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DETERMINANTS OF THE QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH SICKLE CELL DISEASE AT SIAYA COUNTY REFERRAL HOSPITAL, KENYA

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ABSTRACT

Sickle Cell Disease is a high-morbidity and early-mortality ailment if not managed and controlled properly. Several challenges are usually experience by both the caregiver as well the family unit since the children are usually highly dependent on them for their daily activities. This study, therefore, sought to establish the determinants of quality of life of individuals taking care of children with SCD attending care at Siaya County Referral Hospital, Kenya. The study adopted a descriptive analytic study design. This research was theorized by the Quality-of-Life Major Domains Model by Basavaraj et al (2010), and the WHOQOL tool for data collection. The study population were caregivers of children suffering from SCD seeking care at the Siaya County Referral Hospital in Kenya. Sixty (60) participants were sampled to collect the desired data. The identification of the study participants was achieved through a convenience sampling method. Data from both pretests and study population was analyzed using IBM's SPSS version 25. Findings from the study indicated that 70% of the caregivers had good quality of life; employment X^2 *(1, N = 60) = 9.3, p = .002, financial security* X^2 *(1, N = 60) = 7.1, p = .008, monthly income* X^2 *(1, N = 60) = 6.6, p = .01, acquisition of new information* X^2 *(1, N = 60) = 6.5, p = .011, support from friends* X^2 *(1, N = 60) = 4.4, p = 0.037, ability to get around life (*X^2 *(1, N = 60) = 13.6,* $p < 0.001$*) and quality of sleep (*X^2 *(1, N = 60) = 25.7,* $p<0.001$*) impacted positively on caregivers' quality of life. Results also indicated that frequency of hospitalization (*X^2 *(1, N = 60) = 0.0510, p = .021) and frequent negative feelings (*X^2 *(1, N = 60) = 4.5, p = .033) impacted negatively on the caregivers' quality of life. Predictors of QoL included source of income, ability to acquire new information and satisfaction with relationship. In conclusion, no association was observed between Socio-demographic factors and QoL however there is significance association between economic and psychosocial factors and Qol. Health education should be strengthened and incorporated in the special clinics to provide necessary information to the caregivers. All levels of government should provide financial empowerment to caregivers of children with chronic illnesses.*

Key Words: *Sickle Cell Disease in Children, Caregivers, Quality of Life, Hospitalization*

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INTRODUCTION

Sickle Cell Anaemia is one of the haematological disorders resulting to prolonged or chronic debility and even early deaths especially when the ailment is not vigorously managed and proper control measures ensued (McGann, Nero, & Ware, 2013). According to a World Health Organization report done by DeBaun & Galadanci, (2019), it is estimated that the global Sickle Cell Disease (SCD) burden is approximately 23 out of 10,000 people or more. The report further postulates that more than 5 out of 100 persons globally possess the SCD trait (DeBaun & Galadanci, 2019). An array of researches conducted globally has proven that the highest prevalence of SCD is in African countries majorly because the occurrence of SCD more rampant amidst individuals from a section of the global population where malaria has been reported throughout the year (CDC, 2019). The researches propose that 3 out of 4 of all those affected with SCD globally reside within the African continent (Macharia, et al., 2017).

Clinically, patients having this genetically inherited haematological disorder present mostly with a long-standing deficient red blood cells or anaemia and innumerable acute “painful crises”. These long-standing incurable subjective manifestations require quotidian care and sometimes rigorous medication. All these challenges contribute greatly to the negative impact on the physical functioning of the patients in addition to the impaired sleep, decline in their performance in school, and their overall quality of life (QoL) which in turn calls for the caregiver support (Badawy, et al., 2018).

A review of studies has already indicated that caregivers of clients suffering from long standing illnesses inhibit the character of developing psychological disorders such as depression and anxiety (Wonkam A. , et al., 2014; van den Tweel, et al., 2008). Various scholars also established a correlation between SCD, caregivers and psychological distress disorders and have postulated that approximately 30 to 40% of caregivers of children having SCD often show symptoms of psychological distress (Badr, Al Radda, Al Jaouni, Mohab, & Al Awa, 2016). Literature reviewed revealed that there was no research evaluating the determinants of the QoL of the individuals supporting the medical care of the pediatric population diagnosed with SCD at the Siaya County Referral Hospital, Kenya

Studies conducted in developing countries with similar socio-demographic characteristics have demonstrated that there is a substantial amount of emotional and monetary burden on caregivers of SCD patients (Tunde-Ayinmode, 2012). In this study by Tunde, the researcher established that caregivers who were subjected to severe emotional and financial strain stood a higher chance of experiencing psychological challenges which in turn affected how they took care of the children afflicted with the SCD. This study intends to investigate some of the determinants of the quality of life of caregivers of children with SCD attending Paediatric Outpatient Clinic of Siaya County Referral Hospital in Kenya. Different dimensions of caregivers' factors will be examined together with some of the risk factors linked to their peculiar experiences.

