SEXUALITY AND SICKLE CELL DISEASE

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Chronic illness can impact negatively on sexuality and sexual satisfaction. A group of 44 patients with sickle cell anemia and a control group of 42 individuals with no chronic illness completed the Derogatis Sexual Functioning Inventory (DSFI). The sickle cell anemia group also completed the Psychosocial Adjustment to Illness Scale—Self-Report (PAIS-SR). Cumulative scores on the PAIS-SR were used to divide the sickle cell anemia group into two subgroups—those who were poorly adjusted to their illness and those who were well adjusted to their illness. Analysis of the scores showed significant differences in sexual functioning and sexual satisfaction between those in the sickle cell group who were well adjusted to their illness and those who were poorly adjusted. Of note was the fact that there was no statistically significant difference between the DSFI scores in the well adjusted group and the control group. Other significant factors included the lack of accurate sexual information in the sickle cell anemia group and the importance of satisfaction with the health-care system in total adjustment to illness. In addition, results revealed that severity of illness had little impact on adjustment to illness. (*J Natl Med Assoc.* 1993;85:113-116.)

Key words • sexuality • sickle cell anemia • sickle cell disease

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There are between 50 000 and 60 000 persons with sickle cell anemia in the United States. Advances in knowledge and improvement in medical care have decreased the morbidity associated with sickle cell anemia and significantly improved the medical prognosis for patients with this disease. However, other aspects of their quality of life remain compromised.

According to the National Association for Sickle Cell Disease, 70% of those with sickle cell anemia either partially or totally depend on public assistance or their families for financial support. In addition, many have difficulty entering and sustaining marital and other close personal relationships. These problems are often directly related to the stressors affecting the sickle cell patient. These may include repeated hospitalizations, multiple interruptions in normal activities, a lifetime of unpredictable pain, growth retardation, and delayed puberty.

These stressors can promote a sick mentality and low self-esteem. The higher level of self-esteem needed to become independent, responsible adults capable of living meaningful, productive, sexually fulfilling lives is often lacking in individuals with sickle cell anemia.

This study was undertaken to determine the impact of sickle cell disease on sexual adjustment. It was hypothesized that sickle cell anemia impacts negatively on sexual adjustment and that individuals with sickle cell anemia generally exhibit different sexual behaviors and attitudes about sexuality compared with nonaffected individuals.

MATERIALS AND METHODS

Study Population

Eighty-six individuals participated in the study. Of these, 44 (20 women and 24 men) comprised the sickle cell anemia group and 42 (23 women and 19 men) comprised a control group. The sickle cell anemia group included patients who underwent treatment at the

TABLE 1. DEROGATIS INVENTORY SCALES*

Scale	Sickle Cell Group				Nonsickle Cell Group	
	Good Adjustment Group		Poor Adjustment Group			
	Male (n=12)	Female (n=9)	Male (n=12)	Female (n=11)	Male (n=19)	Female (n=23)
Information†	33.9±7.6	44.3±14	34±10	33±4.1	43.1±9.8	49.4±8.8
Experience	44.9±12.2	41±7.6	48±9.4	43±17.5	41.4±6.5	43.8±8.4
Drive	43.4±16.2	43.5±5.7	48.5±10.4	42.4±4.7	48.1±8.3	46.8±9
Attitude	35.4±10.2	36.8±7.2	40.3±8.5	34.1±6.4	39.3±8.8	38.3±8.6
Symptoms†	42.5±12.4	50.3±11.2	31.3±7	34±6.5	40.5±14.3	40.1±8.8
Affect†	55±12.9	51.5±16.6	42.8±14.2	38.5±10.7	47.9±11	49.6±10.7
Role†	42.7±6.1	62.8±8.3	45.7±10.1	54.6±12.2	35.4±7.5	55.4±15.3
Fantasy	46±11	40.2±14.6	46±7.6	45.4±12.1	43.4±10	46.8±9.2
Body	44.8±10.4	46.3±11.3	38.1±13.1	43.5±10.9	45.6±10.9	44.2±14.5
Satisfaction	51.8±6.5	50.5±8.8	46.5±6.1	46.3±6.2	46.8±11.9	46.9±10

*Mean ± standard deviation.
†Significant difference between groups by multivariate analysis of variance ($P<.01$).

Sickle Cell Center of the Wayne State University Health Center and the Sickle Cell Detection and Information Program between September 1988 and June 1989. The individuals in the control group were selected from the community and matched with the sickle cell group for age and sex.

