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Perceived stress factors and coping mechanisms among mothers of children with sickle cell disease in western Nigeria

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Abstract

While many studies have looked at the stressful effects of chronic illness of those who suffer such conditions, less is known about the effects on caregivers, especially in developing countries. Mothers in particular must bear the brunt of care and stress for children who have sickle cell disease (SCD). A sample of 200 mothers attending six SCD clinics in both public and private hospitals in the Ibadan–Ibarapa Health Zone of Oyo State, Nigeria, were interviewed. Stress levels were measured using an instrument comprised of stressors listed by mothers themselves in focus group discussions that preceded the survey. Higher levels of stress were associated with less educated and older women, as well as non-married women and those in polygamous households. Stress levels were also greater when there was more than one child with SCD in the family and when the index child was of school age. Coping mechanisms varied according to the category of stressor. Financial stress and disease factors were met with confrontation, while family sources of stress were either complained about, accepted or avoided. Knowledge of the different types of mothers who experience more stress and of their preferred coping mechanisms can be useful in designing clinic-based counselling.

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Introduction

Managing a life-long chronic illness such as sickle cell disease (SCD) is burdensome on those affected and has been correlated with the psychological well-being of the sufferers (Bamisaiye *et al.*, 1974; Olatawura, 1976; Akenzua, 1990; Olley *et al.*, 1994; Ohaeri *et al.*, 1995). Of equal concern should be the burden of disease on the caregivers within the family. In the case of a disease that affects children from birth, it is the mother who bears most of the burden and is therefore subject to the most stress.

Stress, if not coped with, may be detrimental to health and manifest in problems such as coronary heart disease. While the results of stress have been amply documented in research on the male population, less is known about what happens when women experience stress (Kushnir and Kasan, 1992–93; Hall *et al.*, 1993). Studies have found that working class women (which would likely include a majority of women in southwestern Nigeria where this study took place), who often lack strong social support systems, are three times as likely to experience coronary heart disease than their counterparts in white collar jobs (Hall *et al.*, 1993).

Coffman and Levitt (1993) reported that actual hospitalization of infants, not their risk status, was associated with maternal stress. Hospitalization itself often resulted in relationship changes, with less contact with friends and relatives who could provide social and emotional support in coping with the stress.

Most often the impact of these emotional disorders is felt more by the mother of the affected

child than even the father or any other member of the family, especially since the responsibility of caring for a sick child is usually part of the home-making role of the mother. According to McBride and Black (1984), mothers appear to be more sensitive to troubled children, because it is the mothers who bear the children. They are more likely to feel responsible for a diseased condition. Breslay (1983) and Gallagher *et al.* (1983) established that, except in rare instances, it is the mother who will provide the extra-ordinary care required by a developmentally disabled child.

In comparing the health status of 209 chronically ill children and their mother's mental health status, Jessop *et al.* (1988) found that children with more functional limitations had mothers who were more symptomatic of mental disease. In a study that identified symptoms of grief and patterns of coping in mothers of chronically ill children, Han (1990) found that the mothers worried about the ill child's future and her responsibilities in taking care of the ill child. Most of the mothers used similar ways of coping that included problem-focused coping, detachment, wishful thinking, seeking social support and focusing on the positive.

Eiser *et al.* (1992) investigated age and gender differences in parents' adjustment to chronic disease in their children who suffered from diabetes, asthma, cardiac disease, epilepsy or leukemia. When the ratings concerning adjustment to the disease condition were compared between mothers and fathers, the mothers were found to adjust less.

Weissman *et al.* (1987) found maternal depression to be correlated with significant physical, mental health and school or behavioural problems among their school-aged children. Thus high levels of depressive symptomatology have implications for the well-being of children.

Studies have shown that psychological distress among mothers of children with SCD may influence the prognosis of the child (Diggs and Flower, 1971; Fleming *et al.*, 1979; Aniowu *et al.*, 1981). A particularly stressful aspect of SCD management is the unpredictability and episodic nature of the illness and its attacks on children. These continued attacks result in shopping around for a 'cure', placing mothers in the hands of often unscrupulous spiritual, herbal and even orthodox healers. There is also fear and anxiety related to the future of subsequent pregnancies (Olatawura, 1976).

