

## INFLUENCE OF HEALTH-RELATED QUALITY OF LIFE ON COPING STRATEGIES AMONG PERSONS LIVING WITH SICKLE CELL DISORDER IN NIGERIA

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### ABSTRACT

Sickle cell disorder (SCD) has been identified as a monogenetic disease that is lifelong and characterized by recurrent ill-health, progressive organ damage, and shortened life-span. SCD has been shown to be related to health-related quality of life and as such, it is assumed that knowledge about its influence on coping strategies among people living with the disorder may be beneficial in planning therapeutic strategies that would assure coping rather than just pain alleviation. This research, thus, examined the influence of health-related quality of life on coping strategies among persons living with sickle cell disorder. Cross-sectional survey research design was adopted for this study and the purposive sampling method was used to engage a total of 74 SCD patients in a sickle cell centre in Nigeria in this study. Copies of a questionnaire comprising of Short Form 12 items Health Survey Questionnaire (SF-12) was used to evaluate health related quality of life while coping strategies was measured using the Brief COPE scale which was developed by Carver (1997). Participants for the study comprised of 39(52.7%) females while 35(47.3%) were males. Participants age ranges from 16 to 63 and their mean age is 34.02 years. Result of data analysis using the independent samples' t-test showed that health related quality of life had significant influence on adaptive coping strategy [ $t(72) = 3.52; P < .05$ ]. However, health related quality of life had no significant influence on maladaptive coping strategy [ $t(72) = 1.73; P > .05$ ]. It is concluded that people living with SCD should always be encouraged to be optimistic and positive in their thoughts so that they could employ adaptive coping strategy which would, in-turn, help them to adapt and adjust better with the challenges that accompany their health condition. Also, therapeutic interventions for SCD patients should consider humor and religious beliefs in developing cognitive re-orientation strategies for the patients.

**Keywords:** Coping Strategies, Sickle Cell Disorder, Health Related Quality of Life, Sickle Cell Patients, Nigeria.

### INTRODUCTION

One of the issues that border on health and quality of life may be whether the various treatments being used in any way help relief the burdens of ill-health. Thus, the evaluation of quality of life puts patients at the centre of inquiry and gives due weight to their opinion, according to Berlim and Fleck (2003). In their own submission too, Akinbami, Kalejaiye, Ebele Uche et. al. (2021) submitted that the care for health-related quality of life is generally poor in sickle cell disorder patients in Nigeria and this calls for serious concern among professional human helpers in general.

Health related quality of life has been defined as an individual's or group's perceived physical and mental health over time. And to manage the perceived mental and physical health, coping strategies are required. Ahmed, Rana, et. al. (2022) for example posit that coping methods are emotion-driven efforts which are geared towards handling stress that has a link to improved mental and physical health. Improved mental and physical health are necessary components of health-related quality of life. It suffices therefore to posit that the perceived mental and physical health of individuals will have implications for the methods of coping with stress that accompany their health conditions.

The Monitoring and Blunting Theory (Miller 1980, 1987) serves as the theoretical foundation for present study. This theory posits that a person can reduce the impact of a stressful life event or



situation by using his or her cognitive processes. The cognitive processes of coping with stressful situations in the theory are labelled as Monitoring and Blunting. The monitoring strategies include emotional management, and information processing which help to deal with the stress and the associating anxieties. The blunting strategies include denial and distraction which help to overlook or ignore the stressors. This theory therefore implies that in coping with their health conditions, persons living with SCD could employ any of the cognitive processes which can either be adaptive or maladaptive.

Sickle cell disorder (SCD) is by far the commonest inherited disorder in the world (WHO, 2006). It is identified as a monogenetic disease that is lifelong and characterized by recurrent ill-health, progressive organ damage, and shortened life span. It is also said to have a carrier prevalent rate of 25 percent in Nigeria (Adewoyin, Alagbe, Adedokun, and Idubor, 2015). It is believed that the high prevalence of undiagnosed non-communicable diseases, as SCD, contribute to excess mortality in children under five years. Some scholars (e.g., Piel, Hay, Gupta, et. al., 2013, Odame, 2014, Tisholo, Kafando, Sawadogo, et. al., 2008, and Kadima, Mukanyangezi and Uwizeye, 2014) have also argued that nearly 90 percent of the world's SCD population lives in three countries: Nigeria, India, and the Democratic Republic of Congo, where, according to them, the disease affects up to 3 percent of the population, and the carrier prevalence rate (sickle cell trait) is as high as 10 to 30 percent. In Nigeria alone, estimate shows that at least 150,000 newborns are born with SCD annually.

Although estimates are challenging because of the lack of federal newborn screening programs; however, approximately 700,000 births occur per year and the prevalence of SCD in newborns was 3 percent in a regional newborn screening program (UNICEF, 2015).

