# Subjective Well-being of Adults with Homozygous Sickle Cell Disease in Jamaica

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***ABSTRACT***

***Objectives:*** *This study compared the subjective well-being of adults with homozygous sickle cell (SS) disease to a matched group of healthy adult peers. The differential influence of sociodemographic factors on the subjective well-being of Sickle Cell patients was also examined.*

***Methods:*** *The Ferran and Powers Quality of Life Index and the Positive and Negative Affect Schedule were used to assess subjective well-being. Seventy-five homozygous sickle cell (SS) disease patients and sixty-seven matched controls (adults with normal haemoglobin: AA) from the Sickle Cell Disease Cohort Study in Jamaica were interviewed. Analysis of variance (ANOVA) was used to examine differences between the groups.*

***Result:*** *Patients with Sickle cell (SS) disease were less satisfied than matched controls with their lives overall, their health and functioning, social and economic situation and psychological functioning. Sickle cell disease patients reported lower levels of positive affect but similar levels of negative affect as controls. Unemployed sickle cell disease patients were less satisfied than all other adults with their lives overall, health and functioning, psychological functioning and social and economic situation. Sickle cell disease patients with lower occupational status were less satisfied with their family life than all other adults.*

***Conclusions:*** *These findings suggest that subjective well-being is compromised in patients with homozygous sickle cell disease. These patients may benefit from interventions designed to improve their subjective well-being.*

**Keywords:** Adults, Jamaica, negative affect, positive affect, subjective well-being, sickle cell disease, quality of life.

# Bienestar Subjetivo de los Adultos con la Enfermedad de Células Falciformes Homocigóticas en Jamaica

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***RESUMEN***

***Objetivos:*** *Este estudio comparó el bienestar subjetivo de los adultos con enfermedad de células falciformes homocigóticas (SS) con el de un grupo pareado de adultos saludables. También se analizó la influencia diferencial de factores sociodemográficos sobre el bienestar subjetivo de los pacientes con la enfermedad de células falciformes.*

***Métodos:*** *El Índice de Calidad de Vida de Ferrans and Powers, y las Escalas de Afecto Positivo y Afecto Negativo (PANAS) fueron usados para evaluar el bienestar subjetivo. Setenta y cinco pacientes con enfermedad de células falciformes homocigóticas (SS), y sesenta y siete controles pareados (adultos con hemoglobina normal: AA) del Estudio de Cohorte de la Enfermedad de Células Falciformes en Jamaica fueron entrevistados. El análisis de varianza (ANOVA) fue utilizado para estudiar las diferencias entre los grupos.*

***Resultado:*** *Los pacientes con enfermedad de células falciformes (SS) mostraron en general un menor grado de satisfacción con sus vidas, su salud y funcionamiento, situación social y económica y funcionamiento psicológico. Los pacientes con la enfermedad de células falciformes reportaron*

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*niveles más bajos de afecto positivo, pero mostraron en cambio niveles similares de afecto negativo en relación con los controles.*
*Los pacientes con la enfermedad de células falciformes desempleados estuvieron menos satisfechos con sus vidas en general, su salud y funcionamiento, su funcionamiento psicológico, y su situación económica y social, que todos los otros adultos. Los pacientes con la enfermedad de células falciformes de un nivel ocupacional más bajo, estuvieron menos satisfechos con su vida familiar que todos los otros adultos.*
***Conclusiones:*** *Estos hallazgos sugieren que el bienestar subjetivo está comprometido en pacientes con la enfermedad de células falciformes homocigóticas. Estos pacientes pueden beneficiarse de las intervenciones destinadas a mejorar su bienestar subjetivo.*

**Palabras claves:** Adultos, Jamaica, afecto negativo, afecto positivo, calidad de vida, enfermedad de células falciformes, bienestar subjetivo