Ilfield (1977) stated that as the number of stressors to which a woman was exposed to increases, the risk of depression also increases. One might infer then that reducing the number of stressors to which a woman is exposed could lead to a reduction in risk of depression. In the case of SCD in Nigeria, it is first necessary to determine the various stressors that confront mothers, to assess their relative strength and to identify which groups of mothers are especially prone to experience these stressors. That is the purpose of this study.

Methods

The study took place in the Ibadan–Ibarapa Health Zone of Oyo State, Nigeria, which is one of four administrative zones formed by the State Ministry of Health. Ibadan, the capital of Oyo State, is the largest indigenous subsaharan African city with an estimated population of 2 million (Mabogunje, 1968). The Ibarapa District is a rural area with approximately 250 000 inhabitants located in the transition between forest and savannah just west of Ibadan (Ogunlesi, 1989).

Mothers of children aged 21 years and younger, who had SCD, were the focus of study. The option of a community-based study was overruled because of the relatively low prevalence (1.5–2%) of SCD (Fleming *et al.*, 1979; Adewuyi and Akintunde, 1990) and the corresponding need to undertake an epidemiological survey to identify the SC status of children. This led to the decision to recruit respondents at health facilities that had a formal SCD clinic. A major criterion for inclusion in the study was having registered at the SCD clinic at least 2 months prior to the study. This time period was intended to provide the mother some experience with the potential stressors associated with treatment.

A review of health facilities in the zone identified six where SCD clinics were held on a regular

(weekly or monthly) basis. These included one Federal Government institution, the University College Hospital, the teaching hospital of the University of Ibadan, and three state government facilities, Oni Memorial Children's Hospital, Adeoyo State Hospital and Igbo-Ora Community Hospital. The latter was the only facility offering a SCD clinic found in the rural Ibarapa District. One private facility, Alafia Hospital, and one mission facility, Our Lady of Apostles Catholic Hospital at Oluyoro, rounded out the list.

A non-probability sampling method was used. Each facility was visited on its SCD clinic days during a 1 month period. All eligible mothers present on those days were interviewed. Estimating a standard deviation of 10 (considering a potential stress score range of 0–90) and a minimum mean score difference of 4 points, a total sample size of 198 was calculated for $\alpha = 0.05$ (two sided) and $\beta = 0.20$. Review of hospital records found that a total of 4169 patients attended these six clinics in the previous year, yielding a monthly average of 347 clients, well beyond the desired study sample size. Unfortunately, the study began in July 1993, a time of national turmoil. It was therefore necessary to visit every clinic in each facility for 2 months before 200 non-repetitive attenders were identified and interviewed.

The central focus of the survey instrument was a 30-item stress factor scale using Likert-type statements (see Appendix). The scale items were constructed from mothers' own experiences as shared in focus group discussions (FGDs). This involvement of the mothers enhanced content validity by recognizing mothers as experts in their own right (Nunnally, 1978). Four FGDs of eight participants each were held among attenders of the identified health facilities. Mothers talked about stressful situations in the management of their children, as well as their coping mechanisms for these stressors.

Analysis of the FGDs yielded six categories of stress situations:

(1) *Hospital Factors*: stressful situations that arise as a result of attending clinic and being on admission, including waiting for staff, staff attitudes, blood transfusions, potential admissions, general routines and keeping appointments.

(2) *Disease Factors*: aspects of the nature of the illness, including crises, other infections and the potential of death that were perceived as stressful.

(3) *Financial Factors*: stress arising from the cost of treatment and home management, including transportation costs and the expense of feeding the child a good diet.

(4) *Familial Factors*: social stress within the family arising from the illness including sibling rivalry, marital discord, lack of support from extended family members, and interference with domestic and economic activities.

(5) *Psychological Factors*: stress resulting from the worries and concerns of the mother herself about the potential of having other children with SCD, fears of crises at inconvenient times and thinking about alternative treatments and hope for a cure.

(6) *Child Factors*: stress resulting from the performance and character of the affected child, including absence from school, poor growth and physical features of the disease, and the child's demands for certain foods and rejection of others.

The resulting survey instrument also included questions about coping with these six broad stress areas as well as basic demographic information about the mother and child.

