



# Living with sickle cell disease and depression in Lagos, Nigeria: A mixed methods study



Bolanle A. Ola<sup>a</sup>, Scott J. Yates<sup>b</sup>, Simon M. Dyson<sup>c,\*</sup>

<sup>a</sup> Department of Behavioural Medicine, Lagos State University College of Medicine (LASUCOM), Ikeja, P.M.B. 21266 Lagos, Nigeria

<sup>b</sup> School of Applied Social Sciences, De Montfort University, Room 0.19a Hawthorn Building, Leicester LE1 9BH, United Kingdom

<sup>c</sup> Unit for the Social Study of Thalassaemia and Sickle Cell, De Montfort University, Room 1.27 Hawthorn Building, Leicester LE1 9BH, United Kingdom

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## ABSTRACT

Sickle cell disorders (SCD) and depression are both chronic illnesses of global significance. Past research on SCD and depression struggles to make sense of statistical associations, essentializes depression within the person with SCD, and treats stigma as an automatic correlate of chronic illness. A mixed methods study (March 2012–April 2014) was undertaken with people living with SCD and depression in Lagos, Nigeria, examining *depression-as disease* (questionnaires); *depression-as-illness-experience* (individual depth interviews), and *depression-as-societal-sickness* (focus groups). 103 people with SCD attending an outpatients clinic were administered the *Patient Health Questionnaire-9*, and 82 self-identified with some level of depression. Fifteen were subsequently interviewed about their illness experience. Their lives were characterized by being extensively subjected to vicious discriminatory remarks, including from significant others, negative experiences they felt contributed to their depression and even to suicidal thoughts and actions. Contrary to misconceptions of the relational nature of stigma, respondents recognized that stigma resulted not from their SCD but from assumed broken social norms and expectations, norms to do with educability, employability and parenthood. They recounted either that they successfully met such expectations in their own lives, or that they could conceivably do so with reasonable societal adjustments. Ten respondents with SCD and depression further took part in two series of three focus groups with five people in each series of groups. In groups people living with SCD were able to challenge negative assumptions about themselves; to begin to recognize collective social interests as a group, and to rehearse backstage, in discussions between themselves, social actions that they might engage in frontstage, out in wider society, to challenge discriminatory societal arrangements they held to contribute to their depression. To the extent that depression in SCD has social origins, then social interventions, such as anti-discrimination laws and policies, are key resources in improving mental health.

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## 1. Introduction

Sickle cell disorder (SCD) is a chronic illness of global public health importance (UN, 2008). Up to 330,000 infants are born globally each year, and this figure is expected to increase to over 400,000 by 2050 (Piel et al., 2013). SCD has been recognized as a public health priority by the World Health Organization in Africa (WHO, 2010). Globally, Nigeria has the greatest absolute number of people with SCD, with up to 150,000 infants with SCD born each

year (WHO, 2006). Depression is a major chronic illness globally in its own right, and is described as a major contributor to global health burdens (Moussavi et al., 2007). Numerous studies have documented an association between SCD and depression (Ohaeri et al., 1995; Hasan et al., 2003; Asnani et al., 2010). However, since pain is itself highly, and reciprocally, related to symptoms of depression (Kroenke et al., 2011) and since both acute vaso-occlusive painful crises and chronic pain are integral to the experience of living with SCD (Smith et al., 2008), it is unremarkable that people with SCD should also be prone to depression (Levenson et al., 2008). Indeed, the two may be mutually reinforcing, as depression also predicts frequency of reported SCD pain days (Gil et al., 2004).

\* Corresponding author.

E-mail addresses: [wobola@yahoo.com](mailto:wobola@yahoo.com) (B.A. Ola), [syates@dmu.ac.uk](mailto:syates@dmu.ac.uk) (S.J. Yates), [sdyson@dmu.ac.uk](mailto:sdyson@dmu.ac.uk) (S.M. Dyson).

It was [Brown and Harris \(1978\)](#) who first drew attention to the potential for a social genesis of depression. In the case of low-income urban women in the UK, they argued for social pathways to depression, with vulnerability factors comprised of stressful life events such as early loss of a mother or unemployment; provoking agents that acted as stressors for more vulnerable isolated women who lacked social support; and protective factors such as the existence of a close confiding relationship. Whilst the salience of this concept for an urban Yoruba-speaking setting and for men as well women requires checking, this in turn leads us to consider possible social pathways to depression, in our case the relationship between sickle cell and depression, albeit in the different socio-cultural context of the Lagos metropolis in Nigeria.

However, applied to SCD, such pathways are not reducible to the idea that culture is a static, monolithic variable that drives the stigmatizing of SCD. SCD in Nigeria has been associated with discrimination ostensibly deriving from supernatural belief systems, such as the *ogbanje* (sick children, reincarnated within families, a process orchestrated by supernatural spirits), and early childhood deaths from SCD show large overlaps with constituencies of children deemed to comprise such malevolent spirits ([Nzewi, 2001](#)). However, such cultural ascriptions are historically contingent and context-dependent. For example, [Dennis-Antwi et al. \(2011\)](#) show that, with the implementation of newborn screening for sickle cell over a twenty year period, access to basic medical care, and social support of parent groups, the discrimination against those living with SCD - which is allegedly “cultural” - begins to erode.

In this article we start by using the social model of disablement ([Oliver and Barnes, 2012](#)) as a conceptual foil to the dominant position in the existing literature, which tends to locate depression in SCD either in individual clinical symptoms or in (allegedly flawed) individual psychological responses to the condition. We aim to begin not from this perspective, but from an open, critical exploration of experiences of SCD and depression that includes a focus on the social environment. In framing our research strategy from this starting point, we adapt [Kleinman's \(1988\)](#) classic work from social psychiatry to frame a mixed-methods study of questionnaires, individual interviews and focus groups of people living with SCD and depression in Lagos, Nigeria. The focus of both individual and group discussions returned frequently to experiences of stigma, and accordingly the analysis and discussion of the findings also critically draws upon key sociological theories of stigma ([Goffman, 1968](#); [Scambler, 2006](#)).

