

Psychological well-being in sickle cell anemia: The influence of perceived stigmatization and perceived social support

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Abstract

This study investigated psychological wellbeing, perceived social support and stigmatization among people living with Sickle Cell Disease (SCD). A total of 213 people (M=107 and female=106), living with sickle cell disease were purposively selected from the National Sickle Cell Centre (NSCC) built by the Sickle Cell Foundation of Nigeria in Lagos State. Three psychological tests consisting of Warwick Edinburgh Mental Well-being Scale (WEMWBS), Multidimensional Perceived Social Support Scale (MSPSS) and Discrimination and Stigma Scale (DISC-12) were administered to the participants. The data collected were analyzed using Pearson product-moment correlation, regression analysis and independent t-test to test the proposed hypotheses. The results showed that there was a negative relationship between stigmatization and psychological wellbeing of people living with sickle cell disease. Also, perceived social support had a significant relationship with psychological well-being among people living with sickle cell disease. Furthermore, there was a significant joint relationship between perceived social support and stigmatization and the psychological wellbeing of people living with SCD. The results also revealed a significant difference between single and married participants on psychological well-being. The study concluded that perceived social support and stigmatization have critical implications for the psychological well-being of people living with SCD in Lagos metropolis. It was recommended that the scope of psychological well-being should be expanded to cover individual or intrapersonal strategies including treatment, counselling, cognitive-behavioural therapy, empowerment, group counselling, self-help, advocacy and support groups.

Keywords: Sickle Cell Anemia, Social Support, Stigmatization, Psychological Wellbeing.

1. Introduction

Sickle cell disease (SCD) is a genetic blood disorder that affects 20–25 million people globally with high morbidity and mortality rates, and about 50–80% of infants born with SCD in Africa die before the age of 5 years (Aygün & Odame, 2012) as there was a time when babies born with sickle cell anemia rarely lived past age 5. In recent times, healthcare providers are able to diagnose sickle cell and begin treatment that eases symptoms and complications and people are living into their 50s with sickle cell anemia. However, people who have sickle cell anemia tend to live 20 to 30 years less than people who don't have the condition.

It is an inherited disease caused by a mutation in one of the genes for haemoglobin (the substance inside red blood cells that binds to oxygen and carries it from the lungs to the tissues). It is characterized by Sickled haemoglobin (HbS) which is a structural variant of the normal adult haemoglobin. SCD includes a series of pathological genotypes resulting from the inheritance of HbS. It has also been estimated that 240,000 children are born with SCD annually in sub-Saharan Africa (Makani et al., 2011; Chakravorty & Williams, 2015). Sickle-Cell Disease (SCD) is one of the major inherited illnesses that can usually affect a person's psychosocial adjustment because of frequent hospitalization, medical crisis, loss of schooling time (among children and adolescents) and limited job opportunities to mention a few. Mood disorder is one of several psychological factors affecting individuals living with Sickle cell disease (SCD) including low self-esteem, feelings of hopelessness, anxiety and depressive symptoms. WHO (2006) stated that about 150,000 Nigerian children are born with sickle cell anaemia (HbSS), the prevailing type of SCD in this part of the world. About Fifty million Nigerians are healthy carriers of the S gene; they are either HbAS or HbSC (Aygün and Odame 2012). According to statistics from experts, Nigeria has the largest burden of sickle cell disorder (SCD) in the whole world. Akinyanju (2019). The estimated population of SCD affected persons in Nigeria is about 2.6 million, owing to a high rate of premature deaths. Sickle cell disorder is a complex condition that requires care so the child born with it would not die prematurely before the age of five due to lack of access to early diagnosis and proper care. Some Sickle Cell children have stroke, some have crises which makes them visit the hospital on a regular basis while others have leg ulcers when they are in their teenage years.

Stigmatization can be simply be defined is the process of identifying an attribute of a person or group of persons and associating the attribute with a negative stereotype that labels or brands another in a way that is perceived as abnormal by the society. More specifically, health related stigma refers to a form of devaluation, judgement or social disqualification of individuals based on a health-related condition (Weiss, Ramakrishna, & Somma, 2006). Research has found that stigmatized individuals living with sickle tend to have decreased quality of life and face many mental health challenges (Bediako et al., 2016; Wakefield et al. 2017). Stigma associated with SCD can be traced to various sources such as disease status, socioeconomic status, and pain episodes that require treatment and multiple visits to the hospital, which can be expressed by family, friends and others. Internalized stigmatization in people living with sickle cell disease can increase concerns about different aspects of their lives, such as getting married or having intimate relationships, fear of being viewed differently and delayed pubertal developments. A study by Ola et al., (2016) in Nigeria found that individuals living with sickle cell disorder who reported depressive or suicidal symptoms also reported having experienced stigma or discriminatory remarks from others.