The questionnaire was translated into the Yoruba language and pretested among 20 mothers attending the SCD clinic of the University of Ilorin Teaching Hospital in neighboring Kwara State. During the survey, consent to participate was sought from each mother. Interviews were conducted in a private room next to the particular SCD clinic.

Results

A total of 200 mothers were interviewed. They ranged in age from 21 to 60 years with a mean of

34.5. The majority (89.5%) were married, while the remainder were single, separated, divorced or widowed. Most (59.5%) had at least primary education. Trading formed the major occupation (65.5%), although artisans such as seamstresses (11.0%), teachers (7.0%), civil servants (6.5%) and professionals such as nurses (5.5%) were also represented. Five women (2.5%) were unemployed. Some of the mothers (27.5%) had more than one child with SCD.

Of the six facilities visited, the University College Hospital accounted for the largest number (49.5%) of the 200 respondents, while the smallest group (6.0%) attended the special Sickle Cell Clinic at the state government hospital in Igbo-Ora, the only facility outside metropolitan Ibadan. Two other state facilities, Oni Memorial Children's Hospital and Adeoyo State Hospital, accounted for 19 and 8.5% of respondents, respectively. The private Alafia Hospital provided 9.5% of the study group and Our Lady of Apostles Catholic Hospital, at Oluyoro, Ibadan contributed 7.5%, as seen in Figure 1.

The ages of the children whom the mothers had brought to the clinic ranged from 1 to 21 years with a mean of 8.9. Nearly half (48.5%) of the children were female. Those under 5 years of age, i.e. the preschool group, accounted for 16% of the total, and only two of these 32 children attended nursery school. Not all of the school-aged children actually attended school. Among the 73 children aged 5–9 years, Most (48) were enrolled in school. Two in the 10–14 year age group did not attend school and all older children were enrolled.

Stress scores for the 30-item scale were computed by awarding individual responses as follows: 3 points if an item was termed very stressful, 2 for moderately stressful, 1 point for not stressful and no points if an item were not applicable. Overall scores ranged from 33 to 79 with a mean of 59.3. Figure 2 shows that scores peaked in the 60–65 point range.

As explained, the stressors were grouped into six categories. Average scores for each category were calculated by adding the scores for each item in a category and dividing by the number of items

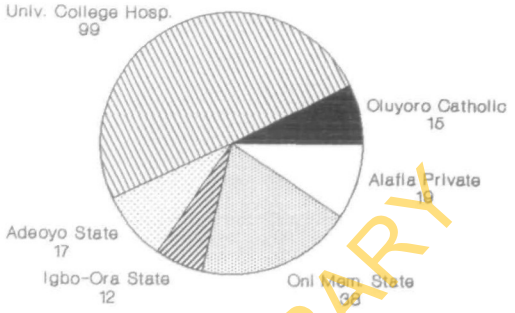

Fig. 1. Distribution of patients among SCD clinics. N = 200.

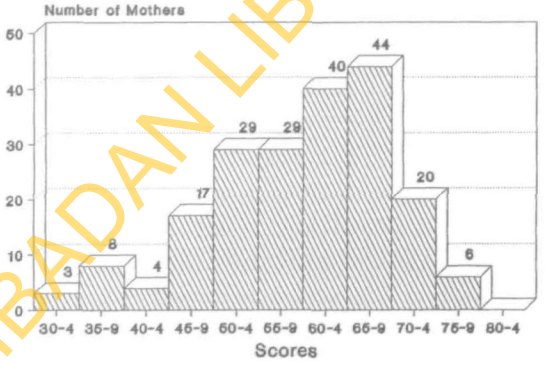

Fig. 2. Distribution of stress scores. Scores could range from 30 to 90. $N = 200$.

in the category, with an average score of 3 points representing the highest level of stress. The actual highest average score of 2.4 was found among the four disease related stressors. This was followed by 2.3 for both the five financial stressors and the three psychological stressors, and 2.1 for the treatment/hospital category. Lower scores were obtained for the eight family-related stressors (1.5) and the four child-related factors (1.5). These differences were found to be statistically significant as seen in Table I.

Because the distribution of scores was skewed as seen in Figure 2, non-parametric statistical test results were used to determine association between stress scores and independent variables as seen in Table II. Level of perceived stress was found to decrease steadily and significantly as the mothers' educational level rose. Those with no formal education scored an average of 62.2 points, followed by 59.1 among those with primary education, 57.6

with secondary schooling and 48.3 for mothers having post-secondary education.