Problem Statement

Managing a child suffering from SCD has proved to be a grueling ordeal to both the caregiver as an individual as well the family. Children suffering from SCD are usually highly dependent on the caregiver for their daily activities which subjects the caregiver to constant pressure (Erdem, et al., 2013). Studies have proven that the supporting individuals of siblings inflicted with the SCD are bewildered with countless challenges and are always subjected to constant pressure, emotional, financial burden and sleep impairments (Adegoke et al., 2012; Madani et al., 2018) which in turn affects the care they give to their sick children (Fazlıoğlu et al., 2010). Further research has demonstrated that approximately 30-40% of caregivers of children afflicted with SCD tend to develop psychological distress. These levels of distress affect the QoL of the caregivers which then in turn impairs their potentiality of taking care of the babies’ troubled with the Sickle Cell menace thus leading to a deteriorated general health or a declining quality of life of the very patients they are taking care of (Adegoke & Abioye-Kuteyi, 2012).

Caregivers have been referred to as secondary patients (Reinhard, Given, Petlick, Bemis, & Hughes, 2008) and are said to be in crucial need for attention, mental and physical health and safety from both the physicians and authorities (Fazlıoğlu, Hocaoğlu, & Sönmez, 2010). Triangular studies on the association between the invalid, the ailment, and the caregiver have also elicited the fact that caregivers who are in most cases are mothers have a higher likelihood of experiencing adverse psychological challenges and physical agony as they are tasked with the burden of ensuring continuity of care, treatment compliance, and social support of the patient.

In Kenya, SCD has its highest prevalence in malaria-endemic regions mainly the Coast and Nyanza regions (Kuta, Njuguna, Tenge, & Ganda, 2017). A study conducted by the World Health Organisation (WHO) in conjunction with Masinde Muliro University of Science and Technology (MMUST), shows the Kenyan western region accounts for 30% of all sickle cell cases in the country as this is also considered a malaria endemic zone (Oloo, Chunge, Oloo, Ngala, & Wanzala, 2016). However there is a dearth of literature on the determinants of the QoL of caregivers of children with SCD in Kenya and more so at Siaya County Referral Hospital. The study thus purposed to establish determinants of the QoL of caregivers of children with SCD seeking care at SCRH, in Kenya.

Objectives of the Study

The study established the determinants of the quality of life of caregivers of children with sickle cell disease at Siaya County Referral Hospital, Kenya. The study's specific objectives were:

- To determine the relationship between Socio-demographic factors and QoL of caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya
- To establish the relationship between economic factors and QoL of caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya
- To determine the relationship between psychological factors and QoL of the caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya
- To establish relationship between social-demographic, economic & psychosocial factors and QoL of caregivers of children suffering from SCD at Siaya County Referral Hospital, Kenya

The study was guided by the following research questions;

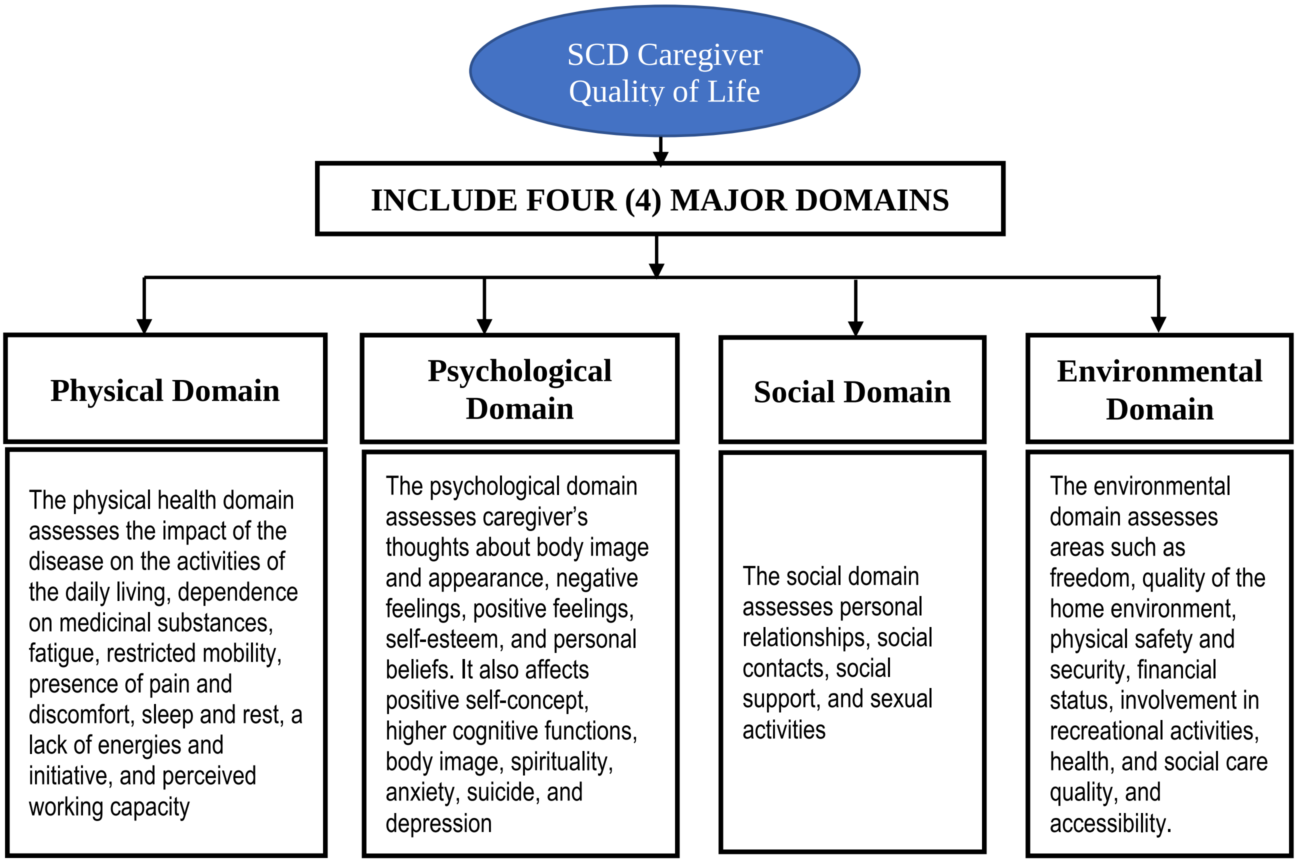
- What is the relationship between Socio-demographic factors and the Quality of Life of caregivers of children suffering from sickle cell disease?
- What is the relationship between economic factors and QoL of caregivers of children suffering from sickle cell disease?
- What is the relationship between psychosocial factors and QoL of the caregivers of children suffering from sickle cell disease?
- What is the relationship between socio demographic, economic & psychosocial factors and QoL of caregivers of children suffering from SCD?