**West Indian Med J 2011; 60 (2): 182**

## INTRODUCTION

Advances in treatment have improved the prognosis for Sickle Cell patients who often die young. However, surviving until adulthood brings additional challenges to sickle cell patients. In addition to the normal developmental challenges of adulthood, sickle cell patients must also cope with the multiple disease-related complications and restrictions of their illness. These challenges may make coping with the normal changes of adulthood difficult resulting in elevated levels of stress and negative emotions, and low levels of subjective well-being. Subjective well-being is an important approach for evaluating the outcomes of chronically ill patients. It involves both cognitive and affective appraisals of life (1−3). The cognitive component represents one's judgment of life satisfaction as a whole and/or satisfaction with specific aspects of life. The affective component represents one's positive and negative emotional evaluations of life circumstances. Past studies have mostly focussed on sickle cell patients' negative affective evaluations of their experiences. This study adds to past research by exploring patients' cognitive and positive affective appraisals of their life circumstances.

The transition to adulthood can be a challenge for some healthy people; however for sickle cell patients this transition brings additional challenges. Adulthood is the period of life when individuals begin to live independently, find a job, engage in self-discovery, develop intimacy with others recreational interests and social networks (4−5). In addition to these normal developmental changes, sickle cell patients must cope with the multiple disease-related complications and restrictions of their illness. These challenges may make coping with the normal changes of adulthood difficult resulting in elevated levels of stress and negative emotions. Sickle cell patients may also be required to follow a lifelong treatment regimen that sometimes can be complex and multi-focussed adding to the difficulties patients experience. The course of the illness can be painful and unpredictable, making it a difficult illness to cope with. All of these factors may negatively affect sickle cell patients' subjective well-being, that is, how patients perceive themselves, their abilities and the state of their lives.

Relatively few studies have looked at sickle cell patients' affective evaluations of life. Of these studies, most have focussed on patients' negative experiences (6−10). In general, these studies found that patients experienced anxiety, depression and psychological distress. In 2001, Thomas *et al* (10) examined sickle cell patients' cognitive coping strategies, finding that patients coped with their illness by using negative self-statements: catastrophizing, ignoring, hoping and praying. Neither of these sets of studies examined patients' positive experiences or their judgements of life satisfaction. This study adds to past research by looking at both the cognitive and affective components of subjective well-being among sickle cell patients.

The aim of this study was to compare adults with homozygous sickle cell (SS) disease to healthy adult peers in terms of their overall life satisfaction, satisfaction with specific aspects of their lives (health and functioning, social and economic situation, family life and psychological functioning) and their positive and negative affect. We expected that adults with homozygous sickle cell disease would have lower overall life satisfaction and satisfaction with specific aspects of their lives compared with adults without the disease. We also expected that adults with homozygous sickle cell disease would have lower positive affect and higher negative affect compared with adults without the disease.

## SUBJECTS AND METHODS

A sub-sample from the Jamaica Sickle Cell Cohort study was selected to participate in this study. The Jamaica Sickle Cell Cohort study comprised a group of 315 babies detected with SS disease from 100 000 live births at the Victoria Jubilee Hospital in Kingston, Jamaica, between June 1973 and December 1981. The first 125 babies of this group were matched with two babies without the sickle cell trait (AA genotype), of the same gender and born closest in time to sickle cell births (one baby was born immediately before and

the other baby was born immediately after the baby with sickle cell). In all, a total of 250 babies served as the control group. All of the sickle cell and the matched non-sickle cell babies have been followed prospectively at the Sickle Cell Unit in the Tropical Medicine Research Institute of the University of the West Indies. At the time of the study, these subjects were between 23 and 31 years of age. Free medical care is offered to these subjects by the Sickle Cell Clinic if they are unwell (9).

The intended sample used in this study consisted of 200 participants: one hundred were a random sample of the 125 homozygous sickle cell patients [Homozygous Sickle Cell disease is the most severe form of the disorder, having the highest rates of mortality and morbidity (11)] while the other 100 were one of each sickle cell participant and age and gender matched non-sickle cell controls. Of this sub-sample, only seventy-five sickle cell patients and sixty-seven non-sickle cell patients participated in this study. The other subjects were not available for the study due to migration, death and refusal to participate.

