

East African Medical Journal Vol. 78 No. 4 April 2001

ATTITUDES AND BELIEFS OF RELATIVES OF PATIENTS WITH SICKLE CELL DISEASE

J. U. Ohaeri, MD, Professor of Psychiatry and W. A. Shokunbi, Consultant Haematologist, College of Medicine, University of Ibadan, Ibadan, Oyo State, Nigeria

Request for reprints to: Dr. J. U. Ohaeri, Department of Psychiatry, Psychological Medicine Hospital, P.O.Box 4081, Safat, Kuwait, 13041.

## ATTITUDES AND BELIEFS OF RELATIVES OF PATIENTS WITH SICKLE CELL DISEASE

J. U. OHAERI and W. A. SHOKUNBI

### ABSTRACT

**Objectives:** To assess the attitudes and beliefs of relatives of eighty one SCD sufferers on aspects of the disease, the relationship of their responses with global rating of burden, and compare with the responses of relatives of cancer patients from a similar previous study.

**Design:** Cross-sectional survey.

**Setting:** Haematology outpatient clinic.

**Measurements:** Burden questionnaire and Goldberg's GHQ-12.

**Results:** Natural/genetic aetiologies were the most commonly proffered (>70%), compared to 19.2% for cancer. Only 8.6% believed in re-incarnation theory for SCD. More than eighty three per cent believed that caring had made family ties closer. Though 43.2% felt depressed about patient's condition, 83.9% felt glad with caregiving roles, and there was no evidence of stigma from the neighbourhood. Only 4.9% had known about possibility of SCD before marriage. Over twelve per cent believed that SCD induced inferiority feelings in patient, and 33.3% that SCD caused lower intelligence. Beliefs and attitudes were not significantly correlated with global rating of burden.

**Conclusion:** Beliefs about aetiology reflect availability of proven knowledge. The caregivers evidenced emotional disposition for community psychosocial support roles if they can be supported by social welfare and health education.

### INTRODUCTION

Sickle cell disease (SCD) is a family of blood disorders, including sickle cell anaemia (HbSS), sickle cell haemoglobin C disease (HbSC) and sickle cell B thalassaemia (SB Thal), which have in common a tendency for red blood cells (RBC) to sickle (or distort into a crescent shape) under certain conditions. The effects include, recurrent bone pains (sickle cell) crises (which always necessitate emergency hospitalisation), chronic anaemia, frequent bacterial infections, gradual deterioration of tissue and organ function, and the risk of shortened life expectancy.

SCD afflicts up to 100 million people worldwide, predominantly in black people (in Africa, Europe and the Americas), Arabs and those of Asian ancestry(1). In Nigeria, the incidence of HbSS is about two per cent and that of HbSC is approximately 0.7%(2). The life expectancy of patients with SCD is quite variable. Some die at an early age while others have virtually unrecognised condition and are able to live active lives, but a few live till advanced age. Patients who are older than 30 years of age are called long term survivors. Progress in the scientific knowledge of SCD and community awareness programmes have made it possible for patients to have access to treatment techniques that have helped many of them to live longer than before. With this achievement, attention is now focussing on the psychosocial dimensions of the illness, in order to achieve better quality of life for SCD sufferers and their families.

Psychological responses to SCD could be influenced by cultural factors, such as attitudes to heredity, illness and disability. Any relationships between illness and environment, would be mediated by factors such as perceptions, attitudes, knowledge, behavioural styles and use of coping strategies(3). Cognitive factors of this kind may be much better predictors of overall adjustment than either illness or environmental factors(4).

There is need to assess underlying misconceptions, ignorance and unhelpful attitudes because an understanding of these will help to facilitate changes in service provision. Understanding these attitudes will help to fashion appropriate public health education programs to increase awareness and knowledge of the condition. Jackson(5) has suggested that a most important facet of any service program in SCD is that of creating an awareness of the disorder, followed by presentation of accurate information.

