

PSYCHOSOCIAL AND ECONOMIC VULNERABILITY OF INFORMAL WOMEN CAREGIVERS OF SICKLE CELL DISEASE IN NAIROBI, KENYA

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ABSTRACT

Informal women caregivers of sickle cell disease care for people with a life-threatening recessively inherited hemolytic blood condition with wide-ranging erratic and severe symptoms necessitating lifelong support. Care giving is neither quantified nor remunerated. Women take it on as their expected societal gender role. The objective was to investigate the psychosocial and economic vulnerability of informal women caregivers of sickle cell patients in Nairobi, Kenya. The theory of resilience in care giving guided the study. The conceptual proposition was that if all stakeholders intervened in their roles, caregiver's vulnerability would diminish enabling resilience. The study was a cross-sectional survey using both qualitative and quantitative data. 56 caregivers were sampled from 510 women. Narratives were analyzed thematically. Care giving affects caregiver's relationships in different spheres, finances and workload precipitating financial 98%, social 72%, psychological 26% and physical health 52% challenges. The study recommends support to caregivers, development of a sickle cell policy, awareness programs and support groups.

Keywords:

Women Caregivers, Sickle Cell Disease, Psychosocial, Economic, Vulnerability, Gender,

1.0 INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 The Background of the Problem

Informal care giving is provided in a wide range of situations – ‘diseases or circumstances’. It is usually a lasting situation related to multiple demands, responsibilities, events and tasks that eventually impact on the caregivers’ life. These conditions are all considered stressors, as they can challenge the homeostasis of the caregivers and inhibit their normal functioning (Losada-Baltar, 2017; Bekhet & Avery, 2018). Some caregivers are resilient and do not succumb to the negative effects of caring and manage to recover from, resist or adapt to the physical and psychological demands (Petriwskyj, Parker, O’Dwyer, Moyle, & Nucifora, 2016). Care giving is usually provided by a person, normally a woman who is attached emotionally to the person in need of care. It is a private invisible task done at home that is undervalued both socially and economically (Rodríguez-Madrid et al., 2019). The work is not remunerated as women operate in the double standard that only perceive the market sphere of the production of goods and services, hiding reproductive processes that have no market dimension (Mauro, Medel, & Diaz, 2006).

A caregiver is anyone providing assistance to another person who is, to some degree, incapacitated (Alspach, 2009). She is accountable but it is usually taken as a sense of duty (Frey, 2009). Globally, most caregivers at home are women because of their perceived gender role as caregivers (Mauro et al., 2006; Burnes et al., 2008). In the US, caregivers of critically ill patients give all kinds of support including, cleaning, laundry, cooking, escorting to hospitals, soothing pain, emotional and psychological support. Knowledgeable SCD caregivers observe routines to minimize occurrence of stressors that precipitate crises and also give nursing care (Alspach, 2009). The level of care depends on the complications for instance stroke may expand care to include toileting, feeding, bathing and dressing.

In 2008, SCD affected 20 – 25 million people worldwide and 12 - 15 million were in Africa (Mulumba & Wilson, 2015). Some caregivers take care of more than 2-3 patients (Adegoke & Kuteyi, 2012). In Africa, SCD related mortality and complications befall mostly children below five years, adolescents and pregnant women. The median survival rate is five years and below with 50%–90% of infants being born with HbSS dying before their 5th birthday (WHO Africa, 2010; Grosse et al., 2011). In Kenya SCD patients rarely live past 20 years (Ojwang et al., 1987).

Socially, WCGs handle the most difficult care giving tasks physically while male caregivers usually help with arrangement of care or finances which are less taxing (Hounsell et al., 2019). In line with the Harvard Analytical Framework which looks at gender equality from the assigned gender roles, in most societies, women engage in reproductive roles done repeatedly on daily basis and usually neither quantified nor remunerated. The men engage in productive activities that are seasonal and remunerated giving them an upper hand as they control of family resources and have more time to relax and plan for more beneficial. In Kenya, women are also socialized to do care giving work as societal expectations of feminine roles (Muchangi, 2014).

Psychologically, WCGs struggle with anxiety over losing their marriages, child's premature death, isolation and stigma, inadequate healthcare and helplessness in Canada (Burnes et al., 2008). In UK, SCD care giving impacted ones quality of life as it affected the physical, psychological, occupational and social well-being as well as levels of independence (Thomas & Taylor, 2002). 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 Nigeria SCD provoked emotional problems that influenced interpersonal relationships among caregivers (Adegoke & Kuteyi, 2012). In Gachie, Kenya 79% of women caring for children with intellectual disability were at risk of clinical depression and anxiety (Mbugua, Kuria, & Ndeti, 2011). In Kilifi, Kenya SCD women caregivers were stigmatized out of ignorance (Marsh et al., 2011).

Economically, caregivers save families and governments a lot of money (Frey, 2009). Care giving 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 care for other people. In 2013, the National Alliance of Care giving in the US estimated that 65.7 million (29%) Americans were informal caregivers, involving 31% households (Hounsell et al., 2019). SCD requires frequent hospitalizations due to pain or routine checkups (Amendah, Mukamah, Komba, Ndila, & Williams, 2013). This translates into time taken from work. Persistent pains traumatize caregivers and interfere with their ability to work or attend school (Brandow, Brousseau, & Panepinto, 2009). Being in hospital requires money yet caregivers are forced to leave work.

In Canada, health insurance plans refused to cover prescribed medication for SCD forcing parents to pay cash (Burnes et al., 2008). This increases expenditures and reduces disposable income. In India terminal illnesses pushed caregivers to take hazardous jobs or engage in illegal activities to survive (Emanuel et al., 2010). In Nigeria financial stress in SCD was linked to two or more admissions. Caregivers lost income, financial benefits or take out loans to care for the sick (Adegoke & Kuteyi, 2012). In DRC, estimated cost per SCD patient care in hospital annually is more than US\$ 1,000 (Tshilolo, L. et al 2009). In Kilifi, SCD patients required high level of care, but mothers lost freedom to engage in IGAs, leading to loss of finances and ability to provide for their families (Marsh et al., 2011; Amendah et al., 2013). Absenteeism had serious implications at work. In Kenya SCD complications were exacerbated by extraneous factors like nutrition, infections and minimal medical care (Ojwang et al., 1987).

1.2 Objective

This study sought to establish the psychosocial and economic vulnerability of informal women caregivers of patients with sickle cell disease in Nairobi.

1.3 Methods

The study used a cross-sectional survey in 2016. Out of the population of 510 caregivers, stratification and purposive methods were used to select 56 caregivers, 10 key informants and 36 members of 3 FGDs. Structured interview guides, FGD guide and an observation checklist were used to collect data. Narratives were collected through recorded interviews, presented per objective and analyzed thematically using N-Vivo and Excel.