Data were collected through three interviewer-administered questionnaires; as well the medical records of both sickle cell and control participants were examined for evidence of recent illnesses. A demographic information questionnaire collected data on participants' age, level of education, employment status, type of employment, living arrangement, union status, social amenities (type of water source and type of toilet facility), household possessions and an index of crowding in the household as assessed by the number of people per room. These questions have been used in previous studies and have been demonstrated to be valid and reliable (12).

A shortened and modified version of the Ferrans and Powers Generic Quality of Life Index (13) was used to measure life satisfaction. The scale generates scores for overall life satisfaction and satisfaction with specific aspects of life (health and functioning, social and economic situation, family life and psychological functioning). It was scored following the guidelines established by Ferrans and Powers (13). Scores ranged from 0 to 30 with lower scores representing less life satisfaction and higher scores representing greater life satisfaction. Two-week test-retest reliability of the shortened instrument was good for overall life satisfaction (0.83) and the health and functioning subscale (0.87). However, the social and economic situation subscale (0.61) and the family life subscale (0.62) had moderate levels of test-retest reliability while the test-retest reliability of the psychological subscale was somewhat low (0.47).

A modified version of the Positive and Negative Affect Schedule [PANAS] (14) was used to measure positive and negative emotions. Participants indicated the amount of time during the past month that they experienced ten positive and ten negative emotions. They rated the frequency that they experienced each emotion on a 5-point scale ranging from not at all (1) to always (5). The positive affectivity score was the mean of the responses for the 10 pleasant emotions, while the negative affectivity score was the mean of the responses for the 10 unpleasant emotions. Higher scores reflected more positive or negative affect. Two-week test-retest reliability was 0.80 for the negative affect subscale and 0.82 for the positive affect subscale.

The health records of both sickle cell and control group participants were examined for evidence of physical illness in the 90 days prior to the date of their interview or on the date of the interview.

Means, standard deviations and percentages were calculated to describe the sociodemographic characteristics of sickle cell patients and non-sickle participants. Chi-square and *t*-tests were performed to examine group equivalence on these sociodemographic characteristics. Analysis of variance (ANOVA) was used to test for differences between sickle cell and non-sickle patients' overall life satisfaction, satisfaction with specific aspects of their lives, and positive and negative affect. Data were analysed using SPSS 11.5 for Windows with the level of statistical significance set at $p < 0.05$.

## RESULTS

*Background characteristics of the sample*

The sociodemographic characteristics of the participants are presented in Table 1. The groups did not differ significantly in gender, crowding index, total household possessions or social amenities. For the sickle cell group, 45.3% were males and 54.7% were females. For the non-sickle cell group, 44.8% were males and 55.2% were females. Participants from both groups had similar mean scores on the crowding index and total household possessions. Approximately, the same proportion of people from both groups had their own flush toilet and inside water source.

The groups however, differed significantly in age, marital status, living arrangement, education, employment status and occupation. The sickle cell patients were younger than the non-sickle cell subjects ($t = -7.14$, $p < 0.001$). A greater proportion of the sickle cell patients reported living with family as compared with non-sickle cell patients and fewer sickle cell patients lived with a spouse as compared with non-sickle cell subjects ($\chi^2 = 28.81$, $p < 0.001$). In the sickle cell group, the proportion of married respondents was lower than those in the non-sickle cell group, but unlike the single persons in the non-sickle cell group, many more of the single sickle cell patients had visiting relationships ($\chi^2 = 10.95$, $p < 0.01$).