Findings suggest that people living with SCD in Nigeria occupy a socially marginalised and devalued position in which they experience labelling stigma and widespread social disapproval for their perceived inability to live up to a range of social expectations. Aside from direct harmful experiences of social devaluation, rejection and isolation, there is a danger of individuals internalising this stigma and their socially devalued identity with negative impacts on their self-esteem. It is these processes of stigmatization and social devaluation, more than SCD or its symptoms, which emerge in participants' accounts as the primary factors affecting mental health. It was also noted that, in group discussions, participants shared these experiences, formulated challenges to them, challenged negative self-evaluations in peers, and affirmed positive identities associated with having SCD. The implications of these findings for future research and social action are also considered.

## 2. The social model of disablement and SCD literature

The social model holds that people are dis-abled (verb transitive, opposite of en-abled) not by their “condition” but by social attitudes, physical/social barriers and social conventions, and that it

is these that need to change not the person themselves ([Swain et al., 2004](#)). To locate the problem in the biology or psyche of the person themselves is, according to this model, to further oppress the person concerned, to “depoliticize the unavoidably political” ([Oliver, 1992: 105](#)), and to individualize problems that should properly be seen as social. To this extent, extant literature on sickle cell and depression is rendered problematic.

First, most of the existing medical and psychological literature merely describes an (unsurprising) link between SCD and depression followed by exhortations for clinical interventions to treat depression as well as the SCD itself ([Asnani et al., 2010](#)) or to treat depression earlier and more aggressively ([Jerrell et al., 2011](#)), sometimes with the hope of improving the disease state as well ([Hasan et al., 2003](#)). Secondly, studies frequently locate the “problems” which precipitate depression within the person with SCD themselves, arguing for example that it is complications connected with SCD that place “patients at risk for poor psychosocial adaptation, including depression and anxiety symptoms.” ([Simon et al., 2009: 317](#)), or that depression is associated with “behavioural inhibition” ([Carpentier et al., 2009: 158](#)), or insufficient “locus of control” ([Gibson et al., 2013: 451](#)). Thirdly, there is a danger that items on diagnostic scales through which depression is identified might themselves reinforce societal prejudices. For example, the 12-item General Health Questionnaire, used in [Ohaeri et al. \(1995\)](#), contains an item on thinking of oneself as worthless, which as we shall see, is a key social feature of living with SCD in Nigeria, since family, friends, neighbours and strangers are reported to regularly tell people living with SCD precisely this. Fourthly, attempts to link to social variables produce associations but no real insights (see [Pawson and Tilley, 1997](#), on the limitations of variables-based research in establishing plausible and transferable pathways to intervention). Thus whilst, for example, an association between pain episodes and measures of depression may be established, the primary purported solution remains to treat the physical symptoms ([Asnani et al., 2010](#)). Indeed, when the expected association of disease severity and depression fails to materialize as expected (such as where those with the allegedly less severe form of SCD, Hemoglobin SC disease, appear to have greater levels of depression than those with the supposedly more severe sickle cell anaemia), then the problem is again located in the psychologies of individuals, with an ascription to the “lower coping mechanisms in those with the less severe form of disease” ([Asnani et al., 2010: 6](#)). Fifthly, depression, as with the symptoms of SCD itself ([Atkin and Ahmad, 2001](#)), is variable over time. It is not always a feature of SCD, and though some authors raise the possibility of developing resilience ([Simon et al., 2009](#)), the focus remains firmly on intrapersonal factors. Finally, limited strategies are then suggested. Few studies refer to broader socio-economic and socio-political contexts (though [Hasan et al., 2003](#) refer briefly to low family income), and, although some studies refer to social support decreasing depressive symptoms ([Sehlo and Kamfar, 2015](#)), in others this concept is degraded to mean merely support with appointment-keeping and adherence to health activities ([Belgrave and Lewis, 1994](#)).

In summary, much of the existing research into SCD and depression fails to propose appropriate mechanisms to advance the cause of those living with SCD – a situation that, as noted above, has been problematised by many disability researchers and disability rights commentators writing from a social model perspective (e.g. [Oliver, 1992](#)). The social model of disability could perhaps more properly be considered the social model of disablement, or to better convey the meaning, *dis-ablement* – the act of placing social barriers in the way of people, not dismantling those that are there, and failing to conceive, enact and enforce processes that better enable disabled people to flourish in their particular societal context. The model is therefore potentially apposite in

framing a critical approach to research considering the lives of people with chronic illnesses (as well as disabilities).

This brings us to a consideration of stigma, a concept widely misused outside its sociological context (see Scambler, 2009) and illustrated at the highest level of policy-making by the World Health Organization's statement that: "Persons with SCD are often stigmatized, and SCD has major socioeconomic implications for affected persons, families, communities and the nation" (WHO, 2010: 2). This statement essentializes stigma within the individual (in the first part of the sentence) and then invokes the spectre of health care costs, constructing people with SCD as potential economic burdens and thus actively constructing the issue in a manner liable to create the stigma it purports to describe.

In framing our study, we are mindful of such critical issues, and draw on the sociological theory of Goffman (1968) and the political strategy of the social model of disability (Oliver and Barnes, 2012). The two approaches are connectable through work that requires us to attend to the social, cultural and material contexts of interaction (Scambler, 2009) and to recognize that, in enacting stigma, the stigmatizers are in positions in which they can subordinate, regulate or exclude others on the basis of power (Link and Phelan, 2001, 2014). Notwithstanding developments in stigma theory, the enduring legacy of Goffman is often underrated. Goffman emphasized that stigma is a theory of relationships, not attributes. Stigma is therefore not an "obvious" correlate of living with a chronic illness such as SCD, and such assumptions on the part of health workers may have more to do with their own professional identity formation than the nature of stigma (see Dennis-Antwi et al., 2011). Stigma is a special discrepancy between actual identity and imputed identity, in relation to the breaking of social norms or expectations.