While the 21 non-married mothers had a higher mean stress score (82.8) than married women (59.9), the difference was not significant. On the other hand, when married women were divided into two groups by type of marriage, monogamous and polygamous, it was found that the former, who scored 56.9, had significantly lower stress scores than either those in polygamous marriages (61.3) or the non-married women.

Younger mothers, that is those less than 35 years, reported significantly less stress (57.6 points average) than the older women (61.4). Mothers whose religion was Christianity also scored lower (57.6 points average) than their Moslem counterparts (61.4).

The number of children with SCD in the family was associated with the mothers' perceived stress.

Table I. *Comparison of mean scores among the six categories of stress factors*

Category of stressor	Number	Mean	SD
Hospital	200	2.139	0.454
Financial	200	2.353	0.747
Disease	200	2.440	0 531
Family	200	1.527	0.472
Child	200	1.526	0.521
Psychological	200	2.344	0.497

$F = 143.98$, d.f. = 5;995, $P < 0.0001$.

Table II. *Comparison of stress scores with characteristics of mothers and children*

Characteristic	Number	Mean score	SD	*H* value	*P* value
Education					
none	81	62.2	8.886	22.123	0.000061
primary	54	59.1	9.521		
secondary	54	57.6	9.618		
post-secondary	11	48.3	9.264		
Marital status					
married	179	58.9	9.806	2.450	0.117500
single	21	62.8	9.097		
Marriage type					
monogamous	96	56.9	9.285	13.011	0.001495
polygamous	83	61.3	9.921		
single	21	62.8	9.097		
Religion					
Christian	80	56.2	10.000	15.904	0.000067
Moslem	120	61.4	9.081		
Age of mother					
<35 years	107	57.6	9.075	8.746	0.003103
≥35 years	93	61.4	10.226		
Children with SC					
one	145	56.6	8.997	55.527	0.000000
more	55	66.7	7.822		
Age of child[a]					
preschool	32	50.2	9.802	29.440	0.000000
school age	168	61.1	8.775		
Type of facility					
government	67	62.0	8.823	8.556	0.013872
private	34	55.4	12.235		
university	99	58.9	9.003		

[a]Child brought to clinic.

Those with only one child having SCD scored a mean of 56.6, while mothers having more than one affected child scored an average of 66.7 points. The age of the child (i.e. the child brought to clinic) was also associated with levels of perceived stress. Mothers of preschool children experienced a lower level of stress (50.2 points average) than mothers of older children (61.1 points).

Religion may be a confounding factor. Moslem mothers, who experienced a higher mean stress score (61.4 points) than Christian mothers (56.2), were also likely to be less educated (85% of those with no education were Moslem, while no Moslem mothers had post-secondary education). Moslem mothers had significantly more children with SCD (1.4 on average) than Christian mothers (1.2 children; $t = 3.102$; $P < 0.0026$). Finally, 63% of Moslem mothers were in polygamous marriages compared to only 9% of Christians.

Type of hospital was found to show some association with stress levels. Mothers who brought their child to a state government hospital had the highest average stress scores (62.0), followed by those who attended the University's teaching hospital (a Federal Government facility) (58.9). Lowest mean scores (55.4) were recorded for mothers who brought their child to private hospitals (including the mission hospital).

Coping styles, as seen in Table III, varied among the different categories of stressors. Four major approaches to these stressors were reported including confrontation (problem solving), avoidance, acceptance/resignation and complaining. For the cost or financial stressors, mothers were unanimous (100.0%) in confronting the problem. They would get money from husbands, relatives, borrow from other sources or try to earn the money. Multiple responses to the stressors associated with hospital and treatment regimen showed another coping pattern. Acceptance (80.0%) was the predominant mode of coping, although up to 38.0% would try to avoid the problem, 19.5% would complain and 10.0% would confront it.

Again, confrontation or positive action was the approach mothers used most (84.0%) in handling the stress associated with manifestation of the disease. Some would complain (25.0%), while others would either passively accept (9.0%) or avoid (2.5%) the problem. Resort to native medicine and private clinics (for those attending government facilities) were alternative courses of action for disease associated stressors.

