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Perception of Stigmatisation among Adult Sickle Cell Disease Patients in South-South, Nigeria

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Abstract

Background: Sickle cell disease (SCD) impacts the physical, emotional and psychological aspects of life of the affected persons, often times exposing them to disease-associated stigmatization from family members and/or the community and this in turn affects their health-related quality of life (HRQoL). There is paucity of data from southern Nigeria as regards stigmatization among SCD patients, hence this study was aimed at determining the level of stigmatization amongst them. ***Methodology*:** It was a cross-sectional study involving two hundred and twenty-four SCD patients recruited from three well recognized health facilities that offer comprehensive care for individuals with SCD in Benin City, Nigeria. The measure of sickle cell stigma and the sickle cell disease health-related stigma scale psychometric tools were used for this study. ***Results***: One hundred and sixty- four (73.2%) participants were not married despite attaining marriageable age. One hundred and seventy-one (76.1%) were dependents, living with their friends and family members. Sixty-eight (47.7%) had a severe disease course and one hundred and eighty-five (82.6%) had perceived/ experienced stigmatization. ***Conclusion***: The study found a high prevalence of stigmatization among SCD patients.

Keywords: Sickle Cell Disease, Stigmatization, Patients.

INTRODUCTION

Sickle cell disease (SCD) is a chronic illness of global public health importance. Approximately 330,000 infants are born globally each year and this figure is expected to increase to over 400,000 by 2050 [1]. Sickle cell disease has been recognized as a public health priority by the World Health Organization (WHO) in Africa [1]. The prevalence of the disease in Nigeria is about 23.7% and approximately 150,000 babies with SCD are born yearly with a prevalence of 20–30 per 1,000 live births [2]. The prevalence in Benin City was reported to be 2.39% [3].

The concept of stigmatization is increasingly cited as a central concept in chronic illness research, hence it is an important consideration for adults living with SCD [4]. 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 [4]. It is well established that stigmatization has health-related consequences and may contribute to the burden of the disease [5]. It has been reported to be a major public health problem especially among people living with haemoglobinopathies [5]. Health-related stigma refers to a form of devaluation, judgment or social disqualification of individuals based on a health related condition [6]. Therefore SCD patients without adequate support system and services are at risk of impaired health related quality of life (H-QOL) and health-related stigmatization [7].

It is possible that some of the physical complications associated with SCD can be a source of stigmatization and have noteworthy implications of health-related outcomes [4]. For instance chronic leg ulcers and jaundiced eyes are two prominent symptoms of SCD that may engender anxiety and shame and may thereby discourage interpersonal social interactions [4]. Studies have reported that stigmatization complicates the burden of the disease on affected individuals and families and may ultimately result in a poor HRQoL [6].

More so, the psychosocial aspects of SCD may also contribute as sources of stigma. Some authors have reported that SCD health-related stigma have being compounded by feelings of racism (actual or perceived) and that this can pose significant barriers to getting appropriate care [8]. For example, some patients seeking medication for chronic or acute pain have been misperceived as drug addicts or individuals who need to rest from fatigue caused by SCD may be falsely thought of as malingers by friends, relatives and even co-employees/ employers.

Unfortunately, even the health care system has been recognised as a source of stigmatization as some reports have shown that stigmatization from health care providers has negatively affected the physical and psychological wellbeing of SCD patients [8]. This could present as a false belief by medical personnel that some affected patients are exaggerating their pains (when actually they may truly be experiencing a vaso-occlusive crises (VOC)) or seeking analgesic to satisfy their addiction. This has resulted in some affected patients having mistrust in their healthcare providers and thus prefers to remain in extreme pain and fatigue rather than seeking medical intervention or probably self-medicate.

Sickle cell disease (SCD) has numerous effects on the social and emotional well-being of affected individuals, with stigma being one of the most influential and ominous influencers of health [9,10]. Individuals with SCD have been reported to show poor social interactions, isolation, denial and feelings of being different. Psychosocial aspects of SCD may also constitute sources of stigma [11].

This study therefore aimed at assessing the prevalence of SCD patients living in Benin City, Nigeria, who perceive to be stigmatized or were actually stigmatized and also to ascertain the sources of stigmatization. The study also examined some sociodemographic patterns affecting the quality of life of SCD patients in the study area.

