

# Quality of Life among Caregivers of Persons Living with Sickle Cell Anemia: The Influence of Psychosocial Factors



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## Abstract

Patients and caregivers of patients with sickle cell disease may experience physical and psychological dysfunction in their daily lives. These dysfunctions are not unconnected with the distressing symptoms associated with providing care for the wards. Although several studies have revealed the distress and outcome in terms of reduced quality of life experienced by the persons living with the condition themselves, there appears to be a dearth of research on the role of some psychological and social factors on the quality of life of the care givers. It is against this background that this study examined the influence of psychological capital (hope, resilience, optimism & self-efficacy) on the quality of life of caregivers of persons living with sickle cell anemia in Lagos state, Nigeria. Using a cross-sectional survey design, data were collected from 101 caregivers of sickle cell patients in Lagos state using a convenient sampling technique, (males = 57, females = 44) with a mean age of 34.43 years.

The results showed that there was a significant sex difference in the quality of life experienced by the caregivers, with males reporting higher quality of life than females ( $t = 2.040$ ;  $df = 99$ ;  $p < .05$ ). The results further showed that psychological capital of hope ( $\beta = -.279$ ;  $t = -2.527$ ;  $P < .05$ ) and optimism ( $\beta = -.260$ ;  $t = -2.472$ ;  $P < .05$ ) significantly predicted quality of life independently, while resilience and self-efficacy did not significantly predict quality of life. Lastly it was observed that caregivers from monogamous families reported significantly higher quality of life than their counterparts from polygamous families ( $t = 2.040$ ;  $df = 99$ ;  $p < .05$ ). The results therefore recommended that interventions to boost the quality of life of caregivers of sickle cell patients' should target creating a new life orientation in terms of having an optimistic approach to life no matter the condition alongside refusing to give up hope. Also, it was recommended that attention should focus on female caregivers and caregivers from polygamous families with the aim of improving their quality of life.

**Keywords:** Quality of Life; Sickle cell anemia; Psychosocial factors

## Introduction

Sickle cell disease affects approximately 100,000 Americans and has been established to affect about 1 out of every 365 Blacks or African-American birth, about 1 in 13 Black or African-American babies is born with sickle cell trait (SCT) (WHO, 2014). Sickle cell disease is a genetic blood disorder that affects the haemoglobin within the red blood cells and has been found to cause death among Blacks or African-American children, younger than 4 years of age which fell by 42% from 1999 through 2002 (WHO 2014), this significant drop was because of the advent of vaccine in 2000 that protects against invasive pneumococcal illness in individuals (WHO 2014). Sickle cell has not been given adequate recognition by the Nigerian Government in recent time, despite several non-governmental organizations creating awareness of this illness (Nigerian Medical Association, 2015).

There are insufficient studies out on psychological factors influencing quality of life in patients and caregivers of patients living with sickle cell disease [1]. Most previous studies on the

quality of life of sickle cell patients have neglected the quality of life of the caregivers of these patients [2,3]. The sickle cell disease has a significant implication for the physical and psychological wellbeing among affected individuals; as a result, psychological capitals including self-efficacy, optimism, hope and resilience has been indicated to be importance on the quality of life among people living with sickle cell disease [2].

The concept of quality of life is a multidimensional concept that has called for attention recently from the researchers. Quality of life is the satisfaction of needs that are determined by the perceived discrepancy between one's aspiration and achievements [4]. From the definition, the higher the satisfaction experienced with life, the higher the quality of life among individuals and vice versa. The quality of life in an individual's experience is critical in determining their overall health and wellbeing, and hence, imperative to focus on unravelling psychological capitals influencing of quality of life among individuals. It is also essential

to understand the quality of life of sickle cell patients because there should be new approach aside from the medical approach to understanding this quality of life. [2] reported that besides merely pharmacotherapy, restoration of overall quality of life should be the mainstay of management of patients with sickle cell disease, as well as their caregivers or significant others.

