



Self-Esteem and Perceived Stigmatisation as Predictive Factors of Coping Among Individuals Living with Sickle Cell Disease.

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Abstract

Sickle cell disease (SCD) is a genetic disease that is lifelong. Studies indicate that there is a relationship between self-esteem, perceived stigmatization and coping but the influence of these variables on coping among SCD persons is yet to be examined. This research investigated self-esteem and perceived stigmatization as predictors of coping strategies among persons living with sickle cell disease. Cross-sectional survey design was adopted for this study; A total of 74 SCD patients participated in this study; more of the participants were females 39(52.7%) while 35(47.3%) were males. Results indicate that low self-esteem significantly predicted maladaptive coping [$t(72) = 3.66$; $P < .01$], perceived stigmatization significantly predicted maladaptive coping, [$t(72) = 5.72$; $P < .01$] and both self-esteem and perceived stigmatization jointly significantly predicted adaptive coping strategy [$R = .35$; $R^2 = .13$; $F(2, 70) = 5.01$; $P < .05$]. It is concluded that self-esteem and perceived stigmatization significantly predict adaptive coping among persons living with SCD. Also it is recommended that counseling and psycho-education should be regular part of routine treatment for SCD patients so as to help patients identify faulty thoughts that increases perceived stigmatization, improve their self-esteem and in-turn prevent maladaptive coping.

Keywords: adaptive coping, maladaptive coping, perceived stigmatization, self-esteem, sickle cell disorder.

Introduction

Sickle cell disease (SCD) is a genetic disease that is life-long, it is a disorder of hemoglobin with the primary abnormality being distortion of the normal spherical shape of red blood cells into sickle or crescent shapes. It is among top ten non communicable diseases causing significant disability, morbidity and mortality (Alhassan, 2014). Sickle Cell Disease has a global spread and it is a public health concern commonly found in people of African origin. Sub-Saharan Africa has the greatest burden of spread, and this is as a result of not having uniform access to medical care and public health strategies to decrease morbidity and mortality. (Dialo & Tchernia 2002, Odame 2014, Piel & Williams 2017).



Coping has to do with the ability to self-regulate in response to different experienced stressors. According to Blum, Brow and Silver (2012) people must fairly consistently monitor and adjust themselves to the change factor (stressor), or the environment – in order to regain that sense of stability. It is in this sense that coping is emphasized. In other words, coping is a factor that must play out when there is need for proper adjustment. Coping helps to decrease the potential negative impact or outcome of a life challenge. However, coping could be adaptive or maladaptive. Maladaptive coping describes coping responses that reduce the level of fear associated with the stressful event without reducing the danger associated with the situation whereas, Adaptive coping describes coping responses that removes/reduces fear and danger associated with the stressor and lead to reduced anxiety and constructive, healthy psychosocial and physical outcomes for the individual (Giancola et al., 2009). Adaptive coping serves as a protective factor that reduces the adverse effects of life stressors when they occur and that can also reduce the likelihood of stressor occurrence (Folkman & Moskowitz, 2004). In other words, people who use more of adaptive coping strategies, such as problem solving and information seeking, tend to adapt better to life stressors.

More individuals are living with SCD beyond the fourth and fifth decades of their lives, and a growing number of researchers have begun to point out psychological and social factors such as self-esteem, health related quality of life, and perceived stigmatisation that influence coping and well-being among adults (Caird et al., 2011; Mann-Jiles & Morris, 2009).

Also, World Health Organisation (WHO) and United Nations continues to emphasize the need for more researches on SCD especially in countries where there is high prevalence (Nigeria for example) in order to improve the lives of patients and increase knowledge of SCD amongst the indigenous people of such country. This implies that more research will lead to more awareness and consequently reduce the incidence of the disease and also reduce morbidity and mortality of those already affected with SCD (WHO Regional Committee for Africa, 2010).



Findings from a cross-sectional study of adult SCD patients suggests that demographic factors such as age is a significant factor in predicting patients' coping; younger patients were more likely to ignore their pain, while older patients were more likely to employ religious (or hope-based) coping strategies (sanders et al. 2010). Similarly, the study by Jonasaint et al., (2010) also indicates that demographic variables such as education and sex were significant predictors of coping styles among persons with SCD. However, it remains unclear whether psychological variables such as those of interest in this study will influence coping among adults who have SCD.

