

## **The Burden and Characteristics of Family Caregivers of Persons Living with Sickle Cell Disease in Nairobi City County in Kenya**

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## **ABSTRACT**

Nearly 90% of the burden of the sickle cell disease (SCD) has been in Sub Saharan Africa and a greater proportion of the burden of the disease usually fall on the Involuntary Family Caregivers (IFCGs). Some form of impairment and related caregiving vary in duration, intensity, dependency and impoverishment. Persons Living with Sickle Cell Disease (PLWSCDs) are typically accompanied by prolonged, intensive, dependency and impoverished caregivers. This study intended to identify the psychosocial economic vulnerability of IFCGs of PLWSCDs in an urban centre of a Low-to-Medium Income Country (LMIC). The specific objective was to assess the burden and characteristics of the IFCGs. The study was guided by three theories namely the psychosocial-economic vulnerability, the psychosocial-economic resilience and the gender empowerment. The study used a survey design with in-depth interviews of caregivers living in Nairobi in 2016. From a population of 510, a sample of 226 IFCGs was determined. Results indicated that the average age of IFCGs was 43 years, 81% were married, 60% had secondary or higher and 56% were knowledgeable about SCD. In addition, 58% of IFCGs lived in informal settlements, 60% of IFCGs earned less than \$320 which is the average income for households per month and spent an average of \$286 which was higher compared to \$153 which is the average expenditure per month. Overall, 60% of IFCGs had provided caregiving for a period of 6 to 20 years. The study recommended developing a SCD policy, an enhanced medical insurance policy for the PLWSCDs and incorporation of caregivers in social protection schemes.

### **Keywords:**

Characteristics, Burden, Family Caregivers, Gender, Sickle Cell Disease.

## **1. THE BACKGROUND TO THE PROBLEM**

About 14% (1 billion people) globally live with some form of disability and require some form of caregiving (WRD 2017, 2011). Outside the professional clinical care, there are family (informal) caregivers, usually family members, friends or neighbours who provide care to an individual with an acute or chronic condition and needs assistance to manage a variety of tasks ranging from bathing, dressing, taking medications, tube feeding and ventilator care (Reinhard et al., 2015). As survival rates increase due to medical advances, caring for Persons Living with Sickle Cell Disease (PLWSCD) involves caring for people of all ages. The level of care however depends on the complications (Mitchell et al., 2009).

Sickle Cell Disease (SCD) was declared as a public health challenge in 2006 (WHA 2006, WHO 2006; WHO Africa, 2010), but its management 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-to-Middle Income Countries (LMICs), Sub-Saharan Africa (SSA) and among the low income population. 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 PLWSCDs in Nairobi, the nature of the caregiving and the vulnerability to psychosocial economic wellbeing.

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). 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 PLWSCDs 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, PLWSCDs 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 PLWSCDs has been accompanied typically by a large disproportional gender burden, large vulnerabilities and impoverishment. 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. 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). Reports indicated that in the West Africa Region (WAR) 60% of the caregivers had completed basic education, 35% tertiary education and 5% university education. Similarly, in the WAR, an average of 58% of the caregivers held vulnerable occupations that included petty traders, artisans or full-time house-wives and 42% were employed in public and private sectors.

## 2. OBJECTIVE

This study sought to establish the burden and characteristics of informal family caregivers of persons living with sickle cell disease in an urban centre of a LMIC - Nairobi city county in Kenya.

## 3. METHODS

The study used survey design with in-depth interviews of IFCGs living in Nairobi in 2016. Out of the population of 510 caregivers, a sample of 226 was determined using the formula by Yamane (1967) through systematic sampling of every second person. The sample was verified with the table of 95% confidence by (Krejcie & Morgan, 1970). Purposive methods were used to select key informants and FGDs. The data collection instruments were pretested for purposes of validity and reliability. Data was collected using interview guides and an observation checklist. Narratives were collected through recorded interviews, presented per objective and analyzed thematically using N-Vivo and Excel. All ethical considerations were observed.

## 4. RESULTS

This study sought to establish the burden and characteristics of the informal caregivers of PLWSCDs and the results presented below.