2.0 RESULTS

This paper established that Women Caregivers were vulnerable to psychological, social, economic as well as physical health challenges. The vulnerability affected their resilience to Sickle Cell Disease and ultimately their performance in different spheres of their lives.

2.1 The Vulnerability to Psychological Challenges

This study found that 70% of WCGs were vulnerable to psychological challenges which manifested as emotional and mental health challenges. They were precipitated by fears of the unknown, occurrence of symptoms, WCGs experiences, inability to work, stigma, social isolation and the impact on their reproductive decisions. The challenges occurred as post-morbidities in 98% of WCGs. The manifestations were grouped stressful dispositions 11%, depressive disorders 19%, anxiety disorders 36% and other unspecified symptoms 4%. The following expressions and dispositions were observed in WCGs; 17% seemed calm/stable/resigned, 4% took it in stride, 6% broke down completely and wept or fought back tears, 9% pensive, 4% desperate, 6% trusted that God for healing, 6% hopeful for the medical support, 4% felt tired, 6% pained and 4% felt lonely but hoped for a spouse or job to give them stability.

2.1.1 Stress

Stress was triggered by lack of support in caring for the person at home, traumatic events, lack of adequate finances, inability to work or do business, stigma, social isolation, lack of adequate medical support and dealing with erratic painful events. Stress manifested through stressful routines, shock, Denial, physical pain, restlessness, indecisiveness, regrets and guilt.

1. Stressful Routines, Shock and Denial: This study reveals WCGs find the care giving work exerting and draining and has minimal involvement from husbands. WCGs focus on the child and neglect themselves. WCGs are stressed because they cannot fully trust hired help or unresponsive people who think the patients are pretending or pampered or when they are blamed for the child's illness in spite of their hard work. Watching the child in crisis, having to tell medical teams what to do during a crisis or being denied service in hospital is stressful. Shock, a psychological response to a traumatic, terrifying experience affected 19% of WCGs. It was triggered by the knowledge of what they were going to deal with, by stories they had heard or how they had observed other sickle cell patients. Denial, a defense mechanism which involves refusal to accept reality if the situation is too much to handle affected 11% of WCGs. It manifested by couples blaming each for the SCD or crediting witchcraft. Denial led to more harmful decisions like visiting witchdoctors or moving from one hospital to another hoping for different results. Some just acted as if SCD was not there.

"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

"I cried. A cousin had a child with SCD who died at age 20. I never thought it could happen to me. I suffered denial but eventually accepted." WC27 on 5.4.2016 at Ngomongo

1.0 Pain, Restlessness and Despair: There were 15% of WCGs who experienced despair foreseeing future painful moments while occurrence of symptoms made 32% feel pained. The pain is triggered by the knowledge of what one has to deal with but cannot escape or painful memories of people who died SCD. Stress led to some physical ailments like headaches and stomach ulcers and high blood pressure. This occurred more in WCGs who were single; had no support and no income. WCGs with financial stability or insurance suffered less stress. WCGs experience restlessness physically and mentally as they are always thinking how to help the child and find money for bills. They get unsettled and hyper vigilant when they hear of the death of someone they know wondering if their child may be next.

*“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. It’s very painful. He was big and he just died!”*WC3 on 8.1.2016 at Huruma

*“She becomes restless physically, emotionally and mentally as she thinks how to find the money”*WC2P1 on 13.7.2016 at Saika

Indecisiveness, regrets and Guilt: Indecisiveness occurs when faced with important choices regarding the child’s health. When the child gets sick, she thinks of how to raise money for bills, which hospital to go to, which offers credit facilities or the kind of services she seeks. She has to decide whether to take the child to hospital or keep him home, chooses between the child’s health and the progress of siblings when resources have to be diverted to pay bills. WCGs regretted having chosen spouses who contributed half the SCD genes or a husband who is unsupportive. Others regretted lack of information about their genotype at the time of their marriage and also regretted having babies with SCD. Guilt comes when WCGs wish inwardly that the child passes on to end the painful cycles, then feels guilty for having such thoughts about their own child. She feels guilty using resources to support the sickly at the expense of other family members and for not spending time with her husband or other children.

“I Get confused about who to call or tell or where to take him” WC14 on 6.8.2016, Kayole

“Mom regrets marrying my father! There is no peace” WC2P1 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

2.1.2 Depressive Disorder Symptoms (DDs)

Depressive Disorders induced by various routines and situations affected 34% of WCGs. They manifested in form of fatigue, discouragement, self-pity, bitterness, lacking peace, withdrawal, sorrow, helplessness and struggle to accept the condition.

1. Exhaustion, Discouragement and Self Pity: Emotional and physical exhaustion occurred in 6% of WCGs. It was caused by juggling resources for unending bills; dealing with pain and other symptoms; repetitive chores, loss of appetite, answering difficult questions from the children with SCD and physical involvement in the care giving tasks when social support was not forthcoming.

Discouragement affected 13% of WCGs when they realized they were in for a long period of time, occurrence of symptoms, erratic vaso occlusive crises that foil the WCGs social and financial plans, counseling appointments to be judged as unreliable. This makes the WCG to feel low, disoriented, victimized, desperate, frustrated and pitying themselves. They cry to relieve overwhelming pressure or to feel lighter but others feel worse after crying. Some pray for God's intervention. Self-pity occurs when they do not know how to act and painful events are relentless. Inability to support other mothers affects those who really want to help. They shared below.

"I was 35 years but I changed you would think I was much older. It bothered me. That time we did not 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

"Disorienting, one almost loses hope. It's horrible watching someone in pain all night and day." WC2M9 on 19.7.2016 at Nairobi CBD

"I pity myself but remember that after the pity party, I've have to act." WC2, 7.1.2016, Huruma

2. Anger and Lack of Peace: Occurrence of symptoms made 4% of WCGs feel angry. Bitterness comes when WCGs do not understand why God chose them to carry this cross. It helps for them to meet other WCGs in group therapy sessions or during peer to peer counseling. Losing a child may make one bitter especially when there was no support medically, financially or socially. Some exhibited anger and frustration when they did not have money for bills in times of crisis. The knowledge that the interventions will not change much in the child's life troubles them leading to lack of peace and desperation.

