick. There is usually no surplus.” WC21 on 3.4.2016 at Umoja
“I wanted to buy an over-lock machine to have a good finishing for clothes for about 25,000 but until today, this project is on hold.” WC6 on 16.1.2016 at Lucky Summer
“Admission fee unmanageable; Deterred development for the whole family; work but no progress – one step forward and one step back” P11B 27.7.2017, Kileleshwa
“I need a home with a clean environment. I had to buy a heater to heat their room on cold days and this comes with a monumental electricity bill.” WC24 on 4.6.2016, Karen

Caregivers reported struggling to work which impacted their incomes or profits negatively. IFCGs who wanted to work with their children such as street vendors reported that PLWSCDs could not be exposed to the cold, dust and other elements that triggered a crisis and were forced to find premises/shelter from elements resulting in higher costs of doing business and reduced profits. In most cases IFCGs reported that they abandoned most of their plans because a greater amount of their resources were absorbed by medical bills especially when there was no insurance. Some caregivers shared the following.

“There was a time I was almost fired at work for asking for permission to stay with the baby in hospital. At that point, I begged them to understand because my wife had a little baby. I had to find another lady to help me at night. This lady needed to be paid. At home they needed help to buy food and rent” M5 on 21.7.2016, Kahawa S.
“I was unable to pay loans because I spend too much time in hospital so I can’t do business to get money. When I don’t have money, I can’t do anything.” WC12 on 13.1.2016, Komarocks
“By maintaining the person with required drugs, I can’t plan. If she coughs, I stop everything for anyone to attend to him. Every month she must attend clinics. WC19 on 9.8.2016 at Kiambiu

4.3.3.3 Eroded Financial Security (Capacity)

There were 20 caregivers who experienced eroded financial security (capacity) and who reported lack of adequate financial resources for food, housing and hospital bills among others (table 4.17) above. Specifically, these 20 caregivers reported that to raise money, they borrowed from family, friends and church (49%), went to hospital without money (12%), took loans (8%), chose affordable hospitals (7%), sold household goods (7%), took salary advances (2%), fundraised (2%) (table 4.22) below.
Table 4.22: How IFCGs raised money during a crisis, Nairobi 2016

<table>
<thead>
<tr>
<th>What IFCGs Do to Raise Money During Crisis</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borrow from family, friends or church</td>
<td>9.7</td>
<td>49</td>
</tr>
<tr>
<td>Went to hospital without money</td>
<td>4.7</td>
<td>24</td>
</tr>
<tr>
<td>Took loans</td>
<td>2.3</td>
<td>12</td>
</tr>
<tr>
<td>Chose affordable hospitals</td>
<td>1.3</td>
<td>7</td>
</tr>
<tr>
<td>Sold household goods</td>
<td>1.3</td>
<td>7</td>
</tr>
<tr>
<td>Salary Advances</td>
<td>0.3</td>
<td>2</td>
</tr>
<tr>
<td>Fund raising</td>
<td>0.3</td>
<td>2</td>
</tr>
<tr>
<td>Total (N=20) 18%</td>
<td>20.0</td>
<td>100%</td>
</tr>
</tbody>
</table>

Of those who borrowed, 9% were lucky to get help without having to pay back, another 9% got help once or twice then donors got tired and distanced themselves while 31% did not get any help at all. The caregivers who always got help to pay medical bills without having to pay back reported that borrowing did not always guarantee getting the kind of support they sought. Most times, the help was not sufficient to cover their needs. The IFCGs who reported getting help once or twice reported that when the crises became perpetual, those assisting suffered from donor fatigue and distanced themselves from the caregiver. There were caregivers who reported that they borrowed but got no support for various reasons being: the family or community members were poorer than the caregiver and struggled financially; some IFCGs were uncomfortable asking for help, did not want to share their problems or they did not want to earn the title of “beggar”. Caregivers also reported that people did not simply want to give but would rather lend. Other caregivers reported never having been in the position of needing help because of a good medical insurance cover or their PLWSCD had never been too ill or the bill had never been too large to handle.

“I sometimes run to church. The priest wrote me a letter to guarantee payment in hospital and gave me money for transport.” WC21 on 3.4.2016 at Umoja

“Yes, I get help from family members and friends.” WC8 on 10.1.2016 at Kamulu
“They help all the time not to pay back.” WC30 on 13.2.2016 at Mathare
“Relatives are tired. They don’t even pick calls.” WC3, 8.1.2016 at Huruma
“No, because they depend on me” M4 on 4.4.2016 at Gikomba
“I don’t ask. Most neighbors don’t have proper jobs like me.” WC11, 11.1.2016 Baraka
“I don’t talk about my problems.” WC19 on 9.8.2016 at Kiambiu

When borrowing was not possible, IFCGs reported resorting to fundraising commonly referred to as ‘harambee’ in Kenya that seldom yielded the anticipated amounts. Other caregivers reported taking salary advances which interfered with the family budgets. Some caregivers reported being loaned the money to be paid back without interest while others had to pay with interest even from Shylocks. The process was cyclical and kept caregivers in perpetual indebtedness. Whenever they ran out of the above options, some IFCGs reported that they sold household items usually below market rates to cover medical expenses. Additionally, some IFCGs reported seeking credit facilities in health centres to pay after discharge and that sometimes they got locked up for months after discharge. Some caregivers asserted below.

“Was admitted and couldn’t raise money at discharge. I was locked in hospital. We called for a fundraising which didn’t work.” P5B on 21.7.2016 Kahawa Sukari
“With a ceiling of Kshs250,000 per admission once costs went up to 600,000. I consulted and had a family fundraiser. The employer also assisted.” WC4 on 12.1.2016 at Tasia
“We took salary advances. This made me feel desperate. It ate into the salary for the month.” WC26 on 10.2.2016 at Jamuhuri
“She borrows from a Chama, we deplete our savings and if the bill is too high, we take loans even from shylocks. This keeps us in debt.” M5 on 14.4.2016 at Mathare NA2
“I sold my sewing machine” P5B on 21.7.2016 Kahawa Sukari
“Mom sold HH items and farm produce to pay bills.” P1B on 13.7.2016 at Saika
“In that private hospital, the doctor treats us and I pay later. That is why I like him.” WC6 on 16.1.2016 at Lucky Summer

4.3.3.4 Employability of IFCGs

This study established that SCD caused families to have financial challenges when it became difficult for the caregivers to work consistently, hence becoming dependent on others financially. When this happened, IFCGs reported that they struggled financially. In response to the question regarding missed opportunities to make money, table 4.23 below
illustrated that only 6% of IFCGs had not experienced any difficulties working with one WCG saying her employer understood. On the other hand 94% of IFCGs had missed a chance to make money and of these, 55% reported that SCD had affected their employability while 39% reported that SCD had affected their ability to run businesses.

Table 4. 23: IFCGs Loss of Income Sources, Nairobi 2016

<table>
<thead>
<tr>
<th>Loss of Income Sources</th>
<th>Freq</th>
<th>Frequency Combined</th>
<th>Percentage Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missed work or employment</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quit, left or stopped working</td>
<td>34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fired / dismissed from work</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missed employment or passed for promotion</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affected income generating activities</td>
<td>26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost customers or Business Associates</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closed down businesses</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used business capital for bills</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affected investments</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Let business opportunieis to to</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited impact on income sources</td>
<td>26</td>
<td>226</td>
<td>6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>226</td>
<td>6%</td>
</tr>
</tbody>
</table>

IFCGs reported that their jobs were affected because they were vulnerable to being dismissed or fired, quitting employment, missing promotions or opportunities, missing employement or never attempting to work at all. They reported that some employers regarded them as either wasting the organizations time during their absences or that they were not contributing enough. They reported that their when their employers got fed up, they hired other people to replace them. Most of the employers were reported to be either ignorant of the IFCGs challenges or were simply focused on the profitability. These IFCGs below were fired for absenteeism.

“I got a job at KEMRI, and the child got sick the same week and was hospitalized for a week. They just terminated me and said I was lying.” WC27; 5.4.2016 at Ngomongo
“My mother was a subordinate staff at a hospital. She spent 3 days in hospital with me. When she reported back, she found a dismissal letter.” P5B; 21.7.2016, Kahawa S
“Mother used to work for Unga Ltd. We were admitted for 4 days. After discharge, she lost her job... She was replaced.” P7G on 22.7.2016 at Dandora
“I lost my job in Harambee SACCO. They said my contribution was minimal. SCD was a bother. When they got a chance to retrench, I was the 1st to go.” WC17 on 20.1.2016 at Baraka
“I stayed away from work a lot when the babies got sick. Finally, my contract not renewed as colleagues believed I used the babies’ sicknesses to go accomplish my own private businesses. I am not able to take on a business or a job that would keep me out of town away from them for long. I fear I will be called back before I even settle. Once I left a conference in Kampala to run back to Nairobi when the PLWSCD got admitted.” WC24 on 4.6.2016 at Karen
“I do ‘Kibarwa’ selling Matumbo in someone shop for Kshs 200 a day. The day I take her to clinic, I am not paid.” WC7 on 5.1.2016 at Mathare

The second group of IFCGs reported that they opted to quit employment to go and support their sick children by themselves usually after a series of frustrating episodes at work. They reported that it was tiring for them to keep talking about their PLWSCD during performance reviews or having their salaries deducted for the days they were away from work. Sometimes IFCGs reported deciding to run a business which they hoped to control and not have to fear of employers. Many such businesses were reported to fail due to absences that necessitated closing shop especially when they had no help. Some caregivers shared the following statements below.

“I quit my job marking exams for KNEC for his sake. I was absent a lot. The boss talked very badly and I got frustrated and quit.” WC14 on 6.8.2016, Kayole
“I used to work but I had to leave work to take care of him. I took early retirement’” P10B on 9.5.2016 at Kibra, Fort Jesus, Karanja
“There was always pressure at work because of having to rush to hospital, absences, lateness etc. Employers don’t always understand. I left work and now run a business that is more flexible.” M2 on 5.7.2016 at Baraka
“Yes, I lost my job. I used to work with Asians who kept cutting my salary when I was absent. I decided to quit.” WC21 on 6.8.2016 at Park Road

The third group of IFCGs reported that they were unable to take on jobs because the jobs were demanding and they did not have a reliable person to leave the PLWSCD with while they worked. They said that jobs with little flexibility were not favourable for them
as they needed some time to attend to the child. Caregivers reported that some of them had resources to hire helpers at home while they worked but others did not especially women caregivers without supportive husbands. They shared the statements below.

“I used to work at Nairobi hospital from 5am till evening; the child was not fed and cried. My husband just slept. The child suffered so I stopped working” WC32, 14.2.2016 at Mathare

“I got a job out of Kenya but I could not go because no one wanted to remain with the baby. They said the baby was a lot of work and they didn’t understand SCD.” WC31 on 7.8.2016 at Huruma, John Saga

The fourth group of IFCGs asserted that they were left out during promotions as they were labeled unreliable especially when they kept cancelling appointments when when called to attend to the PLWSCD. That most times their colleagues did not understand their lack of planning as they termed it. This led to them being denied promotions or more responsibilities due to absenteeism. They reported that some malicious colleagues could deny them opportunities pretending to care for their PLWSD at home. They asserted below.

“I decided not to go on mission and opted to stay and care for him when he was 5 years old. I forwent a master’s program and also a post graduate diploma in HRM which are offered in the evening and I needed to be home. I complain less when others are promoted because of not being able to pursue my studies.” WC26;10.2.2016, Jamuhuri

“Promotion, I was not promoted and they sighted absenteeism as the reason they couldn’t give me more responsibilities. Salaries remain the same.” WC4 on 12.1.2016 at Tasia

“I used to make money in sports. They used my son’s SCD status as an excuse to put me out of the team travelling to Rwanda. That has haunted me! WC9 on 12.1.2016 at Huruma

The fifth and final group of IFCGs reported that they realized that there was no use trying to get a job because of the workload at home. That having more PLWSCDs was one of the challenges they had. They reported being perpetually in hospital most of their lives with all or either one of their children with SCD and suffered from the fear of always waiting for ‘that call’ to get them back home. Some caregivers reported that it was not easy to delegate PLWSCDs because many people were ignorant of SCD and feared for a
detrimental outcome as they were likely to make wrong decisions. IFCGs reported that SCD rendered them unable to work and pay medical bills or pay for a help which created a demand for them to be available at home for the child themselves. Therefore lack of reliable support prompted the mother not to even try to get a job as seen below.

“Mother couldn’t get into any meaningful job because of 3 babies with SCD among others. Time and energy was spent on the children.” P2 on 14.7.2016 at Kayole

“I can’t hire a house help because I can’t pay. I can’t work because I can’t keep a job due to crises with 3 babies’ admissions. We can’t get what we want.” WC3 on 8.1.2016 on Huruma

“I can’t go to work to keep asking for permission. Employers and colleagues do not understand.” WC4 on 12.1.2016 at Tasia

“The child needs watching so I can’t look for money” WC19 on 9.8.2016, Kiambiu

Studies reviewed have reported that caregivers experienced reduced income levels due to challenges maintaining work and this hindered IFCGs from raising the funds that they needed for bills and upkeep. Reduced work hours led to reduced pay, benefits, profits, retirement income; out of pocket expenses and increased financial strain, benefit loses and unpaid leave. This occurred due to tardiness, taking leave of absence, switching to part-time work, giving up work, losing work benefits or turning down promotions (Alspach, 2009; Frey, 2009; Graff et al., 2010). Inability to work meant that IFCGs could not provide essentials for the family (Marsh et al., 2011). Some IFCGs resorted to hazardous jobs or illegal activities to raise some money (Emanuel et al., 2010).

This study took place in an urban center of a Lower-Middle Income Country (LMIC), where the burden of SCD had remained substantially high. Studies reviewed have reported that most caregivers of PLWSCDs (45.59%) were unemployed with 58.09% having income of 1-3 minimum wages (Costa et al., 2016) and 54.1% had family incomes of up to one minimum wage (Da Silva et al., 2012). In Kenya, by 2020, the average low income in the general population stood at KES 23,670 (US $ 209) per month (KNBS 2020). In this study, the modal income of caregivers was below KES 10,000 ($100).
Studies have reported that the frequency of painful events and long hospital stays led to inability to work or run a business. That lingering post discharge crisis pains interfered with their ability to work or attend school (Brandow et al., 2009; Panepinto et al., 2009). While this is the case, caregiving work usually done by women required a lot of commitment but was neither quantified nor remunerated (Frey, 2009; Mauro et al., 2006). Not remunerating work that takes up the caregiver’s entire day disadvantaged them economically.