Fewer sickle cell patients reported having college or university education compared with non-sickle cell patients ($\chi^2 = 10.86$, $p < 0.05$). Also, fewer sickle cell patients reported that they were working compared with non-sickle cell patients ($\chi^2 = 15.65$, $p < 0.001$). A greater proportion of sickle cell patients were in unskilled labour compared with non-sickle cell patients and far fewer were in highly skilled labour compared with non-sickle cell patients ($\chi^2 = 28.82$, $p < 0.05$).

Table 1: Sociodemographic characteristics of the sample

| Sociodemographic variables | Homozygous sickle cell disease Frequency (%) | Non-sickle cell group Frequency (%) |
|---|---|---|
| Age (mean, sd)[a*] | 28.1 (1.4) | 29.4 (0.6) |
| Gender | | |
| Male | 34 (45.3) | 30 (44.8) |
| Female | 41 (54.7) | 37 (55.2) |
| Marital Status[b*] | | |
| Single | 26 (34.7) | 12 (17.9) |
| Visiting relationship | 33 (44.0) | 24 (35.8) |
| Married or Common Law | 16 (21.3) | 31 (46.3) |
| Living Arrangements[b***] | | |
| Live alone or with a Friend | 15 (20.0) | 14 (20.9) |
| Live with family (*eg* mother, father) | 53 (70.7) | 23 (34.3) |
| Live with spouse/ husband/fiancé | 7 (9.3) | 30 (44.8) |
| Toilet | | |
| Pit | 8 (10.7) | 7 (10.4) |
| Shared flush | 12 (26.0) | 14 (20.9) |
| Own flush | 55 (73.3) | 46 (68.7) |
| Water Source | | |
| Pipe inside house | 56 (74.7) | 46 (68.7) |
| Pipe outside house (in yard or outside yard) | 19 (25.3) | 21 (31.3) |
| Crowding (mean, sd) | 1.4 (1.0) | 1.7 (1.1) |
| Total household possessions (mean, sd) | 7.6 (1.9) | 7.6 (1.5) |
| Occupation[b*] | | |
| Unskilled | 17 (22.7) | 6 (9.0) |
| Semi-skilled | 21 (28.0) | 21 (31.3) |
| Skilled | 32 (42.7) | 27 (40.3) |
| Highly skilled | 5 (6.7) | 13 (19.4) |
| Education[b*] | | |
| Grade 6, 7, 8 | 15 (20.0) | 20 (29.9) |
| Grade 10, 11 | 31 (41.3) | 18 (26.9) |
| Vocational/skills training | 22 (29.3) | 12 (29.3) |
| College, University | 7 (9.3) | 17 (25.4) |
| Working[b***] | | |
| No | 28 (37.3) | 6 (9.0) |
| Yes | 47 (62.7) | 61 (91.0) |

Note: [a.] *t*-test, [*] $p < 0.001$, [b.] $\chi^2$, $p < 0.05^*$, $^{**}p < 0.01$, $^{***}p < 0.001$

Seventy-four of the 142 participants had one or more visits to the Sickle Cell Clinic for healthcare in the 90 days prior to their interview. Of these participants, only 15 reported a symptom of an acute illness. The vast majority of these participants reporting an acute illness were sickle cell patients (13 participants with sickle cell *versus* two control participants). Results of a chi-square analysis indicated that sickle cell patients were more likely to report having one or more symptoms of illness in the 90 days before or on the day of the interview ($\chi^2 = 7.71$, $p < 0.01$).

*Subjective well-being*

Marked differences existed between the two groups on overall life satisfaction, satisfaction with health and functioning, social and economic situation, psychological functioning and positive affect (Table 2).