"The loss of my son haunts me. When I was about to lose the child, people including my sisters talked about my lack of seriousness at work. They thought the boy was pretending. He died that time. It was bitter – I still recall." WC10 on 14.2.2016 at Komarocks

"I give water, food and Panadol. I can't have peace. I understand that you can't keep them at home once in pain." WC13 on 18.1.2016 at K. Olympics

Withdrawal, Sorrow and Helplessness: Stigma is that bad feeling that makes WCGs to withdraw or socially isolate themselves to avoid people who make insensitive comments that hurt their feelings. This triggers discouragement and loneliness, confusion and distress as her social life gets cut off or when opportunities to socialize are limited by the child's erratic needs. WCGs get hardened and do not display emotions easily which gets them judged as insensitive. They also experience sadness whenever their children are in pain. Sadness occurring many times leads to sorrow. Helplessness comes due to inability to do something useful to improve the situation. It affected 15% of WCGs. It comes with depression, sympathy, empathy, getting emotional and losing faith. They get emotional and just cry when things get out of their control like dealing with unhelpful medical personnel; lacking funds when a child is critically ill; when a child screams ceaselessly or when denied permission at work to go to the child during a crisis. WCGs suffer more than the patients in their helplessness to act as it's out of their hands and also knowing crises will happen often. Sorrow and helplessness unchecked can lead to depression. Even with availability of information, 17% of WCGs still struggled to accept living with SCD and relating to complications that keep occurring. A child blossoming encourages WCGs greatly and brings them hope.

“I get cut off from people who cannot identify with what I am experiencing. Some think I am not social.” WC24 on 4.6.2016 at Karen

“I cry with them. Going to hospital where people are not cooperative makes me sad.” WC17 on 20.1.2016 at Baraka

“Apathy - I feel completely helpless. I pray, I reach out and do self-medication (Cataflam, paracetamol, even anti-biotics like Zinnat & Augmentin)” WC16 on 7.6.2016 at Kitengela”

2.1.3 Generalized Anxiety Disorder Symptoms (GADs)

Caregivers endure a lifetime of anxiety disorders that manifested in 21% of them. GADs manifested through fear, desperation, worry, impairment of social and occupational areas of functioning, feeling caged, irritability, sleep disturbance and difficulty concentrating. Anxiety was triggered by fear of painful events, untimely death 49%, non-attainment of developmental milestones and independence in future 30%, stigma 11% and finances 6%.

1. Apprehension, Worry and Desperation: WCGs were anxious of their children getting infections, painful crises or dying early. The fear of death is caused by myths, previous deaths or thinking about the future. This fear is legitimized by the 56% of patients' who die by the age of 15 years, 75% by the age of 20 and 90% by the age of 30 years with the mean age being 16 years. At least 12 households had lost 1-3 children to SCD. Those who lost a child before, those unable to conceive were more apprehensive. Fearing death makes them worry about where to bury children disowned by fathers. Inadequate medical support makes WCGs thoughtful, discouraged, feel low and fearful that they may never see them grow to marry and give them grandchildren. They fear giving birth to more children with SCD as 81%, given opportunity to choose again would not marry a carrier of SCD. Given genotype information and a legal choice, 34% would terminate a pregnancy of child with HbSS even if it's against the law, a risk to their own lives or if they will not have another child. WCGs wished abortion was legal in Kenya. 63% would however carry the baby to term motivated by grown patients, religious beliefs, fear of never getting other children and the belief that one can still have a beautiful life with SCD. To others, abortion was a moral dilemma.

WCGs endured a lifetime of worrying. They worry about rate of pain; money; indebtedness; developmental milestones; virility; handling periods, marriage, pregnancy and child birth; maintaining a home; if their spouses will treat them right and their independence in future. Major symptoms like strokes impair their physical and mental functioning. The 13% of WCGs who did not understand SCD and those with negative experiences or misinformation worried. Even after gaining knowledge 13% still worried about their independence while 19% worried about re-occurrence of symptoms. This worry precipitated stress, depression, loss of appetite, restlessness, misery, confusion, helplessness, terror and feeling that life is not fair.

Desperation affected 49% of WCGs when they lacked money and the child was sick. Her finances are tied to the frequency of illness, comfort, warmth, medication and nutrition. It was frustrating for them to sell everything to pay bills and know that a crisis can occur again anytime. Some saved for emergencies to reduce anxiety but others are completely unable to. The erratic nature of crises makes her unable to commit to appointments disabling her from participating successfully in public spheres. When rejected by spouses it compounds her desperation as she shoulders the whole burden. WCGs wished SCD was a physical blemish like a disfigured body part and not a situation requiring resources all the time. Others thought it was a punishment from God.

“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 on 18.1.2016, Kibra O

“I worry how he will be when I am dead because of the stroke, leg ulcers and hand. I worry that no one will help him.” WC30 on 13.2.2016 at Mathare N/A3

“I feel desperate and hurt because I don’t like to borrow for that purpose as it cuts in the salary for the month.” WC26 on 10.2.2016 at Syokimau”

2. Impairment the Caregivers Functionality: Stigma leads to a difficult co-existence of the WCG and the community because it leads to social isolation. When she quits groups that form her social capital, it impairs her social functioning. When fired from work, she loses economic functionality. She even loses spiritual networks. 4% of WCGs felt tied down which made them give up all social and economic activities to focus on the patient. Care giving therefore becomes a barrier to her economic and social growth as she remains tied down while others do exploits. WCGs react with irritability or agitation at insensitive comments, lack of understanding and when systems do not work like hospitals that are not able to handle a crisis. They are not able to sleep well during a crisis as they support patients to rub and sooth pain, monitor medical equipment or treatments. Prolonged crises affect their sleep cycles leading to exhaustion and lack of concentration.

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

“It pains, I can’t concentrate nor go to work. Something should be done to avail drugs.” WC12 on 13.1.2016 at Komarocks

1.1 The Vulnerability to Social Challenges

The population represented the following ethnicities in Kenya: Luo 53%, Luhya 38%, Kisii 2%, Kamba 2%, Mijikenda 2% and Kuria 2% corresponding to findings that SCD affects people in malaria endemic zones (Ojwang et al., 1987; Aluoch, 1997; Mulumba & Wilson, 2015). This study found that 72% of WCGs were vulnerable to social challenges like stigma, social isolation, broken relationships, blame, denial, rejection, lack of support and feeling manipulated. They occur in different spheres: individual 17%, family 22%, workplace 29%, community 28%. At individual levels, they lacked time to socialize, missed functions, stigma, withdrawal and lack of intimacy. At a family level, there was blaming, rejection, stigma, social isolation, hatred and lack of support. At a community level, there was stigma and social isolation while at the workplace relating to colleagues was difficult.

1.1.1 Stigma and Social Isolation

Stigma comes when patients are seen as bewitched/malign, treated differently, fearful of being judged by myths and discomfort when answering strange questions about the illness. Stigma can be created when family structures in patriarchal systems deny WCGs opportunities to participate equally because they are outside structures of power and decision making. When the child is stigmatized, the stigma proliferates to the mother as the child is an extension of who she is. When judged as women whose children don't grow well, are ever sick, unhealthy or deemed have an infectious disease like HIV, it creates stigma. Some people reacted with stigma when they saw a painful crisis and avoided being seen with the WCG believing the association may hurt them.