Studies have reported that some IFCGs got jobs without sick leave or flexible work hours and absenteeism lead to job losses and very few employers are supportive (Brandow et al., 2009); (Graff et al., 2010). This study revealed that IFCGs had challenges in the workplace relating to absenteeism, quitting work, being fired or contracts not being renewed, not being paid for days not worked, relational issues with the colleagues, missed promotions and denied opportunities to thrive. Some caregivers did not even bother to look for work. Caregiving therefore became a barrier to getting employment for IFCGs.

4.3.3.5 Loss of Income Generating Sources

The study established also that caregivers experienced loss of income generating sources. Specifically, the study established that 39% of IFCGs lost businesses in various scenarios (table 4.18) above. IFCGs reported that they used capital and/or profits from the business to pay medical bills to avoid borrowing. IFCGs reported that the businesses were completely drained when the sickness was protracted or when the frequency of hospitalizations became too high creating recurrent bills. Most times the IGAs never picked up again as they needed fresh capital as explained below.

“I had a job making clothes as a tailor. Because of too many offs, I was fired; I tried to open my own business but when my son died, all the capital was used up. I haven’t picked up. Now I sew from the house for lack of cash and my customer base has shrunk thus buying materials and rent is a problem” WC3 on 8.1.2016 a Huruma
“I tried business for about one year. I went to KNH for two months with a sick jaundiced child. After hospitalization all the funds were exhausted.” M7 on 4.7.2016, Mathare

“Our hotel business failed as we used up all the cash.” WC23 on 9.2.2016 at Mathare

The second group of caregivers in this category who could not be employed reported starting businesses which they lost when they frequently closed down their premises for unpredictable number of days. Frequently being away made businesses to decline. They reported that the most affected by frequent closures were those selling perishable goods because the goods would often be given away for free or decayed when the caregiver rushed off to hospital making the capital to go up in smoke. They reported that customers also lost faith in caregivers who were service providers and looked for more stable providers elsewhere bringing loses to the caregiver’s business. IFCGs were therefore always struggling to start afresh and attract new customers. This limited the growth of such businesses and eventually they closed up.

On the other hand, IFCGs in business with employees to help run their businesses reported that they suffered loses when they are away because the workers took liberties in their absence to misappropriate resources or goods and would not handle customers as well as when the owner was present. Therefore, the loss of customers, merchandise or misappropriated resources made these caregivers realize that they could not sustain the businesses. They reported that businesses with non-perishable goods like tailoring, second hand clothes, and shops had lingered on a little longer. It was a vicious circle. Some caregivers shared the following.

“I worked at EPZ but could not continue. I started a vegetable business, but every time the child got sick, everything stopped so I closed up. The child is sick a lot.” M5 on 14.4.2016 at Mathare NA2

“I used to sell uniforms. One time when he was admitted for two weeks then again another 2 weeks, the business had to stop.” WC30 on Mathare NA3

“I had a business in which I lost customers and quit. I became a housewife.”

“After losing my job at Unga, I decided to do business. Many times, I closed and missed appointments.” P7G on 22.7.2016, Dandora
“I tried business – buying nets and fishing. When I was away, I ’d find the nets missing. The workers lied about nets being lost. I could not replace them because the money goes to bills. If it wasn’t SCD, I would not frequent Nairobi for clinics.” WC27 on 5.4.2016 at Ngomongo

The third group of IFCGs reported letting the business opportunities go due to extraneous circumstances. That they chose to attend to their sick children in hospital or at home for a period of time when there was need. IFCGs reported that they were had to choose between the child and the business and the PLWSCD always won while businesses lost irreparably. They shared the following.

“ I left work to run home to care for the child. My clients became unhappy. It happened 2-3 times and they were gone. ” M1 on 10.3.2016 at Kariobangi South
“I got grounded, it disabled my ambitions. I am the one who knows how to pick out signs of trouble to avoid mid-night journeys to hospital. I do businesses that can be closed. I give away what might spoil when the child gets sick needing admission. M8, 12.7.2016 at Rongai

Studies have reported that caregiving services in the US were worth $470 billion annually in 2013 (Hounsell et al., 2019). That mothers giving care to PLWSCDs had difficulty setting up or maintaining IGAs hence lost income and that the unpredictability of painful events increased the chances of rushing away from work always pending (Marsh et al., 2011; Graff et al., 2010)

This study also revealed that caregiving was a burrier to employment and that when securing employment or keeping job failed, some caregivers decided to start some income generating activities. They however discovered that running business too had challenges for IFCGs of PLWSCDs and that those who had tried businesses closed when they spent so much time in hospital and lost clients to competitors, used profits and/or capital to pay bills, lost merchandise that perished, got stolen or got mismanaged by employees in their absence. The loss of employment or business was therefore an opportunity cost for IFCGs who gave up work to care for their loved ones.
The studies reviewed reported that besides productive capacity of IFCGs and the level of input into the care of the patients, caregiving remained largely unpaid, socialized, confounded by low socio-economic endowment, poverty, vulnerable employment and related resource constraints (Addo et al., 2018; Nortey 2017, WHO, 2017). Financial stress worsened with more babies with SCD, more admissions and lack of insurance (Adegoke & Kuteyi, 2012; Wonkam et al., 2014; Burnes et al., 2008). This included reports that complications and conditions like stroke, organ damage evolved and worsened with time (Serjeant, 2001; Graff et al., 2010; Mitchell et al., 2009). As the PLWSCD matured, different complications also presented needing to be handled medically (Serjeant et al., 2009). Hemolytic anaemia could be exacerbated by extraneous factors like nutrition, infections and minimal medical care (Ojwang et al., 1987).

The studies reviewed reported that SCD necessitated regular clinic visits, treatment, daily medication, high levels of care and high costs of running a home (Marsh et al., 2011; Amendah et al., 2013). Studies have reported that caregivers experienced financial burdens that affected various aspects of their lives leading to lowered satisfaction levels (Madani et al., 2018). The study has reported under social deprivation and exclusion in 4.2.2 that siblings in families with PLWSCD experience relationship problems. There was sibling rivalry, resentment and aggression towards the PLWCSD when resources meant for other development projects, school fees or use in the home was diverted to healthcare. Economic vulnerability was also seen in derailed developments like construction of residential homes when resources were used for healthcare of the PLWSCD. Job losses due to caregiving positions increased the IFCGs poverty and impacted negatively on their personal development.

Studies reviewed reported that caregivers took loans to pay healthcare costs leading to sickness poverty cycles within affected households (Adegoke & Kuteyi, 2012). This
occurred especially when they did not have medical insurance. Other studies reported selling household assets, borrowing a lot or withdrawing children from school to pay for healthcare when dealing with terminal illnesses which pushed them towards multigenerational poverty. Studies also reported harmful decisions like taking hazardous jobs or resorting to illegal activities like making and selling alcohol to raise funds (Emanuel et al., 2010). Poverty propagated by SCD was reported to push caregivers to limit the number of children for fear that the next child could have SCD (Wonkam et al., 2014).

4.4 Coping Strategies by Informal Caregivers of PLWSCD

It will be recalled that objectives 4 was to identify coping strategies and therefore the study assessed the coping strategies towards managing the challenges of caregiving of a PLWSCD. Coping has been defined as a process of addressing stressful conditions and also to include measures to adapt or overcome the condition. Accordingly, in this study, coping and adaptation to stressful situations were used as synonymous and therefore interchangeably. This section therefore assessed the adaptive strategies employed by IFCGs to mitigate the effects of caregiving of a PLWSCD.

4.4.1 Strategies Adopted by Caregivers

Caregivers reported several measures as summarized in (table 4.24) below. Among the key strategies included: prayer (34%), talking to someone to find encouragement (24%), crying (10%), keeping positive (8%), projecting (7%), persevering or encouraging oneself (7%), withdrawing (6%), promptly taking action (2%) and keeping busy (2%).
Further, to cope with financial challenges especially when the PLWSCD was in crisis, IFCGs borrowed, took loans, salary advances or sold household goods among others as seen in section 4.3.3.3 above. In addition, key informants reported that IFCGs coped by either accepting the situation, seeking social or medical support, just existing and going through motions, quitting jobs and becoming reliant, starting flexible businesses, giving up and starting to exhibit negative self-image and depressive symptoms. It will be noted that these coping strategies have tended to be grouped under spiritual, physical, psychological or economic strategies. It will also be noted that some IFCGs indicated that some of the strategies were more useful and bore positive outcomes while others were much less useful. Other studies also reported that caregivers sought appropriate professional support that reduced frustrations and enabled coping through awareness, psychological and financial support (Burnes et al., 2008; Brown et al., 2010).

To survive a situation with more challenges that rendered IFCGs vulnerable, it was vital for them to build resilience, adaptability and transformability to what was occurring around them. These included building of competencies that included coping strategies,

### Table 4.24: Coping Strategies employed by IFCGs, Nairobi 2016, Nairobi 2016

<table>
<thead>
<tr>
<th>Coping Strategy</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prayer</td>
<td>77</td>
<td>34</td>
</tr>
<tr>
<td>Sought social support for encouragement</td>
<td>54</td>
<td>24</td>
</tr>
<tr>
<td>Crying</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>Keeping positive</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Projecting</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Persevering or encouraging oneself</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Withdraws</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Promptly taking action</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Keeping busy</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total (N=226)</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
social skills above the average memory and educational abilities (Lin et al., 2013; Folke et al., 2010). Some strategies that enhanced coping included.

“She borrows from a Chama, we deplete our savings and if the bill is too high, we take loans even from shylocks. This keeps us in debt – even now.” M5; 14.4.2016 at Mathare

“I go to church. Families in the neighborhood from the same church prayed with her. Priest and catechist were close to her.” P2B on 14.7.2016 at Kayole

“She seeks formal and informal forums that help in teaching about management of the condition.” M9 on 19.7.2016 at Nairobi CBD

“Talking to someone who understands or who makes me laugh” WC24; 4.6.2016, Karen

“Talk to my colleagues and just vent properly.” WC29 on 15.5.2016 at Buruburu

“She is prompt in giving attention to the child. The father also responds quickly.” M1 on 10.3.2016 at Kariobangi South

Some strategies that inhibited coping of caregivers included:

“She becomes very harsh on the sick child. I take child to away.” M7, 4.7.2016 Mathare

“She moves away, withdraws to be alone.” M4 on 4.4.2016 at Gikombka

“Feels sad, worries a lot and doesn’t say out a lot.” P8G on 25.7.2016 at Dandora

“I cry a lot - shed tears especially when asking doctors for help and they don’t respond positively. I cry when frustrated.” WC17 on 20.1.2016 at Baraka

“’Nilivumilia ndoa’ I persevered in marriage but I have never experienced happiness.” WC30 on 13.2.2016 at Mathare

“When I left marriage, I thought I will find peace but ended up being too stressed without money with a child who was disturbing” WC31; 7.8.2016 at Huruma, J. Saga

Studies reviewed reported positive outcomes of caregivers’ strategies. That SCD caregivers coped with chronic sorrow by praying, religion, information seeking and relying on family and friends for support. That counseling also helped caregivers survive emotional turmoil (Northington, 2000; Rose & Clark-alexander, 1998). Problem-solving strategies like planning and taking direct action were also linked to positive outcomes (Mullan, 1998). In this study too, when the going got tough, IFCGs devised survival strategies to cope. The strategies that bore constructive outcomes included being proactive, prayer, seeking social or medical support, crying, striving to keep positive, acceptance of the situation, persevering and encouraging oneself, taking prompt action and trying to start a flexible business. Emerging positive strategies included crying, striving to keep positive,
accepting the situation, persevering, encouraging oneself, taking prompt action and starting a flexible business.

Studies reviewed also reported existence of negative outcomes of the caregivers coping strategies. Emotion-focused approaches like escapism, discharging emotions, and blaming oneself were linked to poor outcomes (Mullan, 1998). Some caregivers chose a good cry, a shouting match with their spouses (Atkin & Ahmad, 2000). This study also revealed that there were coping strategies that made the coping worse including letting out on others, withdrawal, crying, inability to rest enough, chasing every cure, self-medication, discharging the child too early, quitting jobs to become reliant, making drastic decisions, overcompensation or exhibition of depressive disorder symptoms like escapism, apathy, negative self-image. Some of the strategies are healthy or constructive therefore leading to positive outcomes while others are unhealthy or destructive leading to negative outcomes.

4.4.2 Experiences That Enhance Coping

This section assessed situations that enhanced coping with caregiving of a PLWSCD. Caregivers reported experiences that included availability of support systems from medical teams, community, home, teachers and workplace 30%. This was followed by knowledge about sickle cell disease 23%, financial power or financial support 15%, seeing PLWSCDs who are well 15%, belonging to support groups 13%, prayers 11% and lastly seeing grown-up PLWSCD 6% (figure 4.9) below. The key informants also reiterated that seeing PLWSCDs who are doing better, social support systems, affordable/subsidized healthcare and awareness made coping easier for IFCGs.
According to IFCGs in this study, there were three support systems that they desired; (i) Medical/technical support, (ii) belonging to a support group and (iii) having social support systems beyond other people battling with SCD. Caregivers reported that supportive medical team really encouraged them to believe they would come through this phase because it gave them hope. These were health workers who showed concern and understanding, who were loving, encouraging, knowledgeable, empathetic, who were not judgmental and also looked out for the needs of the caregivers. Most caregivers reported that getting a meal in hospital went a long way as some were IFCGs never visited during admissions. They also reported that hospitals that did not turn away PLWSCDs in crisis without money were preferred so that IFCGs could pay later.

The caregivers reported appreciating affiliation with support groups. In this groups, IFCGs gained knowledge and information provided during peer to peer counseling/education. This information empowered them, pointed them to services, generated positive energy, created a sense of hope and belonging and shuttered myths which served to break the stigma and isolation. In this groups, IFCGs got counselled,
provided safe spaces for venting and found and opportunities to found good friendships. IFCGs reported that they felt valued when people walked alongside them and that it helped to not feel isolated. That sharing thoughts when spouses worked with them looking for solutions helped to reduce emotional and physical exertion. It was therefore important for IFCGs when families, communities, work spaces and schools were supportive with the PLWSCDs, funds and encouragement as seen in the statements below.

“Knowledgeable and empathetic health workers” WC24 on 4.6.2016 at Karen
“I find it easier because the people around me understand in hospital. The nurses and doctors were loving.” WC1 on 5.1.2016 at Donholm
“When doctors encourage and teach us.” WC6 on 16.1.2016 at Lucky Summer
“The Baraka project gives me hope. Knowing I can go anytime.” WC5, 15.1.2016, Brk.
“My volunteer work. It teaches me a lot. As I counsel others, I find myself counseling myself.” WC29 on 15.5.2016 at Buruburu
“Safe spaces or groups to share what they are going through. Emotional support from husbands and community” WC26 on 10.2.2016 at Jamuhuri
“Social support from friends, joining groups, moving together has really encouraged me to belong and a prayer group. WC14 on 6.8.2016 at Kayole
“Those who visit us in hospitals – we really appreciate.” WC3 on 8.1.2016 at Huruma

This study revealed that having knowledge and information about SCD and its management helped IFCGs a lot. They reported that sharing experiences how other people interacted with SCD in relationship to one’s own experience became an eye opener. IFCGs reported that learning about the origins of SCD and dispelling myths; learning how to manage SCD; where to get help and realizing sometimes that they were in a better position than many other IFCGs. For instance, IFCGs realized they were lucky when they learnt about other caregivers with more children with SCD or others dealing with more severe symptoms. On the other hand, they reported getting encouraged by PLWSCDs who were doing well with their health, in schools or careers and PLWSCDs who had grown into responsible adults with families. Some caregivers shared the following.