METHODS AND MATERIALS

Study Design

This was a cross- sectional study done in Benin City, Nigeria. The study was carried out in three centres in Benin City. Participants were recruited from the Haematology department of University of Benin Teaching Hospital (UBTH), Edo specialist hospital (ESH) and the Sickle Cell Centre Benin. University of Benin Teaching Hospital is a federal government owned hospital with over 800 bed spaces, located in Egor local government area in Benin City. Edo Specialist Hospital, is a 200-bed space hospital co-owned by the state government in partnership with a private firm and is located in Oredo local government area in Benin-city. The Sickle Cell Centre is a non-governmental organisation funded by the Sickle Cell Foundation of Nigeria, set up to offer comprehensive health care to individuals with SCD.

Study Population

Patients aged 18 years and above with confirmed diagnosis of SCD were recruited in this study. Patients with diagnosis confirmed through documented results of haemoglobin electrophoresis or haemoglobin quantification using high performance liquid chromatography (HPLC) were recruited. These participants were recruited from the wards, outpatient clinics and emergency departments of the above centres.

Exclusion Criteria

1. SCD patients with a history of mental health disorders including but not limited to depression, bipolar affective disorder (BAD), mania, Post-traumatic stress disorder (PTSD) and schizophrenia.
2. SCD patients with congenital cognitive diseases.
3. SCD on psychotic, mood stabilising and anti-depressant medications

Data Collection

Eligible patients were informed and educated about the study. Once consented, participants were administered a copy of the questionnaire either as a paper or electronic (soft) copy.

Study Instrument

The Measure of Sickle Cell Stigma (MoSCS) and the Sickle Cell Disease Health-Related Stigma Scale SCD-HRSS) were used in this study. The MoSCS is an 11-item, self-administered questionnaire that measures the degree of stigma experienced by SCD patients. The protocol includes 4 subscales measuring social exclusion, internalized stigma, disclosure concerns and expected discrimination. The SCD-HRSS is a 30-item proforma with three subscales measuring perceived health-related stigma from doctors (physicians), family and the general public using a 5-point Likert scale.

Sample Size Estimation

Using the sample size formula for a known disease prevalence study where the confidence interval was 95% and precision of 2%.

$n= Z^2P (1-P) \div d^2$

n= Sample size

Z= Statistic for level of confidence (1.96 for 95% confidence level)

P= Prevalence of the disease (2.39%) [3]

d= Precision (2%)

Therefore, $n= 1.96^2 \times 0.0239 (1-0.0239) \div 0.02^2 = 224.1$

That is, 224 SCD patients were recruited in this study.

Data Analysis

Data obtained was analysed using Statistical Package for the Social Sciences (SPSS) version 23. Probability values less than 0.05 ($p < 0.05$) were

considered as significant. Results were presented in tables.

RESULTS

Two hundred and twenty-four SCD patients were recruited in this study comprising of 136 (60.9%) males and 88 (39.1%) females (Table 1). Majority of the participants in the study were aged between 18 and 25 years (39.9%) and were unmarried (73.2%). One hundred and eight-seven participants (83.3%) had tertiary education, thirty-one individuals (13.8%) had secondary level of education and two persons (0.7%) had no formal education. Eighty persons (35.5%) were employed of either public or private owned organizations, while five participants (2.2%) were self-employed. The study involved seventy-five participants (33.3%) who were unemployed and sixty-four students (29.9%) in either tertiary or secondary schools. As shown in table 1 one hundred and seventy-one people (76.1%) of different age cadre lived with a family member, nine individuals (4.3%) lived with unrelated persons and the rest lived alone (19.6%).

Clinical Characteristics of SCD Population

One hundred and ninety-nine (89.1) participants were homozygous SS, twenty (8.7%) were heterozygous SC and the remaining were distributed amongst various sickle cell disease variants (2.2%). One hundred and fifty-eight (70.3%) SCD patients were observed to be compliant with their routine medications and eighty- six (38.4%) persons were presently on hydroxyurea. One hundred and forty-three (63.8%) had been admitted in the hospital in the last one year. Sixty-eight (47.7%) of persons admitted in the last twelve months had severe disease while the remaining had less than three admissions (52.3%). Most of the SCD patients in this study (76.8%) had been transfused in their life time and ninety- seven (43.4%) persons in this study had more than three units of blood transfused in the last one year.

Stigmatization Assessment

One hundred and eighty-five (82.6%) participants in the study had experienced one form of stigmatization from individuals and/or group of individuals. Majority of the responders felt stigmatized more by individuals other than family members, attending doctors and nurses (79.%) and the least group perceived stigmatization from attending physicians.

Majority of respondents (77.5%) perceived stigmatization and discrimination from family members, members of the community, employers and teachers/trainers leading to a fear of disclosing their SCD, however they did nit relay any concerns about Stigmatisation with their health care provider. A large proportion (47.1%) experienced social exclusion from friends and family and community members. A hundred and one participants (44.9%) had experienced an expected discrimination from others while seventy-six (34.1%) had inherent fear of being discriminated (internal stigmatisation).