A caregiver may isolate herself from people who cause her pain to avoid evoking negative feelings. They avoid ignorant people who back bite, liken SCD to starvation, to infectious diseases, who think patients exaggerate or are spoiled, who compare their children with healthy ones or call them names like 'Mbu' for stunting, 'Macho mayayi' for jaundice, or the dead 'Marehemu'. Non-participation in integral social events that weave the fabric of society makes her isolated from the community especially if others retaliate as she's branded proud, snobbish or antisocial. Other times people isolate her to avoid being asked for financial support or to avoid association with the disease and the stigma associated with it. People who do not know how to assist may avoid her to stem awkward moments. In social groups, they are denied responsibility, causing her to lose self-esteem triggering feelings of timidity. They then give up leadership and membership in such groups. Fines imposed and becoming the focus of gossip also make belonging to a group untenable. Others in leadership felt that their faith is challenged when their children appeared sicker.

"Neighbours think we are victims of HIV. They refuse to sell us groceries for fear of infection. They shut doors in my baby's face. We are isolated. Only one friend visits. Even church people don't visit." WC2M7 on 4.7.2016 at Mathare

"Some back bite, others think its lack of food. It hurts me. Others think it's a sickness like any other – why exaggerate it?" WC28 on 11.2.2016 at Umoja

1.1.2 Indifference and Blaming

Indifference is lack of interest, concern or sympathy and stems from ignorance or lack of interest to assist. Some people were indifferent to the WCGs challenges and some were even happy to see her struggle with SCD as reported by 11% of WCGs. Some were unaware of the real situation because the WCG did not share and they did not ask or were not affected directly. Indifference makes WCGs to feel alone in her problem making it seem heavier.

Blaming is done by people who are in denial. Denial occurs when one refuses to accept the news and as a way of distancing oneself from the problem and loading it on another person. Parents who refute their contribution to the gene blame their spouses. Men blame women for the gene 'bad blood' or infidelity that resulted in misaligned paternity while women blame the men's family. One WCG blamed the community for bewitching her daughter and others blamed the doctors who made the diagnosis. Husbands for lack of involvement and support as 71% of WCGs do all the work by themselves. Fathers blame WCGs for lack of vigilance leading to the child's painful crisis. WCGs on the other hand blame patients for actions precipitating the crisis out of frustration, envisaged missed opportunities and financial implications. Some WCGs blame themselves for silently wishing the child died to end the painful cycles to free her. Patients are blamed for broken

relationships when marriages end. Husbands may blame WCGs for lack of quality time and intimacy while the community blames her for lack of participation in social events and for bewitching or stopping the husband from socializing. When she chooses not to lend money to reserve for her erratic emergencies, she is blamed for being selfish, mean or inconsiderate. Patients are blamed for derailed developments or careers/studies or lost opportunities of other family members when money is diverted to pay medical bills. WCGs have been blamed for ‘wasting’ resources on a child who will just die or using the child as an excuse to avoid work.

“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 N/A4

“A lot of men don’t know how to react and could develop very short temper. Shouting and blaming women for actions that contributed to crisis. Mothers are blamed for not watching the children... money issues come up – quarrels.” WC2 on 14.7.2016 at Kayole

1.1.3 Rejection and Broken Relationships

At the community level, the impact on relationships with parents of a person with SCD bordered on denial, stigma, blame and rejection. Blamed WCGs experience rejection and lack of support. Men use misaligned paternity to reject WCGs causing her to suffer a broken heart and increased care burden. Men go a step further to reject the child alongside their mother in some instances. It gets worse if the children are not biologically his. Most mothers on the other hand would not want to throw away their baby so they only reject the reality of sickle cell. Only two mothers in this cohort left their children entirely while another one stayed but neglected her affected child. Some men compel their wives to stop giving birth then proceed to sire outside wedlock. They enter these unions ignorantly and sometimes yield more children with SCD. Rejection can proliferate to patients and their siblings when considered bewitched or malign. Occasionally her participation rights in events are curtailed when rejected as unreliable.

At a family level, 13% of relationships were negatively affected by SCD. Rejection led to broken or tasteless marriages occasioned by lack of quality time, emotional distance, lack of intimacy and lack of financial and moral support. Lack of intimacy was triggered by the frequency of sickness, witnessing pains and staying in hospitals. Painful events make WCGs lose appetite leading to low energy levels and diminished desire for sex. Focus on the sick child makes couples to forget each other. Thoughts of other children with SCD discourage couples from engaging in sex. Infidelity also makes WCGs witch off romantically. Other relations may not break but become superficial and dissatisfying for example men’s minimal involvement makes WCGs bitter. Men who reject SCD as part of them also reject children who deplete their resources. The husbands who feel they do not get sufficient attention from their wives may divert to more available women. Divergent from the norm, 4% of WCGs in this study quit their marriages and remarried

“My husband’s elder brother never associates with us. He removed his children from a school when I took mine there.” WC8 on 15.1.2016 at Mathare

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

1.1.4 Lack of Support, Neglect and Feeling Manipulated

There was disproportion in sharing care giving work with the woman being disadvantaged. In 71% of HHs, the primary and sole caregiver was the mother. In 19% work shared equally and in 4% had fathers as the main caregiver. Men claimed not to know what to do. This is gender role stereotyping where women are seen as the ones to nature and care for the children. Some husbands support only financially. Stigma makes men to distance themselves from the child and the WCG. Other times WCGs were seen to be wasting resources on a child who will just die. When husbands do not support, his family members follow suit. WCGs had challenges relating with colleagues at work due to their lack of understanding of her care giving position. Colleagues may back bite her straining relations and expecting her to organize her schedules as everybody else. Frustrations make it untenable to work prompting quitting if not fired. Sibling relations are affected negatively in 11% of cases when siblings tire of assisting. They patients may feel rejected, liable and worthless, disrespected, despised or like an outcast. The sick child may be harsh when in extreme pain and often get misunderstood by siblings who may choose to walk away.

The WCG either neglects herself or the other children in the family. In this study SCD triggered sibling rivalry which manifested through resentment, irritation, competition for attention and resources and even aggression when other children felt unloved. Sibling rivalry kills openness, mutual respect and leads to lack of support which further strains relationships. The mother being overprotective to ensure he lives makes siblings think the closeness facilitates the patient to tell on them or that he pretends to have pain to draw attention. WCGs who are not working ask working siblings to help out financially slowing their economic development. This causes resentment too. WCGs get torn between accepting to be manipulated by the person with SCD and showing tough love. When denied their request some patients manifest symptoms pushing the WCG to give in against her wishes. The person overprotected feels special and cared for but it allows the WCG to be manipulated, exhausts her and contributes to delay in having more children.