It has been argued that the developed countries have much fewer numbers of people with SCD. They also have access to more advanced treatments and prenatal screening programs (Weatherall 2008). In Nigeria, where it is said to affect about three out of every hundred children born, it causes suffering for innumerable patients and their families; as such, the disorder is yet regarded as a phenomenon in Nigeria (National Sickle Cell Foundation, 2020, Adewoyin, 2015, Ebele Uche, Olowoselu, Augustine et. al., 2017). Ojelabi, Graham, Haighton et. al. (2018) observed a high morbidity and mortality rate and increasing comorbid complications with advancing age and poor quality of life in Nigeria and submitted that the natural geographical distribution of sickle cell trait mirrors that of endemic malaria.

People living with sickle cell who escape death as infants need care to lead healthy and productive lives (Okumdi & Victor, 2013) and one of the ways to live healthier is to be able to cope with the health condition.

Coping helps to decrease the potential negative impact or outcome of a life challenge. Thus, proper coping on the part of SCD individuals will help decrease the impact of the disease. More so, coping strategies to stressful events has become a popular and critical concept in contemporary psychology, and can be expressed in various ways.

According to Blum, Brow and Silver (2012), coping is defined as the ongoing behavioral, cognitive, and emotional processes people use to manage those life circumstances that threaten feelings of stability.

An important conceptualization of coping is that of engagement or approach coping (also termed adaptive coping), where the intent is dealing with the stressor(s) or related emotions, versus disengagement or avoidance coping (also termed maladaptive coping), which is aimed at escaping the stressor(s) or related emotions (Moos & Schaefer, 1993; Roth & Cohen, 1986). Adaptive stress-coping include several strategies: religion (finding comfort in spiritual beliefs/praying); active coping (putting in decisive efforts on doing something about the situation/taking action to try to make it better); planning (to strategize on what to do/thinking seriously about what steps to take); acceptance (taking the reality that has happened as it is/learning to live with it); positive reframing (viewing the situation from a different perspective, i.e look for something good in it); instrumental support (is getting help and advice from other



people/trying to get advice or help from others about what to do); emotional support (getting empathy, support/comfort and understanding); and humor (making jokes about the situation/making fun of it). Maladaptive stress-coping include several strategies: behavioral disengagement (to quit attempting to cope with the situation); denial (saying to oneself "this situation is not real"/refusing to believe that the event has occurred); self-distraction (occupying oneself with work or other activities so as to take the mind off the situation i.e doing something in order to think less about it); self-blame (blaming oneself for the events that occurred); substance use (is using alcohol or other drugs to help me feel better about the situation); and venting (saying things to express unpleasant/negative feelings).

Similarly, Zimmer-Gembeck and Skinner (2016) defined coping as an adaptive process that is integral to functioning and development. At its most general, coping depicts how people detect, appraise, deal with, and learn from actual and anticipated stressful encounters. Summarily, coping has to do with the ability to self-regulate in response to different experienced stressors. Folkman and Moskowitz (2004), and Koenig (2001) have found that the ability to use an array of adaptive, rather than maladaptive, coping strategies can promote emotional well-being

As already noted, patients in developed countries with better access to advanced treatments are said to have substantially improved life expectancy and quality of life.

In view of the above therefore, the present study hypothesized that the health-related quality of life of sickle cell disordered patients in Nigeria will be a significant factor influencing their choice of coping strategies (i.e. sickle cell disordered patients who are high in their HRQoL will significantly adopt adaptive coping strategy than their counterparts who are low in their HRQoL). It is believed that results from the study can be useful in assisting SCD patients to cope with their health conditions by planning interventions and therapies that would assist them.

## METHODS

### Research Design:

The design adopted in this study is a cross-sectional survey research design. The study was conducted in a selected sickle cell centre in Lagos (National Sickle Cell Centre, Lagos).

### Sample and Sampling Method:

The purposive sampling technique was adopted for the study. The method of sampling was adopted because the study set out to study sickle cell disorder (SCD) patients who are known to be affected by HRQoL

Sample size was determined using Yamane (1967) formula with 95% confidence level; where

$$n = \frac{N}{1 + N(e)^2}$$

where n denotes sample size

N stands for the population of participants under study, and

e stands for the margin of error.

With the above formula used, a sample size of 74 participants was arrived at and used in the study.

### Participants:

Participants for the study are Sickle Cell Disorder patients who were found at the National Sickle Cell centre in Lagos. It was from the population of these patients that the sample who participated

in the current study was drawn. Those involved in the study are 39 females and 35 males. 57 of the participants are Christians, 16 are Muslims while 1 belong to other religion. Participants ages range from 16 to 63 and their mean age is found to be 34.02 years.

### **Variables of Study:**

The study made use of an independent variable (Health related quality of life) and a dependent variable (Coping strategies) among patients with Sickle Cell Disorder.

### **Procedure for data collection:**

The researchers obtained ethical approval for the study from the Social Sciences and Humanities Research Ethics Committee (SSHE) of the University of Ibadan, Nigeria. This was presented alongside with a letter of introduction from the institution at the National Sickle Cell Foundation, Lagos. The researchers were then introduced to the sickle cell club coordinator (the club is an association for the registered members of the foundation). Through the help and directive of the club coordinator, the researchers met and interacted with the participants during their club meetings. Firstly, the purpose of research was made known to participants, and then a consent statement was issued to the participants. Those who gave consent went ahead to fill the copies of a questionnaire used to measure variables of our study. Completed questionnaires were returned to the researcher and participants were given a token for their time.