The relational emphasis of Goffman's work (the relationship between actual and imputed identity) is especially relevant to drawing attention to the relations between the empirical (what others presume people living with SCD could/could not do) and what Bhaskar ([1975] 2008) terms the actual (what they are doing in parts of their life, perhaps unknown to or unrecognized by the stigmatizer) and the real (what they could do were, in line with the social model of disablement, discriminatory practices to be challenged and societal arrangements to be changed). In this way the important distinction between stigma as an (imputed) ontological deficit and deviance as an (imputed) moral deficit (see Scambler and Paoli, 2008) may be borne in mind, the better to trace the moral career of a person living with SCD and depression in Nigeria. The point we draw from the brief review of literature above is that much research in this area erroneously takes an ontological deficit view: that stigma results 'obviously' or 'automatically' from what someone with SCD 'lacks' in their very foundation. By contrast, our study – framed by the social model of disablement as well as stigma theory – examines stigma as derived from a (presumed) ascribed moral deficit, that functions when someone is considered blameworthy because they fail to meet certain key moral expectations of their society. Such presumptions are made without troubling to (1) find out if presumptions about aptitude are borne out; (2) establish if societal adjustments could enable otherwise disabled capacities; and (3) question the moral worthiness of the very norms and expectations of their own society.

### 3. Methods

The research comprises a mixed methods study (March 2012–April 2014) in three parts, conceived as broadly mapping onto the classic distinction made between biological disease, individual illness experience and social sickness (Kleinman, 1988). We first utilize a standardized mental health scale and a

questionnaire to identify and describe a sample of people living with SCD and depression. Having identified such a sample, we move beyond a disease conception to a concern with the illness experience in undertaking in-depth semi-structured interviews with participants aimed at eliciting detailed accounts of their lived experiences as people with SCD. We then re-interpret the third element of Kleinman's triad in the design of focus groups discussions. Instead of social sickness comprising the socio-cultural experience of the illness, (perhaps a validation of the illness state by a competent medical authority, a pre-requisite to claiming the rights inherent in the sick role), we recast the concept, following the social model of disablement, as *societal sickness*. That is, the links made by people with SCD to their concept of what is wrong with society, to societal structures, or cultural circumstances found distressing, alienating or oppressive. Bearing in mind the potential for depression to have social origins, (Brown and Harris, 1978), it is the social attitudes of others that both represents a form of societal sickness, by potentially contributing both to the depression and to the physical symptoms of SCD. In this way, the focus groups complement the interviews but expand on their scope, giving participants the opportunity to share experiences and discuss strategies for challenging and overcoming negative experiences.

Although in practice there are overlaps and interpenetrations, broadly speaking the three elements of Kleinman's model presage three stages in the research processes: questionnaires (disease); interviews (illness experience) and focus groups (societal sickness). Following approval from De Montfort University Human Research Ethics Committee and the Medical Ethics and Research Committee of Lagos State University Teaching Hospital (LASUTH), 103 participants at the state university sickle cell outpatient's clinic gave written consent to take part in the study.

First, in order to identify a sample of people with SCD and depression and describe their demographic characteristics, the *Patient Health Questionnaire-9* was used alongside questionnaires covering demographic and background information. The PHQ-9 is a nine-item self-report questionnaire and mirrors the DSM-IV criteria for major depressive disorder. It is purposely developed for use in primary care and is conventionally used in clinical as well as non-clinical practice and research. It has been reported to have good psychometric properties in both clinical and non-clinical practice (Kroenke et al., 2001; Löwe et al., 2004a, 2004b) including validation on a Nigerian population (Adewuya et al., 2006). The scores on PHQ-9 range from 0 to 27 with scores of 5, 10, 15 and 20 representing mild, moderate, moderately severe and severe depression (Kroenke et al., 2001). The PHQ-9 can also be administered repeatedly with good reliability, which can reflect improvement or worsening of depression in response to care. In terms of internal validity, the PHQ-9 has been demonstrated to closely reflect the actuality of depression (Kroenke et al., 2001).

On the basis of selecting out those not exhibiting depression, and those most severely depressed, the remaining 72 were considered eligible for subsequent stages of the study and 15 were selected for in-depth interviewing based on sampling for diversity. These interviews focused on their understanding of their sickle cell; their everyday experiences of living with SCD; how others treated them (prompting for typical, positive and negative experiences); how they thought people with SCD were regarded generally; and if, how and when they experienced low moods. The interviews (conducted by the bilingual first author in English, with occasional exchanges in Yoruba) lasted around 60 minutes and were transcribed in full by the first author. The interviewer and focus group facilitator (first author) is a Yoruba male doctor, a qualified psychiatrist. There was thus potentially social distance in terms of income and education level between researcher and participants. However, his shared personal experience of the death of a child

with SCD in the extended family, willingness to engage in instances of reciprocity (for example, on the basis of generic medical knowledge, taking time to help participants understand SCD symptoms and treatments more clearly), and a research design based around more than one-off contact, meant that good rapport was established.

Interview and focus group transcripts were analyzed using an open coding approach, staying close to the original testimonies by highlighting scripts in terms of descriptive, linguistic and conceptual comments, identifying emergent themes, and searching for cross-connections between themes. The coding process was iterative, involving reading emerging codes against the other transcripts, refining the coding scheme and re-reading these against the transcripts again until theoretical saturation was reached and the coding scheme mapped appropriately to material in all transcripts.

In presenting the themes we stay close to the original expressions of lived experience, but have been open to connection to theories of stigma from such authors as Goffman (1968), Scambler (2006) and Link and Phelan (2001). Finally, from the 15 who were interviewed, ten were available for subsequent focus groups (the others had work or schooling commitments that took them outside the geographical area). Two focus groups (FGA and FGB) of five people met on three occasions each (in one instance only four attended the second of the three FGB focus groups). The initial focus group covered similar ground to the individual interviews, and second and third focus groups invited further discussion on their perceptions of the challenges facing people with SCD and their ideas for possible change.