In Nigeria, there are few institutional facilities for SCD care, no medical insurance scheme, no national social welfare and effective community based programs. The responsibility for caring for such patients, therefore, largely rests on their relatives (also called informal caregivers). Proper management of SCD should involve attempts at appreciating the attitudes and beliefs of these caregivers towards the disease.

The earliest Nigerian psychosocial research report on these caregivers indicated that 63% of fathers and 93% of mothers felt that SCD in their children had made the marriage an unhappy one(6). Recently, an attempt has

been made to articulate a questionnaire for assessing the psychosocial burden of SCD on caregivers(7). The other Nigerian reports were concerned with assessing the psychological status and adjustments of SCD sufferers(8-10). In spite of the fact that Africa has the highest concentration of SCD sufferers, there are no reports from Nigeria in particular, and Africa in general on care providers perceptions of SCD.

Public attitudes to SCD appear to differ between the developed and developing nations. In the USA and UK, researchers have noted that a social stigma is attached to sickle cell trait, as it is confused with SCD, thereby grossly exaggerating the minimal risk of illness associated with it. For nearly a decade ago, this contributed to significant discrimination against careers in employment, in obtaining life and health care insurance and legislation(3,11,12). In Nigeria, social scientists were concerned with determining whether the local culture labelled SCD sufferers as "Ogbanje" or "Abiku" ("repeater babies") - a reincarnation theory among the Igbos and Yorubas, concerning persons who are supposed to be rapidly cycling into brief periods of earthly existence(13,14). In the series of cases reported from Ghana, Konotey-Ahulu(15) indicated that much medical and social science practice in relation to SCD has conformed to an invisible philosophy that holds that elimination of the genes responsible for SCD is a more desirable objective than support for affected individuals.

In this paper, we report the findings of our study of first degree relatives of SCD patients attending the haematology clinic of a Nigerian general hospital. The objectives of the study were: to highlight the views of these relatives on the possible causes of SCD; to understand how they feel about patients' condition, through assessment of feelings of anger, social embarrassment (stigma) and depression; to find out whether they have difficulty accepting responsibility for caring for patients; to know their views on institutionalisation of patients; to assess caregivers' perceptions of the attitudes of other family members towards the illness; to assess the relationship of responses to the above issues to the global rating of burden of care and; to examine the factors associated with responses on these issues.

The results are compared with the findings of a recent similar study of cancer patients in the same hospital(16) and discussed in the light of the studies from developed countries. The findings of this type of study should help clinicians and policy makers to appreciate the disposition of relatives towards caregiving responsibilities, with a view to understanding the role that these caregivers can play in the community care of SCD sufferers.

## MATERIALS AND METHODS

This report represents part of the findings of a larger study of the psychosocial and economic burden of SCD on relatives of patients attending the adolescent/adult haematology clinic of the University College Hospital, Ibadan.

*Questionnaire (available from the authors on request:* Details of the questionnaire, initially used for cancer caregivers, have been presented elsewhere(16,17). It contained items to elicit "objective" and "subjective" burden of chronic illness on caregivers, following the recommendations of Platt(18) and Hoening and Hamilton(19).

The items of the questionnaire that are of interest to this report concerned the following questions and response options:

- (i) How do you feel about this patient's condition?; No particular feelings; I feel angry for having to be involved.; I feel embarrassed for having such a relative; I feel depressed about his/her condition; I cry frequently because of his/her condition.
- (ii) Do you find it difficult to accept responsibility for caring for this patient?; I am glad caring for him/her; Occasionally, I feel fed up with this responsibility; Frequently I feel fed up with it; In fact, I feel fed up and wish to be released from this responsibility.
- (iii) Would you like this patient to be kept in a hospital or special institution for care always?; No.; Occasionally, I feel the patient should be put away in such an institution where I could visit at my own time; Frequently I feel the patient should be put away in a special institution; Regularly I feel so.
- (iv) What is the attitude of close family members towards this patient's condition?; Responses here were placed in mutually exclusive categories (Yes/No), to elicit feelings of anger, social embarrassment, depression, sympathy and support.
- (v) What is your view about the cause of this illness? Also, responses here were placed in mutually exclusive categories (Yes/No) to assess belief in aetiological factors, such as natural, preternatural and supematural causes(20).
- (vi) How much difficulty do you (and the family) have in coping with this patient's condition?; None at all; Mild difficulty; Moderate difficulty; Severe difficulty.