“My husband left; I do everything, school and all. He left when the first born was in class 7”

WC8 on 11.1.2016 at Baraka

“One son doesn’t understand. He feels that the brother has used most of my money and is least supportive to him.” WC14 on 6.8.2016 at Kayole

“It delayed my decision to have other babies.” WC2P4G on 20.7.2016 at Karen - IPR

1.2 The Vulnerability to Economic Challenges

The mean age of WCGs was 43 years hence, SCD affected the most productive years of the WCGs lives and yet 98% of had not received any financial gain for playing this role. 94% had financial challenges with 81% struggling to pay medical bills. Only 38% had meaningful medical insurance and 62% of WCGs paid cash. The community did not support WCGs at all in 64% cases while 19% got some support which was not usually enough. WCGs struggled to provide for the family, to save, to work and diverted resources for projects to medical bills.

1.2.1 Inability to Provide for the Family

Inability to provide for the patient and the family affected 32% of WCGs. They struggled to pay medical bills, buy medication, food and a favorable environment. Most of the WCGs at 58% were of low socio-economic status living in the slums in 1-2 roomed houses with poor infrastructure, 34% were middle class and 8% lived in affluent areas reflecting their capacity to pay for shelter. The mean expenditure on medical bills per patient per month was 14,750 while 34% of the HHs earned at most Kshs 10,000 and there were 1-3 patients in each HH. The first determinant for choice of hospital for 42% of WCGs is affordability followed by experienced staff 38% and proximity 28%. Trained medical teams give appropriate, targeted assistance that are cost effective in the long run. The nature of the pain is such that it cannot be ignored. SCD forced 26% WCGs to divert resources to healthcare which derails development plans and careers in 38% of cases. It derailed construction of homes, re-acquisition of disposed family assets and careers 'educations, businesses, promotions or opportunities'. While some family members empathized, others showed resentment, irritation, hatred or lack of support. Inability to save by 28% of WCGs related to increased and unplanned expenditures while 21% experienced reduced income because of challenges at work. It was therefore necessary for 19% of WCGs to make adjustments in their lives and routines to cope.

"Project at 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

"Big family of 10, Admission fee unmanageable; Deterred development for the whole family; work but no progress –1 step forward and 1 step back" WC2P11B27.7.2017, Kileleshwa

1.2.2 Affects other decisions

The were 60% of WCGs who's children got sick and they did not have money. To raise funds, 47% borrowed from family, friends and church but 19% needed to pay back without interest 'soft loans' while 17% got help only once or twice before the donors distanced themselves. The help was not enough. Among those unable borrow, 23% gave over the counter medication or visited quacks in any nearby clinic, 23% went to hospital without money and sought credit, 13% left children to brave crisis at home 'in God's hands', 11% took loans even from Shylocks that left them in perpetual indebtedness, 6% chose affordable hospitals, 6% sold household goods for much less than market rates, 6% used alternative medicine like herbs which they later discover don't work, 2% took salary advances which interfered with family budgets, 2% fundraised 'harambees' but it was not always enough and 4% called the foundation for advice any assistance that will be forthcoming.

"When people see me with the baby-sick, they avoid us because they think you are about to ask for a loan, Even relatives." WC2M5 on 14.4.2016 at Mathare

"I sold my sewing machine" WC2P5Bon21.7.2016 Kahawa Sukari

1.2.3 Ability to Work

This study revealed that SCD causes WCGs not to work consistently thus becoming dependent financially as 94% had missed a chance to make money. Employability of 55% and the businesses of 39% were affected. WCGs were vulnerable to being dismissed or fired, quitting employment, missing promotions, opportunities, employment or never attempting to work at all. Absenteeism was seen as wastage of organizations time or WCGs were seen as not contributing enough which gets them replaced. Some WCGs opted to quit after frustrating episodes or due to heavy workload at home. They missed jobs that were demanding, had no flexibility or if there was no support at home. They were often labeled unreliable for counseling appointments during crisis. The ability of 39% to run IGAs was impaired. When crisis strikes, they use any money accessible to pay bills like the business capital. When the crisis is protracted or admissions too frequent, the IGA will be unable to support recurrent bills and will shut down. Most times they never pick up again. Closing premises for unpredictable number of days stagnated IGAs as the WCG lets opportunities go, customers judge her as unreliable and seek services elsewhere, perishable goods are thrown or given away and she has to start afresh and attract new customers. She suffers losses when her workers misappropriate resources, goods or mishandle customers in her absence.

"I used to work for Unga Ltd. We were admitted for 4 days. After discharge, I lost my job... I was replaced." WC2P7G on 22.7.2016 at Dandora

"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

1.3 The Vulnerability to Physical Health Challenges

It emerged from this study that WCGs were also vulnerable to physical health challenges that affected 52% of the population. Key informants described WCGs work as intense, strenuous, rigorous and burdensome that required commitment, learning and understanding, exertion, sleeplessness and huge sacrifices. Most occurred as post-morbidities. These included cardiovascular complications, stomach ulcers, muscle and bone pain, headaches, fatigue, general malaise, losing or gaining weight. Cardiovascular complications like hypertension, tension headaches, stroke and heart problems are caused by stress, weight gain due to lack of exercises and change in diet. Male Caregivers also developed physical health conditions. One father got hypertension and one grandfather got a stroke. These conditions resulted in some deaths.

Fatigue and general malaise occur due to the physical work that is exceedingly overexerting and perpetual. It involves lifting and carrying the person to the toilets and shower, to hospital and nursing care that involves observing routines, a role 71% play without any help. This burdens her physically triggering fatigue. Even when a crisis occurs, 17% of WCGs get no support at all, 32% share all responsibilities with fathers while 45% only get financial and moral support. Fatigue also comes from over protectiveness of the mother who goes far out of her way and burns herself out in the process. Shouting matches between WCGs and medical teams can be exhausting. Fatigue can be precipitated by weight loss and nutrient deficiency, slowed metabolism, dehydration due to loss of appetite during stressful periods. Weariness affects their reproduction decisions to delay having more children or not having any other child.

Occurrence of SCD symptoms makes 32% of WCGs to feel pained, sick or uncomfortable both physically and psychologically. Stress, anxiety and depressive disorders can cause physical pain. Pain also results from physical involvement, supporting the patient for long hours when sick like carrying, rubbing, holding and giving medications. The knowledge of what one has to deal with or memories from the past can cause pain. WCGs hardly know rest because when they are not catching up with back log in the office, they are running with the sick child. The physical pain manifested as stomach ulcers, muscle and bone pain, headaches, general malaise, something similar to labour pains and broken heartedness. WCGs ignored their pain to focus on the child.