Although there is a growing literature on self-esteem and perceived stigmatisation but currently at the time of this research the influence of these variables on coping among persons living with sickle cell disease in Nigeria are yet to be investigated. This study is necessitated to bridge this gap in literature. The main purpose of this study is to examine the influence of self-esteem, and perceived stigmatisation on coping among persons living with SCD. The other objectives are:

1. To test whether self-esteem will significantly independently predict coping among individuals with SCD.
2. To test whether perceived stigmatisation will significantly independently predict coping among individuals with SCD.
3. To test whether self-esteem and perceived stigmatization will significantly jointly predict coping among individuals with SCD.

Psychologists of various orientations have described the importance of self-esteem to psychological adjustment. Self-esteem impacts the coping strategy an individual adopts when faced with stress (KammeyerMueller, Judge, & Scott, 2009). Individuals who believe that they can do something about their distress to resolve the problem tend to use a more adaptive coping strategy than people who appraise their situation as beyond their control (Folkman et al., 1986). It is assume that a high level of self-esteem enhances other factors that will help an individual adjust better to situation/challenges. Also, the result of a study by Adejumo (2009) on the influence



of social support, depression and self-esteem showed a significant main effect of self-esteem on care giver's burden. This further illustrates that self-esteem could also go a long way to predict coping too. One important finding of the role of self-esteem is that it helps to buffer individuals from stressors encountered in daily life (Mann et al., 2004). Individuals with higher levels of self-esteem often attempt to change stressful situations because they believe in their capacity to do so. This therefore implies that individuals who are living with chronic illness and report high self-esteem are more likely to overcome the stress which comes with their health condition by using adaptive coping strategy. However, contrary to popular assertion, Baumeister et al. (2003) posits that high self-esteem do not necessarily lead to good performance. Instead, high self-esteem is partly the result of good performance- that is, good performance could be as a result of high self-esteem and other accompanying variables. According to their report, high self-esteem facilitates persistence after failure.

Furthermore, Human behaviour is driven by needs, one of which is the need for a sense of personal importance, value or self-esteem. Maslow (1943) asserted that average adults in organized societies have certain needs (one of which is self-esteem need) under typical conditions. To Maslow, a satisfaction of self-esteem needs generates feelings and attitudes of self-confidence, self-worth, capacity and the feeling of being useful and necessary in the world. The frustration of these needs leads to feelings and attitudes of inferiority, ineptness, Weakness, passivity, and dependency. Maslow noted that if these needs are not met, an individual either becomes deeply discouraged or develops maladjusted methods for coping with challenges and feelings of inferiority and worthlessness.

Researchers increasingly cite stigmatisation as a central concept in chronic illness research (Goffman, 1963; Link & Phelan, 2006; Weiss et al., 2006, Bediako et al., 2016, Adejumo, 2011), findings maintain that it may also be an important consideration for adults coping. Stigmatisation is a concept which lends its use to a wide range of diverse processes that have in common a sense of social rejection (Coker, 2005).



As a social process that typically results in the devaluation and discrediting of an attribute, stigma leaves an individual who possesses that attribute feeling vulnerable to negative evaluations from others (Goffman, 1963). Literature suggests that stigmatisation might contribute to the burden of an illness, cause delays in appropriate help seeking, and result in premature termination of treatment for health problems (Link & Phelan, 2006; Martinez et al., 2012). Jacoby (1994) described Perceived stigma as a subjective belief or anticipation that having the stigmatising condition will lead to discrimination by others. According to Scambler (2004), perceived stigmatisation can have serious disabling consequences due to the tendency by affected individuals to take, sometimes, extra-ordinary measures to conceal their attribute. Even for life threatening diseases, perceived stigmatisation could lead affected individuals to make deliberate and seemingly irrational decision not to seek help (Sadavoy et al 2004). Moreso, perceived stigmatization can lead to irrational thought which exacerbates the suffering of SCD.

Erving Goffman, (1963) theorize that persons who have chronic illness such as SCD tend to internalize the discredit associated with their illness and develop a sense of being stigmatized. Thus, the individual begin to anticipate discrimination from others. Perceived stigmatisation could be so detrimental that even when the stigmatizing attribute is not obvious, the individual still experience psychological distress. The implication is that the individual seeks means to avoid circumstances that brings his illness to the fore; such as putting up avoidance behaviour, denial and self distraction (which are maladaptive strategies). The long term use of maladaptive strategies could lead to more health problems such as depression.

Heatherton and colleagues further opines that even when the stigmatising attribute is not obvious, those who perceive themselves to be stigmatised often experience psychological distress and have a negative view of themselves (Heatherton, et al., 2003). It is as if the affected persons develop a different view of the world and different way of interpreting events and

experiences influenced by possession of the stigmatising attribute Resultant effect of



stigma could lead the affected individuals to sometimes take extra-ordinary measures to conceal their health attribute (Scambler 2004).