LITERATURE REVIEW

Theoretical Framework

A number of elements influence the outcome of the life lived by the caregivers. A review of some of the factors influencing the outcome of the life lived by the caregivers has been undertaken in this study by the use of Quality-of-Life Theory by Basavaraj et al (2010). In his theory he reviews the determinants of life using four broad categories; the physical, psychological, social and the environmental domains. In this theory whose origin is Abraham Maslow's Theory of Quality of Life, quality of life has been discussed as an evolution towards happiness ad true being on the concept of human needs.

The theory discusses the four determinants as a system and that one component fuels the other and influences QoL outcomes. The study has further adapted theoretical model while making use of the social domain and the environmental domain and how these domains influence the QoL of caregivers of children suffering from SCD. This study will review the two domains from the theoretical model under three broad categories; demographic, social-economic factors and the caregiver's psychosocial factors and Quality of Life.



The physical health domain assesses the impact of the disease on the activities of the daily living, dependence on medicinal substances, fatigue, restricted mobility, presence of pain and discomfort, sleep and rest, a lack of energies and initiative, and perceived working capacity

The psychological domain assesses caregiver's thoughts about body image and appearance, negative feelings, positive feelings, self-esteem, and personal beliefs. It also affects positive self-concept, higher cognitive functions, body image, spirituality, anxiety, suicide, and depression

The social domain assesses personal relationships, social contacts, social support, and sexual activities

The environmental domain assesses areas such as freedom, quality of the home environment, physical safety and security, financial status, involvement in recreational activities, health, and social care quality, and accessibility.

Figure 1: Quality of Life major domains model by Basavaraj et al (2010)

Understanding Caregivers Quality of life

Quality of life (QOL) of the caregiver of any client is the backbone and one of the core areas in the evaluation of a client's health care assessment and management in any health care setting. It forms the basis of measurement of the effectiveness of the management of chronic health conditions. According to Marashi et al (2009), QoL depends on the unique experience of life for each person. Different scholars agree that QoL is a multi-dimensional construct and individuals are the only proper judges of their quality of life as people differ in what they value life. They further refer to it as the physical, psychological and social aspects of an individual (Badawy, et al., 2018). It is a measure of an individual's ability in the fulfillment of their daily life activities as well as a person's feeling on how their health quality influence his or her life. QoL encompasses sufficiency and appropriateness of material circumstances as well as personal feelings about those circumstances. Madani et al., (2018) posits that QoL is the overall subjective feeling of an individual's good health with a closer linkage to the motivation, joy, pleasure and contentment. Badr, et al., (2016) discuses QoL to include the sensory-motor, limbic system, communal, religious, and environmental aspects of a person's life that may be influenced gradually by an ailment, physical motor dysfunctions, or any other pathology. As stated by Imam, et al (2011), QoL generally means how you live your life and the quality of your health.

Empirical research has proven that in African settings, the very diagnosis and communication of the Sickle Cell Disease (SCD) to the family can bring about changes in a household (Lima da Silva, et al., 2012). Whereas structural changes within the family setup have been realized due to other reasons too, research within the African contexts still reveals that most patient caregivers of children suffering from SCD are female relatives. Research on the caliber of life lived by the individuals taking care persons between the stage of infancy through the preadolescence with long standing ailments has been in healthcare focus for several decades. The researches have demonstrated that caregivers of children suffering from SCD are constantly subjected to immense life constraints which many at times affect the patient's quality of life (QoL). The studies posit that SCD poses a significant emotional and financial burden on caregivers particularly in developing countries (Madani, et al., 2018). Further studies demonstrate that SCD caregiving exposes the caregiver to extreme psychological, financial and sleep distress. These distresses pause a bleak future to the caregivers' as well as their quality of life which consequently further impairs their capacity when it comes to the caring role in respect to the children living with hematological disorder -sickle cell anaemia (Adegoke, et al., 2012). It is in this light that Adegoke et al. (2012) concludes that caregivers are in constant need of attention, financial and social support by not only the immediate family and community but also by the physicians and authorities (Adegoke, et al., 2012).