“Knowing it’s a condition that can affect anyone; seeing children with SCD who look fine and knowing I am not alone” WC4 on 12.1.2016 at Tasia
“In hospital, when I see a much weaker child, I thank God for my healthier one.” WC6 on 16.1.2016 at Lucky Summer
“Realizing what was wrong with the child and knowing how to care for him – medication and nutrition.” WC23 on 9.2.2016 at Mathare
“Information has empowered me to act and even teach those who don’t know. I also know what to demand from hospitals” WC25 on 8.6.2016 at Limuru

Informal caregivers reported that financial power or financial support gave them options and reduced financial related stresses. Caregivers reported being contented if they were in a position to pay bills without reaching out to other people. They also reported being grateful to people who supported them so that they did not find themselves in precarious positions as seen below.

“My husband doesn’t respect or care for me – sees that I am not worthy. He takes off when he hears of SCD. When I get some job, it’s better because I get by. People who support me financially after hospitalization to buy drugs and food, when business is low, I can borrow to buy stock to do work I feel better.” WC3 on 8.1.2016 at Huruma
“When I can work/do business and get some money.” WC8 on 10.1.2016 at Kamulu
“When I’ve medicine, I know nothing tragic can happen.” WC18 on 6.8.2016, Park Rd
“Having our own house was such a relief.” WC14 on 6.8.2016 at Kayole

Caregivers reported that they were encouraged in the face the challenges with sickle cell disease with prayer and enduring relationships especially when their marriages remained intact and when spouses were supportive. Women caregivers were the most affected because when marriages broke because they were left with the PLWSCDs and other children to care for alone. In this study, only one man was deserted by the wife with the child because of SCD. Some caregivers reported that prayer and reading the bible brought composure and hope as they left the burden to God. Some IFCGs shared the following.

“When the babies are ok and not sick. It makes me hopeful” WC8, 10.1.2016 at Kamulu
“‘Mzee kukaa bila kutoroka’ - the husband staying and not running away from us helps a lot.” WC13 on 18.1.2016 at Kibra, Olympic
“When I meet older PLWSCD 36 – 40 years plus with grandchildren. It encourages me.” WC31 on 7.8.2016 at John Saga
“I had heard a lot of negative messages how he will not live beyond a certain age. When I came to Baraka and met PLWSCDs above 35 years, I really got encouraged. Now I know my child will grow and my fear went away.” FGDt 19.9.2019 at Strathmore
Caregivers reported that availability of affordable and relevant healthcare for PLWSCDs encouraged them. That relevant targeted interventions reduced admissions because doctors picked up oncoming infections before they got worse when PLWSCDs attended clinics regularly. This saved caregiver’s money that would have paid for irrelevant tests and avoidable inpatient care. The caregivers were educated on SCD management and avoided trigger factors with proactive decision making. They reported that having someone else to pick the medical bills helped caregivers when they were unable to afford healthcare.

Members of the FGD shared the following.

“Baraka gives us free drugs that have sustained our children. I stopped weekly hospital visits for treatment and only come to clinics. Even admission ceased.” FGDa on 12.9.2019 at Baraka

“I used to go to hospital very frequently. Since the time I came to Baraka in 2015 and saw Dr. Wafula, the child has never been admitted nor transfused.” FGD, Baraka

“Since he came here, crises are non-existent. I encourage people to come to Baraka, it may not be high class but what we have found here has saved our lives. It is far better than Nairobi hospital and Agakhan where you may not find such doctors.” FGDd on 12.9.2019 at Baraka

Other studies reviewed revealed that lack of research and information on sickle cell disease was a global problem (Burnes et al., 2008; Wonkam et al., 2014; Marsh et al., 2011). Caregivers of critically ill patients identified the need for general information, emotional support and respite (Alspach, 2009). That having information made coping easier (Atkin & Ahmad, 2000). Other studies revealed that prayer followed by confrontive approach was also used to maintain control (Rose & Clark-alexander, 1998). Other studies reviewed revealed that IFCGs had the capacity to demonstrate resilience despite significant challenges and that caregivers desired more than one parent support group and fathers’ involvement (Slaughter & Dilworth-Anderson, 1988). Studies revealed that social support eased the caregiving burden. Learning physical assessment skills, navigating medical systems and keeping health records for emergencies made some caregivers to cope better as did when (Graff et al., 2010). When appropriate professional support was given, it
reduced caregiver frustrations and enabled coping through awareness, psychological and financial support (Brown et al., 2010).

**4.4.3 Experiences That Constrained Coping**

This section assessed the caregivers’ experiences that made coping with SCD difficult and IFCGs reported as follows: The first was the fear of the child getting infections/sick, painful crises or death that affected 21% of IFCGs. This was followed by derailed developments and inability to stick to plans 15%; financial challenges 15%; lack of medical facilities with trained medical staff for good medical support 12%; myths and misconceptions 11%; lack of support systems 10%; Stigma and social isolation 10%; denial and blame game 6% (table 4.25) below. Key informants reiterated these experiences as contributing to making the coping more difficult.

**Table 4.25: Experiences that Constrained Coping, Nairobi 2016**

<table>
<thead>
<tr>
<th>No.</th>
<th>Experiences that constrained coping</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Fear of frequent infections that lead to painful crises and/or premature death</td>
<td>47</td>
<td>21</td>
</tr>
<tr>
<td>2.</td>
<td>Derailed developments, Inability to stick to plans, Despair and Helplessness, Shock from tragic news</td>
<td>34</td>
<td>15</td>
</tr>
<tr>
<td>3.</td>
<td>Financial challenges (Borrowing, Inability to work, Inability to save, High cost of healthcare, Job loses, High maintenance costs at home)</td>
<td>34</td>
<td>15</td>
</tr>
<tr>
<td>4.</td>
<td>Lack of comprehensive Sickle Cell Management Centres with trained medical personnel</td>
<td>27</td>
<td>12</td>
</tr>
<tr>
<td>5.</td>
<td>Myths and Misconceptions</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>6.</td>
<td>Stigma &amp; Social isolation</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>7.</td>
<td>Lack of support from community systems leading to Stress and Fatigue</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>8.</td>
<td>Denial and blame game (broken relationships, Lack of appreciation, Lack of information and knowledge)</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

As seen in section 4.2.2 of this study above, 56% of PLWSCD die by age 15 years, 75% by age 20 years and 90% by age 30 years. Caregivers reported that these trends worry
caregivers as they reported that they always wondered when their PLWSCD would get sick with a vaso-occlusive crisis or die. They reported that this fear worsened when caregivers heard of other PLWSCDs they knew who had died, or when other PLWSCDs were in hospital. They reported that loss of their own PLWSCDs also brought discouragement especially when they had come a long way with them and were beginning to hope that the disease was beaten. They shared below.

“*She was about 7 years. She used to have a lot of painful events with fever, low Hb, coughs. At least I have learnt how to manage that.*” FGDt on 12.9.2017 at Baraka

“*Seeing other children with SCD who are worse. I wonder if the same will come to mine. Children really die in KNH. I don’t like going there to see – it really discourages me.*” WC2 on 7.1.2016 at Huruma

“*When I heard someone with SCD died, I almost left the group. I used to cry every day. I wondered if we are next in line.*” WC4 on 12.1.2016 at Tasia

“*My 15-year daughter’s death. I had lots of hope but she died. Lose doesn’t give life any meaning.*” WC28 on 11.2.2016 at Umoja Inner core

Caregivers in this study reported that they feared being socio-economically deprived because financial challenges made them vulnerable. Socio-economic deprivation manifested in three major ways: erosion of their capacity to provide basic needs, inability to work or run a business and erosion of caregiver’s capacity to support livelihoods as discussed in section 4.3.3 above. Erosion of caregiver’s capacity to provide basic needs was evidenced by their inability to pay for the cost of healthcare that related to consultation, routine tests, medication, X-rays and routine clinics. Finances were also needed for maintenance at home for nutrition, warmth and general comfort. All these made it hard for IFCGs to save as money that was always used for healthcare purposes. Inability to pay bills made IFCGs to be locked up in hospitals for months as the hospital established if they could pay or not before releasing them. Shortly after, the PLWSCD would be back in hospital with another crisis or complication and the cycle continued leading to despair and helplessness. The frequency of crises rendered IFCGs poor and this got harder with more children in the household having SCD. Caregivers reported borrowing heavily or taking
loans to cover medical bills. Caregivers reported that they struggled with inability to work and support their livelihoods as seen in 4.3.3 above. Some FGDs members shared below.

“Since at Baraka I only pay 300 and get seen well. It’s better than KNH where we pay 550 just for the file and maybe they ask for 1600 for X-ray. Without money, they send you away to return only when you have an X-ray.” FGDt; 12.9.2017, Baraka

“A budget of one child with SCD is like that of 3 children without SCD.” WC13 on 18.1.2016 at Kibra, Olympic

“I am an engineer by profession. I can’t look for work. The 1st week I went to work, the child got a crisis. I had left the child with a sister who overdosed by giving Augmentin twice in two hours. This made the child turn yellow. I was called while in the interview” FGDhh on 3.10.217 at Baraka

“I am a teacher. When the child was admitted for 2 weeks, I was replaced. The head told to me go and take care of the sick daughter. FGDjj on 3.10.217 at Baraka

“I have no investments. I would have been called mother of children but now I am called mother of a child. Those who have been married later than me have more children. Developments are halted because of need to pay hospital bills. People don’t understand my problems so I must try my best because children need to eat dress and get treated. When you start projects with someone, after a month, they leave me behind e.g. merry go rounds, people avoid you in their groups because they know my children will be sick soon.” WC3 on 8.1.2016 at Huruma

Caregivers in this study reported that lack of equipped medical facilities with trained medical staff where one could rush a child in crisis for good medical support made coping harder as discussed in section 4.2.9 above. Inadequate facilities resulted in misdiagnosis and mismanagement that sometimes led to death. Other challenges reported by IFCGs included being misunderstood, delayed responses, lack of drugs, getting negative discouraging feedback from doctors who still operated with myths, apathetic doctors who treated patients roughly due to ignorance labelling PLWSCDs as stubborn when they cried in pain, doctors who did not really listen to patients. When hospitals lacked specialists and therefore gave substandard medical care, it made it harder for caregivers to cope. For instance, when medical personnel admitted a PLWSCD for five months without being able to tell what they were really treating was very frustrating. Patients struggled to cope when health facilities were very far. Several caregivers in this study reported traveling to Nairobi from upcountry like Kaimosi and Budalang’i to access proper care in Baraka Medical
Centre which made clinic visits very expensive. Others also reported that it was not easy to find laboratories where confirmatory tests for SCD could be done and the cost was prohibitive. Lack of comprehensive health care management centres were therefore a major factor in making coping difficult. With proper management, the patients and caregivers lives improved. Some respondents asserted below.

“Misdiagnosis - confusing tummy crisis with abortion by the medical teams. They ignore and leave patients to suffer a lot.” P4G on 20.7.2016 at Karen IPR

“When SCD patients do not get assistance... Delays at hospitals... When doctors don’t provide information as key people” P5B on 21.7.2016, Kahawa Sukari

“Misunderstanding e.g. when people think one is pretending ‘kujifanya’ then they don’t give due assistance needed.” P6G on 6.6.2016 at Tasia

“Medical people who give negative feedback that break ones hope e.g. people with SCD don’t live or won’t reach 8 years. They treat you half-heartedly with lots of ignorance looking at the baby as a ‘ghost’.” WC25 on 8.6.2016 at Limuru

“My challenge is that I stay in Kaimosi most times and I need to bring the child to Nairobi. There are no clinics around. I have to travel far and I do not have money... (Weeps). He has been to the clinic in Baraka since 2015.” FGDh, 12.9.2017 at Baraka

Caregivers reported that they struggled to cope with discouraging and deeply hurtful remarks directed at them or their PLWSCDs. For instance, people suggesting that it was better if the PLWSCD died to give the caregiver repose. Caregivers also reported that there were people who confused SCD symptoms with other diseases like HIV or cancer and discussed how the PLWSCDs died early, or that the family abused God and this was a form of punishment. They reported that snide remarks like calling the PLWCSD a ‘walking dead’ hurt caregivers a lot. Some caregivers reported being accused of being dirty as a course of the child’s frequent illness or lack of proper nutrition for their stunting. Reminding caregivers of death discouraged them further because in their subconscious they reported already struggling with this fear daily. Asking insensitive questions also discouraged and annoyed caregivers. These remarks usually come from negative people or those without proper information as reiterated by the FGDs below.

“Snide remarks like relatives saying ‘these are just dead people’ or ‘I don’t have grandchildren in that house’. Helpers at home who are mean to the children and bosses...”
who do not understand. My Mother used to cry every morning simulating how she would mourn when my sister with SCD eventually died.” WC24 on 4.6.2016 at Karen.
“When a dad who’s not acting as a father says ‘this is that usual disease of his’. ” WC30 on 13.2.2016 at Mathare
“Medical people who give negative feedback that break ones hope; Negative gossip ‘this child has really given you stress. It is better that God takes her away so that you can rest. It will also help you save some money.” P7G on 22.7.2016 at Dandora

Caregivers reported that they struggled to cope due to lack of support systems as discussed under gender equality in caregiving (4.2.10 above) and social deprivation and exclusion in (4.3.2 above). The FGDs reiterated the same issues relating to inadequate support at home and in the society that led to IFCGs feeling rejected, stressed and fatigued. In hospitals, bills and unsupportive medical staff made coping difficult. One lady was excommunicated from her church for ‘putting a spleen’ in her baby’s tummy due to a misunderstanding that the swelling was caused by demons. At school the problem was reported to occur when teachers did not support the affected PLWSCDs sometimes making them to quit school. Some caregivers shared the following.