### a. Characteristics of the Involuntary Family Caregivers (IFCGs)

The study assessed the socio-economic characteristics of the informal caregivers of the PLWSCDs; 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. This study established the following characteristics:

#### i. Age of the Caregivers

The age of a someone is usually related with their socio-economic responsibilities and expectations. In view of these responsibilities and expectations, this study assessed the age of Informal Family Caregivers (IFCGs) and results indicated that the majority of caregivers (25%) were between 45 and 49 years of age, that 84% of caregivers were between 30 and 59 years of age. The responses also indicated that the youngest caregiver was 20 years old and the oldest was 60 years. The average age of IFCGs was 43 years of age (Table 4.1).

The age of caregivers in this study is in agreement with the general age of caregivers elsewhere in SSA and in Kenya (MetLife, 2020). Involuntary caregiving therefore occurred during the prime age of caregivers requiring these caregivers to have to compromise productive years to attend to vulnerable PLWSCDs. Depending on the intensity of the caregiving, most caregivers were not able to engage in productive activities like work to support their livelihoods and wellbeing and therefore got disadvantaged.

#### ii. 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 and found that 81% were females and 19% were males.

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; Rodriguez-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).

### ***iii. 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 of the caregivers (81%) were married and 11% were widowed. The rest were either separated or divorced. Of those married, 2% had remarried and were in their 2<sup>nd</sup> marriages while 2% were living in polygamous unions.

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 is usually the mother 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 caregivers' vulnerability to mental, physical, social and economic well-being. The burden women are left to carry as the man walks free causes gender inequality.

### ***iv. 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 caregivers (table 4.2). Majority (23%) had 3 children; and 59% of the caregivers had between 2 and 4 children. This was consistent with the Kenya's national average number of children per household that stands at around 4 children (KNBS 2019). The modal category of the study was therefore consistent with the national average. This shows that apart from the PLWSCDs, 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 PLWSCDs.

### ***v. Formal Education of Caregivers***

Education has been considered an important characteristic and capacity to understand, manage and develop livelihoods. In view of the importance of this characteristic, the study assessed the level of education for the involuntary family caregivers and results indicated that 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.

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% of SCD caregivers 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 reduced 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.

#### ***vi. Income of the Caregivers***

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

In 2008, the World Bank revised figure of \$1.25 at 2005 purchasing power parity. By 2020, the average low income in Kenya was KES 23,670 (US \$ 209) per month (KNBS 2020). Other predictions ranged from KES 12,072 (US \$ 107) to KES 24,144 (US \$ 214). Therefore, 60% of caregivers had low average income. Lingering post discharge crisis pains impeded 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 jobless and 58.09% had income of 1-3 minimum wages (Costa et al., 2016).

#### ***vii. Residential Areas of the Caregivers in Nairobi City***

Someone's residence is used as an indicator of socio-economic capacity of people (Darin-Mattsson et al., 2017; Galobardes et al., 2007; Blakely, 2004). In view of such importance, the study assessed caregiver's residential areas and responses indicated that 58% of the caregivers lived in informal settlements or slums and 34% lived in middle class areas (table 4.3). This clearly reflected the socio-economic capacity of these households in terms of their capacity to pay rent or their work places. The study concluded that most caregivers were low income earners who spend most of their income on medical bills and resources that remained could only afford them housing in these low class areas.

### ***viii. Type of Housing for the family***

The type of housing is also used as an indicator of socio-economic capacity of a population particularly in determining the poverty line (World Bank, 2008). The poverty line is usually determined using the total cost of all the essential resources that an average person consumes in one calendar year. The largest of these expenses is the rent required to live in an apartment. The real estate market and housing prices are used by economists as a strong poverty line affecter. Findings in this study indicated that 57% of the respondents lived in either one room or one-bedroom stone houses. The main motivation for stone houses was warmth knowing that the cold precipitated painful crisis, 15% of caregivers lived in houses made of iron sheets as they could not afford rent for stone houses. Only 9% lived in bungalows, 9% lived in Maisonettes and another 9% in 2-3 bedroom flats. Many IFCGs struggled to pay rent and sometimes needed assistance. One caregiver had relocated to the village because she could not meet rent obligations when she lost her job and income.

This study illustrated that most of the caregivers could not afford to live in an apartment therefore 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. Caregivers reported that SCD depleted funds meant for rent and most caregivers lived in squalor in various slums in Nairobi. They however would choose better houses if they afforded it.

