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Feeling Frequently Depressed Seeing Other Children Without Sickle Cell Disease: An Emotional Experience Of Family Caregivers Of Children Living With Sickle Cell Disease

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Abstract

The ability of family caregivers (FCs) to maintain emotional stability when providing care for their Children Living with Sickle Cell Disease (CLwSCD) remains a global concern. Therefore, this study examined the perception of FCs of CLwSCD in Ibadan, Nigeria. The qualitative and quantitative mixed design was employed, while emotional adjustment measuring and interviews were used to collect information from a total of 117 participants. The findings revealed that the FCs of CLwSCD perceived their emotional adjustment to be moderate, while a large percentage agreed that the state of health of their children is frequently depressive. Conversely, apart from the theoretical implication of these findings which provides a springboard for future studies, social service practitioners should adopt psycho-social interventions that could buffer the emotional adjustment state of FCs of people with chronic diseases.

Keywords: Children with sickle cell disease, emotional adjustment, family caregivers

Introduction

Sickle cell disease (SCD) is one of the top ten non-communicable illnesses causing significant disabilities and deaths. The disease has reportedly affected a million people globally, and of those about 50% have resulted in death, especially when the disease was severe (AL Hassan, 2015). It is mostly common in sub-Saharan Africa, the Middle East, India, and Mediterranean regions (Piel et al., 2013). Despite Africa being the epicentre of SCD diseases (Aboyans & Causes of Death Collaborators 2015), no known medical cure is available in low- to medium-economy countries like Nigeria, but bone marrow transplants are available in advanced countries such as America and Europe (Bernaudin, Pondarré, Galambrun & Thuret 2017). Nevertheless, there are cost-effective treatments to manage pain and other associated conditions associated with the disease (Muoghalu, 2016). Africa has the highest prevalence rate of SCD cases in the western and eastern parts of the continent. The African countries include Nigeria, Cameroun, Gabon, Republic of Congo, Ghana, and Uganda, with Nigeria having the highest burden rate of SCD (World Health Organization (WHO, 2014). Regrettably, Nigeria recorded

the highest prevalence rate of SCD globally, with nearly 40 million persons being carriers of the gene (WHO, 2014).

Historically, SCD is mostly common in nations with a high rate of malaria (National Heart, Lung and Blood Institute (NHLBI), 2010). This occurs when hemoglobin that should make cells circle-shaped becomes abnormal and rather produces sickle-shaped cells, causing irregular blood flow in children and leading to SCD. This means when the gene that carries oxygen through the blood and is responsible for its being red in colour is blocked, an abnormality caused in the iron-rich protein region of hemoglobin. Therefore, due to clogged blood, blood flow to limbs and damaged organs leads to low blood count and causes pain for the victims. Genetically, SCD sufferers inherit the gene from parents with two different genetic materials of the SCD gene; that is, one from each parent. Globally, as reported by Modell and Darlison (2008), 300 000 newly born children are estimated to have SCD, simply because any child whose parents possess the trait stands a 25% chance of getting the sickness.

CLwSCD have some regular physical manifestations ranging from nearly no signs to severe pain episodes, recurrent infections, pulmonary heart disease, acute chest conditions, progressive organ deterioration, chronic fatigue, growth and pubertal delays, stroke, and even death. Despite the challenges faced by the sufferers, medical advancements have increased the chances of survival for CLwSCD, with an 85% survival chance of living for up to 20 years (Welkom, 2012). Also, life expectancy of the sufferers has risen from 45 to 65 years (Bloodgivers.com, 2012). Thus, the psychological well-being of CLwSCD as the sufferers who are aging is enhanced because of the increased life expectancy resulting from efforts of experts and researchers. However, the fact remains that stress, anxiety, uncertainty, dissatisfaction, regret, and frustration are integral experiences associated with the daily life of SCD sufferers (Welkom, 2012). For CLwSCD, the emotional complications of the disease ensuing from the impact of uncertainty on their lives due to frequent crises and negative societal attitudes towards the sufferers are unimaginable. Among other emotional problems encountered by SCD sufferers are increased fear or anxiety, social withdrawal, depression, and death (Anie, 2005).