“The stress got me to have a mild stroke. This affected my health and up to now I still have high BP and live on perpetual medication and therapy.” WC14 on 6.8.2016 at Kayole

“SCD comes erratically and forces me to carry him on my back to hospital which is very far. This weight caused pains in my back, hands and legs because of trekking 5kms. When admitted, I carry him around to toilets which impacted me.” WC2P1B on 13.7.2016, Saika

“I get 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, beseeching medical personnel who don’t seem keen to do the right things.” WC24 on 4.6.2016 at Karen

2.0 DISCUSSIONS

Although the study was looking for women caregivers’ (WCGs) vulnerability to sickle cell disease, it found that WCGs also derived some benefits from the care giving experience as 43% had derived a few emotional benefits, 32% social benefits and 2% financial benefits. Getting encouraged; gaining knowledge; group therapy; strengthened character, giving/getting support, empathy and sympathy were considered as social benefits when received by caregivers and as emotional benefits when given by caregivers. Other social benefits included becoming more organized, building networks, friendships, support systems, spiritual support and strengthened relations among family members. In the US caregivers of the aged found that care giving drew families together through execution of obligations, expression of love, and feeling that caregiver services make a difference in ensuring appropriate high quality care. Availability of informal caregivers also prevented institutionalization of the aged relatives (Davis, 2009). Caregivers of HIV in Oklahoma revealed positive aspects of care giving as self-satisfaction, increased self-respect and reduced costs of care giving (Theis, Cohen, FAAN, & Zelewsky, 1997). A few times the situation created respect from knowledgeable people who appreciated the difficulties families with a SCD patient go through (C. J. Graff et al., 2010).

This study found that Women Caregivers become vulnerable to challenges induced by care giving responsibilities. They were vulnerable to financial, social, psychological and physical health challenges which were triggered by lack of support in various spheres of her life. Psychological vulnerability was reflected by their emotional and mental states in the face of challenges. The vulnerability manifested as stress, anxiety or depressive disorders most occurring as post-morbidities. The WCGs who were more resilient manifested less emotional and mental health symptoms than the vulnerable ones. Stressor scores increased when the caregiver was single,

female, with low education level or if the number of children cared for were more than three (Wonkam et al., 2014). The WCGs with more physical, emotional and medical support were more resilient than those without any support. Hence when the burden of raising children is left to the WCG, it disadvantages her and further augments her vulnerability. Caregivers were known to experience frustration, social isolation, 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). In this study, WCGs feared getting another child with SCD and wished abortion was legal in Kenya. The risk of birthing another child with SCD had negative effects on the mood of mothers (Gesteira, Bousso, & Misko, 2016). In Gachie, Kenya, half of the women caring for children with intellectual disability were at risk of clinical depression and anxiety (Mbugua, Kuria, & Ndeti, 2011). In sickle cell, this occurs when there is impairment of child's normal functioning from symptoms like stroke. SCD caregivers in the UK and those of Alzheimer patients in the US got sick from stress and got hospitalized for depression (Anie, 2005; Center, 2008).

Perpetual inability to pay bills caused stress, anxiety and depression. Being forced to dispose household items to pay bills was frustrating. Administering over-the-counter medication, leaving the child to God or watching the child in pain helplessly causes trauma. Psychological health is also affected by stigma (Adegoke & Kuteyi, 2012). Exposure to jarring traumatic events, like watching a loved one die suddenly or witnessing their struggle with excruciating pain made WCGs to develop post-traumatic stress disorder whose symptoms may lead to impairment in social, occupational and other important areas of functioning of the caregiver (American Psychiatric Association, 2017). WCGs therefore need counseling to support them cope and build resilience to the triggers of emotional distress.

Gender issues come up under vulnerability or resilience to social challenges which occur in indifferent spheres of her life. Care giving affects WCGs relationships at an individual, family, community levels and at the workplace. She is vulnerable to stigma, social isolation, lack of support, indifference, denial, blame, hatred, rejection, broken relationships, neglecting herself and other children, feeling manipulated. Stigma leads to denial, which leads to blame, hatred and rejection which eventually cause broken relationships. Men resisted negative events in their children's lives while women experienced a culture of silence (Burnes et al., 2008). This happens when men are in denial and stigmatized. Denial makes men to accuse women of misaligned paternity in Kilifi (Marsh et., 2011). They do this as a way to abdicate responsibility. In the patriarchal Kenya, women are outside the structures of power so their views and feelings are often ignored. Gender role stereotyping also enforces the belief that women should be doing all the care giving work without expecting support from their husbands. This increases her burden and reduces her resilience. This study found that not only father's distanced themselves from the child's sickness but mothers too. However, the number of women who stayed was much higher than that of men. This could be attributed to their socialization and expectations of their gender roles. Loss of jobs and income increased her reliance on others which impacted those relationships negatively.

Relatives who witnessed a crisis appreciated SCD more and respected parent's concerns while ignorant ones were tactless and reacted out of stigma (C. J. Graff et al., 2010; Alspach, 2009; Theis et al., 1997; Burnes et al., 2008). Contrary to the above finding, some people with knowledge in this group rejoiced at the WCGs struggle with SCD. The Igbo of Nigeria saw children with SCD as malign and stayed away to avoid being stigmatized alongside (Adegoke & Kuteyi, 2012). Stigma constitutes part of secondary stress that extends to WCGs (Mullan, 1998; Rose & Clark-alexander, 1998). Stigma feeds upon, strengthens and reproduces already existing inequalities of class, gender, sexuality and race (Burnes et al., 2008). The gendered blaming relates to the tendency for mothers to be made liable for problems in their children. This is linked to the patrilineal structure, gendered interpretations of responsibility coupled with low awareness of the disease, gendered risk of being blamed for misaligned paternity and limited options for these mothers to protect their children's livelihoods (Marsh et al., 2011). Stigma affects the psychological, financial and social status of caregivers and their families (Adegoke & Kuteyi, 2012). Care giving changes WCGs social circles when financial challenges force them to make adjustments to cope. The reaction of people who form her social capital either aggravates or reduces her vulnerability. There were also more positive adjustments towards challenges in families that worked together.

The economic vulnerability was reflected by their inability to meet the financial demands of SCD and the family. The vulnerability is heightened by inability work due to the frequency of painful events and long hospital stays. Care giving work requires a lot of commitment yet it is neither quantified nor remunerated (Frey, 2009; Mauro et al., 2006). Not remunerating work that takes up the woman's entire day disadvantages her economically as she is unable to participate in public spheres. Job loss increases poverty and impacts negatively on WCGs personal development. The acute and chronic aspects of SCD require sustained medical attention for prevention and treatment. This includes 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; Ojwang et al., 1987). 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). Some complications like stroke, organ damage evolve and worsen with time (Serjeant, 2001; J. C. Graff et al., 2010; Mitchell et al., 2009). As one matures, complications that present at different ages also need attention (Serjeant et al., 2009). Hemolytic anaemia can be exacerbated by extraneous factors like nutrition, infections and minimal medical care (Ojwang et al., 1987). These generate more financial demands necessitating more resources to cover the costs and further increasing her vulnerability.