### ***ix. Comfort in the Home***

The infrastructure in the houses of caregivers was varied. The type of seats, clothing, and beddings were used to gauge the level of comfort in the HHs. This study indicated that, 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 23% of households had scanty uncomfortable seats and the PLWSCD had 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, warm, with comfortable seats and the people dressed well in warm clothes. These households had accessories such as the internet, technology gadgets and carpets indicating they could afford extras. Some 15% of caregivers avoided having the interviews at their homes and opted to meet in the street or elsewhere. Majority (57%) of families therefore lived uncomfortably.

#### **b. The SCD Burden**

The study assessed immediate challenges that were associated with the outcomes of the SCD diagnosis. The immediate challenges (burden) to caregivers included living through the vaso-occlusive crises (26%), day to day caregiving responsibilities (17%), worries of losing the PLWSCD (15%), financial challenges (13%) and losing hope (11%). Being mishandled by medical staff and broken relationships. Given the expenditures on a PLWSCD per month, the number of PLWCDs in a household increased the burden.

### ***i. Symptoms, severity 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. Within a framework of six broad symptoms of the SCD, caregivers reported vaso occlusive crisis (32%), anaemia (25%), end organ damage (17%), frequent infections (12%), body image issues (8%) and change in behaviour patterns (6%). Vascular occlusion that is usually accompanied by a lot of painful episodes presented in form of swelling hands and feet, acute chest syndrome, stomach crisis among others. End organ damage presented as joint and bone leg swelling, leg ulcers, splenic sequestration, avascular necrosis, renal and retinal failure, stroke and pulmonary hypertension. Frequent infections were mostly upper respiratory tract infections and urinary tract infections. These symptoms occurred erratically destabilizing the caregivers' plans and causing anxiety.

### ***ii. 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 IFCGs (26%). 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, at their inability 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 caregivers' 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

The nature of support required by PLWSCDs 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 PLWSCD'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 and resources. Blood transfusions frightened some caregivers who 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. Anxiety 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, 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: One caregiver had two children admitted with painful crises in different wards and both needed her support. Another caregiver had one child who was sick at home and another admitted in hospital yet she needed to care for both of them. Yet another caregiver had to care for her child admitted in an adult male ward which she found very cumbersome. These situations called for flexibility, quick thinking and action while at the same time becoming innovative to survive these circumstances. Respondents shared the following statements.

*“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. Whenever they were faced with choosing between work and their children, the PLWSCDs always won but this often led to job losses that eventually resulted in reduced income at the household level. On the other hand, caregivers dealt with some medical teams who are not supportive and who mishandled them. This made caregivers to experience frustration, anxiety and stigma. Some of these IFCGs experience acted as triggers for the psychological, economic and social vulnerability. To determine the health facility to take the PLWSCD, 38% of IFCGs appreciated hospitals with knowledgeable medical teams while 9% appreciated empathetic medical teams as seen 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*

Painful crises in PLWSCDs can be very severe and differ in duration, place, type, and severity (Fuggle et al., 1996). Reports in other studies have indicated that the 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  $16.08 \pm 9.88$  years and 89.2% of caregivers 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).

### **iii. Number of Persons Living with Sickle Cell Disease per Caregiver**

In most cases, caregivers were also the mothers of PLWSCDs and therefore carriers of the SCD. In view of this biological-inheritance, the study assessed the number of PLWSCDs per caregiver and established that there were 329 PLWSCD in the study sample, 151 (46%) girls and 178 (54%) boys. There were at least one PLWSCD per caregiver. However, some caregivers had more than 2 to 3 PLWSCDs. One caregiver had five children with SCD and three were deceased at the time of the study. Having more than 2-3 PLWSCDs greatly increased the per HH. A part from the children who had SCD, there were 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. The number of PLWSCDs in this study were consistent with other studies which indicated that financial stress worsened where there were 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).

