

# Component Structure of the SF-36 in Jamaicans with Sickle Cell Disease

M Asnani<sup>1</sup>, G Lipps<sup>2</sup>, M Reid<sup>1</sup>

## ABSTRACT

**Objectives:** Sickle cell disease (SCD) is the commonest genetic disorder in Jamaica and greatly affects the quality of life (QOL) of those who are afflicted. The Short Form 36 survey (SF-36) questionnaire is one of the most commonly utilized measures of QOL. Physicians cannot interpret QOL measures until the instruments being used to make assessment are adequately established in their population. The Jamaican cultural and educational systems expose its people to many stresses which likely impact on their QOL. It is thus postulated that the QOL construct may exhibit a different structure for the population with sickle cell disease.

**Subjects and Methods:** The SF-36 v.2 was interviewer administered to the Jamaican Sickle Cell Disease Cohort Study participants ('Cohort' sample) and a random sample of adult sickle cell unit patients ('Main' sample). Demographic data were also collected on both groups. Both of the samples did not meet the five rule criteria for compliance with the original SF-36 component structure. Hence, principal components analysis was used to determine the component structure of the SF-36 in both groups.

**Results:** Three dimensions may underlie the SF-36 for both groups and these could be labelled 'Physical Health', 'Mental Health' and 'Role Limitations'. This solution accounted for 45.8% of the variability underlying the SF-36 in the 'Cohort' sample and 54.6% of the variability in the 'Main' sample.

**Conclusions:** It concluded that within Jamaican samples of patients with sickle cell disease, the SF-36 has a component structure which is quite distinct from that initially proposed by its creators.

# Estructura de los Componentes del Cuestionario de Salud SF-36 en Jamaicanos con la Enfermedad de Células Falciformes

M Asnani, G Lipps, M Reid

## RESUMEN

**Objetivos:** La enfermedad de células falciformes (ECF) es el trastorno genético más común en Jamaica y afecta grandemente la calidad de vida (CdV) de quienes la padecen. El cuestionario de salud SF-36 es una de las mediciones de la CdV más comúnmente usadas. Los médicos no pueden interpretar las mediciones de la CdV hasta que los instrumentos usados para realizar la evaluación se establezcan de forma adecuada a su población. La cultura y los sistemas educacionales en Jamaica, exponen a su población a muchas formas de estrés que afectan probablemente su CdV. De este modo, se postula que el constructo CdV puede presentar una estructura diferente para esta población.

**Métodos:** El cuestionario SF-36 v.2 fue aplicado por el entrevistador a los participantes en un estudio de cohorte de la enfermedad de células falciformes en Jamaica (muestra de "cohorte") y a una muestra aleatoria de pacientes adultos de la unidad de anemia falciforme (muestra "principal"). Se recogieron datos demográficos de ambos grupos. Ninguna de las muestras satisfizo los cinco criterios normativos de conformidad con la estructura original de los componentes del SF-36. Por consiguiente, se recurrió al análisis de los componentes principales a fin de determinar la estructura de componentes del SF-36 en ambos grupos.

From: <sup>1</sup>Sickle Cell Unit, Tropical Medicine Research Institute and <sup>2</sup>Department of Psychology, Sociology and Social Work, The University of the West Indies, Kingston 7, Jamaica, West Indies.

Correspondence: Dr M Asnani, Sickle Cell Unit, The University of the West Indies, Kingston 7, Jamaica. Fax: (876) 927-2984, e-mail: monika.parshadasnani@uwimona.edu.jm.

**Resultados:** *Tres dimensiones pueden subyacer en el SF-36 para ambos grupos. Estas pueden ser llamadas "salud física", "salud mental", y "limitaciones de roles". Esta solución dio cuenta del 45.8% de la variabilidad subyacente en el SF-36 en el caso de la muestra de "cohorte" y el 54.6% de la variabilidad en la muestra "principal".*

**Conclusiones:** *Se concluyó que en las muestras de pacientes de Jamaica con la enfermedad de células falciformes, el SF-36 posee una estructura de componentes que puede ser bien distinta de la que inicialmente propusieron sus creadores.*

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## INTRODUCTION

Quality of life (QOL) measures are becoming increasingly important in the gamut of measurements that define the burden of disease on an individual (1). They are used not only as a measure of the psychosocial impact of the disease but in evaluating the efficacy of medical treatment (2). Quality of life constructs are usually measured by means of multi-item health status questionnaires. However, it is important to note that these measures should be validated for different populations due to the cultural and other social differences which exist between populations (3). To that end, the World Health Organization QOL (WHOQOL) Group has defined QOL as "an individual's perceptions of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (4).