In a study by Ong et al., (2016) some coping strategies such as substance use, behavioral disengagement, and venting were found to be positively correlated with psychological distress and, hence, considered to be maladaptive coping strategies; whereas, Positive reframing was negatively correlated with psychological distress. Their study found a relationship between coping strategies and psychological distress but this present research will further establish a predictive association between the variables. Similarly in the study by Ehwarieme et al., (2021) people living with SCD reported using more adaptive coping strategies such as active coping, instrumental support; by way of obtaining advice and information from professionals, religion and emotional support. The result of the analysis indicates that participants who used these coping methods reported improved psychological wellbeing. Also, Anie et al., (2017) investigated the psychosocial aspects of sickle cell disease in the UK and Nigeria participants; it was found that Nigerian participants reported the use of psychological Active Coping strategies more often than their British peers. These coping methods including distraction techniques (e.g., reinterpreting pain sensations i.e, reframing), and increased activity tend to have a positive effect on pain by reducing it. Nigerians also commonly used praying and hoping as a Coping strategy, which seem to be influenced by external factors such as religion, faith in God, superstitions and stigma. In other-words, to cope with pain and other symptoms, Nigerian patients are perhaps more likely to turn to their beliefs than those in the UK.

Nguyen et al. (2019) opined in their work that those who have a higher self-esteem do not tend to put undue focus, self blame, self-doubt or hopelessness on things about themselves they do not really like. They also are better able to cope with situations of stress, anxiety, and pressure in various aspects of their lives. In a similar way, Keane and Loades (2017) found that there is an association between low self-esteem and negative outcomes for young people's behavioural and mental health problems, including health compromising behaviours such as substance abuse



and eating problems. The implication of their finding is that young people whose self-esteem is low tend to put forth behaviours that are detrimental to proper adjustment. There is need to investigate if this kind of influence exists on coping among people who are living with sickle cell disease. Atkin and Ahmad (2001) carried out a qualitative study of 51 young people with SCDs, and they found that those in their mid teens evaded anything that marked them out as different including adherence to their treatment regimes. That is to say that they would rather not adhere to treatment regime than to allow their health condition come to the fore so as to avoid being stigmatized. This kind of scientific results apart from implying that young people use maladaptive means to avoid stigma, it also necessitates finding out how perceived stigma influences coping adaptively with SCD.

This research will be of benefit to Health organizations. The findings of this study may be of help to counselors and health educators of SCD patients. Thus, it will help provide potential guidelines for designing counseling, education and social support interventions to assist individuals with SCD. Also, the research would add to the growing amount of literature investigating into factors that influence coping strategies among people living with SCD. This is imperative in helping SCD affected persons lead more beautiful lives

Method

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). The researchers adopted a purposive sampling technique.

Sample size was drawn using Yamane (1967) formula with 95% confidence level.

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

Procedure



The researchers obtained Ethical approval for the study from the Social Sciences and Humanities Research Ethics Committee (SSHE), this was presented alongside with a letter of introduction from the researcher's institution at the National Sickle Cell Foundation. The researcher was then introduced to the sickle cell club coordinator (the club is an association for the registered members of the foundation). By the help and directive of the club coordinator the researcher 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 in which it was made known to them that all responses given will be treated with utmost confidentiality. Those who gave consent went ahead to fill the questionnaire. Completed questionnaires were returned to the researcher. Participants were given a token for their time.

Self-esteem was assessed with the Rosenberg Self-Esteem Scale (Rosenberg 1965). The scale is reliable and widely used Self-esteem Scale. The scale is a summative 10-item Likert scale with items answered on a four point scale - from strongly agrees to strongly disagree (scored 1-4). Higher scores indicate higher self-esteem (range 10-40). It has an excellent Internal Consistency (Cronbach Alpha 0.86).

Perceived stigmatization was measured using the Stigma in Sickle Cell Disease Scale (Adult Versions) developed by Leger, Wagner, & Odesina (2018) The scale contain item such as "People believe that a person with SCD is lying about their pain" followed by a choice on a four level likert format (not at all; rarely; sometimes; and often). The potential scores for the scales range from 0 to 120. The scale has a chronbach alpha of .858

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** which include 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, such that higher scores indicate greater use of maladaptive coping. **Adaptive coping** which 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, such that higher scores indicate greater use of adaptive coping.

Data Analysis

Descriptive and inferential statistics were used for the analysis of the data collected. Demographic factors were analyzed using simple frequencies and percentages. The hypotheses stated were tested using T test for independent means and multiple regression analysis. All analyses were carried out using Statistical Package for Social Sciences (SPSS) version 21.0 at 0.05 level of significance.