#### 4. Results: questionnaire

The questionnaire was given to 103 consenting patients attending the sickle cell clinic aged 16–50 (mean age 25.3, *sd* 7.7) of whom 40 were male and 63 female. The majority of their parents were from a background of petty trading, but respondents themselves had education at least to secondary level (57) if not also to tertiary level (46). Their own occupations included students (57); vocational work (17); petty trading (12); teacher (5) administration (4); accountant (4); nurse (2) and unemployed (2). The majority were Yoruba (90), either Christian (65) or Muslim (36), and all but two had the HbSS sickle cell genotype (Further demographic details in Supplementary Tables A–D). Reported median expenditure on medication for SCD was equivalent to 100% of median personal income and ten per cent of overall household income. Median number of days off work/school was seven (though with one reporting being unable to work for an entire year); median pain days per week was one; and median hospital admission per year was one (see Supplementary Table D).

Of the 103 participants, 29 were found not to be depressed, and 74 to score at some level of depression (23 mild, 42 moderate and seven moderately severe depression). A further two who scored at levels of severe depression were excluded from the study as requiring urgent support and were offered a referral to the mental health clinic, an offer both accepted. For purposes of analysis, persons with SCD were classified as depressed (score  $\geq 5$  on PHQ-9) or not depressed (score  $< 5$  PHQ-9) and were then compared in order to explore factors that might be associated with SCD and depression. Gender, ethnicity, family type, religion, father/mother's level of education; experience of blood transfusion and family history of mental illness were not statistically correlated with depression (see Table 1). Indeed, there were no significant differences on many of the variables except for two variables often used as markers of SCD severity: hospital admissions and presence of leg ulcers, and the variable of age.

In the context of our mixed methods study the primary purpose

of this stage was to identify a group living with both SCD and depression, and to provide a description of this sample. Although some statistically significant associations between background variables and depression can be identified here, as we have argued, our research aims to move beyond this type of correlational analysis to arrive at a deeper understanding of participants' life experiences and the potential interactions of social factors and their mental health. Merely correlational research cannot fulfil this aim and, as we have argued, is open to criticisms of reifying an individual deficit model of depression and of failing to problematize potentially harmful social arrangements and impacts (e.g. Oliver, 1992). For example, from Table 1, it is not clear if leg ulcers lead to depression, if depression (perhaps via lack of self-care) leads to greater risk of leg ulcers, or if a third factor such as poverty is driving both variables. What would be missing from such analyses is any account of the context of people's lives and the meanings of their experiences to them. It is to the illness experience of individuals living with SCD and depression that we next turn.

#### 5. Results: in-depth interviews

Fifteen adults living with SCD and depression were interviewed, and a description of each, anonymized by use of pseudonyms, is given in Table 2. The main themes emerging from the in-depth interviews included experiencing disapproval from significant others (family, 'friends', neighbourhood, school peers, teachers, hospital workers, people not known to them in the wider community) often linked to the monies that SCD treatment in a fee-for-service health system required; the disbelief of others concerning key SCD symptoms such as pain; the experience of stigma in relation to breaking societal norms (of physical appearance, of economic independence, of presumed physical ability or capacity, or of life expectancy); the sense that unknown community members appropriated the right to morally police the behaviours of those living with SCD; their own conceptualization of being different from others; strategies for living resiliently with SCD; and thoughts of death, including self-conscious risk-taking, suicidal thoughts and reported attempts at suicide.

An implicit endorsement of the in-depth interview approach was given by one respondent, who, in the context of explaining why her aunt was cynical about her need for drugs for pain relief, stated:

She thinks I have a kind of affliction that could be washed away by prayers or by juju (traditional healing). She gives me money grudgingly. She does things like that and I don't like them. It makes me very sad. I feel lonely. *I don't feel I am heard, I don't feel she understands what I feel and go through.* [our emphasis] [Ifeoluwa]

Many participants reported explicit disapproval and devaluation from significant others, which they connected with causing their low mood, reporting feeling "sad" [Eniola], "bad" [Babalola], "helpless" [Hannah], "uncomfortable" [Damilola], "[having] no chance to live and enjoy life" [Aderonke], "like dying" [Funke and Babalola], and "unwanted" [Ifeoluwa]. As indicated above the interviewees all recounted the serial negativity of others in society, a negativity that persisted irrespective of whether or not the stigmatizer was known to the person living with SCD.

People say negative things to you and you are not happy to move with them. You pretend to live; you are a living dead; you can't live like others because of the restrictions: 'don't do this, don't do that'. It is a terrible disease; you are not happy to tell people you have SS. It is killing; you lie to people because of sickle cell.

They call you all sorts of names your parents did not give you: “ogbanje”, “sunwonan” “wasting money”, “it would have been better to have her pregnancy terminated”. I always feel bad. “You are lazy, you are pretending.” I get embarrassed, I become lonely and ashamed, I get depressed and cry. [Eniola]

One important aspect of the testimony of Eniola is that she herself identifies the name-calling, the disabling attitudes of others and the feelings that these engender in her. She is the target of stigmatizers (I get embarrassed), experiences social rejection and lack of social support (lonely), and internalizes the stigma she is subjected to (I become ... ashamed). She then makes the link from these experiences to mental distress (depressed) and its expression in her behaviour (cry). In short, in common with the majority of interviewees, she makes an explicit link between the disabling attitudes of others in society and her own depression. In this next extract she counts her own family members, and indeed her own mother, amongst those others dis-abling her through discriminatory attitudes.