“When babies get sick a lot and there is no peace in the house leading to quarrels. I feel tired and my mind gets clouded.” WC8 on 10.1.2016 at Kamulu
“My husband never cares and cannot bring the child to the clinic because he says people stay too long.” FGDd on 12.9.2017 at Baraka
“When my husband was running around with other women, I felt like running away and leaving the child here.” WC30 on 13.2.2016 at Mathare N/A3
“The problem I have is stress. When I enter church everyone looks at me and says I have majini in the baby’s stomach. I don’t go to church anymore... They don’t want the woman with majini. I don’t know if this spleen will get finished or not. I don’t know what I am supposed to do. Once they see me, they ask me to go back to where I got the spirits to put in the baby.” FGDn on 12.9.2017 at Baraka
“Some teachers have bad attitudes. One is sick daily and someone remarks ‘are you the ones who abused God?’” WC10 on 14.2.2016 at Komarorock

This study also identified sigma and social isolation as one of the experiences that made IFCG’s coping difficult. IFCGs reported that people avoided them or treated them differently making them feel stigmatized and isolated. Sometimes the IFCGs isolated themselves to avoid answering questions insensitive questions like why the child was
stunted or had yellow eyes. Other times caregivers are labeled witches, as possessing demons or spirits, or saw their children as strange. They reported that stigma caused the PLWSCD to be rejected or treated like lepers, for instance denying admission to schools. This stigma proliferated to caregivers as well. The fear of being treated differently made caregivers hide their struggles with SCD from people. Rejection of caregivers occurred at family, community and workplace and even in churches. They shared below.

“I was called a witch in my home and where I am married. They said that my deceased son was killing my in-laws’ son who was named after him.” WC3, 8.1.2016 at Huruma

“I feel frustrated. When my son was sick for a whole year and had to repeat a class. They were refusing to re-admit him because he was on crutches.” WC12 on 13.1.2016 at Komarocks

“Stigma from people who are supposed to be supportive like teachers who think a caregiver has pampered her child and asking everyone to do the same. Sometimes instead of being supportive they treat the child like a leper.” FGDz, 19.9.2017 at Strath

“Around the time I discovered the child had SCD, I happened to get a lot of money. People started associating the money with the sickness. They said that this baby is the one who brought the money. Said that when the money ends the child would die and when the child dies, the money will end.” FGDb on 12.9.2017 at Baraka

Caregivers reported that they suffered from denial on hearing something they were not ready to deal with for example, after diagnosis of SCD discussed under negative mental health outcomes in 4.3.1 above. Those who experienced denial, often apportioned blame. Denial and blame often were reported to lead to broken relationships. Some caregivers reported the following.

“I went home and asked my mother in law about SCD. She kept very quiet. She has not spoken of it to date. Once I asked her where it came from, I said I did not know anyone in our place that had this bad blood. She also told me that she had never heard of it in her place and that it’s me who knows where I got it from.” FGDn, 12.9.2019 at Baraka

Additional issues that made coping difficult brought up in the FGDs were despair when dealing with pain, fatigue, broken relationships, rejection of children or their mothers and stress as indicated below. All these were discussed in detail under 4.3.1 and 4.3.2 above.

“The intensity of pain experienced by patients makes me exasperated especially when the child cries and asks me to find someone to take away the pain. The patients wish
audibly that they died yet I do not have the right medication to help with pain rendering me as helpless as patients are. When I heard the Hb was 2 and the child could die. This really freaked me out.”  FGDdd on 1.9.2017 at Strathmore
“The child used to get sick a lot. I used to get admitted every two weeks and I would stay for months. I was going crazy.  FGDn on 12.9.2019 at Baraka

Previous studies have reported that women desired public awareness to dispel misconceptions and myths about SCD (Burnes et al., 2008). Other studies have reported that 50 – 80% of children born with SCD die before their fifth birthday in Africa and that PLWSCD rarely lived past 20 years (WHO Africa, 2010; Ojwang et al., 1987). IFCGs of PLWSCDs were uncertain about the direction of the disease (Alspach, 2009). The SCD burden in Africa has increased and led to major public health and socioeconomic implications (WHO Africa, 2010). Inability to stick to schedules prevented IFCGs from working well as colleagues tagged them as unreliable and lacking in seriousness at work (Marsh et al., 2011; Burnes et al., 2008). SCD caregivers most likely had jobs without sick leave or flexible work hours making caregiving a barrier to employment and that multiple absences from work led to job losses (Brandow et al., 2009).

One study indicated that SCD patients required high level of care, running homes and treatment (Marsh et al., 2011; Amendah et al., 2013). The high level of care necessitated financial resources. Expenditure levels went up in the absence of insurance as caregivers were required to pay cash (Burnes et al., 2008; Marsh et al., 2011).

Handling a sick child had financial implications namely; inability to work, reduced work hours and wages; reduced pay, benefits, profits, retirement income; out of pocket expenses, financial strain, benefit loses, and unpaid leave (Alspach, 2009; Frey, 2009).

The ignorance of medical staff was frustrating. Fathers’ attitudes undermined the mothers’ ability to cope and pain made coping strategies vulnerable (Burnes et al., 2008). The ineptitude and unsympathetic reactions from medics undermined ability to cope and worsened feelings of isolation, inadequacy and helplessness (Brown et al., 2010). Fathers
denying paternity and blaming the SCD on the mother especially when more than one child is affected made coping difficult (Marsh et al., 2011). Blaming Caregivers for SCD by sisters-in-laws represented discriminative practices against women by women linked to patriarchal power structures (Muchangi, 2014). Stigma affects the psychological, financial and social status of caregivers and their families (Adegoke & Kuteyi, 2012). This study established that stigma and social isolation made coping for informal caregivers more difficult.

In this study, experiences that made coping more difficult also increased the caregiver’s vulnerability. These included fear of the child getting sick or dying which created uncertainty and inability to stick to schedules, socioeconomic deprivation, lack of accessible medical facilities with trained medical staff, discouraging remarks, lack of support systems, stigma, social isolation, denial, blaming and despair. This study found that the modal life expectancy of sickle cell patients is 13 years leading to the constant fear caregivers have of sickness and death from SCD.

4.5 Necessary Measures to Reduce IFCGs Vulnerability

It will be recalled that objectives 5 was to identify necessary measures to reduce IFCGs vulnerability related to caregiving of a PLWSCD. Accordingly, the study examined aspects that respondents considered to be useful in providing caregiving to a PLWSCD.

4.5.1 The Needs of IFCGs of PLWSCD

Caregivers reported that they needed financial support (53%), a hospital where urgent and comprehensive treatment is provided (38%), social support systems (34%), support in accessing medication (25%), psychological help (19%), support for proper diet (15%), information (15%), medical insurance support (9%) and (4%) spiritual support. Those who did not know what they needed were only (2) (table 4.26) below.
Table 4.26: Needs of Informal family caregivers of PLWSCD

<table>
<thead>
<tr>
<th>Needs of IFCGs of SCD patients</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial support</td>
<td>56</td>
<td>25</td>
</tr>
<tr>
<td>Comprehensive SCD Management Centre</td>
<td>41</td>
<td>18</td>
</tr>
<tr>
<td>Social support systems</td>
<td>36</td>
<td>16</td>
</tr>
<tr>
<td>Access to Medication</td>
<td>25</td>
<td>11</td>
</tr>
<tr>
<td>Counselling</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td>Nutritional support</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Information</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Medical insurance</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total N=226</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Members of the FGDs reported that IFCGs needs included support groups, supportive house helps, genetic counseling, knowledge and information, access to medication, insurance cover, proximity of SCD clinics and more clinic days than one. Key informants perceived IFCGs needs to be awareness, budgeting and protocols at hospitals, psychosocial support, patient support groups, financial support and economic empowerment. Some respondents shared the statements below.

“*Awareness for practitioners and the general public, budget for their treatment of SCD, protocols guidelines for every facility that manage SCD, avail blood for SCD patients and involvement of the ministry of health.*” KI1 on 12.9.2016 at Baraka

“*Psychological support, a care pathway that is reliable for their SCD dependent relative, proper health education, healthcare, patient groups and resources.*” KI2, 16.9.2016 at MoH

“*Empowerment, support systems, family involvement, acceptance, social support and economic empowerment.*” KI8 on 27.11.2016 at Strathmore

The highest priority need reported by IFCGs was financial support to support day to day management of SCD as well as financial support to enable them start or run IGAs that would empower them economically. In this vein, caregivers also wished for understanding and support from business associates. As seen in section 4.3.4 under socio-economic
deprivation, IFCGs’ desired employers who were supportive and empathetic to enable them keep jobs and care for their PLWSCDs. IFCGs reported that they desired support in obtaining medical insurance without exclusions that made it untenable. Insurance was the 7th need that would ease their financial burdens as discussed under IFCGs’ experience with insurance companies in section 4.2.9 above.

“Help to establish myself so that I am empowered with funds when crisis strikes.” WC7 on 5.1.2016 at Mathare
“Jobs. Some caregivers have husbands and some don’t – they need support.” WC23 on 9.2.2016 at Mathare
“Financial support from employers or community support - all relatives should know and help.” WC17 on 20.1.2016 at Baraka
“Understating from business associates” WC24 on 4.6.2016 at Karen, Hardy

The second priority of needs reported by IFCGs were comprehensive management centres for PLWSCDs that were accessible, with free, affordable or highly subsidized medical services. This enabled IFCGs who could afford treatment to be assisted. IFCGs reported that they always feared that the PLWSCDs might not be able to pay their medical bills when the caregivers were gone/dead. In this vein, structures that would allow patients to be treated without bills or affordably would ease their anxiety. This included free consultation, testing, diagnostics and medication. For instance, the sickle cell clinics in Baraka, Strathmore and Oasis were being run every Tuesday at the same time to the convenience of volunteers who committed one day in a week to serve. IFCGs wished there were more days dedicated to SCD clinics because patients did not fall sick on Tuesdays only. They wished for more clinic days because they paid a subsidized fee of KES 300 while the rest of the days they would be required to pay the full amount for services rendered. During the clinic days they got a full monthly dose of medication prescribed by specialist doctors, which was denied the other days of the week. Access to free or affordable medication was the 4th priority of needs for IFCGs. Some caregivers shared the statements below.
“It would be nice if they can increase the days when we can walk in and get the specialist doctors to see us. One cannot also be given the monthly dosage for a patient that is allowed on Tuesday.” FGD5d on 3.10.2017 at Baraka

“Help in complete treatment. To help me get a way of supporting him whenever he is sick. For him to be treated even if I am broke or dead.” WC30; 13.2.2016 at Mathare

“Access to affordable care both in and out patient i.e. comprehensive Sickle cell Centre.” WC29 on 15.5.2016 at Buruburu

“If the government can help us to have these daily drugs given to patients freely as is done for other diseases like HIV and TB” FGD5e on 19.9.2017 at Strathmore

Caregivers reported that the ability of the medical facilities to provide urgent care comprehensively including inpatient care when the need arose was important to them. That meant that the facilities needed to have trained knowledgeable medical teams and to be equipped with requisite diagnostic tools. If the facility did not admit, it was very useful to IFCGs if ambulance services were available in the event one needed referral to another health facility. IFCGs also reported desiring a facility that was near their residences. Proximity was very important for emergencies as seen in section 4.2.9 of this study above. Caregivers reported that there were times when patients developed complications that required immediate attention and they did not always have quick means of transport to rush the PLWSCD to hospital. It therefore helped to be at a place where the caregiver could run on foot or on a bike to hospital. Sometimes emergencies occurred in the night and waiting for morning to come to go to hospital had led to some deaths. Transportation was also reported to cost less when the facility was nearer the caregiver’s residences as seen below.

“Psychological support; A hospital for admission and for full urgent care when need arises that is accessible and affordable.” M2 on 5.7.2016 at Baraka

“In hospitals, doctors need to learn about SCD and treat it as emergency that requires attention even in outpatient.” WC9 on 16.1.2016, Lucky Sukari

The sixth priority in order of needs of IFCGs reported was knowledge. Many caregivers reported that they really appreciated when they were given education and information on care, management and diet. Information about SCD helped to dispel myths and misconceptions about the disease empowering women to talk about it authoritatively.
Knowledge also enabled them to defend themselves when accused of bringing the illness or misaligned paternity. They reported that education helped them to know how to circumvent the crisis triggers by putting in place structures that supported implementation of strategies that prevented and mitigated vaso-occlusive crises. Information also went a long way in making the IFCGs knowledgeable of the right facilities and medical people to work with, as well as knowing about medications and their importance. This was also discussed under knowledge in 4.1.6 above. IFCGs wished for information to empower their children to run businesses or work and be independent when they grew up. They shared below.

“Most caregivers are only informed of the SCD trait when they have already had a child with SCD. Many wish they had this knowledge before they got married. At least they may have chosen to marry someone else.” FGD2 on 19.9.2017 at Strathmore

“They were delighted to hear there are 90 year olds who are alive with sickle cell disease with children and grandchildren.” FGDaa on 19.9.2017 at Strathmore

IFCGs reported experiencing psychosocial deprivation because of their caregiving positions as seen in section 4.3.2 above. This necessitated counselling services to help them deal with their mental health challenges that occurred in their caregiving journey. These included genetic counselling to reduce births of more PLWSCDs. Psychological support was the fifth in the priority of needs for IFCGs. Some IFCGs shared the following.

“Counselling: Education how to live with the children and dealing with relatives. Business education to enable them to run a business and make money to buy food, clothes, fees, so that they don’t live in houses like the disabled.” WC3 on 8.1.2016 at Huruma

The third priority in order of needs reported by IFCGs was the need for social support from communities around them. That meant support from within the family, from the community, at the workplace, in schools, support groups, health centres and role models. IFCGs appreciated support from their husbands and other family members. A caregiver when relieved could rest and have time to plan their life and strategize. To be able to work,
IFCGs needed support from their employers to understand when they needed to get away to attend to the PLWSCD. They reported needing family support to watch the PLWSD at home while they worked. Paid helpers played a role of standing in for the IFCGs to allow them to work. Caregivers reported that support groups helped them to identify with other people going through similar challenges and provide a space for IFCGs to learn from each other, counsel each other and vent without fear of being misunderstood. They also got encouraged and hopeful with the knowledge they acquired and experiences they witnessed.

In this study, IFCGs and patients found role models to encourage their journey in support groups. Apart from social support, in the eight position, IFCGs needed spiritual support. The reported that knowing of a higher power made them to have some place they could take their burdens with hope that the almighty takes control of the situation. This is what they shared.