In another study, Barakat, et al. [5] found that physical and psychological functioning significantly diminished in patients of sickle cell disease. Similarly, Ayinmode [6] reported a psychosocial dysfunction in children and caregivers of persons living with sickle cell disease, the psychosocial decline included tension and anxiety among patients' family. This reflects that apart from patients of sickle cell disease, even the quality of life of their caregivers can be affected, as such, quality of life should be given attention to in every treatment process, formulating treatment plans for patients with terminal illness, interventions should aim at improving the quality of life should also be incorporated into the treatment plans. The quest to understand the reasons for the poor quality of life experienced by patients with terminal illness and their caregivers is what informed this current study.

Moreover, Bentsen [7] examined self-efficacy as a predictor of improvement of health status and overall quality of life, results showed that self-efficacy predicted both improvement of health status and overall quality of life. Also, Cramm [8] reported that general self-efficacy influenced the quality of life of patients with multiple sclerosis. Similarly, Haugland [9] examined the association between self-efficacy and social-support on the quality of life of cancer patients and caregivers, and findings showed that self-efficacy influenced the quality of life of cancer patients and caregivers. These findings from literature therefore suggest the need to examine more roles self-efficacy play in the overall physical and psychological wellbeing of individuals.

Furthermore, optimism as another concept of psychological capital affiliated with positive potentials within individuals, having a positive feeling about life is essential in facilitating recovery from ill health and in maintaining a good health. In Mazanec [10], it was reported that patients who had positive feelings about their lives were willing to adopt healthy lifestyle to keep them healthy after diagnosed with cancer. Additionally, Conversano [11] documented optimism and its impact on mental and physical wellbeing and reported that optimism had significant impacts on overall mental and physical wellbeing. Equally, in Vilhena's [12] study among Portuguese patients diagnosed with chronic disease, it was reported that optimism played a significant role in the quality of life experienced.

Among Chinese sample, optimism showed a significant influence on quality of life among cancer patients [13,14], optimism contributed significantly to the quality of life in family caregivers. This suggests a new dimension for approaching chronic disease among patients and its impact on the family and their caregivers. In addition, Jafari [15] reported that hope which is positive emotions in cancer patients enhanced their adherence

to medications and recovery. Likewise, hope as a psychological factor affects quality of life in patients with psoriasis [16] and played a significant role in the quality of life experienced in the family [17].

In the same way, resilience as the process of adapting well in the face of adversity, trauma, tragedy, threats, or significant sources of stress (American Psychological Association, 2014), has been found to significantly determines quality of life [18], positively associated with quality of life among Chinese cancer patients and their families Li, Yang, Liu & Wang, 2016. Resilience significantly predict quality of life among Pakistan outpatients with heart disease [19], caregivers of patients with posttraumatic stress disorder [20], among dementia caregivers in Latin America [21] resilience and demographic information was also found to significantly influence quality of life among caregivers in Iranian sample [22], with males reported significant higher quality of life compare with females [23].

Following the above literature review on psychological capital (hope, resilience, self-efficacy and optimism) as a predictor of quality of life, numerous gaps have being identified from literature such fewer or no published studies has been done on the influence of psychological capital (self-efficacy, hope, resilience and optimism) on quality of life using Nigerian sample, this propel the researcher to further embark on this present study and thus form a platform upon which this current study can continue from. This study would provide a pathway for understanding the quality of life experienced by caregivers of patients with sickle cell disease. Findings from this study would form the bedrock for the psycho-education of caregivers of sickle cell disease patients. This study would also enlighten healthcare professionals in managing patients with sickle cell disease. As a result of this study, caregivers of sickle cell disease patients would be included in the treatment approach.