People rejected me. I felt I was alone in this world. My mum even told me I was a shame for her. Everybody started calling me names. They say look at what our mother is going through. She is bringing our mother down. Because of her we might be poor, we don't even have our father with us. I was depressed. I thought my world should end that day. I don't want to remember it again. There was nobody to tell me sorry. I was ashamed of myself, I was sad. [Eniola]

As Brown (1996: 157) indicates, a major risk for developing depression is the “lack of a close confiding relationship”. Here, then, the undermining of a secure bond with a supportive mother, by virtue of the mother herself shaming her daughter, is an issue of some significance. In two cases, such feelings of complete lack of support from significant others in relation to physical pain, the pain of isolation, social pain, and distress at experiencing discrimination, lead to reported preparations towards suicide:

I would pray to God to please take my life. I would prefer to be dead. There was even a time I took Lysol, you know Lysol? It is for wound. It is poison. My mum bought it for a cousin of mine to use to treat her hand wound. When I took the Lysol, I wanted to drink it and I wanted to die. I was in serious pains. I called my brother on phone; he said he had no time for me. I don't even want to call mum because she would not be able to leave where she was at that time. She was busy with her boss. My brother refused to come. I opened the Lysol and was about to take it, that was when my brother came in. When he saw me, he started to beg me not to kill myself. [Eniola]

It would be understandable if participants made a link between their SCD and the fact they are widely stigmatized in Nigerian society, but it transpires that the respondents have a more sophisticated understanding of the sociological concept of stigma than those, who, as Scambler (2009) notes, have come to systematically misuse the notion in academic and medical research. In the following account the person living with SCD demonstrates that

**Table 1**

Comparison of those with SCD who are depressed with those with SCD who are not depressed according to PHQ-9 on socio-demographic dimensions.

	Not depressed	Depressed	Value	df	P-value
<b>Age</b>	21.93 ± 7.86	26.44 ± 7.63	0.322	80	0.014
<b>Number of hospital Admissions</b>	0.25 ± 0.52	0.74 ± 0.85	7.967	80	0.007
<b>Gender</b>					
Female	16 (25.4)	47 (74.6)	0.610	1	0.435
Male	13 (32.5)	27 (67.5)			
<b>Ethnicity</b>					
Yoruba	23 (25.8)	66 (57.1)	1.713	1	0.188
Others	6 (28.2)	74 (71.8)			
<b>Family type</b>					
Monogamous	21 (27.6)	55 (72.4)	0.039	1	0.843
Polygamous	8 (29.6)	19 (70.4)			
<b>Religion</b>					
Christianity	20 (30.8)	45 (69.2)	1.318	2	0.517
Islam	8 (27.2)	28 (77.8)			
Eckankar	1 (50)	1 (50)			
<b>Father's level of education</b>					
None	2 (16.7)	10 (83.3)	0.000	1	0.995*
Primary	5 (38.5)	8 (61.5)			
Secondary	11 (32.4)	23 (67.6)			
Tertiary	11 (25.0)	33 (75.0)			
<b>Mother's level of education</b>					
None	2 (26.1)	17 (73.9)	0.020	1	0.886*
Primary	3 (23.1)	10 (76.9)			
Secondary	15 (36.6)	26 (63.4)			
Tertiary	5 (19.2)	21 (80.8)			
<b>Leg ulcer in lifetime?</b>					
Yes	2 (9.1)	20 (90.9)	3.900		0.031**
No	27 (33.3)	54 (66.7)			
<b>Blood transfusion in lifetime?</b>					
Yes	15 (22.7)	51 (77.3)	2.676	1	0.102
No	14 (37.8)	23 (62.2)			
<b>Family history of mental illness?</b>					
Yes	1 (20.0)	4 (80.0)	0.000	1	1.000***
No	28 (28.6)	70 (71.4)			

\*Linear by Linear Association test; \*\* Fisher's Exact test; \*\*\*Continuity Correction test.

Mother's occupation Likelihood Ratio test 10.141 df 8 p 0.255; Pearson's Chi test 9.967 df 8 p 0.267; Father's occupation Likelihood Ratio test 10.504 df 9 p 0.311; Pearson's Chi test 7.963 df 9 p 0.538.

**Table 2**  
Demographic characteristics of interviewees and focus group participants.

Pseudonyms	Age	SCD type	Sex	Ethnicity	Marital status	Education	Domestic circumstances	Employment	Religion	Focus group
Aderonke	43	SS	Female	Yoruba	Widow	Tertiary	Widow w children	Unemployed	Christianity A	
Babalola	22	SS	Male	Yoruba	Single	Secondary	Polygamous home	Artisan	Islam	–
Comfort	42	SS	Female	Yoruba	Single	Tertiary	Lives alone	Secretary	Christian	B
Damilola	29	SS	Female	Yoruba	Married	Tertiary	Pregnant	Seamstress	Christianity B	
Eniola	23	SS	Female	Yoruba	Single	Secondary	Single mother	Student	Christianity A	
Funke	32	SS	Female	Yoruba	Single	Tertiary	Polygamous	Teaching	Christianity	–
Gbenga	21	SS	Male	Yoruba	Single	Tertiary	Polygamous	Student	Christianity B	
Hannah	27	SS	Female	Yoruba	Divorced	Secondary	Father died	Trader	Christianity B	
Ifeoluwa	23	SS	Female	Edo	Single	Secondary	Living with auntie	Student	Christianity A	
Joke	39	SS	Female	Yoruba	Single	Secondary	Father dead	Catering	Christianity B	
Ope	24	SS	Male	Yoruba	Single	Secondary	Living with parents	Signage	Christianity	–
Bolaji	25	SS	Male	Yoruba	Single	Tertiary	A National Youth Service Corps member	Accountant	Islam	–
Niniola	25	SS	Female	Yoruba	Single	Tertiary	Monogamous	Community Health Worker	Eckankar	A
Adekola	28	SS	Male	Yoruba	Single	Secondary	Orphan	Tailor apprentice	Islam	–
Odekunle	50	SS	Male	Yoruba	Married	Tertiary	Monogamous	Journalist	Christianity A	

she appreciates that stigma is a relational concept:

... yes there are causes of depression especially when you are *supposed* to get something you don't have it. When you are *supposed* to have a baby and you don't have it, you will get depressed after a while. If you are *supposed* to have a job and you don't have, it would give you depression. There are some things *somebody needs in life at a stage that you need to get*, and if you don't get them it would depress you [Comfort][our emphases]

This participant echoes the original point made by Goffman that stigma is not an attribute of, for instance, a medical condition. Instead it represents a special discrepancy between the person concerned and the (alleged or actual or anticipated) breaking of social norms or expectations. Of course pathways to depression in SCD are likely to be gendered precisely because the normative expectations that are assumed to be broken in the genesis of stigma are themselves gendered expectations. For example, in a society highly valuing lineage, women are expected to bear children, and the anticipation that a woman may be unable to become a wife and mother is recognized by Comfort. This assumption, that women with SCD could not fulfil the expected societal role of motherhood, was one that was *actually* contradicted by the two of the ten women in our overall sample who had children, and could *really* (in the sense of Bhaskar's realm of the real) be contradicted through the potential of women with SCD to have children safely given appropriate health services and health staff knowledgeable about SCD (see Smith et al., 1996 on this):

My neighbors have nothing good to say about me.(...) Don't allow her to carry that load, if she did now, tomorrow she might not be able to stand up and she would be in the hospital. I cannot obey the norms of society. For instance, if an elder is with luggage, you are supposed to take it away and help carry, but in my case, they would not allow me to do that. The elders would say, thank you, please don't bother, I don't want to be responsible for your admission or death. They say words that would send you reeling backwards in shame and that sear through your heart. [Hannah]

All interviewees reported negative, discriminatory, remarks against them that were extreme and persisted over time, remarks made by family, neighbours, school/work colleagues and strangers alike. In this respect, it is noteworthy that eleven interviewees recounted thoughts of suicide, two recalled self-conscious risky behaviours and another two recounted specific preparations for an attempt at suicide including preparing to take insecticides and

antiseptic solution respectively. Conversely, some interviewees were able to note the potential of societal discrimination to produce self-fulfilling results, and to use this awareness as the basis for resilient thoughts:

People should try and encourage people with sickle cell. They should not be saying that "these people, their life is too short, we cannot accommodate them, we won't give them job, and things like that." Some relations are even afraid to marry people with sickle cell. They believe that they would die during childbirth or they will die not long after childbirth. These are attitudes of people generally against people with sickle cell. So when you live in these kinds of attitudes, you will become afraid, you will not be confident. You will start to worry a lot. You will not want to mix with people. We need a lot of encouragement. People with sickle cell can live long, they can become good manager at work, they can contribute well to the society but they need the encouragement and support of people in the society. [Bolaji]

The in-depth interviews provide an opportunity to give voice to those whose views are routinely silenced, but, as the following extract suggests, it is not a voice that is empowered, and the final phrase, where the respondent declines to speak further, appears to bear out Bellaby (1991) who cautions that recollections elicited through interviews may, at different points, be therapeutic or further disempowering.

I can only tell other people with sickle cell that they should be happy, they should not be depressed. One day things would change and there would be solution with drugs. That's all I can say. And then those who treat us badly would not know what to do. When we don't have crisis, what will they use against us? Nothing. I don't want to talk again. [Ifeoluwa]

Relevant to note here are issues raised above relating to what Oliver (1992) would call the social relations of research production. To the extent that it confines itself merely to description and empathy with experience, research utilizing only in-depth interviews has little potential to challenge and change oppressive situations that participants report. Such research has been charged with being exploitative in that it advances the career of the researcher but leaves the researched abandoned to their current situation (Oliver, 1992). This was an important part of what motivated our use of focus group discussions as part of the research strategy, since these hold the promise at least of breaking isolation by bringing together people who share a common bond. The next section examines the results of these focus groups.

## 6. Results: focus groups

Ten respondents were available to take part in a series of focus groups, and five people each took part in Focus Group A and Focus Group B (FGA and FGB), with each group meeting three times. The first focus group in each series reiterated many themes from the individual interviews, as participants were introduced to one another for the first time, and shared their challenging experiences of living with SCD in a discriminatory society. Even in the first FGs complex exchanges suggested good rapport was established early between the participants (see the [Joke-Gbenga-Damilola-Comfort-Gbenga] exchange, below, p7). However, by the second and third focus groups, the people living with SCD had moved beyond lamenting their own life-world. Instead they were able to note their own survival into adulthood as a counter to discourses of despair that presumed an early death was inevitable in someone with SCD; use the fact of being in a group to enable self-disclosures and mutual encouragement, and even to re-conceptualize the ability to endure pain, the emblematic symptom of SCD, as an affirmation of a positive SCD identity.

Aderonke: But with sickle cell, you can cope with all kinds of pain. Any pain that comes your way, you can cope better than someone that is not an SS patient.[...]. Each time I see this, I get stronger and stronger. It makes me feel that my blood is a wonderful blood.[...] The pain that SS patients go through and they survive if other people go through it they will die. An SS patient when he goes through pain, he would get up and move around, but some others when they go through that pain, that's the last of them. They will not make it, the next thing is they are in the mortuary. So that keeps me going.

Odekunle: Yes that is true.

Niniola: They cannot bear pains like us

Eniola: Yes, you are right [FGA1: 18].

In the focus groups participants began to share information with one another, such as the existence of a sickle cell clinic with better treatment for SCD; the whereabouts of a sickle cell club where good guidance on self-management was to be found, and strategies found successful in self-managing pain. This developed into discussion of the potential for mutual support and for mutual support groups, including discussions about looking after others with SCD who lacked family support; providing information to guide parents; protecting the next generation with SCD; and providing support directly for young people with SCD. This also included discussion about group support directed to those who, in striving to contradict negative stereotypes of people with SCD, are tempted to go beyond the limits of what appropriate self-care would suggest:

Joke: I know of a sickle cell woman that pounds yam for seven people in the household to make them happy.

Gbenga: Ha! She wants to kill herself.