“Work. If employers could be more understanding of the need to get away to attend to the children and still allow one to have a job. I would love to work but to be understood - So we do not disagree. Also near where you can attend to the child.” WC8 on 10.1.2016, Kamulu

“Someone to talk to in order to be encouraged, role models. People with SCD who are grown-ups.” P8G on 25.7.2016 at Dandora

“They were so happy to have a group where they met other caregivers to discuss and learn from one another or call when at home but needing an opinion.” FGDaa on 19.9.2017 Strathmore

Studies reviewed have revealed that while most developed countries have comprehensive health care management, in Africa, these centers did not exist (Serjeant et al., 2009; WHO Africa, 2010). The ineptitude and unsympathetic reactions from medics undermined ability to cope and worsened feelings of isolation, inadequacy and helplessness (Brown et al., 2010). There is therefore need for comprehensive sickle cell management centers that are affordable and in close proximity to the caregivers.
Studies reviewed have also reported a notable gender bias in caregiving that affected women’s ability to plan their future with confidence (Burnes et al., 2008). Helplessness in caregivers was triggered by lack of support from family and friends during the painful crises (Welkom, 2012). In societies like Kenya where power is mainly ascribed to the males increased the rate of stigma on women rendering them more helpless (Marsh et al., 2011). IFCGs interacted with different people in different spheres and being understood and supported in all these places helped them to develop resilience and to cope. Caregivers have also needed economic empowerment to enable them pay medical bills without having to get into precarious situations like borrowing, taking loans, being turned away with a sick PLWSCD or being locked up in hospitals after discharge. In this study, caregivers therefore have the need for support from their spouses, immediate family members, society and work place to care of the PLWSCDs to mitigate the psychosocial economic vulnerability.

Caregivers needed self-understanding, tolerance of negative effects, self-confidence, positive cognitions, a sense of coherence and competency (Lin et al., 2013). These personal characteristics of resilience included being able to accept and embrace change and being willing to move on, work hard, and bounce back (Lin et al., 2013). This study also revealed that caregivers needed to develop personal social skills, to solve problems, to be persistent, creative with a good sense of humor as well as communication skills - attributes that enabled her to thrive in spite of stressful situations.

4.5.2 Measures to Relieve IFCGs Challenges

Following the needs identified above, IFCGs also identified measures to relieve challenges related to caregiving. The measures were intended to be carried out by the relevant stakeholders/agencies (family, community, medical teams, government, development partners) to reduce the IFCG’s psychosocial economic burdens. Specific measures included making available comprehensive SCD management centres (44%),
followed by affordable medication and healthcare (22%), education and awareness (21%), SCD Policy (16%), diagnostic tools in hospitals (10%) and Training of health workers (9%), availability of Financial empowerment of IFCGs (23%), Counseling centres which included new born screening (23%), Access to meaningful medical insurance (13%), Institutional support (8%), Protection from segregation by employers (8%) and Nutrition support (4%) (table 27) below.

Table 4.27: How women caregiver’s challenges can be mitigated, Nairobi 2016

<table>
<thead>
<tr>
<th>How IFCGs challenges can be mitigated</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Comprehensive Sickle Cell Management Centres in every sub-county</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Availability of the Centres</td>
<td>51</td>
<td>23%</td>
</tr>
<tr>
<td>b) Training Health workers</td>
<td>16</td>
<td>7%</td>
</tr>
<tr>
<td>c) Availability of Diagnostic tools</td>
<td>16</td>
<td>7%</td>
</tr>
<tr>
<td>d) Counselling Centres - Genetics &amp; Family involvement</td>
<td>16</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Sub total</strong></td>
<td><strong>99</strong></td>
<td><strong>44%</strong></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Affordable/subsidized Medicines &amp; Healthcare</td>
<td>39</td>
<td>17%</td>
</tr>
<tr>
<td>b) Insurance/NHIF</td>
<td>9</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Sub total</strong></td>
<td><strong>48</strong></td>
<td><strong>21%</strong></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Education and Awareness</td>
<td>31</td>
<td>14%</td>
</tr>
<tr>
<td>b) Partnerships with private sector, patient support groups and the Ministry of health</td>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Sub total</strong></td>
<td><strong>36</strong></td>
<td><strong>16%</strong></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Economic empowerment</td>
<td>15</td>
<td>7%</td>
</tr>
<tr>
<td>b) Nutrition support</td>
<td>3</td>
<td>1%</td>
</tr>
<tr>
<td>d) Protection from segregation by employers</td>
<td>5</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Sub total</strong></td>
<td><strong>23</strong></td>
<td><strong>10%</strong></td>
</tr>
<tr>
<td>5. Sickle Cell Disease Policy</td>
<td>20</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>226</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

The key informants suggested provision of education and awareness, genetic counseling, comprehensive clinics in each county, training of health workers, subsidizing healthcare costs, partnerships between patient support groups and the ministry of health,
NHIF full funding, economic empowerment and family involvement. These have been discussed in this report below.

The priority intervention measure proposed by caregivers in this study is a comprehensive management center that is an accessible and affordable with adequate facilities to manage PLWSCD in every county especially in SCD endemic zones that have high prevalence. The facility should have trained medical personnel, diagnostic equipment, required medication, transfusion facilities, treatments and information as expounded below. Informal caregivers reported that they wished for expansion of hospitals to have special treatment centres/wings for SCD patients only. They hoped comprehensive centres would help pay closer attention to PLWSCD on a full spectrum of care from prevention to management. That hopefully, these clinics would offer free, affordable or highly subsidized services. To support inpatient care, they hoped that the centres should have separate wards for SCD patients so that PLWCSDs do not pick nosocomial infections and that SCD clinics that had protocols for clinicians to use and resource materials for those who want to learn. Other services caregivers wished to be offered at no cost for PLWSCDs included: consultation, education and awareness, essential antibiotics and other medications which treat stubborn infections as well as infusion sets and blood transfusion and vaccinations. They wished that the medical fraternity should be sensitized to prioritize SCD patients for blood transfusion. A multi-disciplinary approach will ensure participation of various stakeholders (schools, hospitals, churches and the local community). They shared the statements below.

“Open more SCD clinics at least two per county so that patients can be attended to quickly and get professionals who understand SCD to serve in these clinics. Primary health care facilities to stem complications.” M5 on 14.4.2016 at Mathare NA2
“Set up some special units for people with SCD so that they don’t mix them with other patients so that SCD patients interact and get proper medication” P1B; 13.7.2016, Saika
“Daily drugs need to be sustained (Pen V, folic, paludrin, Hydroxyurea) as they are a lifeline. In fact they should be free.” M8 on 12.7.2016 at Rongai

“Medicines and checkups at affordable rates or free.” P7G on 22.7.2016 at Dandora

“Go to grass roots to educate people about SCD.” P7G on 22.7.2016 at Dandora

“Awareness in schools from primary to tertiary institutions.” WC26 on 10.2.2016, Jamuhuri

The caregivers stated that they wished there was a sickle cell policy in Kenya. The Kenyan constitution provides for protection of people with medical health challenges in article 43 under access to health. Policy would support guidelines and budgets which are paramount to meaningful implementation. Early response is lifesaving but can only be supported by protocols in hospitals. Caregivers reported that supportive policies would ensure the needs of the PLWSCDs are taken care of. They asserted that the SCD policy should include genetic counselling for those intending to get married; for the whole family and communities; counselling for IFCGs to deal with psychosocial issues; for IFCGs to be allowed to stay with their PLWSCD when admitted. They shared the following statements.

“To allow mothers to stay with SCD Patients when admitted. For adult patients, caregivers are sent home yet they really need help with drugs.” WC3 on 15.1.2016 in Mathare

“Have adjustments of protocols in the health sector and Ministry of education to cater for sickle cell patients.” WC16 on 7.6.2016 at Kitengela

“Get professionals who understand SCD to serve in these clinics.” M5 on 14.4.2016, Mathare

“GoK staff to attend as many workshops globally that discuss SCD like REDAC.” P5 P5B on 21.7.2016 at Kahawa Sukari

“Enable Born marrow transplant to be done in Kenya by availing technology and training doctors.” WC32 on 14.2.2016 at Mathare

Caregivers reported institutional and legal support to institutions that assist IFCGs would assist them in realizing their objectives through partnerships. This included protection from segregation, economic empowerment and family involvement. Lobbing for favorable policies with respectable partners would help to achieve the desired changes for instance, changing labor laws to avoid segregation that led to loss of jobs and allow inclusion. Others included projects targeting SCD and having a leeway to voice their
grievances. A functional comprehensive medical insurance would take away the financial stress from IFCGs as well as the burden of soliciting for funds all the time as seen in 4.3.3 above. If NHIF could do this, most Kenyans would be covered. IFCGs reported wishing for someone, maybe NGOs to help them pay for the insurance package since some of them were indigent and unable to raise the premiums. This went hand in hand with subsidies for medical services so that everyone could access healthcare. Other caregivers requested for support in establishing IGAs or employment so that they could have resources to pay premiums for the medical cover or for bills. The caregiving work was rigorous and it went a long way when IFCGs felt loved, appreciated and supported. They reported that emotional support could be given by family members, friends, churches, social work/welfare departments in hospitals, community leadership, NGOs or volunteers. They shared the following statements.

“Partnering with SCD foundations to ensure that major challenges are dealt with” KI11 31.10.2016 at CSCF
“Employers not to segregate people with SCD.” P3B on 15.7.2016 at Ziwani
“Commitment by NHIF to include SCD in the non-communicable disease package, increased funding for prevention, care and control of sickle cell” KI4; 25.9.2016, MoH
“Financial support for IGAs support so she can take care of herself to buy drugs, ambulances, hospitalizations and to pay for NHIF” WC11 on 11.1.2016 at Baraka
“Having pillars of support from family, friends & healthcare personnel.” KI1 31.10.2016 CSCF

Studies reviewed reported that in places where neonatal screening was done and follow up by CHCM, the under-five mortality rate was ten times lower (WHO Africa, 2010). Patients who reached 70 years in developed countries had access to CHCM (Serjeant et al., 2009; Thomas & Taylor, 2002). Other studies reported seeing caregivers wishing to escalate, needing emotional support and respite and fearing untimely deaths, isolation, stigma and inadequate healthcare (Burnes et al., 2008; Alspach, 2009). In Africa, SCD is ignored and this had led to an average mortality rate of five years (Wambebe, 2001;
WHO Africa, 2010). Lack of research and information on SCD is therefore a global problem (Burnes et al., 2008; Marsh, Kamuya, & Molyneux, 2011; Wonkam et al., 2014). In Kenya the National Health Insurance Fund (NHIF) covers only 20 – 35 % of the population (Anangwe, 2008). Insurance companies refusing to pay for prescribed drugs precipitated financial stress complicating coping (Burnes et al., 2008).

In this study caregiver needs that were reported related to comprehensive care for both patients and their caregivers. Most places in Africa lacked Comprehensive Health Care Management (CHCM) centers. IFCGs in this study also longed for an insurance that is comprehensive and one that did not discriminate against people with sickle cell disease. Comprehensive SCD Management Centres at affordable medication and healthcare, Education and awareness, SCD Policy, Training of health workers, availability of diagnostic tools in hospitals, Financial empowerment, Counseling including new born screening, Medical insurance, Institutional support, Protection from segregation and Nutrition support.
CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

It will be recalled that the purpose of the study was to investigate the psychosocial economic vulnerability of informal family caregivers (IFCGs) of persons living with sickle cell disease (PLWSCDs) in Nairobi, Kenya, a town in a low and medium income country (LMIC). Accordingly, this chapter presents summaries of findings, emerging implications, conclusions and recommendations along the five study objectives namely: (i) To identify the characteristics of SCD in an urban center of a LMIC (ii) To assess the characteristics of the informal caregivers of PLWSCDs and their households (iii) To assess the psychosocial economic vulnerability of the caregivers of PLWSCDs (iv) To assess coping strategies by the IFCGs of PLWSCDs (v) To identify necessary measures to reduce IFCGs vulnerability (vi) To make recommendations.

5.1 Summary of Findings

5.1.1 Characteristics of Involuntary Family Caregivers (IFCGs)

Majority of IFCGs (84%) were between 30 - 59 years of age; where the youngest was 20 years, the oldest 60 years and the average age was 43 years. The respondents consisted of 81% female caregivers and 19% male caregivers; where 81% were married, 11% widowed. Most of IFCGs were mothers and fathers to the persons with SCD. The majority of IFCGs (59%) had between 2 and 4 children in their households. The caregivers with secondary education and above were 60%, those with primary education were 36% and those with no education at all were 4%. The study established that 56% of IFCGs understood SCD while the rest were had limited knowledge of SCD. IFCGs had a mean income of KES 35,900 but the graph was skewed towards the left with over 60% of HHs
earning less than the mean. The modal income was below KES 10,000 and the median income KES 14,346. The study also established that 58% of IFCGs lived in vulnerable settlements. In view of the level of education, income and residential areas, the study concluded most of the IFCGs were of low socio-economic status and vulnerable to shocks associated with caregiving of persons with SCD. Available reports indicate that the proportion of the female caregivers globally range from 57% to 87% and usually the wives, mothers or daughters and 84% of these are between 30 – 59 years old (Akpan-Idiok et al., 2020; Rodríguez-Madrid et al., 2019; MetLife, 2020).

5.1.2 Characteristics of Sickle Cell Disease (SCD)

The symptoms with the greatest occurrences (commonly reported) included swelling of hands and feet (68%), joint and bone pain (57%), low blood levels (anaemia) (49%), acute chest syndrome (45%), frequent infections (42%), stomach crisis (38%) and painful events in different parts of the body (38%). The key categories of the symptoms included vascular occlusion commonly referred to as ‘crisis’ (32%), anaemia (25%), end organ damage (17%), frequent infections (12%). The study established that majority of PLWSCDs (58%) were less than 15 years of age, 77% were less than 20 years of age, 85% were less than 25 years old and 90% were less than 30 years old. Accordingly, only 10% were more than 30 years old. The average age of PLWSCD was 16 years reflecting a limited life expectancy. The distribution of PLWSCDs consisted of the following ethnic communities; Luo (54%), Luhya (38%) and the rest were distributed among the Kuria, Mijikenda, Kisii and Kamba (8%); with greater density among the communities around the Lake Vitoria basin.

This study established that only 56% of IFCGs had knowledge of SCD as a genetic blood disorder that is chronic and incurable characterized by hemolytic processes that cause anaemia which in turn predisposes affected people to other illnesses. The study established
that upon diagnosis, caregivers received the news of SCD with negative emotional reactions based on their past experiences with the disease or fear of the unknown and reacted with shock, lack of understanding, pain, worry and denial. Although the highest number of years in experience was 45 years, majority of IFCGs (60%) had provided caregiving to PLWSCDs for a period of 6 to 20 years, 28% for more than 20 years and 12% above 30 years. At the time of the study, 70% of IFCGs had been prepared for the caregiver role. The burden of caregiving involved insensitive and long hours of caregiving averaging 18 hours a day, the number of PLWSCDs per caregiver, worry over early deaths, increased caregiving expenditure, discouragement and social exclusion and livelihoods deprivation. Most of the IFCGs reported limited and strenuous access to medical services (healthcare); particularly in terms of affordability and proximity. The study established also that some of the caregivers suggested the possibility of avoiding a spouse with the SCD trait (HbAS) (81%) and others emphasized the need to screen pregnancy with a view to terminating if the foetus has the homozygous HbSS (sickle cell disease) (34%). In terms of gender roles this study established that 71% of the primary caregivers were mothers, 19% shared roles and 10% included fathers, sisters and grandmothers. The hallmark of SCD is anaemia and vascular occlusion that is erratic and presents in extremely painful episodes referred to as crisis and it causes long-term tissue and organ damage to multiple body organs and sometimes causes death in the long run. (Foy H. and Kendall A.G., 1974; Mulumba & Wilson, 2015). Health related caregiving tasks at home are done mostly by women throughout their lives regardless of their economic or social status (Mauro et al., 2006).