The first part of the questionnaire contained items on social-demographic characteristics of the patient and respondent. Disease severity was assessed by collecting information on frequency of hospital attendance and hospital admissions, severity of pain during crises, and how frequently the patient is taken to sleep at church for prayers, and to the traditional (native) healer's for treatment. The last part of the questionnaire consisted of the 12-item version of Goldberg's General Health Questionnaire (GHQ-12)(21). The GHQ-12 is a screening instrument to delineate probable psychiatric caseness. It is particularly useful for physically ill subjects, because it does not contain somatic symptoms, which may well be caused by the physical illness. It has been used by our group in previous studies of non-psychiatric subjects(10,16,22).

We have already reported on the highly significant reliability indices of the questionnaire when used for cancer relatives. The validity of this slightly modified version for relatives of SCD patients was tested by being presented for comments to senior haematologists and nurses in the specialty. They all made complimentary remarks on the questionnaire.

*Procedure:* The study involved private interview of first-degree relatives who accompanied consecutive SCD patients to the adolescent/adult haematology clinic of the University College Hospital, Ibadan (UCH), Nigeria, for treatment. To be included in the study, the patient had to be accompanied to hospital by adult relatives (at least 16-year old), who were directly involved in informal care giving roles at home (either living with the patient or seeing the patient regularly). In our culture, it is quite common

for patients to be accompanied to hospital by relatives(16,17). Also, as is usual in our culture for this type of study, all the patients and relatives approached, consented to be interviewed.

For each patient, the first degree relative that was most intimately involved in care giving roles was interviewed privately. All the interviews were conducted by a senior female research nurse (on regular employment for that purpose), and who also interviewed the relatives for the earlier study of relatives of cancer patients. She was trained in the use of the questionnaire by the senior author. Data collection commenced when we were satisfied that she had achieved high competence in reading out the items of the questionnaire in Yoruba, (the local language), and rating the responses. In consideration of the relatively low literacy rate in our country, and in order to make for uniformity, all the subjects had the items of the questionnaire read out to them, and the research nurse rated their responses. Subjects literate in English were interviewed in that language, while the others were interviewed in Yoruba language.

In view of frequent work stoppages occasioned by political instability and industrial strikes, we could only recruit 81 relatives between September 1995 and August 1996, who fulfilled the study's inclusion criteria.

*Data analysis:* Data were analysed by computer, using frequency counts and Chi-square tests (with Yates' correction, where necessary) for categorical variables. Continuous variables were analysed by means of t- tests, Pearson's correlation, and multiple regression analysis, at 5% level of statistical significance. Multiple regression analysis was used to delineate factors that could predict felt subjective burden, using the item on how much difficulty the relative experienced coping with the patient's condition, as dependent variable.

## RESULTS

*Social-demographic characteristics of patients and caregivers (Table 1):* Majority of caregivers (58%) were mothers, and 74 (91.4%) lived in daily contact with the patients. There were no significant sex differences in age, social-economic indices, indices of burden and psychological distress scores. In view of their age groups, majority of patients were either students or junior civil servants, while most of care-givers had at least secondary school education (68.1%), and were gainfully employed (59.3%) as civil servants, teachers and in medium and large scale private businesses.

*Beliefs and attitudes of caregivers (Table 2):* The most favoured aetiological factor was the natural/genetic one (over 70% of responders). Preternatural (curse by enemies and "Satan's work") and supernatural (witchcraft) factors were cited by less than 19% of subjects, while only 8.6% care-givers believed that SCD sufferers were "repeater babies" (*Abikus/Ogbanjes*). After responding to the list of possible causative factors, care-givers were requested to choose the factor that was of utmost importance. Only one caregiver believed that the reincarnation theory (*Abiku/Ogbanje*) was of utmost importance.