Hence, the following research questions were derived from the literature review and on the focus of this current study would be answered: Are there gender differences in the quality of life reported among caregivers of sickle cell patients? Do self-efficacy, optimism, resilience and hope have significant joint and independent influence on quality of life among caregivers of sickle cell patients? Do socio-demographic information (age, religion, educational level, and marital status) have significant joint and independent influence on quality of life among caregivers of sickle cell patients? The purpose of this study would be to answer the aforementioned research question. In doing this, following hypotheses were formulated and tested:

- a) Self-efficacy, optimism, resilience and hope will have a significant joint and independent influence on quality of life among caregivers of sickle cell patients.
- b) Socio-demographic information (age, ethnicity, religion, family background, educational level, and family size) will have a significant joint and independent influence on quality of life among caregivers of sickle cell patients.

c) Male caregivers will be higher on quality of life than their female counterparts.

d) Caregivers from monogamous background will be higher on Quality of Life than their polygamous counterpart.

## Methods

### d.1. Design

A Survey Cross-sectional research design and a purposive sampling technique was adopted in this study, because the researcher aimed investigate the influence of psychological capital (hope, resilience, self-efficacy and optimism) on quality of life among caregivers of sickle cell patients.

### d.2. Setting

The study was carried out in two different private hospitals in Lagos state, Oshodi-isolo local government area namely G.O Private Hospital Ikeja and Pinecrest Private Hospital Mafoluku, airport road Oshodi Lagos. These hospitals are government approved primary health care centres that provide general medical services to their clients. They also provided specialized services in the area of sickle cell anemia for persons with the condition.

### d.3. Participants

A total of 101 participants were involved in the study. Participants age ranged between 18 and 56 with a mean of ( $x = 34.3$ ;  $SD = 8.5$ ). On gender, 44 (43.6%) of the participants were males, 57 (56.4%) were females. On religion, 58 (57.4%) were christians, 40 (39.6%) were Muslims, and 3 (3%) belong to the traditional religion. On ethnicity, 35 (34.7%) were of the Igbo extraction, 23 (22.8) were Yorubas, 6 (5.9%) were Hausa, and the remaining 37 (36.6%) belong to other tribes. On educational qualification, 10(9.9%) were primary school certificate holders, 26 (25.7%) were SSCE certificate holders, 57 (56.4%) were B.Sc/HND/NCE certificate holders, and 7 (6.9%) were M.Sc certificate holder, and 1 (1%) holds Ph.D certificate. On family structure, 59 (58.4%) came from a monogamous background, and 42 (41.6%) came from a polygamous background. On family size, 28 (27.7%) belong to one family size background, 14(13.9%) belong to two family size background, 16(15.8%) belong to three family size background, 20(19.8%) belong to four family size background, 11(10.9%) belong to five family size background, and 12(11.9%) belong to six family size background. Only caregivers of patients living with sickle cell anemia participated in the study.

## Research Instruments

A structured questionnaire was adopted in this study which comprised six sections:

**Section A:** Demographic profile of the participants which are gender, age, religion, family background, educational level, marital status, ethnicity and family size.

### Section B

**Hope Scale:** The adult trait hope scale by Snyder, Harris, Anderson, Holleran, Irving, Sigmon, Yoshinobu, Gibb, Langelle,

and Harney [24] was used to measure the hope level of the participants in this study. The scale consists of 12 items and was on 8-point likert response format. High scores indicated high hope, while low scores indicated low hope. Snyder et al. [24] reported a good internal consistency of 0.88 for the scale using Cronbach's alpha, while in this study, Cronbach's alpha of 0.98 was established.

### Section C

**Resilience scale:** The resilience scale developed by [25] was adopted to measure resilience of the participants. The scale consisted of 12 items and was on a 5-point Likert response format. High scores meant high resilience while low scores meant low resilience. Nicholson reported a good internal consistency of 0.75 for the scale using Cronbach's alpha. In this study, Cronbach's alpha of 0.87 was derived.

### Section D

**Self-efficacy scale:** The general self-efficacy scale developed by Schwarzer and Jerusalem (1995) was used to measure the self-efficacy level of participants. The scale consisted 10 items and was on a 4-point Likert response format. High scores meant high self-efficacy and low scores meant low self-efficacy. The author reported a good internal consistency of 0.92 for the scale using Cronbach's alpha, while 0.95 was reported in this study.