### **iv. Life expectancy in Persons Living with Sickle Cell Disease**

Morbidity, mortality and life expectancy formed part of the burden for the caregivers. PLWSCDs were predisposed to getting infections that led to vaso-occlusive crisis and frequent hospitalizations. The life expectancy of PLWSCDs was unpredictable and most died prematurely. The reality that one could lose their PLWSCD anytime was very frightening and discouraging to caregivers. Constant fear was ranked 3<sup>rd</sup> among the difficult experiences by 15% of caregivers. In this cohort, 51/227 (23%) of families had lost one, two or three PLWSCDs to SCD complications. Each loss triggered traumatic experiences which affected caregivers emotional wellbeing like the generalized anxiety, depression and stress. Caregivers lived in fear of losing their PLWSCDs. This fear was triggered by stories of other families who had lost their PLWSCDs, from stories within the community, from myths or from personal 'near death' experiences due to various vaso-occlusive crises or haemolysis. Watching a baby who was struggling to breathe, who was unconscious, with a stroke, with very low blood levels and the hospitals not being responsive really put mothers on edge as reported 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 6.8.2016 at 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 18.1.2016 at Kibra Olympic*

#### **v. Increased Caregiving Expenditures**

Persons with SCD had 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. PLWSCDs 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 like Hydroxyrea, Folic, Zinc, Palludrine as anti-malaria prophylaxis and Peniciline-V as prophylaxis against pneumococcal infections. PLWSCDs require extra vaccinations (Pneumoccal, Typhoid, Meningoccal) to boost their immunity. Nairobi having temperatures of 15°C to and IFCGs being aware that the cold triggered painful events, caregivers bought warm clothes and heaters to keep PLWSCDs warm. They bought water filters for drinking water, boiled water for drinking, bathing and for hot water bottles which increased utility bills, rent and the general running costs of the home.

PLWSCDs tended to get sick or in painful crisis erratically necessitating medical attention. They visited hospitals many times for both outpatient and inpatient care to treat infections, manage pain and complications and sometimes for routine clinic appointments. When they got sick, PLWSCDs required more medications to treat infections like antibiotics, antihistamines, inhalers, stabilizers, analgesics, intra venous fluids, infusions, blood transfusions, chelation, respiratory support and X-rays. They also required dressing wounds, operations like hip replacements and splenectomy. Being with the patient robbed IFCGs time to participate in productive economic and social activities. They shared the following.

*“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*

*“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*

PLWSCDs 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. IFCGs were willing to pay more for warmer more comfortable houses whenever they could.

*“This disease takes money! For X-rays, medical bills; nutrition as recommended in hospital; 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*

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

The average expenditure for an urban low income household in the Kenya was \$153 per month (KIHBS, 2015/2016) while the expenditure on one PLWSCD was \$286. This was \$129 higher than the average expenditure per month. There were 75% of HHs that earned less than \$451 a month while 72% of IFCGs who spent \$90 on SCD alone. Majority (96%) of IFCGs did not have medical insurance and paid cash. Medical expenses impacted greatly on the HH income as 34% of these earned at most \$90. This means that some HHs needed to pay more than they earned to sustain one PLWSCD medically. Some HHs had more than one PLWSCD. Most caregivers did not have medical insurance. They basically worked for medical bills only. They were also obligated to care for the other children and relatives in the household. **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*

#### **vi. 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 caregivers losing children, lacking medical, social or psychological support, caregivers struggling with deaths in the family; symptoms developing and not going away like leg ulcers and uncertainty over the PLWSCDs independence in future. This made IFCGs to lose hope as shared below.

*“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 were doing because they understood the seriousness of SCD. This prevented IFCGs from working well as one might not stick to the schedules when they rushed to support the PLWSCD. Colleagues and clients labelled them unreliable and lacking in seriousness at work. IFCGs were thought to be using the sick children as an excuse to get away from work which created stigma for the IFCGs. Inability to work resulted in reduced disposable income as well as reduced networks or relationships. Without income to hire help, the IFCGs did all the caregiving by themselves 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%). Lack of adequate finances led to the inability to pay medical bills, afford an insurance cover and subjected the IFCGs to borrowing from all quarters which affected their self-esteem and created stigma that led to their being socially isolated. The pain tended to come when one had 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 Saika*

*“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 and 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 and 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 PLWSCDs 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).

## 5. DISCUSSIONS

Most people start building their careers at about the age of 20 years after college. Starting caregiving that requires 24-hour commitment at this age can derail ones' career especially when caring for more than one PLWSCD. 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 their careers. Sometimes, the PLWSCD never really ever become independent such that the IFCG continue supporting them even in adulthood. Caregivers yet to be married may lose relationships compounding their situation and disabling coping.

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 PLWSCDs 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 PLWSCDs.

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).