5.1.3 Psychosocial Economic Vulnerability of IFCGs

The dimensions of psychosocial economic vulnerability in IFCGs of PLWSCD consisted of negative mental health outcomes (26%), social deprivation and exclusion (24%) and socio-economic deprivation (50%). It also emerged that IFCGs also experienced negative
physical health outcomes (47%). Vulnerability in IFCGs occurred because of factors that triggered challenges or factors that inhibited caregivers’ capacity to surmount challenges. These factors included premature deaths of PLWSCD; caregivers age, gender, literacy levels, marital status, family structures and support systems; symptoms and outcomes of the disease; occupation and the socio-economic capacity of the family; availability, accessibility and affordability of medical care; information and inadequate medical insurance. IFCGs inner psychological attributes, context of care, social and community resources available can also cause vulnerability (Joling et al., 2016).

The physical vulnerability in IFCGs manifested in form of fatigue, physical pain discomfort and general malaise. IFCGs acquired cardiovascular diseases like hypertension, tension headaches and stroke; lost or gained weight and developed stomach ulcers. Their perceived health related quality of life was negatively affected by caregiving responsibilities. The sicknesses or fatigue that they lived with day to day also affected their productively in other spheres decreasing their ability to build resilience. This was worse for single uneducated women who had no support from the fathers of the PLWSCDs. The mental health vulnerability in IFCGs occurred in form of stress (17%), depressive disorders (47%) and generalized anxiety disorders (36%) that occurred after the diagnosis of SCD. Stress manifested through shock, stressful routines, self-negligence, physical sickness like stomach ulcers, restlessness, indecisiveness, regrets, worry, panic attacks, absence of peace and guilt.

The social deprivation and exclusion occurred in IFCGs lives at different levels; individual level (17%), family level (22%), romantic (21%), community level (28%) and at the occupational level (29%). Social exclusion and deprivation was fueled by IFCGs lack of time to socialize and participate in societal events and lack of knowledge and information about SCD. Accordingly, social derivation and exclusion led to (i) lack of
support, (ii) stigma, (iii) social isolation, (iv) blaming (v) indifference (vi) rejection (vii) broken relationships, (viii) hatred and (ix) lack of support. This was consistent with other studies that have reported social deprivation of IFCGs (Madani et al., 2018).

The socio-economic deprivation manifested in form of (i) eroded capacity to meet basic needs, (ii) eroded capacity to support livelihoods, (iii) eroded financial security (capacity) (vi) inability to work or be employed and (iv) loss of income generating sources. Usually IFCGs are not remunerated but invest a lot of time in caregiving responsibilities sometimes giving up opportunities for work or business. Most IFCGs lacked medical insurance and did not have financial support to pay medical bills. Challenges obtaining work and keeping a job or a business running affected IFCGs and led to reduced income levels. This hampered IFCGs ability to pay medical bills, provide medication, nutrition, warm clothing and comfortable living environments. Resources diverted to healthcare negatively affected development plans by derailing education, careers and building of family homes. SCD also affected other decisions in the family like borrowing, taking loans, selling household items, caring for the child and even reproduction decisions of the IFCGs.

5.1.4 Coping/Adaptive strategies by the IFCGs

This study reported the following key coping strategies among IFCGs; prayer (34%), talking to someone to find encouragement (24%), crying (10%), keeping positive (8%), projecting (7%), persevering or encouraging oneself (7%), withdrawing (6%), promptly taking action (2%) and keeping busy (2%). To cope with financial challenges IFCGs borrowed, took loans, salary advances or sold household goods to raise money. In addition, key informants reported that IFCGs coped by either accepting the situation, seeking social or medical support, just existing and going through motions, quitting jobs and becoming reliant, starting flexible businesses, giving up and starting to exhibit negative self-image and depressive symptoms. Other studies also reported that caregivers sought appropriate
professional support that reduced frustrations and enabled coping through awareness, psychological and financial support (Burnes et al., 2008; Brown et al., 2010).

This study reported that the following situations reduced IFCGs vulnerability and enabled coping by giving IFCGs hope and reducing their vulnerability to socio-economic, physical and mental health shocks: Supportive systems at various levels like knowledgeable supportive medical teams, community, home, children’s school and workplace; Acquiring knowledge and information relating to SCD, where to get help and seeing grown PLWSCDs who were doing well; Economic empowerment; Belonging to a support groups with safe spaces to vent, sharing information and peer to peer counselling. These support systems were reported as situations that yield benefits to caregivers.

The following situations were reported to complicate increase their vulnerability being: Frequent infections, erratic painful crises and premature deaths; economic disempowerment entailing inability to work, derailed developments, high healthcare and maintenance costs; lack of support systems entailing inadequate information, inadequate medical support; lack of community support, non-supportive employers and broken or tasteless relationships.

5.1.5 Necessary intervention measures to reduce IFCGs vulnerability.

This study reported the following IFCG needs; IFCGs support (53%), a hospital where urgent and comprehensive treatment is provided (38%), social support systems (34%), support in accessing medication (25%), psychological help (19%), support for proper diet (15%), information (15%), medical insurance support (9%) and (4%) spiritual support. Those who did not know what they needed were only (2).

Accordingly, respondents also reported measures to relieve challenges related to caregiving. The measures were intended to be carried out by the relevant stakeholders/agencies (family, community, medical teams, government, development
partners) to reduce the IFCG’s psychosocial economic burdens. These measures included making available comprehensive SCD management centres (44%), affordable medication and healthcare (22%), education and awareness (21%), SCD Policy (16%), diagnostic tools in hospitals (10%) and Training of health workers (9%), availability of Financial empowerment of IFCGs (23%), Counseling centres which included new born screening (23%), Access to meaningful medical insurance (13%), Institutional support (8%), Protection from segregation by employers (8%) and Nutrition support (4%).

In line with the psychosocial-economic resilience theory in caregiving, the capacity of caregivers to overcome the vulnerability by withstand the perturbation and return to equilibrium in order to continue functioning by adapting to the prevailing or emerging conditions depended on the caregivers’ gender, care demand from the patient, support and the environment (Joling et al., 2016). The severity and dependency relation theory also states that the degree of the severity of the disease, the degree of the PLWSCD dependency on the caregiver and related caregiving affected the psychosocial economic resilience or vulnerability. Lastly, the gender empowerment theory can guide us on how women caregivers’ capacity can be enabled to develop capacities to maintain equity in psychosocial-economic life (Huis et al., 2017).

When IFCGs experienced support, the vulnerability seemed to lessen and they coped in a better way returning to equilibrium and even tried and acted normally as though the problem were not there. When this happened, they adapted to living with the prevailing and emerging situations. When they felt alone and unsupported, the vulnerability seemed to increase and inhibited coping with their challenges (Folke, 2006; Walker et al., 2004; Adger, 2000; Garmezy, 1991; Holling, 1986; 1973).
5.2 Emerging Implications

5.2.1 Knowledge and information

It emerged from this study that SCD had no proper local name among affected communities. They used ‘Sickle Cell Disease’, ‘Sickle Cell Anaemia’ or the Swahili name ‘Maradhi ya Selimundu’ which most caregivers were unfamiliar with. This implied lack of familiarity with the disease by the affected populations that heightened the myths and stigma. IFCGs’ knowledge about SCD correlated with their level of education as most IFCGs with primary education and below remained largely ignorant in spite of the education given to them during SCD clinics run by the foundation. Couples were still getting married without genetic counselling and only learnt they were carriers after their babies were diagnosed with SCD. Due to lack of genetic knowledge, some men sought other women outside wedlock to bear them children without SCD only to marry other women with SCT/carriers who bore them more children with SCD.

5.2.2 Vulnerability to physical challenges

This study focused on establishing the psychosocial economic vulnerability but it emerged that IFCGs are also vulnerable to physical health challenges. IFCGs were pained, got fatigued, and acquired medical conditions like cardiovascular diseases and stomach ulcers. These conditions occurred after the diagnosis of SCD.

5.2.3 Gender Dynamics

It emerged from this study: That caregiving does not only disadvantage women to compete with men, but also disadvantaged women competing with other women who do not have similar caregiving challenges; That men who are involved in the care tended to appreciate caregiving challenges and were more appreciative of the woman’s caregiving role; That men who realized that they contributed half of the genes were generally more supportive to their wives than those who remained ignorant and chose to blame; that
knowledgeable women caregivers defended themselves better when their womanhood was attacked by patriarchal stereotypes or when blamed for the SCD than ignorant women. The study also established that men tended to pay attention to strangers telling them about SCD more than their wives. That the desire to distance oneself from the SCD affected mostly fathers as mothers tended to stay and take care of their children. This study however found that 4% of fathers were the main caregivers who chose to stay with the PLWSCDs in Nairobi to access medical care while the rest of the family stayed in the village. Contrary to the belief that women always stay to care for their children, this study found three women who distanced themselves from their children with SCD. Not all mothers therefore embraced caregiving of a PWSCD even if it was their prescribed gender role. Contrary to the belief that women in patriarchal societies gave care to the invalids and the weak members of the family without support from husbands, in 19% of the cases in this study, men were supportive and shared in the caregiving roles equally.

5.2.4 Reactions after learning about Sickle Cell Disease in the family

It emerged from this study that upon learning about the existence of SCD in the family, some reactions from IFCGs not captured from studies reviewed included shock, feeling pained, receiving encouragement and becoming proactive. Not all people who understood SCD and its challenges in the communities were supportive. It also emerged that some people remained unsupportive and also rejoiced at the IFCGs’ suffering. The study also established that people desperate to find someone to blame accused the doctors who made the diagnosis for the SCD. In spite of the bad news IFCGs received, some of those with knowledge had the capacity to develop strength of character, relax and even act calmly while others still struggled to accept their reality, felt tied down and struggled with inability to have more children.
5.2.5 Benefits of caregiving experience

Although caregiving work has a lot of challenges, it also emerged from this study that caregiving also accrued some social and emotional benefits to the caregivers. Social benefits manifested in what the caregiver got from other people like being encouraged or being supported to take care of the PLWSCD. Emotional benefits accrued to the caregiver from what they did to help other people for example when they shared the knowledge they had acquired on SCD or when they encouraged other caregivers with newly diagnosed PLWSCDs. This made them appear stronger and it earned them respect from those they assisted.

5.2.6 Policy and Barriers

It emerged from this study that sickle cell blindness by the Government and lack of synergy by stakeholders was one of the barriers to proactive assistance to SCD patients. Lack of policy and guidelines made stakeholders operate in a space without clear roadmap. A part from considerations for basic facilities, diagnostic tools and trained medical teams as impediments to management of SCD, other barriers included affordability, proximity, medical insurance, empathy by medical teams, and inability to provide inpatient care. IFCGs requested review of the Policy on abortion to allow them choice to carry or not to carry a child with SCD or other genetic conditions.

5.2.7 Additional Expenses

It emerged from this study that SCD brought a lot of additional expenses for IFCGs which ordinarily they wouldn’t have bothered about without SCD in their family. These related to hospitalizations, medication, extra care at home and comforts. IFCGs were willing to pay more for warmer more comfortable houses.
5.2.8 Ability to Work, do Business or Socialize

It emerged from this study that a little help comes to the IFCGs from the larger family to give them flexibility to move around. Conditions surrounding jobs or businesses either enabled or disabled IFCGs to work. For instance, businesses with perishable goods tended to bring more loses than non-perishable goods. Activities derailed by SCD related to both economic and social aspects of IFCGs’ lives. IFCGs worried about independence of their children in future when the IFCGs would no longer be alive to assist them. They worried about the spouses the PLWSCDs would marry, they worried about their own derailed developments and personal careers. Some of the needs IFCGs had included financial empowerment, access to medication and treatments, good diet and spiritual support. It was difficult to save or invest with increased expenditures as IFCGs might not keep up with their work to sustain them. SCD was a barrier to doing business because it increased the cost of doing business.

5.2.9 Resilience and Coping

It emerged from this study that IFCGs going around to people who pray, traditional healers or leaving the situation to God has not been highlighted in other studies. To cope with financial challenges, IFCGs sought survival options like just taking the child to hospital and looking for money to pay or sought credit, fundraised occasionally, took salary advances. The study revealed that some IFCGs resorted to alternative medication like herbs, sought services from quacks or administered over the counter medication. Others sought advice from the support group through the social media platforms especially how to bypass doctors and save on the consultation fee. Those with some disposable income and were organized saved for rainy days anticipating the problem and sought solutions that did not involve other people.
This study established that the barriers to medical insurance uptake included discrimination where the policy documents were riddled with exclusions that discouraged PLWSCDs from enrolling, difficulty affording premiums and ignorance about existence of the medical insurance. IFCGs wished the government helped with payment of insurance premiums or offered free medications and treatment. To cope with financial challenges, some IFCGs relocated from the city to the village when they could not keep up with financial demands of rent, upkeep and healthcare.

It emerged from this study that experiences that made coping easier included babies’ wellbeing and good performance as it encouraged IFCG’s efforts by giving motivation and bringing hope. Support groups also provided IFCGs with information, education and peer to peer counseling which brought hope and created a sense of belonging. Seeing grown PLWSCDs encouraged and motivated those caring for younger PLWSCDs. Affordable or free, comprehensive care gave hope to IFCGs and enabled coping.

It emerged that experiences that made coping more difficult included delays in hospitals, medical facilities being far and wide, discouraging remarks, delayed development milestones, despair and lack of awareness. With knowledge of the genotype before delivery, some IFCGs would abort the child with or without legislation if the child had SCD. IFCGs wished for support systems in form of role models, workplace policies as well as economic empowerment. A policy would trigger a series of strategies and interventions for PLWSCDs.
5.3 Conclusions

5.3.1 Characteristics of Involuntary Family Caregivers (IFCGs)

This study established that the primary caregivers of PLWSCDs were predominantly women usually (71%) versus 4% men usually fathers. In their absence, other women, usually sisters and grandmothers of the PLWSCD took on the caregiving role. This highlighted the disproportionality in caregiving that disadvantaged women caregivers (WCGs) more. There were also secondary caregivers like house helps, teachers and clinical officer whose care the IFCG appreciated a lot. Some WCGs were single ‘widowed, divorced or separated’ and they had to do everything by themselves with no assistance from their spouses. Caregiving occurred during the caregivers prime years between 20 and 59 years. This took away their opportunity to participate in productive activities. This eroded their capacity to compete with their male counterparts as well as other women who did not face similar caregiving responsibilities, a situation that was aggravated by gender stereotypes and biases.