In spite of the fact that many (43.2%) felt depressed about the patient's condition, 83.9% felt glad with their care-giving roles. None of the respondents felt angry or embarrassed for being involved in caregiving roles.

**Table 1**

*Social-demographic characteristics of patients and caregivers (interviewees)*

	n= 81 (%)
<b>A. Patients' characteristic</b>	
1. Sex: Male	44 (54.3)
2. Occupation of patients:	
- Employed	25 (30.8)
- Students	38 (46.9)
3. Age: (years): Mean (SD)	24.5(12.1)
Range	
9-20	36 (44.4)
21-30	33(40.7)
31-40	5 (6.20)
41-85	7 (8.60)
4. Level of education: No formal education	5 (6.2)
5. Marital status: Single	66 (81.5)
6. Relationship with caregiver:	
- Mother	47 (58.0)
- Sibling	14 (17.3)
- Spouse/child	17 (20.9)
7. Whom patient lives with:	
- Parents	63 (77.8)
- Sibling/ child	12 (14.8)
<b>B. Caregivers' characteristics</b>	
8. Level of education	
-No formal education/primary school	25(30.9)
9. Occupation: Unemployed/ petty trader	33 (40.7)
10. Mean age (years) (SD)	41.1 (14.2)
11. Caregiver is married	58 (71.6)
12. Caregiver lives with patient	74( 91.4)
13. Caregiver has at least one child with SCD	30(37.0)
14. Caregiver has lost at least one child by SCD	23(28.4)

**Table 2**

*Beliefs and attitudes of caregivers to SCD (n =81)*

Variable	Frequency (%)
<b>A. Possible causative factors</b>	
- A natural illness	72(88.9)
- Inherited from both parents	58(71.6)
- A form of punishment from God	6(7.4)
- A form of curse by enemies	9(11.1)
- Caused by witchcraft	4(4.9)
- Patient is a reincarnation of someone with similar illness	7(8.6)
- It is God's will	51(62.9)
- It is Satan's work	16(18.5)
<b>B. Attitudes to patients by caregivers</b>	
- Feel depressed/cry frequently because of patient's condition	35(43.2)
- Feel glad caring for patient	68(83.9)
- Would not like patient institutionalized	63(77.8)
<b>C. Attitudes of other family members to patient</b>	
- Strong feeling of sympathy and concern	76(93. 8)
- Helpful and supportive	75(92.6)
- They feel depressed about patient's condition	32(39.5)
- Caring has made family ties closer	68(83.9)
D. Positive attitudes towards doctors and nurses	72(88.9)
E. Patient has recently used native herb ("orin ota")	28(34.6)
F. Patient has recently used other native medications	15(18.5)
G. Parents realized possibility of SCD before marriage	4 (4.9)
H. Know genotype of other children	53(65.4)
I. SCD has made patient's intelligence to be lower	27(33.3)
J. SCD has made patient feel inferior	10(12.3)

Respondents believed that other family members were predominantly sympathetic and supportive (at least 92%), and 83.9% felt that caring for the patient had made family ties closer. There was no evidence of stigma from the immediate neighbourhood.

Caregivers had predominantly positive attitudes towards doctors and nurses (88.9%). However, only four (4.9%) had known about the possibility of SCD before marriage, and a third had not yet determined the genotype of their other children. Only a few (12.3%) felt that SCD had led to feelings of inferiority in the patient, while a third believed that the disease had made the patient's intelligence lower.

In an attempt to delineate factors associated with global rating of psychosocial and economic burden by caregivers, a number of cross-tabulations and chi-square tests were done. None of the beliefs about possible causes of cancer, was significantly associated with global rating of burden ( $p > 0.05$ ). Also, global rating of burden was not significantly associated with the emotional feeling of relatives towards the patients ( $p > 0.05$ ).

## DISCUSSION

The findings cannot be generalised, since the subjects were not a representative general population sample. However, the social-demographic characteristics of SCD patients were similar to those of a previous study of adolescent/adult clinic attendees(10). The care-givers interviewed had similar social-demographic and psychopathological symptom (GHQ-12) scores with junior and middle level civil servants at Ibadan, who were involved in a recent study(22). Hence, there is no reason to suggest that the subjects involved in this study differed in any other way from the Nigerian urban general population in any special way other than the illness variable. In psychosocial terms, the research evidence suggests that families with chronically ill members do not differ significantly from others(23).