Damilola: There are some people who would like to show that they can meet up with responsibilities and would want to satisfy others to the disadvantage of themselves. I cannot do that.

Comfort: This is what I have been saying. We need to be our brother's keeper. I could imagine many persons with sickle cell trying to prove that they are strong and they kill themselves. We can save these persons as a group. When we talk on radio and television and any other means so that people know and understand what we can do and cannot do. When people know you have hypertension, they do not stress you. And the person

with hypertension tells them and will not stress himself. Why can't they do same thing for people with sickle cell?

Gbenga: It is the person with sickle cell who is trying to prove what is not there. It is the person with sickle cell that needs to be taught on what to do and what not to do and to have our backing as a group. She is killing herself under pretense [FGB1: 13].

The participants recognize a particular type of situation in which perceived pressure to meet societal expectations runs the risk of contravening good self-care, and that it falls to them, acting as group on the basis of shared group interests, to advocate on behalf of individuals. The focus groups also permitted the emergence of a collective challenge to the negative attitudes and reactions of others in society, and a group rejection of the negative labels that others attach to people living with SCD.

Damilola: I don't even feel comfortable saying the word 'sickler'. It means I am known with sickness.

Hannah: yes. That word should not even be used for us. It is not a good word.

Joke: It is not a good word ...

Damilola: I think people should know and respect us and give us the space and what we need. It is our nature and that is it.

Gbenga: Once people cannot come to meet me and tell me the rubbish, I am okay. If there is a law that prohibits them from saying that and it is enforced, I am happy. [FGB1: 11].

Other ways in which they rejected negative labels included challenging the attitudes of others who felt they had the right to pass opinions on those living with SCD; developing the resilience to challenge negative labels; conceiving the negative attitude/reaction of others as a form of violence against the person with SCD, and challenging a nurse who projected a negative image of people with SCD by use of disparaging labels. However, in later focus groups, the emphasis moved beyond merely rejecting negative labels, to the realization that the genesis of such labels lies not in themselves but in wider society.

Odekunle: We can then go on as a group to tell people about how to support us and not to exclude us from the society by giving us names that are not our parents' names. So we need to work as a group to learn effective ways of responding individually to such persons and then learn how to address it as a group up to schools, and government levels. If we do it alone on the individual level I know it is not as effective as when it is done on the group level but I think the group can teach individuals to be confident and be strong and then the group can also create awareness on a broad basis so that most people will know and support the individuals. [FGA3: 6]

As [Kitzinger \(1994\)](#) has noted, an important feature of focus groups is the scope they provide for participants to interact, disagree and modify one another's opinions. In these series of focus groups, the participants were able to debate and challenge different proposed strategies for dealing with societal discrimination. In this instance Comfort anticipates an unintended consequence of challenging discrimination by employers, namely that they would then instigate genotype tests for workers.

Joke: I have worked in places where they sent me packing immediately they heard I had sickle cell.

Gbenga: They fired you?

Joke: Yes.

Gbenga: You can sue them. This is true. How can they send me off my job because I have sickle cell? I will fight it.

Comfort: You will worsen the case like that. If you even succeed, it will put other employers on their toes. They will be asking you to do genotype and will not give you work if they know you have sickle cell. They may even use style to send you off to avoid legal case. We need the government to tell all employers that sickle cell is not a basis for rejection or being fired at work [FGB1: 12]

She continues by suggesting an ambitious alternative strategy, one not as vulnerable to recriminations against those living with SCD, namely a policy initiative from government. In a similar vein, participants debated the merits and demerits of employing household help; different strategies for pain management; and under what circumstances a person with genotype SS might marry and have children, either with someone who had AS (a sickle cell carrier) or who themselves also had SCD. Most importantly the participants endorsed strategies that the disability rights movement has found more effective than either vague exhortations to change attitudes, or individualist approaches aiming to raise self-esteem, namely to create laws and policies against discrimination and to enforce the sanctions associated with those laws and policies. Thus Gbenga (above FG1: 11) wants a law against discriminatory remarks and one that is enforced. Odekunle (FGA3: 6) speaks of working at school or government level, that is at organizational levels. Comfort (above, FGB1: 12) argues for government to set compulsory frameworks for employers to adhere to in relation to SCD.

The culmination of focus group discussions was an emergent self-awareness of 'groupness' on the part of the participants, that they shared a common bond, and had collective social interests in common. This was marked, first, by showing themselves willing to begin to address social barriers. For example, they are prepared to talk themselves about sickle cell in public, to share the benefits of standing up for SCD and promulgate the idea that persons with SCD should represent themselves.

Odekunle: I also think we can help ourselves, I mean members of our family, others with sickle cell. As a group they can come to us for counselling, we can support them in times of need, provide emotional support. We can share experiences that make them to realize that living with sickle cell is not a death certificate. We can organize activities for ourselves (...). I know a lot of sickle cell persons that come to me for advice on one thing or the other. As a group we can get more training and be of help to our members. I think we can do this [FGA3: 12].

A particular source of frustration was that the established non-governmental organization did not employ anyone living with SCD themselves, and was felt to speak over and above those living with SCD, with the implication that their interests were not always appropriately represented,

Eniola: I believe there should be house to house awareness or community one. I believe that people are creating awareness about SS but it is not just effective since it is not house to house.

Aderonke: Who are the people creating awareness?

Eniola: We have NGOs now doing it.

Aderonke: How many times have you seen them on air or on the radio? See and I thank God that this thing is being recorded. You see, the NGOs, they are using us to enrich themselves. How will their programs be effective?

Eniola: A non-SS should not speak for us ...

Odekunle: That is how we want it now

Ifeoluwa: Yes, we don't want a non-SS to represent us, we don't want them to speak for us. We can do it and we will do it. [FGA2: 8]

The participants thus recognized that as a group they needed to make strategic links to others who might help them. They realized that they need to canvass support from significant others, whether this was engaging with (currently non-representative) NGOs; educating significant others to be better advocates for SCD, or educating other community leaders about SCD.