SCD affected relationships including family unions because the reason for separation, divorce or polygamy was related the presence of a PLWSCD and related caregiving responsibilities that caused deprivation. On average, there were 2 - 4 children per caregiver’s household that needed the IFCGs attention and resources, some with SCD. The more the PLWSCDs there were, the more the caregiving burden it was to the IFCG in terms of time and resources required. The IFCG’s literacy levels affected the knowledge they acquired and retained about SCD because the number (56%) of caregivers who understood SCD correlated with the number (60%) who had secondary education and above. Most of the IFCGs in this study were poor and lived in informal settlements. Their financial position dictated their choices of the residential areas and type of houses as well as schools.
and hospitals for their children. The expenditures on the PLWSCD was generally way higher than the IFCGs earnings per month impacting their financial status negatively.

5.3.2 Characteristics of Sickle Cell Disease (SCD)

This study concluded that SCD did not affect all the communities in Kenya equally but concentrated in Malaria endemic zones of the Lake Vitoria basin and the coastal region. This is because SCD came about as a result of gene mutation to protect people from Malaria. Caregivers in this study tended to ignorantly marry partners from the same geographical location perpetuating the sickle cell gene. Only 56% of affected caregivers understood that the nature of SCD as a genetic blood disorder and how it affected the PLWSCD. Some key informants who were also decision makers lacked information on the nature and prevalence in the country and were limited in making relevant decisions for the sickle cell community. The IFCGs were therefore not taken care of by the system and survived without support and groped for solutions compounding their challenges.

SCD predisposed PLWSCDs to high morbidity and early mortality. From the life expectancy above, 58% of were deceased by age of 15 Years, 77% by age 20 years and 90% by the age of 30 years. The mean age of PLWSCD in this study was 16 years. The high morbidity occurred due to low Hb and resultant low oxygen concentrations in the body making them susceptible to getting frequent infections. The lifespan of the PLWSCD correlated with the years of experience in caregiving although some caregivers with more than one PLWSCD would have more years of experience in caregiving than the age of their children.

The symptoms and complications IFCGs experienced included vas-occlusive crisis, anaemia, end organ damage, frequent infections (URTIs and (UTIs), change in behavior patterns and loss of self-confidence. These symptoms can be severe requiring immediate medical, financial, emotional and social support. These IFCGs belonged to the Children
Sickle Cell Foundation (CSCF) and had been trained to take care of PLWSCDs at the time of the study. However, before becoming members to the CSCF, some had not been prepared in any way. Gaining knowledge about the condition improved some caregivers’ outlook to the disease and moved them away from the initial shock, pain and anxiety to a place where they became relaxed and accepted the condition or grew stronger. Others however still struggled to accept, continued to worry about the future, felt tied down and even developed medical conditions.

What created or exacerbated the SCD burden to the caregiver were the following: The more the number of children with SCD, the more the resources and time was required from the caregiver. The intensity of caregiving triggered by the nature of symptoms also presented the burden where more complications demanded more from the caregivers. Thinking about early mortality in PLWSCDs triggered stress, anxiety and depression as IFCG considered what would happen to their children in a timeframe they could not determine. Discouragement from other people caused IFCGs to lose hope and made caregivers to sustain the negative mental states. High financial demands on caregivers led them into debt and disorganized their plans and developments causing psychosocial economic deprivation. IFCGs choices for healthcare facilities was informed by affordability or medical insurance, proximity, experience would affect other important daily life decisions of IFCGs like the spouses they would like to have for themselves or their children and also whether or not to have a child with SCD. Other caregivers stopped having more babies all together to avoid another experience with sickle cell disease.

5.3.3 Psychosocial Economic Vulnerability of IFCGs

This study concluded that caregiving of PLWSCDs precipitated IFCGs vulnerability to negative psychological and physical health challenges; social deprivation and exclusion and socio-economic deprivation. In line with the severity and dependency relation theory,
the number and severity of symptoms determined the needs of the PLWSCD and the level dependency of the on the IFCG. These vulnerabilities were precipitated by factors that inhibited their capacity to overcome challenges and become resilient. These factors included the symptoms and outcomes of the disease in patients; socio-demographic factors of the IFCG like age, gender, marital status, literacy levels; caregivers’ physical and mental states; the family structure and support systems; caregivers’ inability to work; the socio-economic capacity of the family; availability, accessibility and affordability of medical care; information and medical insurance. The SCD caregiving burden relating to gender issues further disadvantaged women in sickle cell endemic zones compared to women in other parts of the country.

This study also concluded that caregiving accrued a few social and emotional benefits to the IFCGs. If the caregiving did not break a caregiver, it transformed them into stronger, knowledgeable, more empathetic persons who were more humane and in touch with other people’s pain. IFCGs learnt to reorganize their lives, to multitask, to build networks, support systems and friendships that were useful to them. They gained respect from others whom they taught in group therapies or at home. The Foundation played a vital role in bringing together IFCGs with a common problem to share and learn from each other. The caregiving challenges however far outweighed the benefits.

The study concluded that caregiving increased the IFCGs vulnerability to mental and physical health challenges that affected especially women caregivers because they formed the majority of the primary caregivers. That IFCGs suffered from stress, depressive disorders and generalized anxiety disorders that were triggered by caregiving burden. In line with the societal expectations of gender roles, women were also expected to play the caregiving role due to their socialization hence the high number of families where women were the main caregivers. This made them work without asking for help however difficult
it was balancing the caregiving and other roles she played. The caregiving works predisposed caregivers to getting weary and pained following nursing routines, carrying the sick person, long stays in hospitals or while giving post discharge support. Sometimes the tress, anxiety and depressive symptoms led to other conditions like stomach ulcers and cardiovascular compilations. These effects were lessened among women caregivers who got support from spouses, families and communities around them increasing their resilience.

IFCGs gave up social activities or were unable to participate in integral societal events leading to stigma and social isolation which shrunk the IFCGs social capital – being the people they can seek support from. When the caregivers lost their networks, their resilience became very fragile. The study also concluded that social deprivation was also caused by spouses blaming each other for the SCD especially when they suffered denial. Blame often led to rejection of the PLWSCD alongside the caregiver. Rejection in turn led to broken or tasteless relationships. The study also concludes that the availability of medical/technical support would also reduce the burden of the disease and the resultant social deprivation.

This study concluded that SCD impacted negatively on IFCG’s finances that let to socio-economic deprivation. When pushed to limits, IFCGs made desperate decisions like borrowing heavily, taking loans, taking salary advances or selling household items to pay bills. The financial challenges experienced due to unending bills derailed their development plans or careers, made it impossible to save, impacted on relationships at home and rendered caregivers unable to work or run a business. SCD therefore acted as a barrier to engaging in economic activities. Loss of jobs occurred due to absenteeism, lost opportunities, lack of promotions and professional growth as well as lack of understanding
and support from colleagues. Businesses were lost due to loss of merchandise and customer’s confidence while away or when profits and capital was used to pay bills.

This study concluded that it was impossible for IFCGs to compete with men or women not giving care on a level playing field developmentally. The majority of those affected were however women caregivers because they were the majority caregivers. Within families where men’s and women’s roles were fluid or the community was supportive, the burden of care lessened enabling them to compete equally in all spheres building their resilience to economic and other shocks. The married women caregivers were sometimes lucky and got some financial support from their husbands to reduce their financial burden such that single mothers suffered more for lack of financial support. The caring and participating husbands were however very few. In most settings, men went on working and controlling the family resources and only shared when and what they chose to. This kept the women in a disadvantaged position as they had to rely on their husbands for everything. Even when women caregivers were supported, they were still limited in terms of the decisions they could make and projects they could implement. Finances affected many areas of a IFCG’s life once the sickness became frequent or if a caregivers had more than one PLWSCD. This necessitated looking into ways to support women caregivers to reduce the financial burden given that in Kenya, caring for children is a woman’s gender role and yet dependency work impacted their status as equal citizens.

The psychosocial economic vulnerabilities could be mitigated when the caregivers had support in their various areas of functioning cushioning them from the vagaries of the challenges that got in their way. IFCGs who had more support were more resilient than those without support for example married versus single women, caregivers who could keep jobs versus those who lost jobs or those with medical support and information verses those without. In line with the gender empowerment theory, supporting caregivers to
perform well at all levels would reduce their vulnerability to psychosocial economic vulnerability.

5.3.4 **Coping/Adaptive strategies by the IFCGs**

This study concluded that the psychosocial economic vulnerability resulting from caregiving responsibilities of a PLWSCD predisposed IFCGs to struggle coping with pain, frequent infections, pre-mature deaths, lack of information, inability to work and socialize, lack of support at home, financial challenges, unsupportive medical teams, day-to-day caregiving duties, blaming, broken relationships, stigma and social isolation.

The study also concluded that experiences that made coping difficult included lack of structures to support medical care, communication and advocacy efforts. To avoid getting overwhelmed by the physical, mental, economic and social challenges, IFCGs employed some strategies to survive the shocks. Some of the actions alleviated the problems while others aggravated the impact of the shocks. The study concluded that the negative coping strategies employed by caregivers outweighed the positive strategies keeping them in vulnerable states. There was therefore need to institute measures to counter negative coping strategies to reduce their negative impact on the lives of caregivers and those under their care. This could be done through education, psychosocial support or peer to peer counselling to enlighten them of the negative impacts of the negative coping mechanisms employed.

Some strategies that could help build resilience and enable coping by IFCGs included support systems at different levels ‘at home, in hospitals, in schools, in the community, at policy and program levels’; economic empowerment; free, subsidized, affordable, accessible and relevant healthcare services; psychosocial and spiritual support. At the time of the study in 2016, the government remained sickle cell blind. When a sickle cell policy
will be finalized and guidelines in place, SCD strategies will be implemented from an informed point of view which is expected to greatly boost the resilience of IFCGs.

**5.3.5 Necessary Intervention Measures to Reduce IFCGs Vulnerability.**

This study concluded that IFCGs have a lot of needs as a result of gaps that exist in SCD management in Kenya. Their burdens could be reduced by appropriate technical/medical, social, psychological and physical support. This would help them have a better health quality of life. According to the psychosocial-economic resilience theory in caregiving, to overcome the vulnerability to mental, physical, social and economic challenges, the IFCG needs to adapt to the protective and risk factors influenced by the PLWSCD, herself and the environment in order to withstand the processes that trigger vulnerability and adapt in order to return to equilibrium. Knowledgeable IFCGs with a good financial muscle, functional support systems at home, in the community, at work and supportive medical teams fared better than those without. Vulnerability impaired IFCGs normal functioning while support at different levels produced more positive feelings and actions. There was need to support IFCGs to survive those challenges or mitigate their triggers.

This study concluded that IFCGs could be helped by being exposed to other possibilities of existence where they would realize that they could demand for assistance in the care of the child from spouses for example being exposed to Judith Butlers Postmodernism to deconstruct her current paradigm and enable her to question their socialization and be in a position to demand participation from their husbands. Men on the other hand would become more willing to support their wives without fear of ridicule due to patriarchal stereotypes. The gender empowerment theory could be used to maintain equity in socio-economic life by strengthening the capacities of women with a view to gender equity in caregiving.
This study also concluded that helplessness is experienced both in developed countries as in third world countries when structures are not in place to specifically address the needs of SCD patients. Structures could be set up like comprehensive SCD management centres to support PLWSCDs and reduce the adverse outcomes that make caregivers co-existence with SCD easier. Severity of the illness could be reduced with provision of comprehensive SCD management by trained medical teams and diagnostic tools where the PLWSCDs are managed efficiently to reduce incidences of pain and complications. Comprehensive management centres that would serve to reduce the severity of the illness could also give IFCGs a new lease of life when the patients got stable and they became enabled to participate and compete in public spheres like everyone else. The study also concluded that creating awareness in the affected communities to dispel myths and misconceptions would elicit informed empathy and support to caregivers as knowledgeable people were generally more supportive than ignorant ones who tended to be intolerant. This study revealed the IFCGs desire for all-inclusive, well equipped but affordable medical facilities with empathetic medical teams in close proximity of PLWSCDs to give necessary medical and emotional support. A practical comprehensive medical insurance was also desirable.
5.4 Recommendations

5.4.1 Recommendations for Individual Informal Caregivers

The study recommends the following to the informal caregivers (IFCGs) of persons living with sickle cell disease (PLWSCDs) to enable psychosocial support, knowledge sharing, peer to peer counselling, for safe spaces to vent, to benefit from programs targeting PLWSCD and to join others in lobbying and advocacy efforts to create awareness and push for policy change.

1. IFCGs to join a support groups that support people living with Sickle Cell Disease
2. IFCGs to seek medical or psychosocial support when necessary and not sacrifice their lives for the PLWSCDs. They will take better care of the PLWSCDs when they are in good health themselves.
3. IFCGs to socialize their children to play any role without confining them to the defined societal gender roles so that when faced with caregiving responsibilities, they can play any role without fear and this will reduce the burden of IFCGs who may be around them.

5.4.2 Recommendation for Government and its Partners

The study recommends development and implementation of a sickle cell disease policy that will include the management of family caregivers, enhance medical insurance policy for PLWSCD and incorporates family caregivers in social protection schemes in order to mitigate some of the psychosocial economic challenges.

1. Incorporate sickle cell disease in the 2020 - 2030 health policy, the 2020 NCD strategy and the NHIF policy.
2. Implement the provision of promise in article 43 of the 2010 Constitution “Access to healthcare for all” and the Universal Health Coverage: Tailor health services for persons living with SCD and offer them for free, affordably, highly subsidized
or avail a free comprehensive medical insurance to ease the financial burden of caregiving.

3. Institutional strengthening: Hospitals, Medical teams, Research centres and CSOs. This includes infrastructure development, equipment and diagnostic tools, training of medical teams, clinical trials, medication, advocacy, counselling, education and awareness, economic empowerment and nutritional support.

4. Establish comprehensive healthcare centres for PLWSCDs at national and subnational levels.

5. Social protection to be extended to IFCGs to mitigate income loss risks including mechanisms to ensure their continuity with work/employment and education/career development.

6. Address underlying gender and economic inequalities precipitated by caregiving.

7. Revise the policy on abortion to give women caregivers a legal choice in the matter regarding pregnancies of babies with homozygous HbSS (SCD) gene and other genetic issues.

5.4.3 Recommendation for Further Studies

The study recommends the following titles for further studies.