Socio-demographic Factors Associated with Caregiver QoL

Socio-Demographic components influencing the outcome of the Caregivers tasked with the responsibility of supporting the children ailing with the haematological disease – sickle cell in their day to day medical care comprises of; length of life, sex, cognitive enlightement, number of people in the family, and matrimonial status. Findings from the study by Obozi et al (2018) on the nature of living conditions of the caregivers of persons living with SCD showed that caregiver age had a significant association with social and emotional aspects of the QoL, with younger caregivers being more vulnerable to emotional impairment in comparison to the older caregivers in the social domains of QoL.

The gender factor is associated with QoL of caregivers of children suffering from SCD. According to Asante (2012), women caregivers reported an increase in the rate of stress, emotional lability, and apprehension over a child's health state than their male counterparts. Several studies on QoL of SCD caregivers have revealed that women are the most affected by lower QoL scores compared to men (Adegoke & Abioye-Kuteyi, 2012; Burnes, Antle, Williams, & Cook, 2018). This has been attributed to women sacrificing their livelihood in order to improve the family's welfare in addition to pushing forward any other life activity because they have low income (Burnes, Antle, Williams, & Cook, 2018). Burnes, et al., 2018 further argues that while women are more likely to adhere to the child's treatment regimens due to the importance, they place on their children remaining health, men on the other hand are less likely and will hide their child's' illness hence reducing adherence and in the long run compromise their child's QoL and subsequently their own QoL.

Economic Factors Influencing Caregiver Quality of Life

A Nigerian study by Adegoke & Abioye-Kuteyi, (2012) revealed that the length of time spent caring for a SCD contributed to the deprivation of caregivers' income or suffering the loss of financial benefit. The same study noted that medical expenses towards the SCD child adversely affected provision of the essential family basic human needs such as nutrition, garments or dressing, and housing in addition to the fact that most of the respondents had to take loans to meet the medical expenses (Adegoke, et al., 2012). This study established that slightly more than half (53.3%) of the households where children with SCD life could not adequately cater for basic needs. Almost seven out of ten (73.3%) of the caregivers stated the duration of time consumed in the care of the child significantly contributed to the loss of monetary gains while 19.6% of the caregivers said that they sought financial credit facilities to bridge out the gaps occasioned by the ever demanding patient's illness.

These findings could be explained in part by a research conducted in Saudi by Madani et al., (2018). In that study, Madani et al breaks down time demands and exemplifies why time allocated to care meant loss of income. They established that 77.8% of the respondents were exclusive caregivers meaning they needed to be constantly available for the patient meaning limited or no economic activities for the caregiver. A study by

Wasomwe and Ngoma (2011) puts the low monthly income earned into perspective by illustrating that the enormous financial expenditure incurred towards the care of the SCD child pauses an enormous monetary demands to the families thus elevating the family's anxiety. The study further revealed that caregivers who reported financial challenges had a feeling of gloom and despondency, feelings of culpability, apprehension, and blue moods. The biggest outcome of financial challenges was depression.

Psychosocial Elements influencing QoL of Caregivers

Caregiving for a child with SCD can be a grueling journey. Based on the fact that caregiving is usually family based, caregivers are faced with continuous pressure which may result into physical exhaustion and stress (Adegoke & Abioye-Kuteyi, 2012). Further, research has demonstrated that this physical exhaustion and stress can be attributed to the daily decisions and daily challenges the caregiver gets in managing the SCD (Jensen, et al., 2017). This in turn causes psychological disorders such as depression and anxiety (Madani, Raddadi, Jaouni, Omer, & Al Awa, 2018). Madani et al., (2018) revealed that averagely between three to four out of ten (30-40%) caregivers of SCD children had symptoms of psychological distress (Madani et al., 2018). Common indicators of psychological distress included sleep quality and sexual dissatisfaction. The study also cited emotional distress among caregivers who reported having high levels of anxiousness, gloom and exhaustion.

Self-efficacy is a variable that can dictates the outcome of the caregivers of clients with SCD's quality of life. In addition, it can also be attributing to a conviction on an individual's capacity in executing required actions to realize expected outcomes (Jensen, et al., 2017). Therefore, self-efficacy is a behavior predictor more than a behavior cause. Based on this, it can be deduced that a person with self-efficacy could be confident on undertaking caregiving of patients with SCD.