Table 1: Demographic Characteristics of SCD Participants

Age group (years)	**n (%)**
18 – 25	89 (39.9)
26 – 30	46 (20.3)
31 – 35	39 (17.4)
36 – 40	21 (9.4)
≥41	29 (13.0)
Mean ± SD (Range) (years)	29.8 ± 8.4 (18 – 52)
Sex	
Male	136 (60.9)
Female	88 (39.1)
Level of education	
No formal	02 (0.7)
Primary	4 (2.2)
Secondary	31 (13.8)
Tertiary	187 (83.3)
Marital status	
Single	164 (73.2)
Married	52(23.2)
Separated/Divorced	08 (3.6)
Employment status	
Unemployed	75 (33.3)
Self employed	05 (2.2)
Employed	80 (35.5)
Student	64 (29.0)
Living status	
Living alone	44 (19.6)

With family member	171 (76.1)
With unrelated persons	09 (4.3)

Table 2: Clinical characteristics of SCD Participants

SCD Phenotype	**n (%)**
SS	199 (89.1)
SC	20 (8.7)
Unknown	05(2.2)
Compliance with routine medications	158 (70.3)
Use of hydroxyurea (HU)	86(38.4)
Ever used HU amongst current non-users	119 (52.9)
Hospitalization in past 12 months	143 (63.8)
<3	75 (52.3)
≥3 (severe disease)	68 (47.7)
History of blood transfusion	172 (76.8)
Received 3 or more units in past 12 months	97(43.4)

Table 3: Stigmatization Assessment of SCD Participants

SCD-HRSS	**Mean ± SD**	**Range**
People	37.1 ± 9.2	10.0 – 58.0
Doctor	34.4 ± 8.8	10.0 – 57.0
Family	34.6 ± 7.5	12.0 – 56.0
Nurses	36.4 ± 8.8	10.0 – 58.0
Total	**142.6 ± 27.8**	**45.0 – 220.0**
Proportion of SCD subjects that perceive stigmatization		
	n (%)	
Subscales		
People	177 (79.0)	
Doctor	151 (67.4)	
Family	164 (73.2)	
Nurses	166 (73.9)	
Total	185 (82.6)	
MoSCS	**Mean ± SD**	**Range**
Social exclusion	9.5 ± 4.5	3.0 – 18.0
Internal stigma	8.3 ± 4.7	3.0 – 18.0
Disclosure	12.1 ± 4.1	3.0 – 18.0
Expected discrimination	8.5 ± 2.8	2.0 – 12.0
Total	38.5 ± 12.5	11.0 – 66.0
Proportion of domains that they perceive stigmatization		
	n (%)	
Social exclusion	106 (47.1)	
Internal stigma	76 (34.1)	
Disclosure	174 (77.5)	
Expected discrimination	101 (44.9)	
Total	**145 (64.5)**	

DISCUSSION

Stigmatisation of sickle cell disease (SCD) patients is a pressing health concern. Several factors have been attributed which includes but not limited to physical appearance, analgesic use, racism, disease severity and sociodemographic characteristics [4]. Stigma can stem from sources including institutions, healthcare providers, immediate community, family and friends. Studies have shown that stigmatisation has detrimental consequences such as negative social consequences, impaired interactions, poor physiological/psychosocial wellbeing and health related quality of life.

A large proportion of participants in the index study were adults of marriageable age, but only 23.2% were outrightly married. Amongst those that were single, 3.6% were previously married but presently separated from their spouse. A similar pattern was reported in neighbouring Ghana by Buser *et al*., [12]. The cause of this large proportion of unmarried SCD patients is multifactorial. It could be due to our religious/cultural belief or perception and medical stance concerning getting married to a SCD individual. Some researchers have attributed it to some psychosocial issues including low self-esteem, perception of looking physically

different compared to their peers, concern that the illness will be burdensome to potential suitors and sexual characteristics such as hypogonadism. As regards sexual features, Cobo *et al*., reported that 65% of female correspondence in their study complained of impaired sexuality due to complications related to the disease [13]. Some participants attributed their impairment being due to regular painful crises, discrimination and negative feelings experienced in intimate relationships [13].

Educational attainment was notably good in the index study as 83.3% of participants had attained tertiary education. This is not consistent with findings from several literatures who argued that patients with SCD are at a high risk of frequent absenteeism from school due to frequent painful crisis and hospitalisation for other acute complications [14]. Reports have shown that young people with SCD miss an average of twenty to forty school days in a year [15]. In support of this findings, a similar trend was observed by Harris *et al*., who found that 57% of SCD patient with a history of a stroke completed high school [16]. The reason for the high level of academic attainment observed in this index study could not be ascertained as full details of their academic endeavors in sync with their medical records were not enquired.