### Section E

**Optimism scale:** The optimism scale developed by Scheler and Carver (1985) was used to measure the optimism level of participants. The scale consisted of 10 items and was on a 5-point likert response format. High scores meant high optimism and low scores meant low optimism. Scheler and Carver (1985) reported a good internal consistency of 0.83 for the scale using Cronbach's alpha and 0.80 Cronbach's alpha was found in this study.

### Section F

**Quality of Life Scale:** The SF-12, a multipurpose short form survey with 12 questions, all selected from the SF-36 health survey developed by Ware, Kosinski, and Keller (1996) was used to measure the quality of life of participants. The scale provided a glimpse into the mental and physical functioning and health related quality of life by asking participants to indicate their extent of satisfaction with different areas of their lives. Ware, Kosinski, and Keller (1996) reported a reliability of 0.92 using Cronbach's alpha. In this study, 0.85 Cronbach's alpha was reported.

## Procedure

Upon the arrival of the researcher to the research setting, the letter of introduction and research proposal were presented to the hospital management seeking permission to undertake the study. Approval was granted after two weeks by the hospital management. Participant for the study were selected using accidental sampling technique. Selected participants from the research settings were informed on the research purpose of the study in order to gain their informed consent and enabling atmosphere for administration of the questionnaire. Participants

were also instructed on how to respond to the questionnaire and then given a copy to respond to. After two weeks of administration, 101 questionnaires were satisfactorily filled and were collated for statistical analysis.

**Statistical Analysis**

Data collected in the study were analysed using Statistical Packages for Social Sciences (SPSS) version 20. Multiple regression analysis was used for hypothesis one and two, while independent sample t-test analysis was used for hypothesis three and four.

**Results**

The results where is presented in line with the stated hypothesis. Hypothesis one stated that there will be significant joint and individual influence of hope, self-efficacy, resilience, and optimism on quality of Life among caregivers of sickle cell patients. This hypothesis was tested using multiple regression analysis. Table 1 presents the results.

**Table 1:** Summary table of multiple regression analysis showing the prediction of hope, self-efficacy, resilience, and optimism on quality of Life among caregivers of sickle cell patients.

| Variables     | R     | R <sup>2</sup> | F     | P     | β      | t      | Sig   |
|---------------|-------|----------------|-------|-------|--------|--------|-------|
| Hope          |       |                |       |       | -0.279 | -2.527 | p<.05 |
| Resilience    | 0.334 | 0.111          | 3.007 | p<.05 | 0.001  | 0.011  | p>.05 |
| Self-Efficacy |       |                |       |       | -0.077 | -0.708 | p>.05 |
| Optimism      |       |                |       |       | -0.26  | -2.472 | p<.05 |

Table 1 showed that there was a significant joint influence of hope, self-efficacy, resilience, and optimism on quality of Life of sickle cell caregivers (R<sup>2</sup>= .111, F (4, 96) = 3.007, p<.05) with 11.1% explanation of the variability on the quality of life. Hope (β= -.279; t= -2.527; P<.05) and optimism (β=-.260; t=-2.472; P<.05) had a significant independent prediction on quality of life of sickle cell caregivers. That is, per unit change in hope of the caregiver showed about 27.9% impact on their quality of life and also, per unit change in optimism showed an amount 26% impact on quality of life of caregivers living of sickle cell patients. However, resilience (β=.001; t=.011; P=>.05) and self efficacy (β=-.077; t=-.708; P>.05) did not independently predict quality of life. Therefore, hypothesis one is partially confirmed. The second hypothesis stated that socio-demographic information (age, ethnicity, religion, family background, educational level, and family size) will jointly and individually predict quality of life among caregivers of sickle cell patients. This hypothesis was tested using multiple regression analysis. Table 2 presents the results.