Sickle Cell Disease (SCD) is a chronic disorder. It is a genetic blood disease that is characterized by the presence of large amounts of abnormal haemoglobin in red blood cells (5). This abnormal haemoglobin causes the red blood cells to assume a rigid sickle-shape in certain physiological and pathological conditions which in turn cause occlusion of blood vessels. The main complication involves unpredictable and sometimes extremely painful crises, usually in bony areas. Long-term complications of the disease involve chronic renal disease, proliferative retinopathy, heart failure, degeneration of bones and joints with chronic pain and disability. The course of this disease may be severe and quite variable among patients. The life expectancy is also considerably shortened to about 42 years in males and 46 years in females (6). Sickle cell disease carries a heavy psychosocial burden impacting on physical, psychological, social and occupational well-being as well as levels of independence (7–13).

There have been attempts made to understand the QOL of patients with SCD. Anie *et al* (10) have looked at coping, pain and QOL in their patients with SCD and found significant impairments on various dimensions of the Short Form 36 survey (SF-36) measure of QOL. Kater *et al* (14) found that children with SCD as well as their parents scored significantly lower on the items: general physical, motor and independent daily functioning and on occurrence of negative emotions on a Children's QOL instrument. The PiSCEs (Pain in Sickle Cell Epidemiology Study) group (15), using the SF-36 as their measure of QOL, found that SCD patients experi-

ence a lower health-related quality of life than the general population.

The SF-36 is one of the most common, generic measures of QOL (16) and has been used in numerous studies with chronic illnesses. It is also the most frequent measure employed to study QOL in SCD. The SF-36 is a 36-item questionnaire that was designed in the 1980s to provide a generic measure of health status. It has been reported on in over 1000 publications (17). The scale has eight subscales (dimensions) that can be calculated from 35 of the 36 items (one item about self-reported health transition is not included in the scores). All eight subscales are considered to be independent of each other. These eight subscales have been subjected to factor analysis which has resulted in the development of a 'physical health' component and a 'mental health' component (18). The SF-36 has been translated and adapted in 29 countries. Exploratory factor analyses have been used to determine the factor structure of the SF-36 in 10 different populations (19). Social class, culture, educational systems impact on QOL and no doubt do so in SCD patients in Jamaica.

To our knowledge, the SF-36 has not been used to measure QOL in the Jamaican population with SCD. We therefore sought to determine the component structure of the SF-36 in the population of Jamaicans living with SCD.

## SUBJECTS AND METHODS

### Study participants

Sickle cell disease is clinically the most important haemoglobinopathy in Jamaica. The Sickle Cell Unit (SCU) of The University of the West Indies (UWI) operates Jamaica's only comprehensive sickle cell centre. For some patients, the SCU acts as the initial and sole healthcare provider. In addition to enrolling patients with SCD who are self-referred or referred from other centres, the clinic offers medical care to persons enrolled in the Jamaica Sickle Cell Cohort Study (JSCCS). These individuals are now between the ages of 23 and 32 years and were initially identified from neonatal screening of 100 000 consecutive non-operative deliveries at a single hospital location, with the identification of 552 cases of sickle cell disease, 315 of whom were homozygous for the  $\beta^S$  allele. These patients are seen for routine health maintenance checks and for all significant sick events in an attempt to document the natural history of the disease.

Two hundred and thirty-four patients ('Cohort') from the JSCCS presented for their annual cohort review in January–February 2005. The SF-36 was interviewer administered, by a single interviewer, to this group of patients. All patients (who are not part of the JSCCS,  $n = 233$ ) presenting for routine medical evaluation to the SCU during the period April–June 2005 ('Main') were also administered the SF-36 by the same interviewer. All interviews were conducted after participants signed an informed consent. The study was approved by the University Hospital of the West Indies/University of the West Indies Ethics Committee.