Results

The results obtained after data analysis are presented in tables as follows:

Hypothesis one which states that participants with high level of self-esteem will significantly report higher on adaptive coping and lower on maladaptive coping compared to those with low level of self-esteem was tested using t-test for independent samples and the result is presented on Table 1;

Hypothesis One

Table 1: t-test for Independent Samples Summary Table Showing Results on the Influence of Self-Esteem on Coping

Dependent	Self-esteem	N	Mean	SD	t	df	P
Adaptive	High	40	44.45	9.64	1.93	72	>.05
	Low	34	40.29	8.33			

Maladaptive	High	40	24.45	6.95	3.66	72	<.01
	Low	34	29.88	5.57			

Table 1 presents results on the influence of self-esteem on coping strategies among persons living with SCD. It is shown that there exists no significant self-esteem difference in adaptive coping [$t(72) = 1.93; P > .01$].

It is also shown that there exists significant self-esteem difference in maladaptive coping [$t(72) = 3.66; P < .01$]. Moreso, participants with low level of self-esteem reported higher on maladaptive coping (Mean = 29.88; SD = 5.57) than those with high level of self-esteem (Mean = 24.45; SD = 6.95). This partially confirms the stated hypothesis, hence was retained in this study.

Hypothesis Two

Hypothesis two which states that participants with high level of perceived stigmatisation will significantly report lower on adaptive coping and higher on maladaptive coping compared to those with low level of perceived stigmatisation. This was tested using t-test for independent samples and the result is presented on Table 2;

Table 2: t-test for Independent Samples Summary Table Showing Results on the Influence of Stigma of Sickle Cell Disease on Coping

Dependent	Stigma	N	Mean	SD	t	df	P
Adaptive	High	41	41.07	8.31	1.49	72	>.05
	Low	32	44.38	10.65			
Maladaptive	High	41	30.34	4.49	5.72	72	<.01
	Low	32	22.56	7.08			

Table 2 presents results on the influence of perceived stigmatization on coping strategies among sickle cell disease patients. It is shown that perceived stigmatization had no significant influence on adaptive coping [$t(72) = 1.49; P > .05$].



Also, it is shown that perceived stigmatisation had significant influence on maladaptive coping [$t(72) = 5.72; P < .01$]. Further, participants with high level of perceived stigmatisation reported higher on maladaptive coping (Mean = 30.34; SD = 4.49) than those with low level of perceived stigmatisation (Mean = 22.56; SD = 7.08). This partially confirms the stated hypothesis, hence was retained in this study.

Hypothesis three: Self-esteem and perceived stigmatisation will jointly and independently predict coping styles among persons living with sickle cell disease. This was tested using multiple regression analysis and the result is presented on Table below;

Table 3: Multiple Regression Analysis Summary Table Showing Results on the Joint and Independent Influence of Self-Esteem and perceived stigmatisation on Coping.

Predictors	B	t	Sig	R	R ²	F	P
Perceived Stigma	.24	1.70	>.05	.35	.13	5.01	<.05
Self-esteem	.45	3.15	<.01				
Perceived Stigma	.54	4.60	<.01	.64	.40	23.76	<.01
Self-esteem	-.19	-1.61	>.05				

The table above presents results on the joint and independent influence of self-esteem and perceived stigmatisation on coping strategies among SCD patients. It is shown that self-esteem and perceived stigma had significant joint influence on adaptive coping [$R = .35; R^2 = .13; F(2, 70) = 5.01; P < .05$]. Collectively, self-esteem and perceived stigmatization account for about 13% variance in adaptive coping among persons living with SCD. However, only self-esteem ($\beta = .45; t = 1.70; P < .01$) independently predicted adaptive coping among sickle cell disease patients.

Direction of the beta value for self-esteem ($\beta = .45$) showed that the higher the self-esteem, the higher the adaptive coping adopted by sickle cell disease patients.

Furthermore, Perceived Stigmatisation ($\beta = .54; t = 4.60; P < .01$) independently predicted maladaptive coping among sickle cell disease patients. Direction of the



beta value for Perceived Stigma ($\beta = .54$) showed that the higher the stigma, the higher they adopt maladaptive coping strategy.

Discussion And Conclusion

This research examined self-esteem and perceived stigmatization as predictors of coping strategies among persons living with sickle cell disease.