The obligation of family members who provide care and support for other relatives who may be suffering from some form of illness can be burdensome (Kuerten, et al., 2020). It usually comes with emotional, financial, and physical stress, psychological trauma and sometimes causes confusion given the nature of SCD, which requires consistent support and care by the caregiver (Bioku, et al., 2021; Reader, et la., 2017; Reader, 2020). These responsibilities often trigger anxiety, depression, embarrassment, fatigue, stress, and worry, thus affecting the quality of life as well as mental, physical, psychological, emotional, financial, and general wellbeing of the care providers (Silva et al., 2012). This could be because the sufferer totally depends on the care provider for general support, which often exposes care providers to more emotional and psychological pressure. Therefore, the roles of "caregivers" or "care providers – terms that are used interchangeably in this study – become more demanding, especially with children with SCD because the management of a child or patient living with SCD involves family centered care more than secondary health care (Madani, Al Jaouni, Omer, Al Raddadi, and Al Awa, 2018).

It has also been observed that families and caregivers of Sickle Cell anaemia sufferers have become depressed as a result of daily stress attached to caregiving, such as skipping work, financial burdens, washing clothes, bathing the sick, and sleepless nights. These burdens usually affect the FCs' health, emotional maladjustment, and quality of life in general (Muoghalu, 2016). Therefore, the disturbing experiences of FCs of Sickle Cell sufferers could be quite demoralising, with

feelings of hopelessness permeating all aspects of their lives. Living with this experience requires major emotional resources, as it depletes emotional reserves. The challenges of caregiving are notably great in Nigeria because of poor health care services and lack of social welfare (Adegoke & Kuteyi, 2012).

In addition, the impact of emotional stress on the family caregiver is worsened with each episode of the crisis. The FCs of CLwSCD suffer numerous stresses associated with the genetic problems of SCD. Among other challenges for FCs are work-related problems, the feelings of guilt concerning the genetic inheritance of the disease, financial burdens, everyday routine burdens, feelings of low self-esteem, helplessness, frustration, and changes to daily routines (Adegoke & Kuteyi, 2012). Many FCs of CLwSCD, especially mothers, are at risk of illness, social isolation distress, and depression. No matter how well prepared they are, Bennett (2007) submits that parents are often shocked when their children are diagnosed with SCD. Many parents find the initial acceptance of the diagnosis difficult and some experience the emotion of denial. When accepting the result of the diagnosis, the initial emotional burdens experienced by parents are self-blame, an overwhelming sense of frustration, and feelings of financial inadequacies. Later, they worry about the child's wellness in terms of career and marriage, and their futures in general and other issues that burden parents or primary care providers. All of these are sources of emotional stress for the FCs, which if not adequately managed can lead to emotional maladjustment, loss of hope and negative caregiving attitudes (discourteousness, criticism, resentfulness, and reluctance), creating negative reactions by the sufferers.

The burden of caring for SCD children by FCs is enormous; burdens include being absent from work, impoverishment, and mental health illness. Family members also need to know how to ensure adequate support and care in the management of SCD symptoms and morbidity, which are both very stressful and demanding. More worrisome is increasing, overwhelming tiredness and isolation, usually resulting from the lack of social support, training, and information that are necessary to care for the CLwSCD. Physical and financial stress and traumatic experiences create burdens when caring for children living with SCD. Less attention in research has been given to caregivers who experience regular pain, sleeplessness, fatigue, headaches, and burnout. In addition, the cost of transportation, hospitals, drugs, hospital bills, and healthy fruit and vegetables needed by CLwSCD to boost their immune systems is an added burden. Coupled with all these, the FCs who ensure the wellbeing of children without support from any government agency (unlike other developed nations of the world) are neglected, and this has made their emotional adjustment difficult.