Conceptual Framework

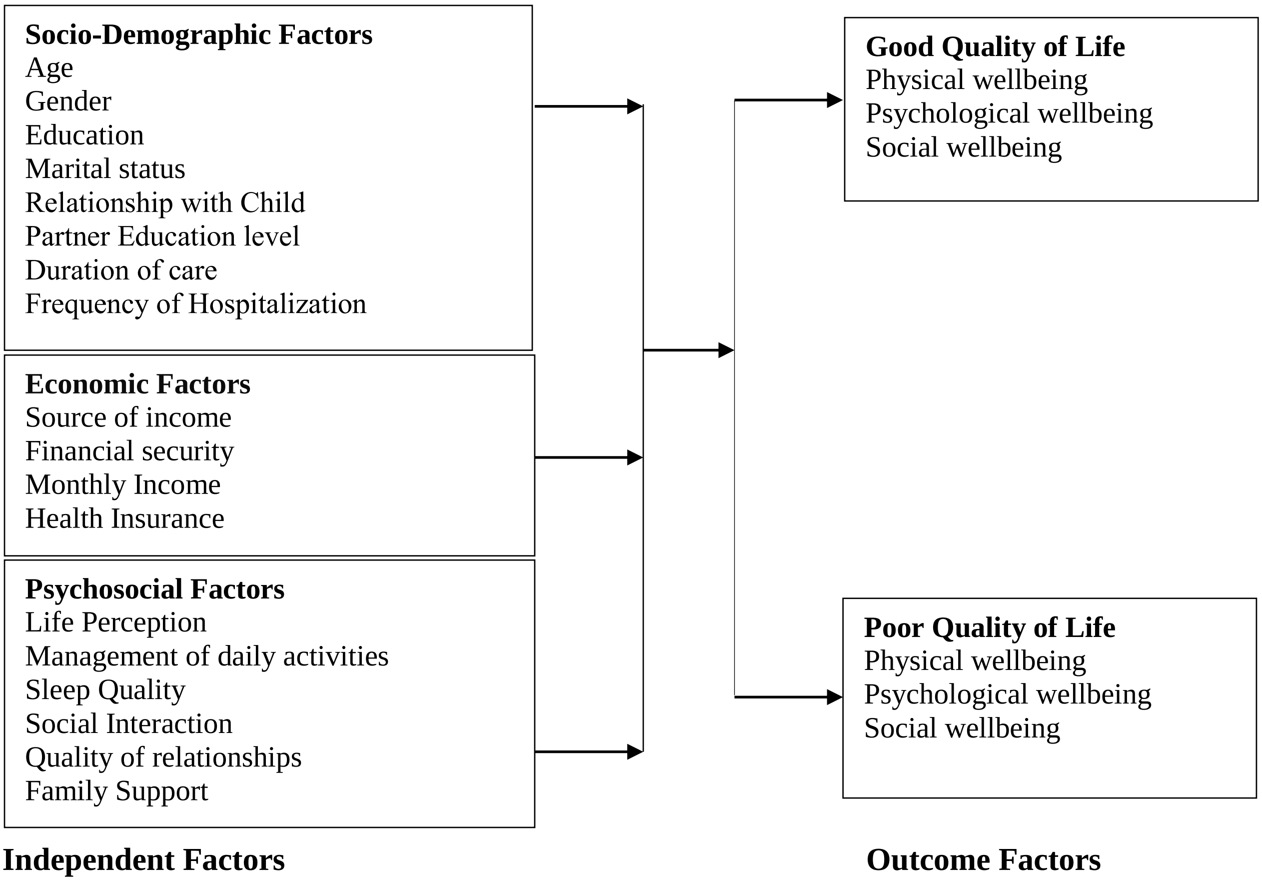


Figure 2: Conceptual Framework

METHODOLOGY

This study adopted a descriptive and analytic cross-sectional study design. According to Kohari (2004) helps researchers to describe the attributes of individuals within a social construct. The population of interest in this study were individuals supporting the care of the individuals suffering from the hematological disease- sickle cell anemia from infancy up to preadolescents and seeking outpatient follow-up care at the Siaya County Referral Hospital in Kenya. Only one respondent was taken per child suffering from SCD. According to the health facility records, the facility had a total of 70 registered clients with Sickle Cell Disease coming to the Pediatric Outpatient Clinic (POPC) every month. The study made use of the Fischer et al. (1990) formula. The total population of patients reviewed for this study was 70. A sample of 60 respondent files were picked as a sample to help answer the study objectives. This study used simple random sampling method. This research study made use of questionnaires for the caregivers of children suffering from SCD and attending the Siaya County Referral Hospital.

FINDINGS

QoL of caregiver of children suffering from SCD

Quality of life was assessed by the use of WHOQOL-BREF which makes use of four domains to provide the profile of Quality of Life. The sum of the domain scores denote or spells out how a person conceives his/her quality of life in each particular domain. A score of 3 and below was regarded as poor quality while a score of 4 and 5 was regarded as good quality life.

Table 1: WHOQOL-BREF Domain scores calculation

Physical domain=	**((6-Q22) + (6-Q23) + Q14 + Q29 + Q30 + Q31 + Q32)**
Psychological domain=	**(Q24 + Q25 + Q26 + Q33 + (6-Q40))**
Social Relationships domain=	**(Q34 + Q35 + Q36)**
Environment domain=	**(Q27 + Q28 + Q15 + Q16 + Q17 + Q37 + Q38 + Q41)**