### Study Instrument: SF-36

The SF-36 yields an eight-scale profile of scores as well as physical and mental health summary measures (17). The reliabilities of the eight scales and the two summary measures have been estimated using both internal consistency and test–retest methods. With rare exceptions, published reliability statistics have exceeded the minimum standard of 0.70 recommended for measures used in group comparisons in more than 25 studies; most have exceeded 0.80. Reliability estimates for physical and mental summary scores usually exceed 0.90 (20).

Prior to administration, the SF-36 was pre-tested using a 'think aloud technique'. This helped to establish that the respondents understood the questions and whether they thought the questions were useful in determining the concepts that were being studied. From this pre-testing, slight changes to the wording of some of the questions (questions 3b, 6, 9a and 9f) were made.

### Analytic strategy

The five criteria used by Ware *et al* (21) to evaluate support for the hypothesized two-dimensional physical and mental health model for the questionnaire were adopted in the present study. These criteria are as follows: (1) eigenvalues for the first two components greater than one; (2) greater than 60% of the total variance in scale scores explained by the first two components; (3) the Physical Functioning (PF) scale correlating highest with the physical component, followed by the Role Physical (RP) and Bodily Pains (BP) scales, and all three scales correlating lowest with the mental component; (4) the Mental Health (MH) scale correlating highest with the mental component, followed by the Role Emotional (RE) and Social Functioning (SF) scales, and all three scales correlating lowest with the physical component; and (5) the General Health (GH) and Vitality (VT) scales correlating moderately with both physical and mental components, with the GH scale correlating higher with the physical component and the VT correlating higher with the mental component.

In the first portion of the determination of the component structure of the SF-36 in the 'Cohort' and 'Main' samples, the eight SF-36 scale scores were calculated as described in the SF-36 user manual (22). The eight scales were

then subjected to Principal Components Analysis (PCA) and compliance with the above five criteria was studied.

In the second part of the structure determination, data from the two samples were submitted to PCA following an exploratory approach. Exploratory PCA using the individual items was conducted as the dimensional structure of the SF-36 in Jamaican samples of sickle cell patients is not known and has not been explored. Several possible solutions within each sample were explored ranging from an eight-component to a two-component solution. Selection of the best number of components to keep in each sample was based on a combination of Kaiser's Rule (eigenvalues greater than one), an inspection of the Scree plot (23, 24), the total amount of variability in the items accounted for by the solution (at least 30% of the total variability in the items), simple structure and psychological meaningfulness. A correlation of 0.40 between an item and the component (component loading) was used to indicate that an SF-36 item loaded on a component. The appropriateness of principal components analysis in each group was assessed via the Kaiser-Meyer-Olkin MSA (measure of sampling adequacy) test (25). The items that did not load on any components (or had poor loadings *ie* component loading  $< 0.4$ ) were removed from the final model. Also items that did not load in the same manner in the two samples were removed from the final model for the SF-36.

SPSS Version 11.5 for Windows was utilized to conduct the above analyses.

## RESULTS

### Demographics

A total of 234 patients from the Jamaican Sickle Cell Disease Cohort group ('Cohort') participated (100% of those attending the 2005 annual cohort review). From the main clinic group ('Main'), a total number of 233 patients were administered the questionnaire during the study period. The demographic details of the two groups are given in Table 1. As expected, the age ranges and the genotypes for the two groups showed significant differences ( $p < 0.01$ ).

### Principal components analysis of the SF-36 subscales

The eight subscales, as defined by the creators of this instrument, were calculated for each sample. Following this, PCA was then performed on these scale scores for each sample.

For the 'Cohort' sample, only the first two components had eigenvalues greater than 1 (Kaiser's rule for determining number of components to retain). These two components accounted for 62.1% of the total variance in scale scores. For the 'Main' sample, only the first component had an eigenvalue of greater than one with this single component accounting for 54.9% of the total variance in the scale scores.