The psychological stressors were met primarily with complaints (77.0%). Some would practice avoidance (42.5%), while a few would accept (7.5%) the situation. None would use confrontational methods. The special stress arising from the needs and demands of the SCD child led mothers to either of two main courses of action, complaining (67.5%) or acceptance (38.5%). Some (16.0%) would confront the issue head on, while a very few (3.0%) would try to avoid the problem.

Finally, family sources of stress had the least clear cut mode of coping. While avoidance (44.0%) and acceptance (41.5%) were common, mothers also complained (23.0%) and confronted (12.5%) stress arising from conflicting needs and expectations from other family members.

Discussion

The results offer potential guidelines for designing counseling, education and social support interventions to assist mothers of children with SCD. In particular, the findings identify women who may be prone to higher levels of stress so that interventions could be tailored to their particular situation.

One such situation is marital status. It could be easily surmised that higher stress levels reported by non-married women would result from their less certain financial status and lack of social support from a husband and his relatives. What was not expected was the direction of the difference between married women in monogamous versus polygamous unions. Assertions have been made that polygamous marriages in Yoruba society may in fact be beneficial and satisfying for the women concerned (Bascom, 1969; Caldwell *et al.*, 1990). Additional wives mean a division of household duties, freeing women to face their trading and other income generating activities. It has also been suggested that polygamy is associated with higher

Table III. *Specific coping activities used for different stressor categories*

Stressor	Coping style and mechanism/percent of mothers using			
	Confront	Avoid	Accept	Complain
Financial	100%: Earn, Borrow, Husband, Relative	*not used*	*not used*	*not used*
Treatment–hospital	10%: Clinic, Native Medicine, Private Clinic	38%: Escape, Neglect	80%: Accept, Tolerate	19%: Anger, Complain, Express, Blame Self, Pray, Weep
Disease	84%: Clinic, Drugs, Native Medicine, Follow Doctors Orders	3%: Avoid Neglect TV/Radio	9%: Accept	25%: Prayer, Blame Self, Weep
Psychological	*not used*	42%: Avoid, Distract, Escape, Ignore, Sleeping, Tablets	7%: Accept	77%: Anger, Talk, Prayer, Blame God, Weep, Express Concerns, Blame Self
Family	12%: Confront	44%: Avoid, Denial, Escape, Ignore	41%: Accept, Tolerate	23%: Anger, Express Concerns, Prayer, Complain, Weep, Blame Self
Child	16%: Give Care, Attend Clinic, Buy Drugs or Native Medicine	3%: Avoid, Neglect	38%: Accept	67%: Anger, Express Concern, Prayer, Weep, Blame Self

status and wealth of the husband, who should therefore be better able to support the mother and child.

What these authors do not reveal is the fact that polygamy also breeds competition among co-wives. As Bamisaiye *et al.* (1974) suggest, a woman's status in a polygamous household is directly related to her ability to produce strong heirs for the father and so competition toward this end ensues among the co-wives. Thus a women who gives birth to a disabled child is less able to compete for the husband's attention. Also in modern, urban society, polygamy is not necessarily associated with wealth. In working class polygamous families, women often have the major financial responsibility for their own welfare and the care of their children. Under these circumstances, a monogamous relationship would appear to offer more stability and produce less stress.

The relationship between lower mean stress levels and younger age of the women has been explained by Pearlin *et al.* (1981). They suggested that younger women have higher levels of energy that enable them to seek extra social and recreational activities, thus providing them with a greater reserve of coping mechanisms than older women.

The mediating role of education on perceived stress could be explained in two ways. An educated mother may have better access to and a greater understanding of information about her child's condition. Also education is likely associated with economic status, such that more highly educated women would have greater access to financial resources to confront the sources of stress.

The higher average stress scores among mothers having more than one SCD affected child are not surprising. What is discouraging is the observation that such families continued to have additional children after their first child with SCD. The fact that over one-quarter of mothers interviewed had

more than one child with SCD might be related family pressures to produce a healthy child. Clearly, preventive counselling within the SCD clinics needs to be strengthened.

When a child with SCD reaches school age, his/her disabilities become more apparent as he/she tries to compete and keep up with classmates. This calls for extra vigilance and, therefore, more stress on the mothers, and may even account for the fact that one-third of primary school-age children were not attending school.