## **6. CONCLUSIONS**

In view of the foregoing data and observations, the study concluded that the caregiving of PLWSCDs in Kenya and SSA have been largely females usually mothers (71%) versus 4% men (fathers). In their absence, other women, usually sisters and grandmothers of the PLWSCD took on the caregiving role. There were also secondary caregivers like house helps, teachers and clinical officers whose care the IFCGs appreciated a lot. The study concluded also that over-representation of women in the caregiving of PLWSCDs in Kenya and SSA has implications on the socio-economic wellbeing of women. Involuntary caregiving occurred during the caregivers prime years between 20 and 59 years. This took away IFCGs opportunity to participate in productive activities. This eroded their capacity to compete with other parents who did not face similar caregiving responsibilities, a situation that was aggravated by gender stereotypes and biases since the majority were women.

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. Some women caregivers (WCGs) were single 'widowed, divorced or separated' and they had to do everything by themselves with no assistance from their spouses. On average, there were 2-4 children per caregiver's household that needed attention and resources, some with SCD. The more the PLWSCDs there were, the more the caregiving burden in terms of time and resources. The IFCG's literacy levels affected the knowledge acquired and retained about SCD because the number (56%) of caregivers who understood SCD as a genetic blood disorder 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.

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 tended to marry partners from the same geographical locations perpetuating the sickle cell gene. Some key informants who were also decision makers lacked information on the nature and prevalence in Kenya and were limited in making relevant decisions for the sickle cell community. IFCGs were therefore not taken care of by the system, survived without support and groped for solutions compounding their challenges.

SCD predisposed PLWSCDs to high morbidity and early mortality whereby 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 PLWSCDs in this study was 16 years. The high morbidity occurred due to low Hb and resultant low oxygen concentrations in the body making PLWSCDs susceptible to getting frequent infections. The lifespan of PLWSCDs correlated with the years of experience in caregiving although caregivers with more than one PLWSCD had more years of experience than the age of their PLWSCDs.

The symptoms and complications of SCD included vaso-occlusive crisis, anaemia, end organ damage, frequent infections (URTIs and (UTIs), change in the PLWSCDbehaviour 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, prior to joining the foundation, some had not been prepared in any way. Gaining knowledge about SCD improved some caregivers' outlook to the condition and moved them away from the initial shock, pain and anxiety to a place where they became relaxed and accepted the SCD 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 IFCGs were the following: The number of PLWSCD per caregiver, the resources and time was required from the caregiver, the symptoms and complications, contemplating early mortality in PLWSCDs that triggered stress, anxiety and depression and discouragement from people that caused IFCGs to lose hope and sustain the negative mental states. High financial demands led caregivers into debt and disorganized their plans and developments causing psychosocial economic deprivation. IFCGs choices for healthcare facilities was informed affordability or medical insurance, proximity, experience of healthcare personnel.SCD affected caregiver's other important daily decisions like the spouses they would like to have for themselves or their children and whether or not to have a child with SCD. Other caregivers stopped having more babies all together to avoid another experience with SCD.

## 7. RECOMMENDATIONS

1. The study recommends the following to the informal caregivers of persons living with sickle cell disease. That caregivers to join a support groups for peer to peer education and psychosocial support. They will also learn from other caregivers the importance of having both parents participating in the caregiving responsibilities to break away from the confines of societal gender roles.
2. The study recommends the following to the Government and its partners: Development and implementation of a sickle cell disease policy that will include the management of family caregivers, enhance medical insurance policy for persons living with SCD and incorporate family caregivers in social protection schemes in order to mitigate somecaregiving burdens. This can be achieved by:
  - a) Incorporation of sickle cell disease in the 2020 - 2030 health policy, the 2020 NCD strategy and the NHIF policy.
  - b) Implement the provision of promise in article 43 of the 2010 Constitution "*Access to healthcare for all*"and the Universal Health Coverage: Offer tailored health services for PLWSCDs for free, affordably orhighly subsidized or avail a free comprehensive medical insurance.
  - c) Revise the policy on abortion to give caregivers a legal choice in the matter regarding pregnancies of babies with homozygous HbSS (SCD) gene.