Considering the quality of life and emotional preparedness of caregiving, emotional adjustment of FCs of the SCD children is desirable. However, the psychosocial and emotional needs of FCs dealing with SCD have not gained the attention of researchers, compared with that given to HIV/AIDs caregivers (Atanuriba, et al., 2021; Oyeyimika, Muheezat, Adenike & Ejiro 2020; Rose & Clark-Alexander 1998; Safo, Knizek, Mugisha & Kinyanda, 2017). If the health complications of SCD are of high magnitude and SCD is lifelong disease, why has equal attention not been given to the FCs of SCD children? This, therefore, raises the question: How can FCs of CLwSCD be helped to attain emotional stability?

Previous studies on related issues focused largely on the psychological wellness of SCD children (Ogunbunmi, 2016; Anie, Egunjobi & Akinyanju, 2010). Although there have been several studies on emotional wellness of children living with HIV/AIDS and their FCs, there are few studies on the family members of CLwSCD. There is, therefore, a dearth of studies which have adopted psycho-educational therapy and token economy therapy

to facilitate the emotional adjustment of FCs of CLwSCD in Oyo-State, Nigeria. In essence, neither economic burden nor emotional wellness of FCs of CLwSCD have been given serious consideration in this part of the world. This study aims to examine the feelings of FCs of CLwSCD in Ibadan, Nigeria. It also explores (1) the level of emotional adjustment of the caregivers, and (2) caregivers' feelings about their CLwSCD. The following research questions were asked to address the objectives set for the study: (1) What is the level of the caregivers' emotional adjustment? and (2) How do the caregivers feel about their children/wards living with SCD?

Theoretical framework

Appraisal Theory Roseman and Smith (2001) is the theoretical framework for this study. The basic assumptions of the theory rest on how an individual perceives events and the coping potential of such an individual; namely, the perceived adjustment of an individual as a result of differing emotional responses. In this theory, appraisal of emotions involves three aspects of an individual: namely, relational, motivational, and cognitive aspects. The relational aspect involves a person's disposition to the environment, which suggests that emotions always involve an interaction between an individual's personality and events. The motivational aspect also involves an evaluation of the desired goals and involves assessment of a situation in which a person determines the response outcome – he is either emotionally well-adjusted, or distressed, leading to mal adjustment (Lazarus, 1991). The cognitive process determines the outcome response. Thus, the personalities of FCs of CLwSCD determine their emotional adjustment responses to environmental events; in this case, the condition of SCD. If the FCs adjust emotionally, personality disposition is critical, and visa-versa.

The Appraisal Theory believes that each emotion is triggered by something within events or situations that one is experiencing. Therefore, an emotional response determines the kind of coping or adjustment strategy that is employed. This adjustment strategy should restore harmony or equilibrium in the relationship between a person and events or environments. Lazarus (1991) concludes that events that trigger emotional reactions, no matter how simple, are usually complex and affect the emotional well-being of the affected person. To understand the emotional adjustment of the cognitive process of FCs of CLwSCD, the influence of the cognitive appraisal must be linked to the type of emotion displayed by the FCs. Nilsson (2007) states that family adaptation and adjustment response in stress and crisis are influenced by family resources, appraisal of the stressor as well as problem solving skills. Therefore, the principle of the appraisal theory provides an understanding of family disposition, cognitive processing, and ability to assess the triggers or stressors in the events. The theory further established that individual FCs' resources – such as social economic stability, shared spiritual beliefs, flexibility, social support, cohesiveness, open communication, and resilience – foster emotional adjustment. In other words, FCs' emotional adjustment could be facilitated as a result of use of resources which could be referred to as emotional coping mechanisms.

Methodology

Design and Population

The design used for the study was a mixed-method. This design comprises collection and analysis of data using both qualitative and quantitative approaches. In this study, room was given to the triangulation of data. The population consisted of FCs of CLwSCD who assist children who are living with SCD in all hospitals in Oyo State, Nigeria. Using a multistage sampling procedure, three hospitals from 18 state hospitals with a high number of children living with SCD in Oyo were selected purposively in the quantitative phase of the study. At stage two, 117 FCs were selected randomly from the three hospitals. In the last

stage, six participants were purposively selected for the qualitative phase of the study.