Table 2: Overall life satisfaction scores, specific domain satisfaction scores, positive and negative affect scores (mean and standard deviation)

| Subjective well-being measures | Homozygous sickle cell disease | Non-sickle cell group |
|---|---|---|
| Overall life satisfaction[**] | 22.0 (4.7) | 24.9 (2.8) |
| Domain satisfaction | | |
| Health and Functioning[***] | 23.5 (5.3) | 27.3 (2.2) |
| Social and economic situation[**] | 19.0 (6.4) | 21.7 (4.4) |
| Family life | 22.8 (5.7) | 24.4 (5.6) |
| Psychological functioning[*] | 24.5 (5.8) | 26.4 (4.6) |
| Positive affect[***] | 3.5 (0.7) | 3.9 (0.7) |
| Negative affect | 2.3 (0.7) | 2.3 (0.6) |

$^*p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.0001$

As expected, sickle cell patients' judgment of overall life satisfaction was significantly lower than non-sickle participants ($p < 0.001$) as well as their evaluations of three of the four specific aspects of life: health and functioning ($p < 0.001$), social and economic situation ($p < 0.01$) and psychological functioning ($p < 0.05$). No statistically significant differences were found between sickle cell and non-sickle cell participants on family satisfaction ($p > 0.05$).

As expected, sickle cell patients had significantly lower positive affect scores than non-sickle participants ($p < 0.001$). However, contrary to expectations, sickle cell patients and non-sickle participants had similar negative affect scores ($p > 0.05$).

*Association of sociodemographic characteristics with subjective well-being*

Further analyses were conducted to explore how sociodemographic characteristics and sickle cell status combine to affect subjective well-being. For example, did having sickle cell disease and being unemployed reduce participants' subjective well-being? The combined relationship (interaction) of sickle cell status and sociodemographic characteristics with subjective well-being were explored using a series of univariate ANOVAs (Table 3). Only work status and occupation combined with the sickle cell status to significantly influence subjective well-being. Work status combined with sickle cell status to significantly influence overall life satisfaction ($p < 0.01$), health and functioning ($p < 0.05$), social and economic situation ($p < 0.05$) and psychological functioning ($p < 0.001$). Sickle cell patients who were not working were less satisfied overall with their health and functioning, social and economic situation, and psychological functioning than sickle cell patients who were working or the non-sickle cell subjects (Table 4). Respondents' occupation significantly interacted with sickle cell status to influence the family life sub-domain (Table 3; $p < 0.05$). Sickle cell patients who were in highly skilled occupations reported greater family life satisfaction than non-sickle cell

Table 3: Univariate tests of significance of the interaction of demographic variables with disease status effect on the dependent variables

| | Sociodemographic variables interacting with group membership | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Subjective Well-being measures*** | **Age** | **Gender** | **Working** | **Occupation** | **Living arrangement** | **Union** | **Education** | **Crowding** | **Household Possessions** | **Toilet Score** | **Water Score** |
| | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** | **F-value** |
| Over all life satisfaction | 0.44 | 0.02 | 8.66** | 1.94 | 0.94 | 0.98 | 1.63 | 0.39 | 2.28 | 1.93 | 0.02 |
| Health and functioning | 0.73 | 0.05 | 6.57* | 0.73 | 1.25 | 1.68 | 1.06 | 1.94 | 1.23 | 1.44 | 0.35 |
| Family life | 2.14 | 0.04 | 2.44 | 3.01* | 1.30 | 0.45 | 1.60 | 1.69 | 2.21 | 1.83 | 0.81 |
| Social and economic | 0.01 | 0.11 | 3.95* | 1.75 | 0.97 | 0.11 | 1.15 | 0.92 | 2.20 | 0.87 | 0.06 |
| Psychological functioning | 0.68 | 0.05 | 7.80** | 1.00 | 1.06 | 1.10 | 1.51 | 1.11 | 1.60 | 1.68 | 0.40 |
| Positive affect | 0.75 | 0.01 | 0.54 | 1.40 | 0.34 | 0.92 | 2.10 | 0.48 | 1.43 | 1.31 | 0.24 |
| Negative affect | 3.55 | 0.01 | 0.01 | 0.12 | 0.06 | 0.91 | 0.45 | 1.49 | 0.27 | 0.44 | 1.97 |