Table 2 showed that there was a significant joint influence of age, educational level, religion, and family size on quality of life of sickle cell caregivers (R<sup>2</sup>= .092, F (4, 96) = 2.440, p<.05) with 9.2% explanation of the variability on their quality of life. Also, religion (β= -.199; t= -1.982; P=<.05) and family size (β=.233; t=2.354; P=<.05) had a significant independent influence on quality of life of sickle cell caregivers. However, age (β=-.101; t=-1.022; P>.05) educational level (β=-.028; t=-.288; P>.05) did

not independently predict quality of life of sickle cell caregivers. Therefore, hypothesis two is partially accepted.

**Table 2:** Summary table of multiple regression analysis showing the prediction of socio-demographic information (age, ethnicity, religion, family background, educational level, and family size) will jointly and individually predict Quality of Life among caregivers of sickle cell patients.

| Variables              | R     | R <sup>2</sup> | F    | P     | β      | T      | Sig   |
|------------------------|-------|----------------|------|-------|--------|--------|-------|
| Age                    |       |                |      |       | -0.101 | -1.022 | p>.05 |
| Education-<br>al Level |       |                |      |       | -0.028 | -0.288 | p>.05 |
| Religion               | 0.304 | 0.092          | 2.44 | P<.05 | -0.199 | -1.982 | p<.05 |
| Family size            |       |                |      |       | 0.233  | 2.354  | p<.05 |

Hypothesis three stated that male caregivers will be higher on quality of life than their female counterpart. This hypothesis was tested using t-test of independent analysis. Table 3 presents the results from table 3 showed that there was a significant difference between male caregivers and female caregivers on quality of life (t= 2.040; df = 99; p<.05). A further observation of means however reveals that male caregivers (=32.2; SD=5.4) reported better quality of life than female caregivers (=30.1; SD=4.9). Consequently, hypothesis one is confirmed.

**Table 3:** Summary showing the difference between male and female caregivers on quality of life.

| Gender of the Caregivers | N  | Mean | SD  | df | T    | Sig   |
|--------------------------|----|------|-----|----|------|-------|
| Male                     | 44 | 32.2 | 5.4 | 99 | 2.04 | p<.05 |
| Female                   | 57 | 30.1 | 4.9 |    |      |       |

Additionally, hypothesis four stated that caregivers from monogamous background will be higher on Quality of Life than their polygamous counterpart. This hypothesis was tested using t-test of independent analysis. Table 4 presents the results. Results from table 4 showed that there was a significant difference between caregivers from monogamous background and caregivers from polygamous background on quality of life (t= 2.040; df = 99; p<.05). A further observation of means however reveal that caregivers from monogamous family background (=31.9; SD=5.4) reported better quality of life than female caregivers from polygamous family background (=29.8; SD=4.7). Therefore, hypothesis four is confirmed.

**Table 4:** Summary showing the difference between caregivers from monogamous background and caregivers from polygamous background on Quality of Life.

| Family background | N  | Mean | SD  | df | T    | Sig   |
|-------------------|----|------|-----|----|------|-------|
| Monogamous        | 59 | 31.9 | 5.4 | 99 | 2.04 | p<.05 |
| Polygamous        | 42 | 29.8 | 4.7 |    |      |       |

**Discussion**

This study examined the influence of psychological capital on quality of life among caregivers of persons living with sickle cell anemia. Four hypotheses were formulated and tested; two were partially supported and two were fully confirmed. The first hypothesis was partially supported as hope and optimism independently contributed to the influence and prediction of

sickle cell caregivers' quality of life while resilience and self-efficacy did not independently influence quality of life among sickle cell caregivers. However, there was a joint influence of psychological capital (hope, resilience, self-efficacy and optimism) on quality of life among sickle cell caregivers. These findings indicated that psychological capital (hope, resilience, self-efficacy and optimism) importantly contributed to the quality of life of sickle cell caregivers this supported the findings of [2,13,14,26] that psychological capitals including self-efficacy, optimism, hope and resilience has been indicated to be importance and influencing factors on the quality of life among people living with sickle cell disease and their caregivers.