Another limitation of our study is the fact that only one care-giver was interviewed per family, so that it is reasonable to expect that a greater depth of information on family burden and attitudes will be obtained by assessing multiple informants, including the patients' adaptation and opinion on burden. Compared with the results of a similar study of relatives of patients with cancer in the same hospital, we found that, although the summary scores on disease clinical severity were much higher for cancer (7.6 versus 4.4), the two groups of care-givers had similar mean GHQ-12 scores (1.3 for cancer, and 1.3 for current study).

However, there were marked differences in beliefs about aetiological factors. While 88.9% of SCD care-givers felt that it was a natural illness, only 19.2% cancer care-givers held the same view. Whereas only 18.5% of SCD care-givers believed that it was "Satan's work", 49.3% of cancer care-givers attributed their disease to this aetiology. However, similar few proportions of both groups

believed in the re-incarnation theory of causation (8.6% SCD and 5.5% of cancer care-givers). The apparently more enlightened opinion expressed by SCD care-givers on aetiological factors cannot be accounted for by social-demographic factors, because cancer care-givers were supposed to be better informed; since they had a higher proportion of subjects with formal education (73.3% versus 69.1%), in gainful employment (70.4% versus 59.3%), and they were younger (35.6, SD, 11.5 years versus 41.1, SD, 14.2) than SCD care-givers. One possible reason for the differences in views on aetiological factors between the two groups is that, since SCD is rather "endemic" to this population, and its genetic basis is well understood, research and public health education on it have a much longer history in the country than cancer(24). In addition, there are far more specialists and institutions engaged in SCD work in the nation than cancer(16). This implies that, contrary to popular opinion(25), care-givers could be discriminatory in ascribing aetiology, in such a way that, those diseases whose aetiologies have been proven, (for example, SCD) are labelled as natural; whereas for disorders that are still an enigma-such as mental disorders(25) and cancer, the supernatural/preternatural beliefs holdsway. This is in line with the opinion that the popularity of the so-called African traditional beliefs is a stage in the historical development of the people, based on available information on disease causation(26).

Compared with the results of a 1970s Nigerian survey, where 63% and 93% of fathers and mothers, respectively, felt that SCD in their children had made the marriage an unhappy one(6), 83.9% of care-givers in our study believed that caring for the patient had made family ties closer. Although there is an impression that marital conflict and strain are more common among families with chronically ill children(3), Ferrari(27) found that some parents reported improvements in the quality of their relationship and the closeness of the family as a result of having a chronically ill child in the family. In the Nigerian case, this positive finding is probably a reflection of the success of over two decades of public health education and increased awareness in the general population, along with increased literacy rate and greater societal sophistication. However, the inadequacy of this public health education is shown by the fact that only 4.9% of parents had known about the possibility of SCD before marriage, while a third had not yet determined the genotype of their other children.

Our findings support the impression that in Nigeria, SCD is neither associated with the *Abiku/Ogbanje* (i.e. "repeater babies") phenomenon(13,14) nor is it socially stigmatising in the immediate neighbourhood. Concerning the social stigma associated with sickle cell trait in the USA and UK, Mohammed(28) has suggested that it is the minority ethnic group status that SCD families belong to that is the problem, rather than the disease, *per se*.

In conclusion, our findings support the impression that, in the absence of national social welfare and medical insurance programs, families with chronically ill members have the emotional disposition and social potentials to

play psychosocial supportive roles, if they are given support by the formal health care sector and social welfare(17).