*$p < 0.05$, **$p < 0.01$

Table 4: Satisfaction with family life for sickle cell and non-sickle cell disease participants by occupational group

| **Occupational Group** | **Homozygous sickle cell disease** | **Non-sickle cell group** |
|---|---|---|
| Never worked or unskilled | 20.24 | 25.88 |
| Semi-skilled | 22.33 | 24.58 |
| Skilled | 23.49 | 24.35 |
| Highly skilled | 29.15 | 23.40 |

patients in highly skilled occupations (Fig. 1). The interaction of all other sociodemographic variables with sickle

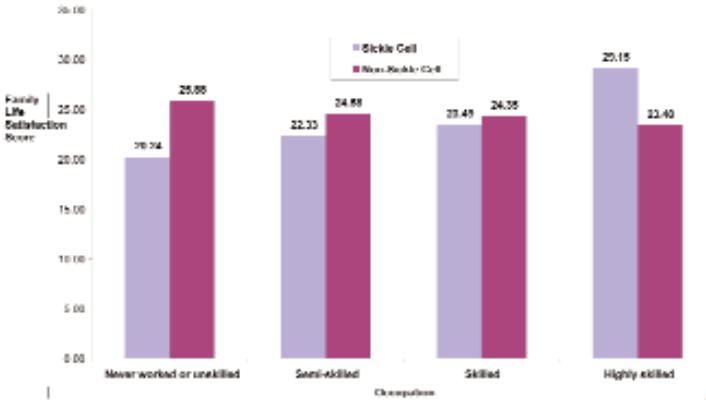


Figure: Sickle cell patients in highly skilled occupations were more satisfied with their family life

cell disease status had no significant relationships to subjective well-being or to positive and negative affectivity.

## DISCUSSION

In this study, sickle cell patients were less satisfied with their lives overall than adults without the illness. The sickle cell patients were also less satisfied with their health and functioning, social and economic situation and psychological functioning. They also reported lower levels of positive affect than non-sickle adults but had almost similar levels of negative affect scores. These results suggest that subjective well-being is compromised in adults with homozygous sickle cell disease.

Both the sickle cell and the non-sickle cell adults experienced similar levels of negative affect. One possible explanation for this equivalence in negative affect could be life and survivorship in Jamaica. The negative impact of the present difficult social and economic situation in Jamaica (15) may increase levels of negative affect regardless of whether the person has sickle cell disease or not. The burden of a physically limiting and unpredictable illness such as sickle cell disease further compounds the impact and diminishes the sickle cell patient's experience of any positive emotions, hence the lower positive affect scores. All of this will have a negative impact on various aspects of patients' lives and will influence their judgment of life satisfaction.

This study also explored how sociodemographic variables moderated the relationship between sickle cell status and subjective well-being. It was generally found that sociodemographic variables did not play a role in perceptions of subjective well-being in people with and without sickle cell disease. However, there were two related sociodemographic variables that did interact with sickle cell status to influence subjective well-being: work status and occupational status. Sickle cell patients who were not working were less satisfied with their life overall and with specific aspects of their lives (health and functioning, psychological functioning and, social and economic situation) than their sickle cell peers who were working and their healthy peers who were not working. Further, sickle cell patients with lower occupational attainment were less satisfied with their family life than other adults.

These findings indicate the extent to which homozygous sickle cell disease affects patients' capabilities to work and their occupational roles. Finding employment and

career planning are two important developmental tasks during adulthood (4−5, 16). The physical limitations and unpredictability of sickle cell disease frustrate these achievements for patients. Because of the illness, patients reported that they have not been able to complete their education, get a job or keep a job if they got one. Not being able to achieve these tasks may evoke discouragement, feelings of fear about the future and feelings of helplessness that leads to lower overall satisfaction with life and aspects of life. In fact, research has shown that employment and career development are problematic for sickle cell patients (5, 17).