People living with sickle cell disease do not only suffer medically but psychologically due to perceived stigmatization that they experience from friends and relatives (Tao, Wang, Kipp, Qian, Yin, Ruan, Shao, Lu & Vermund, 2017). Stigma is usually accompanied by social discrimination and exclusion, and the direct experience of discrimination and exclusion may be enough to arouse fear and high tension which are typical symptoms of anxiety (Grupe, & Nitschke, 2013). Some studies in the USA identified social factors that affected coping with SCD to include tensions often arising from ethnic bias, power differences between care providers and patient's family members, cultural values, economic resources or hardship and social identity. These factors are known to impose hardship on individuals with SCD acting as a hinderance to overcoming the debilitating aspects of the illness; which in turn, generate feelings of guilt, shame, and anxiety that impede or undermine effective coping. (Al-Nasseri, 2019; Nwongoh et al, 2012; Anie et al, 2007).

While Gerrig (2013) suggests that social support is an important resource for coping with stress, he describes social support as the resources which others provide, giving the message that one is loved, cared for, esteemed, and connected to other people in a network of communication and

mutual obligation. He also indicates that anyone with whom the person of concern has a significant social relationship with, such as family members, friends, coworkers, and neighbours is part of the social support network. When there is support from family and health care providers, this may increase compliance and decrease depression, while support from health care providers may increase satisfaction with the healthcare delivery system and decrease the discrimination felt by some patients with SCD. In the same vein, Kirmayer and Paul (2007) in their study of psychological adjustment agree that relationships with others in one's family and community are basic social determinants of psychological adjustment.

Gohain and Halliday (2014) stated that chronic infectious disease stereotypes and stigmatization are found to be significantly positively correlated with anxiety. Fear leads to avoidance; e.g., employers do not want persons with certain illness nearby so they do not hire them. (Bhugra 1989). Alternatively, prejudice turned inward leads to self-discrimination. (Corrigan, et al. 2001). Study reported that self-stigma and fear of rejection by others may lead many persons not to pursue life opportunities for themselves.

The psychological adjustment and psychological wellbeing of Sickle Cell Disease (SCD) patients is of immense importance because it could determine their ability to perform well in their life pursuits, ambitions and other life endeavors. Adegboyega (2021) found that some psycho-social problems of adolescents and young adults with sickle-cell anaemia includes: limitations in their choice of career; difficulty in getting suitable marriage partners; manifestation of emotional upsets or outbursts and learning problems. Findings also revealed that there were significant differences in the psycho-social problems of adolescents with sickle-cell anaemia based on age and educational level. This implies that if the psychological adjustment of SCA patients was high, they may be able to interact well with people around them and their environment. Also, for them to be lucratively employed, they have to be psychologically adjusted, be useful to themselves and the society at large.

Social support has been described as “support accessible to an individual through social ties to other individuals, groups, and the larger community. Social support consists of social relationships that provide (or can potentially provide) material and interpersonal resources that

are of value to the recipient, such as counselling, access to information and services, sharing of tasks and responsibilities, and skill acquisition Li, Luo, and Mu (2021).

Gerrig (2013) has also suggested that social support is an important resource for coping with stress, describing social support as the resources which others provide, giving the message that one is loved, cared for, esteemed, and connected to other people in a network of communication and mutual obligation. He also indicated that anyone with whom the person of concern has a significant social relationship with, such as family members, friends, coworkers, and neighbours is part of the social support network. In contrast to low social support, high levels appear to buffer or protect against the full impact of mental and physical illness. According to Resick (2001), the relationship between good social support and superior mental and physical health has been observed in diverse populations, including college students, unemployed workers, new mothers, widows, and parents of children with serious medical illnesses.

However, there is scanty literature combining the role of perceived social support and stigmatization on people living with SCD, hence this study intends to fill the gap. The study is focused on exploring the role of stigmatization and perceived social support on the psychological wellbeing of people living with SCD in Lagos Metropolis.

The major aim of this study was to investigate the influence of stigmatization and perceived social support on the psychological wellbeing of people living with sickle cell anemia. The specific objectives of the study thus include, to examine the relationship between perceived stigmatization and psychological wellbeing among people living with sickle cell disease, the relationship between perceived social support and psychological wellbeing and the joint influence of perceived social support and perceived stigmatization among people living with sickle cell disease. Also, the study seeks to determine the differences if any, between married and unmarried respondents in their psychological wellbeing.