From the foregoing, it becomes incumbent on health workers to pay particular attention to the needs of less educated and older mothers. Social support needs to increase as the child grows older and begins to develop some independence at school and in the community.

Coping strategies

Among the various categories of stressors, disease factors, financial concerns, psychological stressors and hospital factors topped the list. Reynolds *et al.* (1988) also found that financial and disease/disability factors were major sources of stress among mothers of chronically ill and handicapped children.

These different stressor categories evoke different coping mechanisms. While this study grouped possible coping mechanisms into four categories, other authors have considered as many as 20 possible approaches to stress (Dessler, 1975; Selye, 1976; Manke and Gurklis, 1988). For example, various aspects of avoidance such as escape, drinking excessively and use of drugs have been considered separately. Four categories appears to be more manageable from the standpoint of planning educational interventions.

Fortunately, mothers are willing to confront their financial problems directly. Counsellors may therefore simply guide them in identifying the most reliable sources. Likewise, mothers want to confront the troubling manifestations of the disease. Health staff must therefore make sure that they have services available so that mothers will not be tempted to turn to less effective alternatives. When it comes to the psychological stressors, mothers want to complain, talk and express their emotions.

Health workers need to be ready to provide an empathetic ear. They may also wish to train peer counsellors among the mothers attending SCD clinic for this purpose. Peer counsellors may also provide an alternative source of emotional support when family members feel jealous or resentful of the special attention and resources required of the child with SCD.

Health workers need to examine the quality of the services they provide to children with SCD and their mothers. Hospital factors were among the top four categories of stressors, and mean stress levels were higher for mothers attending government clinics. These facilities are plagued by stressors such as non-availability of medicines and long waiting times. The fact that most mothers use a passive, accepting coping mode in response to these stressors puts the responsibility squarely on the shoulders of health staff to make their services more acceptable.

Finally, as the children themselves get older, and the stress levels in their mothers rise, they too should be provided counselling. If they develop a mature and responsible approach to their own health, some of the child-related stressors facing the mother could be reduced.

In conclusion, while the results of this study have been specific in identifying certain groups of mothers who suffer more stress and the particular stress factors that need attention, the main recommendation arising from this study is more general. Factors like type of marriage and religion point to the fact that stressors and coping mechanisms are culturally based. Therefore, it is recommended that health workers and researchers in other settings pay attention to the methods used in this study. These methods were initially participatory, allowing mothers to voice their own concerns. Based on mothers' real life problems, the researchers were able to construct a survey instrument from which levels of stress and specific target groups could then be identified. In this way counselling and social support interventions can be designed that are relevant to the needs of the clients.

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Appendix: scores for individual stressors

	Mean score[a]
A. HOSPITAL FACTORS	2.1
1. Admission to hospital	2.7
2. Keeping clinic appointment	2.3
3. Waiting for doctors/hospital staff	2.1
4. Blood transfusion	2.4
5. Attitude of hospital staff	1.5
6. Hospital routine	1.8
B. FINANCIAL FACTORS	2.4
7. Cost of drugs	2.5
8. Cost of blood	2.3
9. Hospital bill	2.2
10. Cost of adequate, good food	2.4
11. Transportation cost for clinic appoint.	2.4
C. DISEASE FACTORS	2.4
12. Re-current crisis	2.5

13. People say it is an incurable disease	2.2
14. Thought of death at any time	2.4
15. Fear of sickness/infection in child	2.6
D. FAMILY FACTORS	1.5
16. Sibling rivalry/jealousy	1.6
17. Inhibiting your job performance	2.1
18. Impact of your marital life	1.4
19. Inhibiting your movement/going out	2.0
20. Not getting enough help or support from husband	1.4
21. Not getting enough help or support from in-laws	2.0
22. Not getting enough help or support from house help	0.6
23. Not getting enough help or support from child's school	1.0
E. CHILD'S FACTORS	1.6
24. Absence from school	1.9
25. Growth and physical features	2.0
26. Loving a particular food more than others	1.3
27. Rejection of foods	0.9
F. PSYCHOLOGICAL FACTORS	2.3
28. Fear of crisis at wrong time(night, exam period, etc.)	2.6
29. Thought of alternative means of complete cure	1.8
30. Fear of having another child with sickle cell disease	2.6

[a]Individual item scores range from 0 to 3.