Association between Socio-demographic factors and Quality of Life

Chi-square test was used to evaluate the association while binary logistic regression was used to determine the magnitude of the association. The results indicated that 64.10% and 80.95% of those aged <=30 years and those aged above 30, respectively, had good quality of life. However, the chi-squared test of association indicated that there was no significant association between age and Quality of life (X^2 (1, N = 60) = 1.8455, p = .174). Moreover, all males and 67.9% of the females had good quality of life. The association between gender and quality of life was also not significant (X^2 (1, N = 60) = 1.8367, p = .175). In evaluating the influence of education on quality of life, 63.9% of those who had at most Primary education and 79.2% of those who had above primary education, had good quality of life. This association was also not significant (X^2 (1, N = 60) = 1.6005, p = .206). While 72.3% of the married reported to be having good quality of life, only 61.5% of the unmarried reported to be having good quality of life. The association between marital status and quality of life was also not significant (X^2 (1, N = 60) = 0.5658, p = .452). 69.1% of the parents and 80% of the grandparents to the children had good quality of life. Relationship with the child was also not associated with quality of life (X^2 (1, N = 60) = 0.2597, p = .610). The duration of care was also not significantly associated with quality of life (X^2 (1, N = 60) = 1.0520, p = .305); 55.6% of those who had at most 6 months of care and 72.6% of those who had more than 6 months of care had good quality of life. Moreover, the association between education level of the participants' partners and quality of life was evaluated. 68.8% of those whose partners had primary level of education and below and 68.6% of those whose partners had above primary education had good quality of life. These differences were not significant (X^2 (1, N = 60) =

0.0002, p = .990). 68.8% of those who had not more than 2 previous hospitalizations and 71.4% of those who had more than 2 previous hospitalizations had good quality of life. The association between frequency of hospitalization and quality of life was significant (X^2 (1, N = 60) = 0.0510, p = .021).

Table 2: Sociodemographic factors affecting Quality of life; Univariate logistic regression results

	Quality of Life n (%)			
Variable	Good	Poor	Odds Ratio (95% CI)	p-value
Age				
30 years and below	17 (80.95)	4 (19.05)	Ref	
>30 yrs	25 (64.10)	14 (35.90)	0.42 (0.12 – 1.50)	0.181
Sex				
Males	4 (100.0)	0	N/A	
Females	38 (67.9)	18 (32.1)	N/A	-
Education				
Primary and below	23 (63.9)	13 (36.1)	Ref	
Above Primary	19 (79.2)	5 (20.8)	2.15 (0.65 – 7.11)	0.211
Marital Status				
Unmarried	8 (61.5)	5 (38.5)	Ref	
Married	34 (72.3)	13 (27.7)	1.63 (0.45 – 5.92)	0.454
Relationship with child				
Parent	38 (69.1)	17 (30.9)	0.56 (0.06 – 5.38)	0.615
Grandparent	4 (80.0)	1 (20.0)	Ref	
Duration of care				
≤ 6 months	5 (55.6)	4 (44.4)	Ref	
> 6 months	37 (72.6)	14 (27.5)	2.11 (0.50 – 9.03)	0.312
Partner education				
Primary and below	11 (68.8)	5 (31.3)	Ref	
Above Primary	24 (68.6)	11 (31.4)	0.99 (0.28 – 3.55)	0.990
Hospitalization frequency				
<= Twice	22 (68.8)	10 (31.3)	Ref	
> twice	20 (71.4)	8 (28.6)	1.14 (0.37 – 3.45)	0.021

The Association Between Economic Factors and Quality of Life of caregivers of children suffering from sickle cell disease

A chi-square test of independence was performed to examine the relation between quality of life and main source of income. The relation between these variables was significant, X^2 (1, N = 60) = 9.3, p = .002. Those employed were associated with 7.35 times higher odds of having good quality of life (OR = 7.35; 95% C.I = (1.84– 29.35); p = 0.005). Moreover, chi-square test of independence was performed to examine the relation between quality of life and financial security. The relation between these variables was also significant, X^2 (1, N = 60) = 7.1, p = .008. Those with financial security were more likely to have good quality of life compared to those without financial security (100% vs 61.7%).

In evaluating the influence of level of monthly income on quality of life, chi-square test of independence was performed. The relation between these variables was also significant, (X^2 (1, N = 60) = 6.6, p = .01). 94.1% of those who had income level of at least 10000 and 60.5% of those who had below 10000 as their monthly income, had good quality of life. Hence those who earned at least Ksh. 10,000 were associated with significantly higher odds of having good quality of life (OR = 10.46; 95% C.I = (1.27 – 86.35)); p = 0.029). While 76.2% of those who had health insurance had good quality of life, 66.7% of those who didn’t have health insurance had good quality of life.

Table 3: Economic factors affecting Quality of life; Univariate logistic regression results

	Quality of Life n (%)			
Variable	Good	Poor	Odds Ratio (95% CI)	p-value
Source of income				
Employed	25 (89.3)	3 (10.7)	7.35 (1.84 – 29.35)	0.005
Unemployed	17 (53.1)	15 (46.9)	Ref	
Financial security				
Yes	13(100.0)	0	N/A	
No	29(61.7)	18(38.3)	N/A	
Monthly income				
<10000	26 (60.5)	17(39.5)	Ref	
>=10000	16 (94.1)	1 (5.9)	10.46 (1.27 – 86.35)	0.029
Health Insurance				
Yes	16(76.2)	5(23.8)	1.60 (0.48 - 5.34)	0.445
No	26(66.7)	13(33.3)	Ref	

The Association Between the Caregiver's Psychosocial Factors and Quality of Life of caregivers of children suffering from sickle cell disease

Table 4 shows the results of the association between the quality of life and the psychosocial factors such as frequent negative feelings, acquisition of new information, relationships, quality of sleep, support from friends and the ability to get around. Chi-square test of association was used to evaluate the presence/absence of association while binary logistic regression was used to determine the magnitude of the association. 100% of those who had frequent negative feelings and 67.7% of those who didn't have frequent negative feelings had good quality of life. The association between experience of negative feelings and quality of life was significant (X^2 (1, N = 60) = 4.5, p = .033).