The hypothesis which stated that participants with high level of self-esteem will significantly report higher on adaptive coping and lower on maladaptive coping compared to those with low level of self-esteem was tested using t-test for independent samples; result indicated that there was no significant self-esteem difference in adaptive coping among the sample. However, participants who scored low on self-esteem reported higher maladaptive coping than those with high level of self-esteem. This partially confirms the stated hypothesis. Moreover, this result is in line with the findings of Keane and Loades (2017) whose findings show that there is an association between low self-esteem and negative outcomes for people's behavioural and mental health problems, which is indicative of compromising behaviours such as substance abuse. Also, the result supports the position of Nguyen et al., (2019); their findings indicate that those who have a lower self-esteem tend to put undue focus, self blame, self-doubt or hopelessness on things about themselves they do not really like and also lack the self confidence to handle the situation in a more adaptive way. However, the lack of significant difference in terms of adaptive coping among the sample could be explained by the findings of Baumeister et al., (2003)- that high self-esteem do not necessarily lead to good performance. Instead, high self-esteem is partly the result of good performance.

Hypothesis two stated that Participants with high level of perceived stigmatization will significantly report lower on adaptive coping and higher on maladaptive coping compared to those with low level of perceived stigmatization was tested using t-test for independent samples; the hypothesis was partially confirmed. Result indicated that perceived stigmatization had no significant influence on adaptive coping; this



could be explained by the findings of Heatherton, et al., (2003) which reveals that some stigmatised persons show resilience and are able to ward off negative threats to their self-esteem. Whereas, there was a significant influence on maladaptive coping as participants with high level of perceived stigmatisation reported higher on maladaptive coping than those with low level of perceived stigmatization. This result supports the findings of Coker (2005) and Sadavoy et al., (2004) that perceived stigma creates a sense of rejection which could lead affected individuals to make deliberate and seemingly irrational decision not to seek help. The decision of not seeking help results in maladaptive behaviour. Similarly, Atkin and Ahmad (2001) reported that young people with SCD evaded anything that marked them out as different including adherence to their treatment regimes. That is to say, they would rather not adhere to treatment regime than to allow their health condition come to the fore so as to avoid being stigmatized; this is an avoidant strategy and offcourse maladaptive means of coping. Furthermore, Jenerette et al. (2012) emphasized that patient who reported greater stigma had higher scores on the Beck Depression Inventory which implies that high level of perceived stigma can only lead to maladaptive coping while impeding the desire to seek adaptive coping means among the victims of perceived stigmatisation.

Using multiple regression, the third hypothesis which stated that self-esteem and perceived stigmatisation will jointly and independently predict coping styles among persons living with sickle cell disease was tested. Result show that self-esteem and perceived stigmatisation had significant joint influence on adaptive coping. However, only self-esteem independently predicted adaptive coping among persons living with sickle cell disease. Thus, showing consistency with the findings of Burlew et al., (2000), KammeyerMueller, Judge, & Scott (2009) and Nguyen et al. (2019) that higher self-esteem increases adaptive coping. Also, perceived stigma independently predicted maladaptive coping; which means that as earlier mentioned, perceived stigma creates a sense of rejection which could lead affected individuals to adopt maladaptive means of coping with their health condition.



In line with the findings of this study, the following conclusions were drawn. People living with SCD who have low self-esteem and who also have high perception of stigma tend to use more maladaptive coping strategies and this has implication for their overall well being as more maladaptive behaviour will lead to increased mental health issues such as anxiety and depression. Also, it is discovered that SCD persons who have high self-esteem employ more adaptive coping strategies which inturn helps them adapt and adjust better with the challenges that accompanies their health condition. Also, better coping techniques enables people living with sickle cell disease to live as normal as possible, comparable with people without SCD. Additionally, self-esteem and perceived stigmatization jointly predicts adaptive coping among persons living with sickle cell disease.

Recommendations

Based on the findings of this research, the following recommendations are however made;

This study showed that self-esteem and perceived stigmatisation has significant influence on coping and better adjustment; as such, counseling and psycho-education tailored towards boosting self-esteem and reducing perceived stigma should be regular part of routine treatment for SCD patients as this will help constantly remind them on the need to deal with faulty thought that increase the perception of stigma.; this will also further help maintain a positive self-esteem.

Also, the society as a whole owes individuals who have SCD love and acceptance. Thus, organizations and business owner should not discriminate SCD persons in terms of employment; they can be absorbed into areas that are less physically strenuous. NGOs should do more to create awareness to general public about the need to support this vulnerable population.



Finally, despite several studies in the area of coping, there is need for more SCD specific studies bearing on the variables that directly influence coping as there is paucity of research in this area.

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