2. Method

The research setting for this study was The National Sickle Cell Centre (NSCC) built by the Sickle Cell Foundation of Nigeria, strategically located opposite the Lagos University Teaching Hospital, Idi-Araba, Lagos. Ethical clearance was obtained from the authorities of the centre before the instruments were distributed to the patients. Data collection was done using structured questionnaires containing a section on participants' demographic information about age, gender, marital status. The population for the survey were persons living with SCD while the sample came from those on treatment at the Sickle Cell Foundation of Nigeria centre, Idi-Araba. A sample size of 213 participants was selected using purposive sampling method based on characteristics of the study population and the objectives of the study made up of both in and out patients. Three adapted instruments, the "Multidimensional Scale of Perceived Social Support (MSPSS)" by Zimet, Dahlem, Zimet & Farley, (1988); the Warwick Edinburgh Mental Well-being Scale (WEMWBS) by University of Warwick in collaboration with the University of Edinburgh and the Discrimination and Stigma Scale (DISC-12) by Bakolis, (2019).

The Warwick-Edinburgh Mental Well-being Scale is a 14-item scale used to measure general well-being covering subjective well-being and psychological functioning, in which all items are worded positively and address aspects of positive mental health. The scale is scored by summing responses to each item answered on a 1 to 5 Likert scale with a minimum score of 14 and a maximum of 70. Tennant et al., (2007) reported that WEMWBS showed good content validity. The scale has a Cronbach's alpha score of 0.89 (student sample) and 0.91 (population sample) and a Test-retest reliability of (0.83).

The Multidimensional Scale of Perceived Social Support (MSPSS) has 12 items that measures the amount of social support an individual receives from three sources i.e., friends, family and significant other/special person. The amount of social support is rated on a seven-point Likert scale; with responses ranging from very strongly disagree as 1 and to very strongly agree as 7. The cumulative/total scores range from 12 to 84. The scores are interpreted as, the higher the score, the greater the amount of available social support.

The original version of the MSPSS has three-factor structure, with high internal consistency of ($\alpha = 0.88$), stability ($\alpha=0.85$) and moderate construct validity as the social support scores were

negatively correlated to anxiety ($r = -0.18$; $p < 0.01$) and depression scores ($r = -0.24$; $p < 0.01$). Twenty-two (22) translated versions of the MSPSS have been identified and the psychometric properties which were most often reported included internal consistency, test-retest reliability, structural validity and construct validity.

Discrimination and Stigma Scale (DISC-12): The DISC is an interview-based scale which measures peoples' experiences of being treated unfairly in key areas of everyday life and social participation. According to Bakolis (2019), discrimination and stigma occur when people are treated unfairly because they are seen as being different from others. The scale probes participants about their feelings and perception of discrimination and stigma as it relates to their health problems. This scale has four Subsections and has been used across a number of social contexts such as the workplace, healthcare and family settings; and among different populations including people with different types of mental disorders, and across different geographical contexts (Lasalvia et al, 2013; Thornicroft et al, 2009; Corker et al, 2015; Oshodi et al, 2014; MilacicVidojevic et al, 2015). The validity of the original scale has well documented properties (Brohan et al., 2013) and complies with the conceptual model postulated in the original DISC-12 scale. It has content validity with excellent reliability coefficient (Cronbach's alpha >0.85), good fit (Tucker Lewis Index and Comparative Fit Index value >0.9) and weak to moderate construct validity. The DISCUS scale is a consistent and valid instrument to measure experienced and anticipated discrimination predominantly in personal and social relationships in global settings.

After the above instruments were stapled together and administered to the respondents, they were retrieved, collated and scored according to the manual and coded. Data analysis was done using both descriptive and inferential statistics. Descriptive statistics was utilised to derive the mean and standard deviation. Inferential statistics was selected on the basis of hypothesis testing, deploying correlation and regression analyses to check for possible relationship between variables and t-test for independent mean samples. The regression analysis was used to check for the interaction effect of the variables used in the study. The level of significance chosen for this study is $P < 0.05$.

3. Results

The data collected in this study was subjected to statistical analysis obtaining the means and standard deviation of all the variables. The hypotheses were tested using correlation, regression and t-test.