Instruments

Bell's Emotional Adjustment Inventory (1994) was adapted to collect data from FCs of CLwSCD on the state of their emotional wellbeing in this study. A 15-item inventory has been used across cultures with an initial internal consistency reliability value of .81. The researchers further performed a confirmatory factor analysis by pilot testing the inventory among 30 non-participants of the main study sample. This becomes necessary to ensure the reliability of the instruments. The internal consistency reliability value using Cronbach's Alpha benchmark remained at .81. Samples of such items are: "I often feel miserable having seen other children without sickle cell" and "I sometimes have difficulty getting to sleep even when the child/children does/do not have any crisis". Information were gathered from six participants using an unstructured in-depth interview method in the qualitative phase, while the interviews were then transcribed verbatim. However, "How do you feel seeing other children without sickle cell disease?" is an example of questions covering factors relating to the participants' emotional adjustment.

Procedure

In the process of administration of the research instruments, the researcher strictly adhered to the ethical procedures of the research, as stated in the ethical research clearance. All the data gathered were kept confidential. Participants were from three randomly selected hospitals Oyo State in Nigeria. Of the 156 questionnaires distributed to the FCs in Ibadan, 117 questionnaires were returned adequately completed and returned. A 75% completion rate was achieved, against an attrition rate of 25%.

Ethical considerations

All ethical protocols were observed in this study. Ethical clearance was granted by both the Social Science and Humanities Research Ethics Committee (SSHREC), Ethical ID number UI/SSHREC/2019/001, and the State Ministry of Health. Given the international ethics of any research, participants were assured of the confidentiality of the information provided as it would be only used for research purpose. The authors also informed them that their participation was voluntary, meaning that they were free to decline their participation.

Data analysis

Quantitative and qualitative methods of analysis were used to analyse collected data. The percentages of frequency were used to analyse the quantitative data, while a thematic content analysis which is described as an inductive and direct process of fact-finding about a given phenomenon was performed for the qualitative data. In this case, we were interested in the feelings of FCs of CLwSCD in Ibadan, Nigeria.

Results

Research question One:

What is the level of the caregivers' emotional adjustment? This was analysed using frequency counts, percentages and mean.

Table 1: The level of caregivers' emotional adjustment

SN	Statement	SA n(%)	A n(%)	D n(%)	SA n(%)	Mean
1	I feel there has been a dearth of real affection and love in this family since our child was diagnosed with SCD.	6(5.0)	0(0.0)	29(25.0)	82(70.0)	1.4

2	I sometimes have difficulty getting to sleep even when the child/children does/do not have any crisis.	6(5.0)	12(10.0)	29(25.0)	70(60.0)	1.6
3	Mostly I am not happy when I remember that my child/children with sickle cell can die at time.	29(25.0)	18(15.0)	29(25.0)	41(35.0)	2.3
4	I am easily moved to tears anytime I see my child in pain.	29(25.0)	35(30.0)	23(20.0)	29(25.0)	2.6
5	I am troubled with shyness when I see other children without sickle cell.	29(25.0)	12(10.0)	18(15.0)	59(50.0)	2.9
6	The state of health of my child/children frequently depressed me.	47(40.0)	41(35.0)	9(5.0)	23(20.0)	3.0
7	At time I am discouraged to even take the child/children to the hospital.	29(25.0)	47(40.0)	9(5.0)	35(30.0)	2.6
8	I often time get angry easily because of my child/children with Sickle cell.	35(30.0)	23(20.0)	41(35.0)	18(15.0)	2.4
9	I often feel miserable having seen other children without sickle cell.	0(0.0)	53(45.0)	35(30.0)	29(25.0)	2.2
10	I feel it is unfair having abnormal genotype.	6(5.0)	41(35.0)	41(35.0)	29(25.0)	2.2
11	When my child/children refused to take his/her medication, I can become nervous.	6(5.0)	41(35.0)	23(20.0)	47(40.0)	2.0
12	Seeing my child/children going through pains make easily hurt.	29(25.0)	18(15.0)	18(15.0)	53(45.0)	2.2
13	My neighbours sometime abuse me for having child/children with sickle cell and it gets me disturbed.	53(45.0)	23(20.0)	6(5.0)	35(30.0)	2.8
14	I feel my friends are having a happier life than me since none of their children is living with SCD.	12(10.0)	35(30.0)	12(10.0)	59(50.0)	2.0
15	I worry a lot especially when I am humiliated over my child/CLwSCD.	41(35.0)	6(5.0)	35(30.0)	35(30.0)	2.6
	Avarage mean Value					**2.32**