The nature of sickle cell disease requires patients to continuously adjust to the physical changes associated with their illness. The homeostatic theory of subjective well-being (18−20) assumes that there will be no substantial relationship between subjective well-being and a medical condition due to the process of adaptation. This is due to the action of the body's homeostatic system, causing adaptation to occur in the process of subjective well-being maintenance. But Cummins' homeostatic theory of subjective well-being (18) also indicates that homeostasis can be defeated if the medical condition overly stresses the body's homeostatic system. The impact of sickle cell disease is sufficiently aversive to defeat homeostasis and prevent patients' adaptation. Sickle cell disease is a severe, unpredictable, erratic and painful condition where patients can go for long periods of time without any disease-related complications and then experience complications or may have long periods with complications and then experience no complications for a period of time. The severe and unpredictable nature of the illness results in a persistent lack of security that will test patients' limits of adaptive capacity for subjective well-being maintenance. As such, sickle cell patients are never allowed to reach homeostatic balance, therefore preventing adaptation. For this reason, sickle cell patients are not likely to have very stable levels of subjective well-being.

This study had some important limitations. The sample was selected from a cohort and, as such, is not necessarily a complete and accurate representation of the whole population of homozygous sickle cell patients. Therefore, generalizations from this study can only be made to adults in the cohort. It is apparent that subjective well-being is not static and will fluctuate because people's moods, emotions and self-evaluative judgments fluctuate over time (21). This study is the first to examine the subjective well-being of sickle cell patients in Jamaica. However, the cross-sectional design used does not allow for the estimation of change in the subjective well-being of patients over time. Longitudinal studies of patients' subjective well-being may uncover changes and patterns in judgment that could assist in the planning of suitable care. Despite these limitations, the differences in the two groups' subjective well-being were clear.

Further studies of subjective well-being among sickle cell patients are required so as to assess the stability of the relationships found in this study. Studies also need to be conducted comparing the subjective well-being of sickle cell patients with patients who have other unpredictable chronic illnesses that prevent them from exerting reasonable control over their lives. This broader research will further help to characterize the components of subjective well-being of sickle cell patients, which may help facilitate targeted intervention efforts.

In summary, these results suggest that adults with homozygous sickle cell disease could be unique when compared with persons with other chronic illnesses. They are at an elevated risk for negative psychological outcomes. As such, additional resources may need to be devoted to help them deal with the impact of the illness on their lives. Introducing greater stability into the lives of these patients may lead to higher levels of subjective well-being. It may be beneficial to encourage those sickle cell patients who are not working or who are unable to work to find purpose in their other social roles.

Asking sickle cell patients to report on their subjective well-being may be used to compliment other methods of outcome evaluation. This method goes beyond the opinion of care providers in the evaluation of patients outcomes and extends evaluation of outcomes to the patients themselves. Indeed, only the patients themselves are in a position to report on their experiences of pleasure or pain, and to judge their satisfaction with the quality of their lives. It would be interesting to compare patients' self-perceived well-being to that perceived by their care providers. This self-report method of well-being may also be useful in providing information on whether new therapies or treatments for sickle cell disease improve those dimensions of health and subjective well-being that are most important to patients.

**ACKNOWLEDGEMENTS**

We would like to acknowledge the contribution of: the subjects of the Jamaica Sickle Cell Cohort study who agreed to participate and kindly gave of their time. The staff of the Sickle Cell Unit and the Epidemiology Research Unit of the Tropical Medicine Research Institute including Professor Terrence Forrester, Drs Julie Meeks Gardner and Christine Powell, Yewande Lewis, Amika Wright, Kadene Clarke, Christopher Hibbert, Gary Bernard and Tyronne Keldo. Professor Graham Serjeant, of the Jamaica Sickle Cell Trust, who offered helpful suggestions, advice and assisted with the location of some of the participants. Professor Richard Williams, Dept of Sociology, University of Notre Dame, Indiana, for direction and advice with the conceptualization of the study.

**Footnotes**

Portions of this paper were presented at the Faculty of Medical Sciences Annual Conference in November 2004.

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