Table 1: Means and Standard deviation of the variables of the study - psychological wellbeing, perceived stigmatization and perceived social support according to gender

Description	Variables	Psychological Wellbeing		Perceived stigmatization		Perceived social support	
		Mean	SD	Mean	SD	Mean	SD
Gender	Male	41.99	11.58	47.95	7.76	57.23	16.67
	Female	41.00	11.17	49.53	7.65	59.69	17.58

Table 1 shows the mean and standard deviations for psychological wellbeing, perceived stigmatization and perceived social support by gender. On psychological wellbeing, the result revealed that female participants reported similar mean score ($M = 41.99$; $SD = 11.58$) as their male counterparts ($M = 41.00$; $SD = 11.17$). On perceived stigmatization, male participants recorded lower mean score ($M = 47.95$; $SD = 7.76$) than their female counterparts ($M = 49.53$; $SD = 7.65$). Likewise, on perceived social support male participants reported lower mean score ($M = 57.23$; $SD = 16.67$) than their female counterparts ($M = 59.69$; $SD = 17.58$).

Inferential Statistics: test of hypotheses

Hypothesis 1: There will be a significant negative relationship between perceived stigmatization and psychological wellbeing among people living with sickle cell disease.

In order to determine the relationship between perceived stigmatization and psychological wellbeing among people living with sickle cell disease, Pearson moment correlation analysis was carried out. The result is presented in table 2.

Table 2: Correlation between perceived stigmatization and psychological wellbeing among people living with sickle cell disease

Variable	Mean	SD	R	P
psychological wellbeing	41.49	11.63	1	
Perceived stigmatization	48.74	7.88	-.301*	P<0.05

Table 2 reveals that perceived stigmatization has significant negative correlation with psychological wellbeing among people living with sickle cell ($r = -.301^*$; $p < 0.05$). The negative correlation is due to higher levels of perceived stigmatization scores resulting in lower levels of psychological wellbeing among people living with sickle cell. Thus hypothesis one is hereby accepted.

Hypothesis 2: There will be a significant positive relationship between perceived social support and psychological wellbeing among people living with sickle cell disease.

In order to determine the relationship between perceived social support and psychological wellbeing among people living with sickle cell disease, Pearson moment correlation analysis was carried out. The result is presented in table 3 below.

Table 3: Correlation between perceived social support and psychological wellbeing among people living with sickle cell disease

Variable	Mean	SD	R	P
psychological Wellbeing	41.49	11.63	1	
Perceived social support	58.46	17.13	.591*	P<0.05

P<0.05*

Table 3 reveals that perceived social support has a significant positive correlation with psychological wellbeing among people living with sickle cell disease ($r = .591^*$; $p < 0.05$). The positive correlation is due to higher levels of perceived social support scores resulting in higher levels of psychological wellbeing among people living with sickle cell. Thus hypothesis 2 is hereby accepted.

Hypothesis 3: Perceived social support and stigmatization will jointly predict psychological wellbeing among people living with sickle cell disease.

Table 4: Summary of multiple regression analysis showing the contributions of perceived social support, self-esteem to the prediction of psychological wellbeing among people living with sickle cell.

Variables	Beta(B)	t-value	P	R	R ²	F-ratio	P
Perceived stigmatization	-.189	-3.404	.01	.62	.38	65.41	P<0.05
Perceived social support	.550	9.902	.01				

$p < 0.05$

The results indicated that perceived stigmatization contributed to the variance in psychological wellbeing among people living with sickle cell (Beta= -.189, $t = -3.404$ at $p < 0.05$). Perceived social support also contributed to the variance in psychological wellbeing among people living with sickle cell (Beta= .550, $t = 9.902$ at $p < 0.05$). Jointly, all the variables yielded significant coefficient of regression $R^2 = 0.384$ ($p < 0.05$). This shows that perceived stigmatization and

Perceived social support accounted for 38.4% of the observed variance in psychological wellbeing among people living with sickle cell. However, perceived social support seemed to be a stronger predictor of psychological wellbeing among persons living with sickle cell disease.

Hypothesis 4: There will be a significant difference between married and unmarried respondents living with Sickle cell disease in their psychological wellbeing.

Variables	Marital status	N	Mea n	SD	t-valu e	Df	Sig .	P
Psy Wellbeing	Single	15	38.8	11.4	-6.04	21	0.0	Si g
	Married	6	48.8	8.65				
		57	7		6	1	1	

Table 4: Independent t-test comparison of psychological wellbeing by marital status

$p < 0.05$

From table 4 above, the mean scores of the two groups shows a significant difference between single and married participants on psychological wellbeing of people living with sickle cell. Mean of unmarried participants ($M=38.80$; $SD. 11.43$) and married participants ($M=48.87$; $SD=8.65$). This difference is statistically significant at $df = 211$, $t = -6.046$, $p < 0.05$. The hypothesis which state there will be a significant difference between married and unmarried respondents in their psychological wellbeing among people living with sickle cell is hereby accepted.