Whenever they do not have funds they devise strategies to survive. Taking out loans was leads to sickness-poverty cycles within these households (Adegoke & Kuteyi, 2012). Selling household items, borrowing a lot and withdrawing children from school, pushes them towards multigenerational poverty. Sometimes they are forced to take hazardous jobs or resorting to illegal activities (Emanuel et al., 2010). It emerged that WCGs also fundraised, left the person to brave the pain, took salary advances, gave medicine at home, chose affordable facilities and reached out to support groups for help or advice to survive a moment of crisis.

This study revealed that WCGs had challenges in the workplace. The unpredictability of crises increased their chances of rushing away from work always pending and very few employers are supportive (C. J. Graff et al., 2010). They may get jobs without sick leave or flexible work hours making care giving duties a barrier to employment. Post discharge pains also interfere with the ability to work or attend school (Brandow et al., 2009; Panepinto et al., 2009). Reduced work hours lead to reduced income levels. This occurs due to lateness, taking leave of absence, switching to part-time work, giving up work, losing work benefits or turning down promotions (Alspach, 2009; Frey, 2009; C. J. Graff et al., 2010). Inability to engage in productive work results in dependency, helplessness and hopelessness as he cannot provide for the family (Marsh et al., 2011). SCD affects WCGs ability to work compromising her resilience.

The physical health challenges were an indicator of their coping and resilience. Most health challenges were triggered after diagnosis of SCD in agreement with other studies. WCGs stopped exercising and developed unhealthy eating habits that led to hypertension, heart disease, migraines and low immunity (Frey, 2009). The burden related to suddenness of the diagnosis, severity of symptoms and changes in the affected person (Alspach, 2009). The caregivers experienced declining physical health, higher mortality, sleep disturbances, development of chronic conditions themselves and chronic fatigue, (Alspach, 2009; Theis et al., 1997). A 1999 study in the US showed a 63% higher mortality rate in caregivers than non-caregivers (MetLife, 2020). Caregivers of the critically ill, HIV and Alzheimer's in the US, rated care giving as a difficult 24 hour job requiring long term commitment that could take over one's life with a substantial toll on the WCG (Center, 2008; Mullan, 1998). Care giving therefore impacts women's status as equal citizens when burdens are unequally shouldered (Parks, 2010). With more support in carrying out some of the duties, the WCG can find a way of coping and becoming more resilient to the challenges.

3.0 CONCLUSIONS

This study concluded that care giving accrued a few social and emotional benefits to the WCGs. If care giving does not break a WCG, it transforms her into a stronger, knowledgeable, more empathetic person who is more humane and in touch with other people's pain. WCGs learn to reorganize their lives, multitask, built networks, support systems and useful friendships. They gain respect from those whom they support. The challenges however far outweigh benefits. This study concluded that WCGs were vulnerable to psychological, social, economic and physical health challenges. SCD acts as a barrier to engaging in economic, social and physical activities which result in challenges that create mental, social, financial and physical vulnerability. These vulnerabilities impair her normal functioning and impact her life negatively making her vulnerable to care giving challenges. However, WCGs who had support were more resilient than those who were on their own. Support in her areas of functioning '*individual, family, community and medically*' mitigated the vagaries of the challenges that got her way. The more support she had, the more resilient she became and the less support she got, the more vulnerable became.

The study concluded that gender role stereotyping of the male and feminine roles augmented the WCGs vulnerability. The socialization and gendered interpretations of responsibility that care giving is a woman's role makes only a few males to offer actual care giving support with full support of the community, leaving the WCG heavily burdened. Linked to the patrilineal structure,

men resisted negative events in their children's lives by gendered blaming to make mothers liable for the sickle cell gene, infidelity and misaligned paternity so that he can distance himself from it. This was worse in communities with low awareness of the disease. The study also concludes that WCGs in malaria endemic zones are disproportionately disadvantaged to compete not just against men, but also against women without similar care giving challenges. Lack of a local name for SCD in Kenya and likening it to conditions like HIV, *chira*, *lacina*, cultic demons, kwashiorkor or cancer reveals lack of knowledge and capacity to anticipate and deal with potential shocks.

4.0 RECOMMENDATIONS

1. WCGs to join a support group for psycho-social support, knowledge sharing, peer to peer counseling, for safe spaces to vent, to benefit from programs targeting SCD patients and to join others in lobbying and advocacy efforts to create awareness and push for policy change. They should seek medical or psychosocial support if necessary and not sacrifice their lives for the child. They should also socialize their children to play any role without confining them to the societal defined gender roles at a household level.
2. The Government to implement the 2010 Constitution and the Universal Health Coverage: Offer services for SCD patients for free/affordably/highly subsidized or avail a free comprehensive medical insurance. Develop and implement a SCD policy to support and direct management of SCD in Kenya. These will enable strengthening capacity of institutions managing SCD to enable comprehensive management of patients through infrastructure development, equipment and diagnostic tools, training of medical teams, clinical trials, medication, advocacy, counseling, education and awareness, economic empowerment and nutritional support. Make policy recommendations that will enable WCGs to work by dealing with underlying gender and economic inequalities precipitated by care giving that acts as a barrier to employment. Revise the policy on abortion to give women caregivers a legal choice in the matter regarding pregnancies of babies with genetic issues.