With regard to ease of acquiring information; 90.5% of those who were able to acquire information easily and 59% of those who were unable to acquire information easily had good quality of life (X^2 (1, N = 60) = 6.5, p = .011). The results of the binary logistic regression indicated that ease of acquiring new information was associated with 6.61 times higher odds of having good quality of life (OR = 6.61; 95% C.I = (1.35 – 32.43); p = 0.020). While 91.4% of those who were satisfied in their relationships had good quality of life, only 40% of those who were not satisfied in such relationships had good quality of life (X^2 (1, N = 60) = 18.37, p <0.001). Hence satisfaction in relationships was associated with 16 times higher odds of having good quality of life (OR = 16; 95% C.I = (3.83 – 66.76); p <0.001).

All the participants who reported to be having quality sleep and 40% who reported not to be having quality sleep had good quality of life (X^2 (1, N = 60) = 25.7, p<0.001). Moreover, 88.9% of those who were able to get support from friends and 61.9% of those who were unable to get such support had good quality of life (X^2 (1, N = 60) = 4.4, p = 0.037). Those who were able to get support from friends were associated with 4.92 times higher odds of having good quality of life (OR = 4.92; 95% C.I = (1.0 – 24.3); p = 0.050).

Ability to get around was also significantly associated with good quality of life (X^2 (1, N = 60) = 13.6, p <0.001). 83.7% of those who were able to get around and 35.3% of those who were unable to get around had good quality of life. Hence, getting around was associated with 9.43 times higher odds of having good quality of life (OR = 9.43; 95% C.I = (2.61 – 34.0); p = 0.001).

Table 4: Psychosocial factors affecting Quality of life; Univariate logistic regression results

	Quality of Life n (%)			
Variable	Good	Poor	Odds Ratio (95% CI)	p-value
Have frequent negative feelings				
Yes	9(100.0)	0	N/A	
No	33(67.7)	18(35.3)	Ref	
Can acquire new information easily				
Yes	19(90.5)	2(9.5)	6.61(1.35 - 32.43)	0.020
No	23(59.0)	16(41.0)	Ref	
Satisfied with relationship				
Yes	32(91.4)	3(8.6)	16(3.83 - 66.76)	<0.001
No	10(40.0)	15(60.0)	Ref	
Have quality sleep				
Yes	30(100.0)	0	N/A	
No	12(40.0)	18(60.0)	Ref	
Get support from friends				
Yes	16(88.9)	2(11.1)	4.92(1.0 - 24.3)	0.05
No	26(61.9)	16(38.1)	Ref	
Get around				
Yes	36(83.7)	7(16.3)	9.43(2.61 - 34.0)	0.001
No	6(35.3)	11(64.7)	Ref	

Multivariate Logistic Regression

In developing the multivariate regression model, all the predictor variables were included in the regression model to predict quality of life. Backward elimination was used to identify the 'best' fit for quality of life. Independent variables were dropped one at a time starting with the ones with the highest p-value. The independent variables that presented collinearity were also dropped in the process. The process was repeated until the highest p-value in the model was <=0.15. The final model had age, source of income, the ability to acquire new information and satisfaction in relationship as significantly associated with good quality of life. Those who were employed were associated with 17 times higher odds of having good quality of life compared to those who were not employed (Adj. OR = 17.74; 95% C.I = (2.49 – 126.46); p = 0.004). In addition, those who were able to acquire new information were associated with 9 times higher odds of having good quality of life compared to those who could not acquire such information (Adj. OR = 9.04; 95% C.I = (1.11 – 73.50); p = 0.040) while those who were satisfied in their relationships were associated with 11 times higher odds of having good quality of life (Adj. OR = 11.66; 95% C.I = (2.08 – 65.19); p = 0.005) when compared to those who were not satisfied.

Table 5: Multivariate logistic regression results: Factors affecting quality of life

	Adj. OR	95% CI	p-value
Age			
<=30 yrs	Ref		
>30 yrs	0.18	0.03 - 1.14	0.069
Source of income			
Employed	17.74	2.49 - 126.46	0.004
Unemployed	Ref		
Ability to acquire new information			
Yes	9.04	1.11 - 73.50	0.040
No	Ref		
Satisfied with relationship			
Yes	11.66	2.08 - 65.19	0.005
No	Ref		

CONCLUSION AND RECOMMENDATIONS

The study's first objective sought to determine existence of a relationship between socio-demographic factors and the Quality of Life of caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya. The study established that gender does not determine the caregivers' quality of life. This suggested that there was no substantial dissimilarity between the male caregiver' quality of life and that of the female gender. The outcome results were in contradiction with the argument by Asante (2012), Adegoke and Abioye-Kuteyi (2012), and (Burnes, Antle, Williams, & Cook, 2018)that women are the most affected by lower QoL scores compared to men. The contrariety in the findings could have resulted from the few sum total population of the male representatives taking part in the current study. A bigger chunk of the participants in this study comprised the female gender. Therefore, the observations from male representatives may have been inadequate to provide significant results.