4. Discussion

The main objective of the study was to determine the relationship among social support, perceived stigmatization and psychological wellbeing of Sickle Cell Anaemia patients in Lagos.

The findings of the study shows that perceived stigmatization has a significant negative relationship with psychological wellbeing among people living with sickle cell disease. In other words, and as highlighted by Fred (1998), stigma has a negative impact on the Psychological wellbeing of a substantial proportion of people affected by SCD. People who have a chronic

health condition are more at risk of developing mental health issues in their life course than people who do not. It is estimated that one in two persons affected by SCD will experience depression, anxiety and/or suicidal thoughts at some point in their lives (Ezenwa et al, 2016). However, findings from this study is in support of this claim as most respondents reported significantly high scores on stigmatization and as such it has an influence on their psychological wellbeing. A review by Cerully, Acosta and Sloan (2018) on mental health, stigma and its effects on treatment-related outcomes showed that evidence exploring the direct effect of stigma on treatment-related outcomes is still scanty. Another study suggests that the relationship between stigma and experience of symptoms is nuanced and may depend on the type of stigma and types of symptoms considered. Stigma and discrimination can also make someone's mental health problems worse and delay or stop them from getting help. Social isolation, poor housing, unemployment and poverty are all linked to mental ill health thus trapping people in a cycle of illness.

The result of the second hypothesis reveals that perceived social support has a significant relationship with well-being among people living with sickle cell disease. Thus, increase in perceived social support is associated with increased or better psychological wellbeing among people living with sickle cell disease. This finding is in accordance with the work of Kirmayer and Kenneth (2007) who investigated mental health, social and community wellness and opined that the relationships with others in one's family and community are the basics of social determinants of mental health and psychological wellbeing. In a meta-analysis of the correlation between social support and mental health, Harandi et al (2017) noted that numerous studies on the effect of social support on health, quality of life, and especially mental health over the recent decades on different populations, using different instruments, sampling methods and statistical populations, have resulted in different results. Afrooz & Taghizadeh (2014), found a strong correlation between social support and mental health which is in agreement with this study, while Pahlevanzadeh and Jarelahi, (2011), and Rajai, Aflakseyr, Mollazadeh, (2012) found weak correlations in this regard. Olusoji et al (2021) in their study of psychological adjustment and social support among sickle cell disease patients, concluded that social support significantly influenced psychological adjustment and optimism which might enhance the quality of

interpersonal relationships, effectiveness, happiness, and productivity among their family members, friends, nurses, doctors and counsellors.

Another finding of this study showed that there was a significant difference between single and married participants in their psychological wellbeing with married respondents showing higher levels of mental well-being. This finding is substantiated by Bookwala, (2015) who opined that being married is not only associated with significant psychological and physical benefits, but also the quality of the marital relationship is a critical factor in the accruing benefits and support especially in the domains of health promotion and cognitive function as people age. In societies which emphasize marriage, being married is related to lower depression, lower anxiety, lower suicide risk, and lower substance abuse, on average (Spiker, 2014). In considering the relationship between mental health and marital status, researchers have used two models: causation and selection. Selection models propose that healthy and socially desirable people are more likely to become and stay married while in causation models, it is believed that marriage confers benefits directly to participants. However, depending on social norms and selection factors, social support can be the mechanism through which relationships affect mental health.

5. Conclusion and Recommendations

The findings of this study showed that the level of social support received directly influences the mental well-being of people living with SCD but the scope of mental well-being should be expanded to cover individual or intrapersonal strategies including treatment, counselling, cognitive-behavioural therapy, empowerment, group counselling, self-help, advocacy, and support groups. At community-level, the social support strategies should include education, contact, advocacy, and protests. It is unclear what social support means to us as a society as the only form of support reported by the respondents was basically that gotten from spouses, family members or religious groups. Marital status showed a positive influence on patient's mental well-being level since marriage is a social institution that has effects on mental health across societies despite the fact that majority of our respondents were not married so only a few enjoy this privilege. Social support facilitates therapeutic communication in healthcare. Social support includes behaviors that persuade and convince others that they are cared for and valued and

enhances coping skills by helping people believe they can proactively manage health challenges. Community health workers assist patients with a variety of diseases, acting to provide social support, counselling, and guidance through the health care system, and evidence suggests they would be effective in helping SCD patients to overcome depression and stigmatization from the society. If these are to become our practical measure for social support, ultimately people living with SCD will feel truly loved and cared for.

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