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6.0 APPENDICES

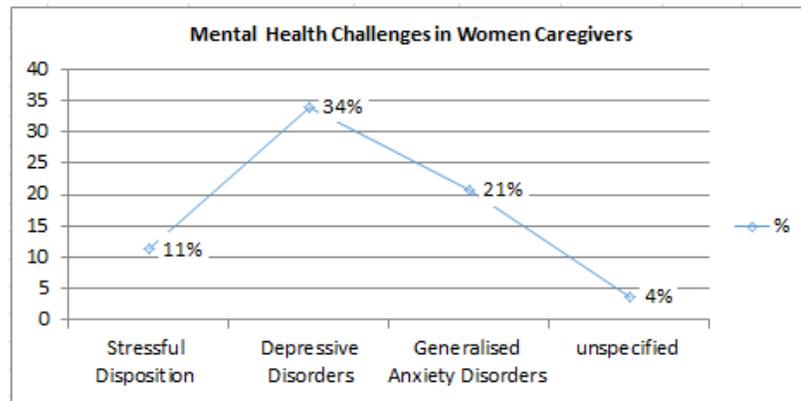


Figure 6.1: Mental health challenges experienced by women caregivers

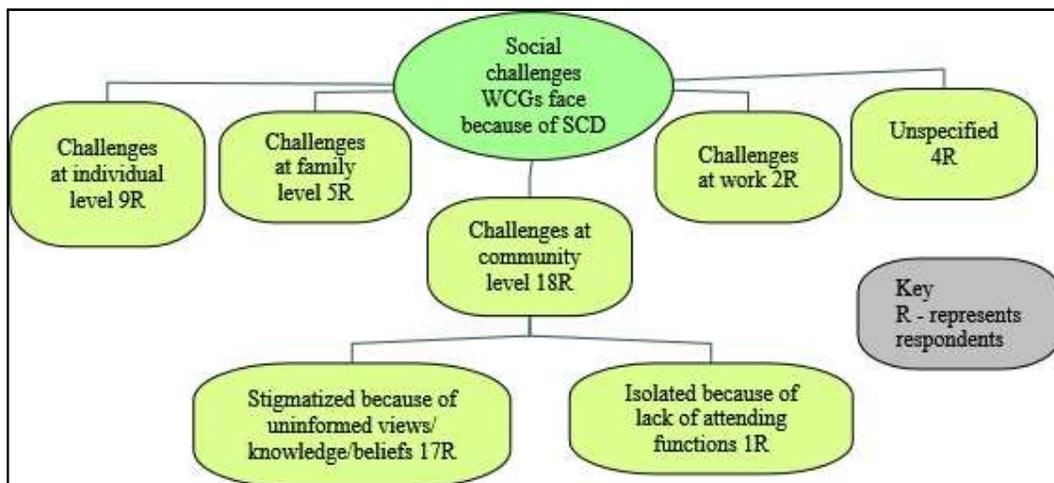


Figure 6.2: Social Challenges experienced by SCD WCGs at Different Levels

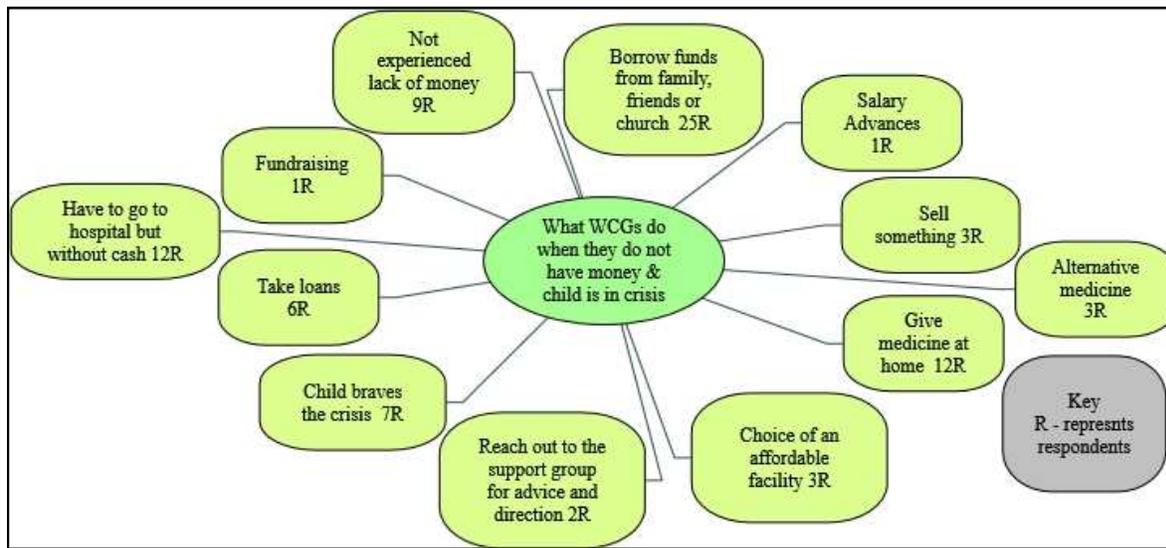


Figure 6.3: What Women caregivers do to get money when the child is in crisis

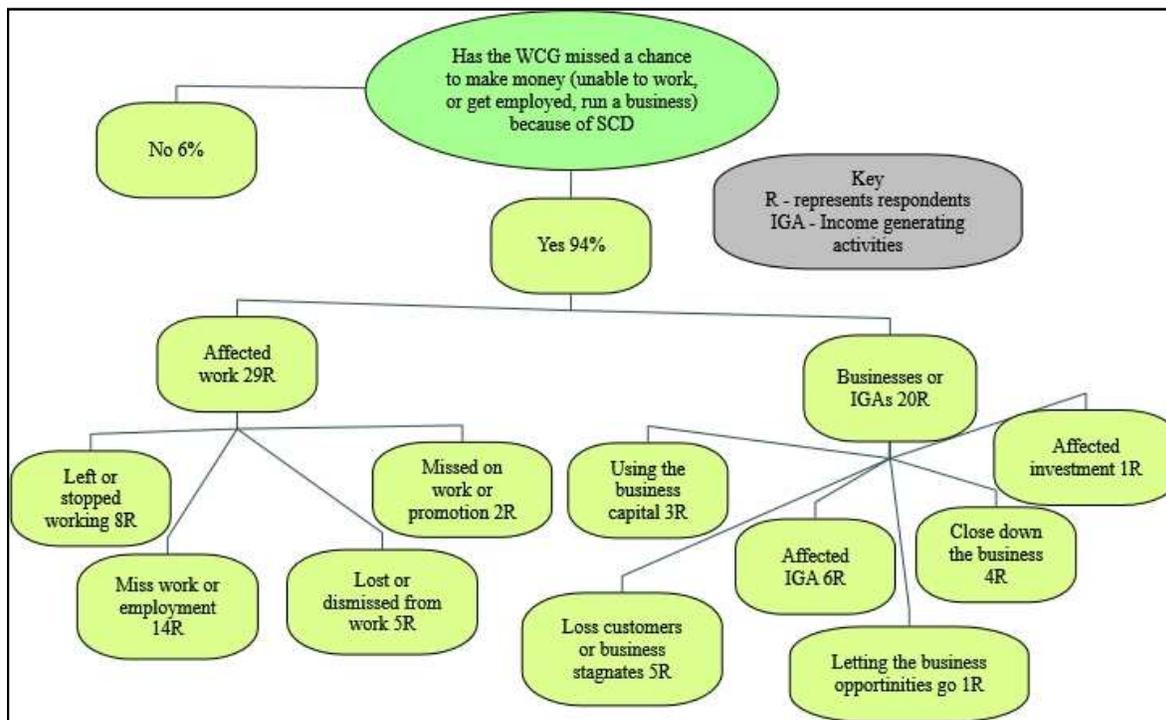


Figure 6: Women caregivers' ability work or do business