Table 1 revealed that the level of FCs' emotional adjustment was moderately low. Of the 15 items that measured FCs' emotional adjustment, only seven items were above the weighted means value of (Mean = 2.32). The rating of the level of FCs' emotional adjustment in Item 5 shows that the majority (75%) of respondents agreed that the state of health of their child/children frequently depresses them (Mean = 3.0). In the same vein, Item 15 revealed that 60.0% of respondents attested that they had emotionally adjusted, as they were not very worried, especially when they were humiliated regarding their child/children with

Sickle Cell (Mean 2.6). The result in Item 13 revealed that 65.0% of the respondents opposed the fact that their neighbours sometimes abused them for having child/children with SCD and it disturbed them (mean = 2.8). The result generated in Item 9 on the FCs' emotional adjustment table also shows that the majority (60.0%) of respondents, contrary to the statement, admitted that they often felt miserable seeing other children without SCD. The result generated in Item 8 revealed equal balance in the numbers of respondents who disagreed and those who agreed that they often became angry easily because of their children with SCD (50.0% respectively) (Mean = 2.4). In Item 3, respondents disagreed that they were not mostly happy when they remembered that their child/children with SCD could die at any time (60.0%, Mean = 2.3).

Considering Items 1, 2, 10, 11, 12 and 14 in Table 4.3, it was clear that percentages of respondents who reported that they had emotionally adjusted were in the majority, although the means were less than the weighted mean value, compared to results in Items 4, 6, 7 and 13, where respondents still reported being down emotionally about their fate, despite having weighted means that was greater than 2.3.

Research question Two

How do the caregivers feel about their children/wards living with SCD?

From the qualitative part of the study, findings revealed that feelings of depression and worry are some of emotional experiences of the participants. As expressed by Adegoke and Kuteyi (2012) and Silva, Ivo, Souza, Pontes and Araujo (2012), providing care and support for children with SCD usually triggers negative emotions such as depression, feelings of guilt concerning the genetic inheritance of the disease, feelings of low self-esteem, frustration, helplessness, stress, and worry. In this study, FCs of CLwSCD attribute their emotional experiences to worry, depression and hopelessness. In their words, the Participants said:

> I am easily moved to tears anytime I see my child in pains, while other children are jumping up and down. But there is nothing I can do to help the child. I feel sad **(FC_1)**.
>
> All my three children are living with sickle cell disease. When we had the first child, we were advised to try may be the second child will not have the disease, unfortunately, the second has it, then the third child also. To be honest, I am not happy when I remember that all my children are with sickle cell and that they can die at time. I feel hopeless (**FC_3)**.
>
> I am frequently depressed with the state of health of my child. She is the only child, and we did not notice on time. She was never sick for the first three years of life, so we never thought of going for test or so, until she was 5 years when she now frequently falls sick. **(FC_4)**
>
> Seeing one's child going through severe pains is very terrible. For me, I often time feel and even get angry with myself. I blame myself for bringing this child to this world for pain. She is the last child out of three. The first two is not with sickle cell disease. She is the most intelligent. To be sincere, I feel dejected **(FC_5)**
>
> It's always hurt me whenever my child is going through pains. At time I will be crying because one cannot predict when the crisis will come. If there is any assurance that the child will survive it, the stress of going in and out of hospital could worth it. Regrettably, the disease drains resources and no provision by any NGO or government agencies for free medicine to support poor parents of children with sickle

cell, like for those with HIV/AIDS. It is really disheartening **(FC_6)**

Given the above expressions, it can be deduced that FCs of CLwSCD often feel depressed seeing other children without the disease, as reported by the participants. Evidently, the participants were feeling emotionally depressed with the state of health of their children with SCD.