All of the study participants completed the Derogatis Sexual Functioning Inventory (DSFI),[1] and the sickle cell anemia patients also completed the Psychological Adjustment to Illness Scale—Self-Report (PAIS-SR).[2] Specially trained social workers who were providing services to the study participants assisted in filling out the surveys. Each participant received a $15 stipend to cover the cost of transportation to and from the center.

The Derogatis Sexual Functioning Inventory

The DSFI is a self-reported omnibus test of sexual functioning oriented toward depicting the nature of an individual's sexual functioning. The DSFI is composed of the following 10 subtests:

- information,
- experience,
- drive,
- attitude,
- psychological symptoms,
- affects,
- gender role definition,
- fantasy,
- body image, and
- sexual satisfaction.

Scaled scores from each subtest are combined to develop an overall DSFI score.

Psychological Adjustment to Illness Scale—Self-Report

The PAIS-SR is a multidimensional, semistructured interview designed to assess the psychological and social adjustment of medical patients, or their immediate relatives, to an illness. The PAIS-SR interview is comprised of 46 items that assess psychological adjustment in the following seven domains:

- health-care orientation,
- vocational environment,
- domestic environment,
- sexual relationships,
- extended family relationships,
- social environment, and
- psychological distress.

A PAIS-SR total score summarizes overall adjustment to illness.

Separate total scores for men and women were tabulated for each of the 10 subtests in the DSFI as well as an overall DSFI score in the sickle cell anemia group and the control group (Table 1). The cumulative scores from the seven principal domains of the PAIS-SR were tabulated for men and women in the sickle cell anemia group. Two subgroups were formed based on the PAIS-SR scores: those with "good adjustment" and those with "poor adjustment" to illness, depending on their score. Total scores for the seven domains ranged from 10 to 75 (mean: 37; standard deviation: 18). Lower total scores indicated a better adjustment to illness. Fifty percent of the participants who scored 37

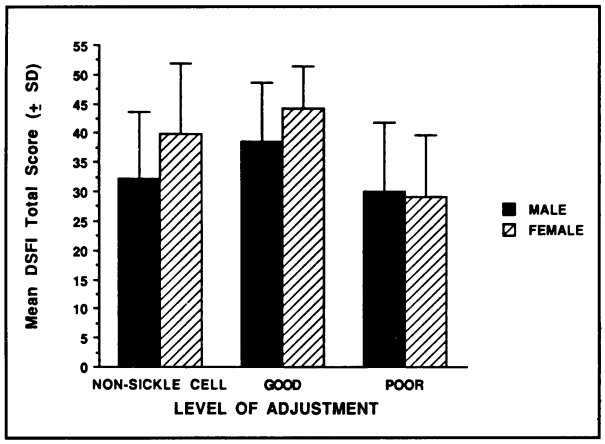

Figure. Male-female Derogatis scores by adjustment to illness.

or above fell into the poor adjustment group. The remainder of the scores ranged from 10 to 33; these individuals comprised the good adjustment group.

Statistical Analysis

Multivariate analysis of variance was used to determine if the DSFI subtest scores indicated any differences in sexual functioning between the control and the sickle cell anemia groups.

RESULTS

Analysis of total adjustment (good, poor, normal) by sex (male, female) revealed an overall significant difference for total adjustment on the DSFI information subtest ($F = 13.95$; $df = 2.80$; $P < .001$). In the normal group, both men and women were better informed on sexual matters than their counterparts in the sickle cell anemia group. However, in both the normal and the sickle cell anemia group, women scored better on the information subtest than men. There was a significant difference in gender role identification when sickle cell anemia men were compared with normal men, with the normal men showing more role polarization and the sickle cell anemia men showing more role integration. As would be expected, there was a difference in the DSFI subtest on symptoms. The normal group reported significantly fewer symptoms of emotional illness than either the good or poorly adjusted sickle cell anemia subgroups ($F = 9.12$; $df = 24$; $P = <.001$).

Of particular note is that while there was no significant difference between the total DSFI scores for the normal and good adjustment sickle cell anemia subgroups, there was a significant difference between the poor and good adjustment sickle cell anemia subgroups ($F = 6.3$; $df = 24$; $P < .001$) (Figure 1). When analysis was performed without separating for good and poor adjustment, no significant differences were found on the individual DSFI subtests between the sickle cell anemia and the control groups.