The findings indicated that frequency of hospitalization impacted negatively on the caregivers' quality of life. This suggested that with high frequency of hospitalization of the sick minor, caregivers' QoL worsens. The findings were supported by Adegoke and Abioye-Kuteyi (2012) who noted that medical expenses towards the SCD child adversely affected provision for the basic needs (nutrition, garments, and shelter) as illustrated by Abraham Maslow to the family and that most of the respondents had to take loans to meet the medical expenses. In addition, Gülendam Karadağ1 (2018) observed that frequent hospitalization made it impossible for the caregivers to offer adequate care to other siblings at home as well as their spouses leading to psychological distress.

The study's second objective aimed at establishing the existence of a relationship between economic factors and Quality of Life of caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya. The findings indicated that employment impacted positively on caregivers' quality of life. The findings were consistent to a study by Carmen Gomez Mandic (2016) who reported an existence of a correlation between employment and the quality of life.

The findings further showed that monthly income impacted positively on caregivers' quality of life. The financial challenges were observed as the biggest contributor of depression and poor quality of living standards among the persons supporting the care of children with SCD in the current study. The respondents who had reported a monthly income less than Kshs. 10,000 (100 USD) are likely to have quality of life below the bar in comparison to individuals who earn more than Kshs. 10,000 (100 USD). The findings concurred with Janet Yarboi (2017) and Wasomwe and Ngoma (2011) observations that caregivers who reported financial challenges encountered melancholy, misery, unhappiness, culpability, worry, apprehension, consternation and blue moods. In addition, Madani, Raddadi, Jaouni, Omer and Al Awa (2018) observed that the need for at-home education and games to the SCD affected child added financial burden to families and approximated the average spending for families with SCD children approximated at 102.5 USD (Kshs. 10,250) in each and every month and for every child or sibling. Similarly, Tunde-Ayinmode (2012) in concurring with this study postulated that the caregivers who were exposed to intense emotional and financial pressure stood a higher chance of acquiring psychological challenges. This similarity in finding could be attributed to that fact that both studies were conducted in developing countries with similar socio-demographic characteristics.

The study's third objective took an aim at determining existence of a relationship between psychosocial factors and QoL of caregivers of children suffering from sickle cell disease at Siaya County Referral Hospital, Kenya. Frequent negative feelings impacted negatively on the caregivers' QoL. The findings received support from Madani et al. (2018) where an observation was made that most psychological disorders emanated from depressions and anxiety. In addition, continuous pressure which resulted into physical exhaustion and stress was also observed by Adegoke & Abioye-Kuteyi (2012). Similarly, Fazlıoğlu, Hocaoğlu and Sönmez (2010) posited that the burden of ensuring continuity of care, treatment compliance, and social support of the patients' attributes to the psychological problems and physical distress of the caregivers. The physical exhaustion and stress that stems from the daily decisions and challenges the caregiver gets in the management of the SCD too contributed to the poor QoL (Jensen, et al., 2017).

The acquisition of new information impacted positively on the caregivers' QoL. Jensen, et al. (2017) observed that a person with self-efficacy could be confident on undertaking caregiving of patients with SCD. The support from friends impacted positively on the caregivers' QoL. These findings were in concurrence with that of Fowora (2016) who demonstrated that social support was significantly correlated to the compliance of the management of various health activities which is said to help alleviate the psychological burden of the caregivers. Similarly, Madani et al. (2018) also supported the findings by positing that the social support plays a vital role in health outcomes both for the patient and the caregiver of the patient. In addition, Mansour Arab (2019) supported the argument that caregivers who received adequate social support experienced better QoL compared to those who did not have.

The study concluded that frequency of hospitalization impacted negatively on the caregivers' QoL. This suggested that with high frequency of hospitalization of the sick child, caregivers' living standard depreciates and worsens. The additionally concludes that employment, financial security and monthly income impacted positively on caregivers' QoL. Further, the study concludes that frequent negative feelings impacted negatively on the caregivers' QoL. In addition, the study concludes that acquisition of new information, support from friends, ability to get around, and quality of sleep impacted positively on the caregivers' QoL. Finally, the study concludes that satisfaction in relationships impacted positively on the caregivers' quality of life.

The following were recommendations on research results, implications on policy, practice, and theory.

- The national and County governments should ensure that those offering support and care to the children afflicted with SCD are provided with employment opportunities.
- The national and County governments should formulate programs aimed at supporting persons taking care or giving social and medical support to children with SCD financially.
- Employers of caregivers of children with SCD should consider raising their monthly income to enable them meet their financial needs.
- Health stakeholders should develop counselling programs aimed at supporting parents or guardians of children with SCD tackle the negative emotions.
- Health stakeholders should formulate and implement programs aimed at educating the father, mother and the guardians of infants, toddlers, preschoolers, school going and adolescents with SCD on matters related to the disease and steps to take towards coping with their situation.
- Caregivers of children with SCD should find time to have rest and have quality sleep since this will enhance their overall quality of life.

Suggestion for Further Research

The study focused on the determinants of the quality of life of caregivers of children with sickle cell disease at Siaya County Referral Hospital, Kenya. Similar studies should be conducted in other counties and countries especially within the East Africa.

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