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## 9. APPENDICES

**Table 4. 1: Age of Caregivers, Nairobi 2016**

Years	Caregivers	Percent
15 - 19	0	0
20 - 24	9	4
25 - 29	14	6
30 - 34	43	19
35 - 39	13	8
40 - 44	29	13
45 - 49	56	25
50 - 54	18	8
55 - 59	25	11
60 - 65	18	8
<b>Total</b>	<b>226</b>	<b>100</b>
Mean	43	
Median	45	
Mode	45-49	

**Table 4. 2: Number of Children for IFCGs, Nairobi 2016**

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

**Table 4. 3: Residential Areas of IFCGs in Nairobi, Nairobi 2016**

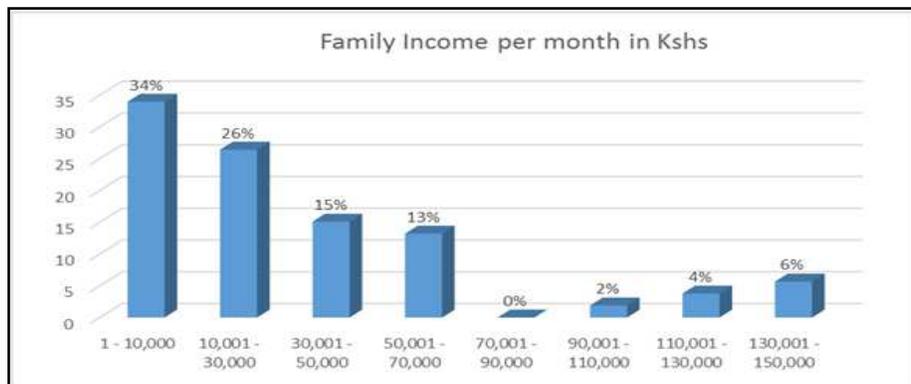
Residential Location	Frequency	Percentage
<b>Lower Class/Slums:</b> Mathare, Kariobangi, Umoja, Kibra, Dandora, Huruma, Ngomongo, Kiambiu	131	58
<b>Middle Class:</b> Donholm, Kayole, Tasia, Buruburu, Kahawa, Embakasi, Park Road, Langata, Saika, Jamuhuri, Ziwani, Komarock, Limuru, Lucky Summer	77	34
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

**Table 4. 4: Reported SCD Symptoms, Nairobi 2016**

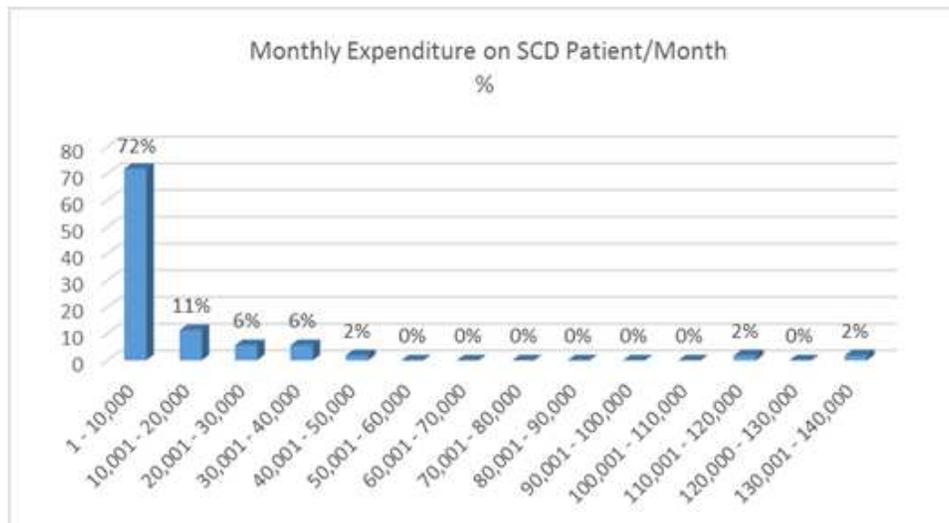
Symptoms	Frequency	Percent
Vaso - occlusion /Painful crisis	172	32
Anaemia	57	25
End organ damage	38	17
Frequent infections	27	12
Body image issues	18	8
Behaviour patterns	14	6
<b>Total</b>	<b>226</b>	<b>100%</b>

**Table 4. 2: Number and Gender of PLWSCDs per Household, Nairobi 2016**

No of PLWSCDs/HH	Frequency (N=226)	Percentage (100%)
1	226	100
2	90	40
3	13	6
<b>Total</b>	<b>329</b>	



**Figure 4.1: Family Income per Month in Kenya Shillings (Caregivers=226), Nairobi 2016**



**Figure 4.2: Monthly expenditure on a PLWSCD, Nairobi 2016**