Despite majority of the respondents attaining a high level of education, a large portion (33.0%) of them was unemployed. This is slightly lower than reports that estimate that between 40% and 60% of people with SCD are not employed [17]. The cause of unemployment in SCD is poorly understood, however some authorities have reported that due to that health related problems it is reasonable to believe that maintaining full-time employment would be more difficult [17]. Interestingly enough, there is also evidence to suggest the contrary, that employment status may not be related to poor health but to behavioral and social factors. In a qualitative study that involved SCD focus groups, patients reported that poor interpersonal relationships among management and other employees, and not their physical health were the main contributors to their unemployment [18]. Other authors have credited personality factors such as low self-esteem or lack of assertiveness, lack of job skills due to irregular school attendance and cognitive deficits as contributors to the high unemployment rate in SCD [17]. This point would not be the cause of unemployment in this study as a high number of participants were well educated and would have learnt enough skills and knowledge to work effectively [19].

One hundred and eighty (80.4%) participants lived with either a family member or with a friend or colleague translating to a high level of dependence amongst SCD patients. Multiple reasons may be responsible for dependency level and high need for support systems including chronic health condition, recurrent pains, recurrent hospital visits, need for compliance with routine drugs and other socioeconomic reasons.

A large proportion of participants (82.6%) anticipated or experienced one form of stigmatisation or the other from friends, relatives and medical practitioners. Adeyemo *et al*., reported that 70.0% of adolescents in their study experienced certain levels of stigmatization that negatively affected all domains of SCD health-related quality of life (SCD-HRQoL) [6]. One of the most affected domains using the measure of sickle cell stigma (MoSCS) tool was disclosure concerns as most patients in this study were apprehensive or worried about disclosing their genotype status. One hundred and seventy- four (73.5%) participants in this study refrained from telling others about their disease status for fear of being stigmatised. Reported reasons for disclosure concerns include fear of being treated differently, either pitied or discriminated against [10]. Studies have shown that the selective nature of SCD patients in disclosing their clinical state can be disadvantageous. A study by Derlega *et al*., showed that individuals that communicate more about their SCD pain had positive psychological adjustment and were more likely to seek care and also had lower awareness of disease stigma [20]. In addition, Bediako *et al*., disclosed that social exclusion and internalized stigma were statistically significantly associated with more frequent hospital admissions for SCD pain [4].

Also, results from the SCD-HRSS showed that the most experienced stigmatization was from the general public rather than from family members and healthcare providers. This is in-keeping with reports from Reed *et al*., who also reported highest stigmatization from the general public items, then, doctor items and lastly family items [10].

Realizing how impactful this stigma/bias can have untoward effects in the general well-being of these individuals, it becomes pertinent to find promising approaches in curtailing its prevalence amongst individuals living with sickle cell disease. In a study done by Munung *et al*., four key strategies were proposed in mitigating SCD- related stigma including increased SCD advocacy, stakeholder education, counseling for patients, and improved clinical management of SCD.[21] Education primarily should involve a multistakeholder approach directed at the general population, families and also the health care providers, thereby addressing critical issues as well as characteristic myths, beliefs and negative labeling of SCD individuals. Similar approaches are advocated by other studies conducted, and this might reduce significantly SCD-related stigma in Nigeria [22, 23].

Limitation of Study

A major limitation of this study is that it was hospital based and the study participants experiences may not be representative of what SCD individuals in the

community might experience especially those who do not routinely seek for maintenance care routinely. More so, their educational attainment is diverse and influences one's perception of stigmatization. Secondly, the qualitative assessments tool utilized in the study may not have provided a real in-depth understanding of stigma experiences of the participants considering the scale of measurements. Hence, other tools of assessment such as using semi-structured individual interviews and focus group discussions may have offered a more elaborate view of these perceptions.

CONCLUSION

Stigmatization against persons with SCD still remains prevalent in our communities as reflected in this study, arising from the general public, down to health care providers who inadvertently propagate SCD-related stigma and discrimination. This stigmatization certainly has detrimental consequences in these individuals as it not only represents a social injustice, but also significantly diminishes their HRQOL. Multilevel approaches aimed at challenging these negative narratives about SCD may eventually improve the QoL of individuals living with SCD.

Authors Contribution

1. Okuonghae M.E: Wrote the Introduction, methodology and results
2. Adeyemi Oluwafemi: Developed the topic, Wrote the discussion and abstract

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