1. Policy implications on sickle cell disease management in Kenya/Africa

2. Factors that affect the decision by African countries not to meaningfully plan and budget for sickle cell disease

3. Investigate why some caregivers still exhibit ignorance and chose to operate with myths in spite of the education given to them in sickle cell clinics.
REFERENCES


APPENDICES

Appendix i: Letter of Introduction

FOULATA T. KWENA

Address: P.O. Box 22275, 00400 Nairobi, Kenya
E-mail: foulatakwena@gmail.com
Cell Phone: +254 722 795773

Dear Sir/Madam,

1st July 2016

Subject: Permission to carry out research on the “Psychosocial Economic Vulnerability of Family Caregivers of Persons Living with Sickle Cell Disease in Nairobi County, Kenya.”

I am a student undertaking a course in Doctor of Philosophy, PhD in Gender Development Studies at Kenyatta University. I am required to submit as part of my research work assessment, a research thesis report on “Psychosocial Economic Vulnerability of Family Caregivers of Persons Living with Sickle Cell Disease in Nairobi County, Kenya”. To achieve this, The Children Sickle Cell Foundation (CSCF) has been selected to participate in the study. The objectives of the study are as follows:

1. To assess the characteristics of the caregivers of PLWSCD.
2. To identify the characteristics of SCD in an urban center of a LMIC.
3. To assess psychosocial economic vulnerability of the caregivers of PLWSCD.
4. To assess coping/adaptive strategies by the IFCGs of PLWSCD.
5. To identify necessary intervention measures to reduce IFCGs vulnerability.
6. To make recommendations

The researcher will use a set of predetermined questions on an interview guide to direct the interviews. There will also be use of an observation check list. Voice recorders and notebooks will be used to record information given. The information collected will be used purely for academic purpose only. Participants will sign consent forms to confirm their voluntarily participation but their names will not be mentioned in the report.

The purpose of this letter is to kindly request full participation of the CSCF members in the study. The findings of the report shall upon request be availed to you. Your assistance and cooperation will be highly appreciated.

Yours sincerely

Foulata Kwena

Cc Kenyatta University
National Council for Science and Technology and Innovation (NACOSTI)
Children Sickle Cell Foundation (CSCF)
Ministry of Health
Appendix ii: List of Approval Letters


5. Jomo Kenyatta University of Agriculture and Technology – College of Health Sciences (COHES), School of Medicine – Acceptance letter by Professor Aluoch J.R. - 7.11.2016

6. Jomo Kenyatta University of Agriculture and Technology – COHES, School of Medicine Submission of CV to the Ethics Committee Professor Aluoch J.R - 8.11.2016


9. Ministry of Education (State Department of Basic Education) - 03.3.2017

Appendix iii: List of Sickle Cell Disease Foundations/Support groups

1. Children Sickle Cell Foundation (Nairobi, Busia, Mombasa, Mumias, Homabay, Siaya)
2. Sickle Cell Strong - Nairobi
3. Denis Awich Foundation - Nairobi
4. Sickle Celler Foundation – Bungoma
5. Jaramogi Oginga Odinga Foundation – Kisumu
6. Siaya Sickle Cell Foundation
7. Sickle Cell Anaemia Foundation (Scaf-Kenya) – Mombasa
Appendix iv: Key Informants and Institutions

1. Registered members of the Children Sickle Cell Foundation (CSCF) in Nairobi County
2. Doctors in Nairobi who have worked with the CSCF
3. Nurses who have supported people with sickle cell disease with CSCF (Baraka and Strathmore medical centers)
4. Ministry of Health officials from the department of non-communicable diseases
Appendix v: Map of Nairobi County showing location of the CSCF Office

Children Sickle Cell Foundation office at Epren Centre, Mesora Court in Buruburu, Nairobi County
Appendix vi: Consent form for Respondents

My name is Foulata Kwena. I am a PhD student from Kenyatta University. I am conducting a survey on “Psychosocial Economic Vulnerability of Family Caregivers of Persons Living with Sickle Cell Disease in Nairobi County, Kenya”. The information will be used for education purposes mainly. I also hope the information will be read and used by the Ministry of Health Officials who may use the information in formulation of pro sickle cell disease policies to improve the lives of people living with this condition. Your free participation will enable me achieve this.

**Procedures:** I will ask you some questions from the questionnaire and make a record of the answers in a notebook and also via an audio recorder. I may ask you to elaborate a point when it’s not very clear. This will take approximately 1 ½ hours.

**Discomforts and Risks:** Some of the questions may be intimate and may be embarrassing or could make you uncomfortable. If this happens, you may refuse to answer these questions if you so choose.

**Benefit:** If you participate in this study, you will help us learn how sickle cell disease affects women who give care to this population and give us insights how these women can be supported in their caregiving role by coming up with policies that support people with sickle cell and their caregivers.

**Confidentiality:** The interviews will be held in the privacy of your homes on one to one basis. Your name will not be recorded on the questionnaire. The questionnaires will be kept in a locked cabinet for safekeeping. Everything will be kept private.

**Contacts Information:** If you have any questions you may contact the following supervisors: Dr. Mildred Lodiaga on 0721-469815, Dr. Grace Okong’o on 0704-913339 and Prof. Joash Aluoch on 0722-719820 or the Kenyatta University Ethical Review Committee Secretariat at chairman.kuerc@ku.ac.ke, secretary.kuerc@ku.ac.ke and ercku2008@gmail.com

**Participant’s statement:** The above information regarding my participation in the study is clear to me. I have been given a chance to ask questions and have been answered to my satisfaction. My participation in this study is entirely voluntary. I understand that my records will be kept in private and that I can leave the study at any time. I understand that I will still get the same care and medical treatment whether I decide to leave the study or not and my decision will not change the care that I will receive from the clinic today or that I will get from any other clinic any other time.

__________________________  ____________  ______________________
Name of Participant                  Date                  Signature or Thumbprint

**Investigators statement:** I the undersigned have explained to the volunteer in a language s/he understands the procedures to be followed in the study and the risks involved.

**Foulata Kwena  2016**

__________________________  ____________  ______________________
Name of interviewer                  Date                  Signature or Thumbprint
Appendix vii: Interview Guide for Involuntary Family Caregivers

Form No.: ____________________________

Characteristics of the Informal Caregivers

1. Gender of the Caregiver [ ] I am a woman Caregiver [ ] I am a male family member

2. How old is the caregiver? (Tick)
   [ ] 60 and above

3. Your upcountry County ______________________________________

4. Ethnicity __________________________________________________

5. What is your marital status (Tick)
   [ ] Single   [ ] Married   [ ] Separated   [ ] Widow   [ ] Divorced   [ ] Other ______

6. What is your level of education? (Tick)
   [ ] None   [ ] Primary   [ ] University   [ ] Secondary   [ ] College   [ ] Other ______

7. Number of family members in the house hold of the IFCG? ________________

8. Number of persons with SCD (PLWSCD) in the household of the IFCG? ___ Boys ___ Girls

9. What is the age of the PLWSCDs? (Tick)
   [ ] Below 5 years   [ ] 5 - 10   [ ] 11 - 15   [ ] 16 - 20   [ ] 21 - 25   [ ] 26 - 30
   [ ] 31 - 35   [ ] 36 - 40   [ ] 41 - 45   [ ] 46 - 50   [ ] 51 - 55   [ ] Above 55

10. How long have you taken care of PLWSCD? (Tick)
    [ ] Below 5 Years   [ ] 6 - 10   [ ] 11 - 15   [ ] 16 - 20   [ ] 21 - 25
    [ ] 26 - 30   [ ] 31 - 35   [ ] 36 - 40   [ ] 41 - 45   [ ] Over 45 Years

11. What is your average family income per month (KES) - (Tick)
    [ ] Below 10,000   [ ] 10,001 - 30,000   [ ] 30,001 - 50,000   [ ] 50,001 - 70,000
    [ ] 70,001 - 90,000   [ ] 90,001 - 110,000   [ ] 110,001 - 130,000   [ ] Above 130,000

12. Distance to the nearest health facility/hospital where you take PLWSCD. (Tick)
    [ ] Less than 1 km   [ ] 2-4kms   [ ] 5-10kms
    [ ] 11-15kms   [ ] 15 – 20kms   [ ] above 20kms
Psychosocial Experiences and Vulnerabilities to Sickle Cell Disease

13. What has been your knowledge of sickle cell disease? __________________________

14. What is the name of Sickle Cell Disease in your language? ______________________

15. How did this PLWSCD get sickle cell disease? _________________________________

16. What was the reaction when you learnt that this person has sickle cell disease? ____

17. What was the reaction of other family members? _______________________________

18. Who cares for the person with sickle cell disease in your household? ______________

19. Were you prepared in any way to play this role after discovering the illness?
   [ ] Yes [ ] No    If yes, please explain ________________________________

20. What complications have you seen in the persons with sickle cell disease? _________

21. How do these complication(s) make you feel? _________________________________

22. How do people around the patient react when witness a crisis? _________________

23. Are there any social or emotional benefits you experience because SCD?
   Social benefits: ________________________________
   Emotional benefits: ________________________________

24. Are there any social or emotional challenges you experience because of SCD?
   Social challenges: ______________________________
   Emotional challenges____________________________

25. How do you react when you do not have money and the child becomes sick? _____

26. Does sickle cell disease affect relationships in the family?  [ ] Yes  [ ] No
   If yes, How? __________________________________________

27. How does SCD affect your relationship with other people (family, community, work
   place, romantic) ________________________________

28. What support do husbands give when the child falls sick? If you are single, skip __

29. Has your health ever been affected as a result of caring for a child/person with SCD?
   [ ] No. [ ] Yes.    If yes, please explain ________________________________
30. Would you have married your husband if you knew that he was a carrier of SCD as yourself and that you would have children with SCD?  [ ] Yes  [ ] No  Please explain your answer:__________________________________________________________

31. If you knew that a pregnancy you carry was of a child with SCD and you had a choice, would you carry the baby to term?  [ ] Yes  [ ] No  Explain your answer:________________________

32. Tell us about the most difficult experience for you as a caregiver? ______________________

33. What are your major worries as you care for someone with SCD? ______________________

**Economic Implications of Sickle Cell Disease**

34. Where does the patient go for scheduled clinics?  
   [ ] Private Doctors  [ ] Private Hospitals  [ ] Public Hospitals 
   Explain your choice of hospital:______________________________________________

35. Approximately how much money is spent per scheduled clinic visit?  
   Kshs _______ Consultation;  
   Kshs _______ Routine Tests  
   Kshs _______ Monthly prescription  
   Kshs _______ other (specify) ______________

36. How many outpatient visits does the child with SCD make in a month on average? ______

37. How often is the person with Sickle cell disease admitted in a year? _________________

38. What has been the least amount of money you paid for an admission? Kshs _______

39. What do you do when the crisis starts and you do not have money? _________________

40. Are there any financial benefits you received as a result of caring for this person? __________

41. Are there any financial challenges you face as a result of caring for a person with SCD? __________

42. How does Sickle cell disease affect household finances? _____________________________

43. Please explain any additional expenses that come up because of sickle cell disease. ______

44. Have you ever meant missed an opportunity to make money because of sickle cell disease?  [ ] No  [ ] Yes  If yes, Please explain? _____________________________

45. What is your experience with health insurance________________________________________?
46. Does the community you live in or family step in to help when the IFCG is unable to pay the medical bills?
   [ ] Yes. Why? ____________________________________________________________
   [ ] No. Why not? ________________________________________________________

47. Has the caregiver given up any activities because of sickle cell disease? ____________

**Coping/Adaptive strategies employed by informal caregivers**

48. What experiences enabled you to cope easily while caring for a PLWSCD? ____________

49. What experiences made coping for you more difficult in caregiving of a PLWSCD? _____

50. What do you typically do to enhance your coping in caregiving of PLWSCD? ____________

51. What did you do that complicated your coping with experiences (in 49)? ____________

**Necessary Intervention Measures to reduce IFCGs Vulnerability**

52. What kind of support do you need to care for the PLWSCD effectively? ____________

53. What mechanisms had the government put in place to support PLWSCD that you know of? ________________________________________________________________

54. What would you like to done that would reduce your caregiving burdens? By who? ____

**Complimentary Observation Data**

55. Nature of Residential areas (estates)

56. Infrastructure in the house (seats, comfort, TV, dressing)

57. Type of house

58. Interaction of family members

59. Indication of medication

60. Diet

61. Emotions and facial expressions
Appendix viii: Interview Schedule for Key Informants

(Doctors, Nurses, Community Health Workers, Ministry of Health Officials and SCD Advocates)

Form No.: ________________________________

1. Designation: ______________________________

2. What experience have you had with Sickle Cell Disease (SCD)?

3. What experience have you had with the family caregivers (IFCGs) of Persons Living with Sickle Cell Disease (PLWSCD)

4. How have you supported IFCGs of PLWSCD and for how long? ________________

5. What have been the primary or key challenges of the IFCGs of PLWSCD

6. What is your opinion about prevalence of SCD in Kenya? ________________

7. In your experience how has caregiving affected the family caregivers? __________
   a. Mental stability
   b. Social stability
   c. Economic stability
   d. Occupational stability

8. In your experience how has insurance been useful to
   a. Attending the person with SCD ________________________________
   b. Supporting the IFCGs of PLWSCD? ________________________________

9. In your view, what measures would be necessary to support the IFCGs of PLWSCD

10. In your view, what mechanisms has the government put in place to support IFCGs

11. What has been the shortcomings in addressing/responding to the challenges of...
    a. Persons with sickle cell disease ________________________________
    b. The family caregivers ________________________________
Appendix ix: Focus Group Discussion Guide

1. What experience have you had with Sickle Cell Disease (SCD)?

2. What experience have you had with the family caregiving of Persons Living with Sickle Cell Disease (PLWSCD)?

3. How have you supported PLWSCDs and for how long?

4. Identify any FOUR primary or key challenges of the IFCGs?

5. In your experience how has caregiving affected the family caregivers?
   - Mental stability
   - Social stability
   - Economic stability
   - Occupational stability

12. In your experience how has insurance been useful to
   - Attending the person with SCD
   - Supporting the IFCGs of PLWSCD?

13. In your view, what measures would be necessary to support the IFCGs?

14. In your view, what mechanisms has the government put in place to support IFCGs?

15. What has been the shortcomings in addressing/responding to the challenges of...
   - Persons with sickle cell disease
   - The family caregivers
Appendix x: Household Expenditure on a Sickle Cell Patient per Month

<table>
<thead>
<tr>
<th>Regular Clinics</th>
<th>Average 6 times PA Regular Clinics</th>
<th>Average Kshs paid for each admissions</th>
<th>Annual Total</th>
<th>Estimate/ Month</th>
<th>No.</th>
</tr>
</thead>
<tbody>
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