### **Measures:**

The Short Form 12 items Health Survey questionnaire (SF-12) was used to evaluate Health Related Quality of Life (HRQoL). This is a 12 items questionnaire (an abridged version of SF-36) developed by Ware, Kosinski, & Keller (1993), used to measure the HRQoL of participants. The measure assesses eight domains that include General Health (GH), Physical Function (PF), Role Limitation Due to Physical Function (RP), Bodily Pain (BP), Mental Health (MH), and Role Limitation Due to Emotional Health (RE), Social Function (SF) and Vitality (VT). The authors reported that the domains are divided into two broad components – physical component summary (PCS) and mental component summary (MCS) scores (Steiner, Pierce, Drahuschak, Nofziger, Buchman, et al. 2008). PCS consist of GH, PF, RP and BP domains while MCS consist of MH, RE, SF and VT domains. Each of SF-12 (QoL) domains, PCS and MCS summary and overall scores ranges from 0-50 for each domain, with a higher score than the mean score indicating a better health status. The scale is scored by first cleaning out of range values for item response choices and reverse scoring four items so that a higher score indicates better health. Indicator variables (scored 1/0) are created for the item response choice categories and are weighted, aggregated, and by adding a constant, according to Ware, Kosinski, and Keller (1995). Huo, Guo, Shenkman & Muller (2018) reported in their study that the 12-items Health Survey questionnaire is suitable and reliable for measuring HRQoL among persons with chronic health conditions. The instrument has internal consistency reliability coefficients (Cronbach's Alpha) for each component. Cronbach's Alpha value ranges from .63 to .70.

Coping was measured using Brief COPE scale which was developed by Carver 1997. Participants using the inventory score themselves from 1 to 4 with 1 being '*I haven't been doing this at all*' and 4 being '*I've been doing this a lot*'. The scale has an internal consistency of ( $\alpha \geq 0.70$ ). The brief COPE scale is a 28-item self-report measure of adaptive versus maladaptive coping skills. Maladaptive coping includes self-distraction, denial, venting negative emotion, substance use, behavioral disengagement, and self-blame. The Maladaptive Coping subscale comprises 12 items with a possible range of 0 to 36 points, such that higher scores indicate greater use of maladaptive coping skill. Adaptive coping skills include active coping, planning, positive reframing,

acceptance, humor, religion, using emotional support, and using instrumental support. The adaptive coping subscale consist of 16 items with a possible range of 0 to 48 points, such that higher scores indicate greater use of adaptive coping.

### Method of Statistical Analysis:

The hypothesis generated for the study was tested using the independent samples' t-test. The SPSS package for statistical analysis (version 20) was used in analyzing the data.

## RESULTS

The results obtained after data analysis are presented as follows:

**t-test for Independent Samples Summary Table Showing Results of the Influence of Health-Related Quality of Life on Coping**

Dependent	Quality of life	N	Mean	SD	t	df	p
Adaptive	High	43	45.58	6.63	3.52	72	<.05
	Low	31	38.32	11.07			
Maladaptive	High	43	25.79	6.25	1.73	72	>.05
	Low	31	28.55	7.47			

Results on the table above shows that health related quality of life had no significant influence on maladaptive coping [t (72) = 1.73; P>.05]. However, health related quality of life had significant influence on adaptive coping [t (72) = 3.52; P<.05]. Furthermore, participants with high level of quality of life reported higher on adaptive coping (Mean = 45.58; SD = 6.63) than those with low level of quality of life (Mean = 38.32; SD = 11.07).

## DISCUSSION

This research examined the influence of health-related quality of life on coping strategies among persons living with sickle cell disorder. Results of data analysis showed that health related quality of life had significant influence on adaptive coping strategies. This implies that participants with high level of quality of life adopts adaptive coping strategies than those with low level of quality of life. This result corroborates the findings of Maleknia and Kahrazel (2015), Serrano, Reyes, Marc Eric, de Guzman and Allan (2022) and Holubova, Prasko, Ociskova et al. (2018) on the relationship between HRQoL and coping strategies. Rzeszutek (2018) also found out that health related quality of life does influence coping strategies in her study of people living with HIV and Hossain, Shafin, Ahmed, et. al. (2022) too found that health related quality of life does influence coping strategy in their study among COVID-19 survivors in Bangladesh.

Results from the present study therefore suggests that an improvement in the perceived quality of life of people with SCD will, in turn, lead to their adoption of better coping strategies with their disorder.

### Conclusion:

In line with the findings of this study, it is concluded that people living with SCD should be taught and encouraged to be positive in their thoughts and be optimistic about life to impact their quality



of life. Such would help them to adapt and adjust better with the challenges that accompany their health condition.

**Recommendations:**

This study shows that health related quality of life has significant influence on coping and better adjustment. As such, parents, family relatives, spouses and friends of people who have SCD should be enlightened on the need to physically, socially, and morally support and care for their persons who have sickle cell disorder as social support have been consistently found to be associated with better health, good educational attainments, and better social outcomes.

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