Discussion of the findings

This study assessed the feelings of FCs of children with SCD. Findings revealed that FCs' emotional adjustment levels were moderately low. By implication, despite the health condition of the child/children of the FCs, adjusting emotionally was slow. This may be so because the health condition of their child/children is beyond how FCs can help and, therefore, they were not happy about the situation. Given the responses from the participants, most of the participants expressed that they were frequently depressed about the health of their CLwSCD. A higher percentage confirmed that they were disturbed when neighbours sometimes abused them for having CLwSCD. Based on the above responses, frequent experiences of depression, trouble and disturbances are indications of low emotional adjustment. These findings support the findings of Grunfeld, Coristine, Glossop, Clinch, Earle, Reyno, Whelan, Willan, Viola, Janz, and Coyle (2014) that primary care providers experience psychological issues such as anxiety and depression, and that caregivers' burdens increase during crises. Similarly, these current findings agree with the findings of Given, Given and Sherwood (2012) that emotional, physical, social, and financial adjustments of FCs were negatively affected, creating burdens for the caregivers.

Furthermore, depression and worry emerged as emotional experiences of the participants in this study. According to the American Psychiatric Association (APA, 2013), symptoms of depression include disturbed sleep, decreased or increased appetite or weight, a persistent sadness/low mood, loss of energy, marked loss of interest or pleasure in activities, poor concentration, feelings of worthlessness or guilt and/or suicidal ideation or acts. Notably, the criteria for major depression, in line with the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-V), is that a persistent sadness/low mood or disturbed sleep would be experienced nearly every day for at least two weeks (APA 2013). It was not established that the participants had experienced two weeks with these symptoms, but caring for CLwSCD is demanding, stressful, challenging and resource-consuming, subjecting FCs to feeling sad, unhappy, stigmatized, socially rejected, and sometimes helpless. These feelings become worse when a child is having episodes of illness. This finding concurs with some previous findings. For example, Townsend and Wilcock (2014) found that FCs felt burdened, because self-care activities at the time of providing care involved great expense. Likewise, Ae-Ngibese, Doku, Asante and Owusu-Agyei (2015); Mthembu, Brown, Cupido, Razack and Wassung (2016) found that primary caregivers felt stressed and burdened because of financial difficulties, depression, emotional stress, and social isolation when providing care for chronically ill children.

This finding also concurred with Silva, Ivo, Souza, Pontes and Araujo (2012) and Vitaliano et al. (2013) that the responsibilities of providing care and support for children with chronic diseases caused caregivers to suffer lower levels of physical health and emotional well-being and increased the risk of being vulnerable to stress, worry, and depression. FCs experience greater physical and financial burden, more symptoms of depression, and lower levels of emotional adjustment. It was found in this study that FCs of CLwSCD often feel sad, depressed, socially rejected, and miserable. Providing care and support for loved ones with chronic health challenges is stressful

and challenging, and often triggers depressive symptoms in the life of caregivers. Among other emotional experiences of FCs caring for CLwSCD, are interference and strain on their personal lives in terms of the time and resources committed to the care of their ill relatives (Udoh et al., 2021).

Conclusion

FCs experience many burdens in the process of caring for their children with SCD, including being absent from work, impoverishment, and mental health illness. Apart from these issues, much attention is given to the sufferers (CLwSCD), whereas FCs feel sad and unhappy. The findings of this study revealed that FCs of CLwSCD had a low to moderate state of emotional adjustment. Further, the qualitative aspect of this study established that feeling depressed when seeing other children without SCD was commonly experienced by the FCs who took part in the study. The authors conclude that the emotional adjustment and wellbeing of FCs of CLwSCD may improve if they can draw strength from being supported and are given hope. According to the Lazarus Appraisal Theory adopted in this study, emotional adjustment depends on a state of hope and socio-economic status. The authors therefore suggest that emotional adjustment interventions should be used. These could include token-economy, psychoeducation, cognitive relabelling, and social support that can deal with depressive symptoms and enhance emotional adjustment of the family caregivers. Advocacy programs, social support, and welfare services for family caregivers of children with SCD are also needed.

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