### Appendix

*Part of questionnaire on: the burden of living with patient with sickle cell disease*

*Opinion of care-givers on aspect of the disease*

- Q1. Whom does the patient live with?  
 Q2. Relationship of caregiver with the patient  
 Q3. Level of education of caregiver  
 Q4. Occupation of caregiver  
 Q5. Age of caregiver  
 Q6. Marital status of caregiver  
 Q7. No. of living children of caregiver  
 Q8. No. of children dead from SCD  
 Q9. Is there any other member of the family who has some serious sickness or serious misfortune in the past one year?  
 Q10. For how long (years) have you been involved in caring for this patient?  
 Q11. Do you live with this patient in the same household?  
 Q12. How often (days) do you see the patient in the week?  
 Q13. How frequently is the patient brought to the hospital/clinic in the past year when not in crisis?  
 Q14. What is the longest period of hospitalisation at any period in the past year?  
 Q15. How many times has this patient been admitted in hospital in the past year?  
 Q16. How frequently is the patient in severe pain or serious discomfort in the past year?  
 Q17. How frequently is the patient taken down to sleep at the church?  
 Q18. How frequently is the patient taken down to see traditional healers or sleep there?  
 SUBJECTIVE BURDEN (please see text for response options to the following)  
 Q19. Has the problem of caring for the patient caused a general atmosphere of tension or hostility in the house?  
 Q20. Has caring for the patient caused disagreements or quarrels or fights among family members?  
 Q21. If there is family/marital disharmony, when did it start with relation to the patient's condition?  
 Q22. Have relatives, friends and neighbours stopped visiting or curtailed their visits to the house because of the patient's illness?  
 Q23. Does the family feel embarrassed that so many people have to know that the patient has this sickness?  
 Q24. Does the family feel secluded or isolated from the neighbourhood (or general community) because of the patient's sickness?

*Attitude of family to patient's condition (yes/no to each item)*

- A. What is your view about the following possible causes of the illness?  
 1. It is a natural illness that can be explained by doctors YES/NO  
 2. It was inherited from both parents  
 3. It is a form of punishment from God

4. It is a form of curse by enemies  
 5. It is caused by witchcraft  
 6. It is God's will  
 7. The patient is a reincarnation of someone who had a similar illness in the past (Abiku/Ogbanje)  
 8. It is Satan's work  
 9. It was inherited from the mother only  
 10. It was inherited from the father only  
 B. Of the above possible causes, which one do you think is the most important  
 C. How much difficulty do you have coping with this patient's condition? (Please see text for response options)  
 D. How do you feel about the patient's condition?  
 E. Do you find it difficult to accept responsibility for caring for this patient?  
 F. Would you like this patient to be kept in a hospital or special institution of care always?  
 G. What is the attitude of close family members (e.g. spouse, parents, siblings) towards the patient's condition (YES/NO responses)?  
 1. Nothing remarkable. No particular feelings YES/NO  
 2. Feel angry about patient's condition  
 3. They feel embarrassed for having such a relative  
 4. They blame God for giving them such a difficult problem to handle  
 5. They feel depressed about the patient's condition  
 6. They cry frequently about the patient's condition (at least one or two of them).  
 7. They feel nonchalant about this problem  
 8. They have strong feelings of sympathy and concern for the condition  
 9. They are very helpful and supportive  
 H. During crises, do other close family members want this patient kept in an institution of care always?  
 J. How has caring for this patient affected family closeness and strength?  
 K. Attitudes towards doctors and nurses  
 How do you feel towards the doctors and nurses concerning the part they play in this patient's condition Graded 6 response options, to choose one  
 L. Does the patient use any traditional medication for this illness? (state type, if YES)  
 L. FOR PARENTS:  
 1. Did you and your spouse realise that you could have children with this type of illness before you got married?  
 2. Do you know the genotype of your other children?  
 M. Your view about the personality and intelligence of the patient  
 1. Do you think this disease has made this patient feel inferior?  
 2. Do you think that this disease has made this patient's intelligence or performance in school and elsewhere to be lower than what it should be?  
 3. What else do you think the hospital should have done for the patient?  
 4. How do you think that this disease can be prevented?

### ACKNOWLEDGEMENTS

Mrs. G. Oyin Awosika interviewed the subjects. Miss Tosin Cole played an invaluable role in data collection and analysis. We thank the relatives and patients who gave of their time to be interviewed.

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