TABLE 2. MARITAL STATUS ACCORDING TO ADJUSTMENT TO ILLNESS BY PAIS-SR SCORE

Marital Status	Sickle Cell Group		Nonsickle Cell Group	
	Poor	Good	Normal	Total
Single	14 (33.3%)	10 (23.8%)	18 (42.9%)	42
Married	1 (4.8%)	5 (23.8%)	15 (71.4%)	21
No longer married	8 (34.8%)	6 (26.1%)	9 (39.1%)	23

A stepwise regression analysis using demographic variables and total adjustment scores was done in an attempt to explain the variation in total DSFI scores among sickle cell anemia patients. Only the total adjustment score on the PAIS-SR, good versus poor, had a significant F to enter and proved significant in explaining how well an individual would score in his or her overall sexual functioning ($R^2 = .535$; $P < .01$). Further analysis to determine what specific factors in the total adjustment to illness score accounted for this correlation revealed that two domains, health-care orientation ($F = 10$; $R^2 = .458$; $P < .01$) and vocational environment ($F = 8.8$; $R^2 = .569$; $P < .001$), were significant.

Table 2 shows the distribution of the good, poor, and normal groups according to marital status. The distribution did not reach statistical significance using chi square analysis ($P = .09$). Although the analysis of the good and poor sickle cell anemia subgroups alone approached statistical significance ($P = .06$), the cell sizes were too small to assume a strong relationship between not being married and being poorly adjusted to the disease.

To determine if there were any variables that would predict what adjustment group the sickle cell anemia patients would fall into, a discriminant function analysis was performed. While no factors were significant predictors of total adjustment in men with sickle cell anemia, three factors were found to be significant in women with sickle cell anemia. The total DSFI score ($F = 12.3$; $df = 1$; $P < .01$), occupation ($F = 9.7$; $df = 2$; $P < .001$), and age ($F = 8.5$; $df = 3$, $P < .01$) combined to

predict the total adjustment to illness group with 85% accuracy.

The ability to adjust to a chronic illness can be greatly affected by the severity of that illness. For sickle cell anemia, an indication of the severity of the illness is the frequency of hospitalizations. For the sickle cell anemia group, the total number of hospitalizations each participant had in the course of the previous year was compared with his or her total PAIS-SR score. No correlation ($r = .11$; $P = .45$) was found between these two variables.

Finally, the following findings need to be emphasized:

- the sickle cell anemia patients who were well adjusted to their illness as indicated by their PAIS-SR score also scored well on the DSFI,
- the sickle cell anemia patients who were poorly adjusted to their illness as indicated by their PAIS-SR score also scored poorly on the DSFI,
- severity of illness (as reflected by the number of hospitalizations in the past year) was not a significant factor in adjustment to illness represented by the PAIS-SR score,
- general knowledge of sexual facts (tested by the Derogatis information subtest) was lacking in the sickle cell anemia group, particularly men,
- those who scored well on the information subtest also had good total DSFI scores,
- sickle cell anemia patients who had better experiences with the health-care system scored better on overall sexual adjustment, and
- men with sickle cell anemia reported a higher level of satisfaction with sex than women with sickle cell anemia.

DISCUSSION

Information emerges as a key factor in reported sexual adjustment and satisfaction. Because individuals with sickle cell anemia are often lacking in both formal and informal education, their knowledge of sexual facts is often limited. This can contribute adversely to sexual adjustment. Educational programs that address the special information needs of the sickle cell anemia patient and that address more than just disease-related topics can have a positive and significant impact on the individual's general life experiences and ability to cope with the challenges of sickle cell anemia. Provider-initiated counseling that specifically addresses sexual topics also may be indicated to assist those who are reluctant to request help.

A second area of intervention that may be indicated from this research is empowerment for individual patients. Those who reported a good experience with their health-care providers felt in control and believed that they were treated with respect and were well-informed on the many aspects of their condition and its treatment. These individuals, in turn, scored well on overall sexual adjustment. However, those who had poor experiences with their health-care providers and who felt lost and powerless in the system scored poorly on overall sexual adjustment.

Adopting procedures that allow for self-determination and allow individuals to feel they have some control over their treatment by the health-care system would contribute to positive self-esteem and better sexual adjustment. This would be particularly true for the men with sickle cell anemia who saw themselves as less masculine, less strong, and less able to take leadership roles.

While the search continues for a cure for sickle cell anemia, additional efforts should be directed toward assisting these individuals to experience a high quality of life, compromised only by the unalterable aspects of the disease. What becomes evident as a result of this research is that assisting sickle cell anemia patients in adjusting to their illness and helping them to normalize their life experiences will increase their chances of having normal, satisfying sex lives.

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