Specifically, hope independently influence quality of life of caregivers of person with sickle cell. This result consistent with [15] who reported that hope enhanced adherence to medications, recovery and quality of life, also in line with the findings of [16,17] that hope as a psychological factor affects quality of life and played a significant role in the quality of life experienced in the family of person's living sickle cell. Additionally, optimism contributed to the quality of life of sickle cell caregivers, better optimistic indicates quality of life of the caregivers.

This outcome confirmed Conversano (2010)'s study conclusion that optimism significantly impacts mental and physical wellbeing, similarly, the results consistent with [13,14], that optimism contributed significantly to the quality of life in family caregivers. Thus, the non-independent significant of self-efficacy and resilience on quality of life negated the findings of [19] who reported significant independent influence of self-efficacy and resilience on quality of life. This invariance may be as result of that these factors (self-efficacy and resilience) tends toward individual characteristics which differs from one individual to another, and this may some consequences and implications regarding their quality of life.

Furthermore, the second hypothesis was also partly supported; the findings showed that religion and family size independently predict quality of life and religion, family size, age, and educational level jointly predict quality of life among caregivers of sickle cell patients. This finding supported [22] who discovered that socio-demographic information was also found to significantly influence quality of life among caregivers.

Similarly, hypothesis three was confirmed as gender differences significantly influence quality of life with male caregivers' significantly better in their quality of life than female caregivers. This result supported Rosenberg et al. [23] findings who discovered that male caregivers significantly scored on quality of life than female caregivers. Moreover, fourth hypothesis was fully supported as caregivers from monogamous background significantly higher on quality of life than their polygamous counterpart. The findings consistent with [22] study outcome that who discovered that socio-demographic information including differences including family background significantly influence quality of life among caregiver's family.

### Conclusion

This study examined the influence of psychological capital on quality of life among caregivers of persons living with sickle cell anemia. Four hypotheses were formulated and tested; two were partially supported and two were fully confirmed. This study established that hope, self-efficacy, resilience, and optimism jointly influence quality of life among caregivers of sickle cell patients; and specially, optimism and hope independently influence quality of life while self-efficacy and resilience did not independently influence quality of life among caregivers of sickle cell patients [27-30]. Also, socio-demographic profile (age, ethnicity, religion, family background, educational level, and family size) jointly while religion and family size independently predict quality of life among caregivers of sickle cell patients. Additionally, gender differences significantly contributed to quality of life, while male caregivers significantly higher on quality of life than female caregivers of sickle cell patients. Moreover, family background of the caregiver significantly important on their quality of life, with caregivers form monogamous family background significantly better on quality of life than care givers form polygamous family [31-40].

### Implication of Findings

One implication of this study is that Nigerian society emphasizes gender roles, these different roles might contribute to the quality of life experienced by the different gender, and therefore gender of caregivers may be an important consideration when trying to improve the quality of life of caregivers. Another implication from this study is that, socio-demographic factors such as religion and family background, family size significantly influence quality of life of caregivers of persons living with sickle cell disease [41-45]. This means that religious affiliation and religious faith, numbers of siblings in a family, support from relatives and family ties contributes to quality of life of caregivers of persons living with sickle cell disease and as such these socio-demographic profiles should importantly considered when trying to boost the quality of life level of caregivers of persons living with sickle cell disease. Furthermore, the joint significant of optimism, self-efficacy, resilience and hope on quality of life indicates the important of psychological capital on quality of life and psychological wellbeing of caregivers of person living sickle cell [45-59].

### Limitations of Study

This study is a cross sectional study which was not under controlled environment, therefore caution must be taken in generalizing the results. Also, this study was restricted to caregiver in Lagos state setting. Future studies should therefore ensure that it cut across wider settings.

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