Finally, this led group participants to consider themselves more akin to group members, who increasingly referred to themselves as people with shared collective interests. It also encouraged them to delineate the areas of social policy that concerned them, which included: campaigning for genotype tests; training people with SCD to be peer counsellors; accessing and using the media for campaigns; the importance of getting many stories of SCD into the public domain because not all SCD experiences are the same; instigating reporting mechanisms for those who abuse people with SCD; ensuring support mechanisms for people with SCD; identifying possible strategies to achieve reasonable adjustments in schools/employment; ensuring strategies for reasonable adjustments for SCD were undertaken in the hospitals, and considering microfinance and cooperative approaches to improve the finances of people living with SCD.

In summary, the findings of the focus groups confirm the experiences more generally of group work (Mullender and Ward, 1991), including group work in the context of research (Fleming and Ward, 2004). Coming together in a group gives people who share a common bond a sense of strength, and through moderated interaction they are enabled to share practical means of support. They can collectively reject negative labels attached to them, for example, that they are the conduits for malevolent spirits, a drain on family income, or that they are defined by their disease, as in the term 'sickler'. They can, in the spirit of the social model of disablement, begin to resist the accusation that the problem lays within their own biology or psyche, and relocate the problem in wider social relations, especially in the disabling and discriminatory attitudes of others. They can recast the issue within their own frame of reference, and identify the challenges on their own terms. Finally, they come to an appreciation that they can work together to challenge barriers to their full participation in society, whether this is in becoming parents, in schooling or employment, or simply in receiving respect from their health care provider.

## 7. Conclusion

For the most part, literature on sickle cell and depression has tended to focus on linking variables, without contextualizing the lived experiences of those with SCD and depression within their social, economic and cultural contexts. We feel that our study counters the limits of extant literature in three respects. First, the study relocates the problem from the clinical symptoms or individual psyche to the dis-abling environments and attitudes that people with SCD face. Secondly, the study relocates the site of enabling action from the researchers to the people with SCD



themselves. Thirdly, the potential for group resistance to disabling perceptions and actions was built into the research strategy, and research contact is conceived as ongoing, not a one-off, and several participants are now working as paid facilitators of further SCD research and advocacy work.

Our study signals the possibilities of a different, social approach to sickle cell and depression. Whilst using a disease conception and standard depression inventory to identify and describe our sample, we have argued that research seeking correlations between depression severity and individual- or disease-level variables would add little to the existing literature and would risk perpetuating an individual model of disease that neglects the role of social factors in triggering depression.

At the level of depression-as-illness-experience, our study contextualizes the experience and meaning of depression within the life-worlds of those living with SCD. The clinical pain associated with SCD is mirrored by a social pain that consists in experiencing the discriminatory attitudes of others, including significant others who in other circumstances might provide the close, confiding relationship that might insulate people living with SCD from depression. These discriminatory attitudes are especially pernicious given the breadth of their spread across social environments and the fact that in many cases they appear to originate in proximal social circles such as family, friends, neighbours, school peers, work colleagues and church members, as well as strangers in the street. Such stigmatizing and discriminatory attitudes and behaviours are conceptualized by people living with SCD as directly contributing to their low moods, depression and suicidal feelings. Moreover, we noticed a number of our participants having the insight to attribute such stigmatizing experiences not to the medical condition of SCD, but rather to social relations and interactions in which they are stigmatized and devalued by a wide range of other people, and in which other people (often erroneously) assume that people with SCD will be unable to live up to societal norms and expectations that are societally valued. In many ways, such as having educational qualifications, undertaking paid or unpaid work, in being parents and by virtue of living as adults our participants embodied a living rebuttal to such assumptions. Where they continued to fall short of expectations in actuality, they would not necessarily do so were reasonable adjustments to the social framework made, in strong school policies (Dyson et al., 2010), in employment practices and in extending health insurance coverage.

At the level of depression-as-societal-sickness, participants were clear in conceptualizing their experiences as (at least partly) the product of societal discrimination. In this respect, it was significant to note the manner in which our participants used the membership of the groups to jointly share and challenge the negative attributions of others, to encourage and support one another in the pursuit of their own goals and potential, to propose and discuss practical means for mutual support, to share awareness of the barriers they face to full social participation, and to explore possible means of achieving social change. In line with our initial hopes for this element of the research, they began to speak not just *in* a group, but *as* a group. In this respect one might conceptualize a trajectory in which the focus group discussions (in Goffman's terms, discussions held "backstage") serve to rehearse their opinions, their resilience to stigma and their collective actions, in anticipation of what social actions might look like "frontstage", out in the wider society where discriminatory attitudes and disabling barriers are to be challenged.

The findings suggest that, contra dominant trends in existing research, a focus on the social environment of people living with chronic conditions such as SCD reveals the existence of progenitors of depression that are connected not to the condition itself, nor to individual psychological characteristics, but to distress that people

experience as a result of stigmatization, social devaluation and rejection. There is much scope for assessing whether innovative social interventions around SCD and depression can improve care outcomes. For instance, do either consciousness-raising or involvement in self-advocacy work improve the mental health of people with SCD? Do robust school policies improve the mental health of young people with SCD? Can economic initiatives such as local exchange trading schemes, credit unions, or microfinancing improve the physical and mental health of people with SCD?

In conclusion, people living with SCD experience extreme discrimination. Rather than focus on the individual – whether on clinical symptoms or on alleged maladaptive psyches – it is useful to focus on broader social contexts. People with SCD themselves link experience of discrimination to their mental distress, and correctly identify stigma as arising from assumptions that they break societal norms, *not* from their SCD *per se*. In groups people with SCD can feel strong, reject negative labels, challenge discrimination, and locate the level at which change is needed as organizations, policies, governments and laws. It is this emerging sense of groupness, and the demands they intend to make as a group, that holds much promise for ameliorating their situations in the future.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2016.05.029>.

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