The rotated component matrix for the 'Cohort' sample (Table 2) suggests that the loadings of the different scales on the components are quite distinct from that proposed by Ware *et al* (21).

Table 1: Demographics of the two samples

Variable	Cohort, n = 234	Main, n = 233	p value
*Age (yrs)	27.1 ± 2.5	35.5 ± 12.6	0.000
Gender (M:F)	103(48.8): 108(51.2)	88(38.8): 139(61.2)	0.032
<b>Genotype</b>			0.000
SS	135 (57)	177 (76)	
SC	72 (31)	29 (12.5)	
SB+	13 (6)	9 (3.9)	
SB0	7 (3)	12 (5.2)	
Others	7 (3)	6 (2.4)	
<b>Marital Status</b>			0.039
Single	213 (91.3)	197 (84.5)	
Married	19 (7.8)	27 (11.6)	
Other	2 (0.9)	9 (3.9)	
<b>Educational</b>			0.036
Primary	30 (13)	43 (18.5)	
Secondary	115 (50)	132 (56.7)	
Skills training	67 (29.1)	46 (19.7)	
Tertiary	18 (7.8)	12 (5.2)	

Values in cells are frequencies (%) \* values are mean ± sd

Table 2: Rotated component matrix for the SF36 scales for 'Cohort' sample

	Component	
	1	2
Social functioning	0.821	
Role physical	0.789	
Role emotional	0.713	
Bodily pain	0.630	0.382
Mental health	0.576	0.491
Physical functioning		0.837
General health		0.749
Vitality	0.498	0.635

**PCA on original SF-36 items: sample one ('Cohort')**

Results of the PCA of the data from the 'Cohort' using varimax rotation suggested that three components underlie the SF-36. While an eight-component solution was explored to examine the hypothesized structure of the SF-36, the items did not cluster in any useful manner nor was this the most parsimonious solution. Indeed, some components consisted of only one item. The solution which best met all criteria was the three component solution (Table 3). This three component solution accounted for nearly half (45.8%) of the total variability underlying the SF-36 items. The first component, which accounted for 28.6% of the total variability underlying the SF-36 items, appeared to assess participants' feelings of sadness or depressive affect. The second component, which accounted for 10.4% of the total variability underlying the SF-36 items, appeared to assess interference with physical, occupational and social activities. The final component which accounted for 6.9% of the total variability in SF-36 items appeared to assess physical health. Surprisingly, items

Table 3: Varimax rotated component loading matrix for the 'Cohort' patients

SF-36 Item	Component		
	1	2	3
Q9H Have you been happy	0.76		
Q9F Felt downhearted and depressed	0.75		
Q9D Felt calm and cheerful	0.68		
Q5B Mental Health: Accomplished less than you would like	0.66		
Q5C Mental Health: Did work or activities less carefully than usual	0.66		
Q9C So down in the dumps that nothing could cheer you up	0.61		
Q9B Have you been very nervous	0.57		
Q5A Mental Health: Cut down on amount of time at work or activities	0.56		
Q9G Felt worn out	0.55		
Q9A Feel full of life	0.54		
Q9I Feel tired	0.53		
Q9E Have a lot of energy	0.49		
Q11D My health is excellent			
Q1 In general what is your health?			
Q11 I am as healthy as anybody I know			
Q4B Physical Health: Accomplished less than you would like		0.84	
Q4D Physical Health: Had difficulty with work or activities		0.83	
Q4C Physical Health: Limited in kind of work or activities		0.81	
Q4A Physical Health: Cut down on time at work or other activities		0.81	
Q8 Interference of pain on normal work		0.81	
Q7 Body pains		0.73	
Q10 Interference of health with social activities		0.62	
Q6 Interference with social activities		0.59	
Q11A I get sick a little easier than others			
Q2 Health in general since last year			
Q3G Health Limitation: Walking more than a mile			0.78
Q3H Health Limitation: Walking several hundred yards			0.72
Q3E Health Limitation: Climbing one flight of stairs			0.72
Q3B Health Limitation: Moderate activities			0.71
Q3I Health Limitation: Walking 100 yards			0.66
Q3D Health Limitation: Climbing many flights of stairs			0.64
Q3F Health Limitation: Bending, kneeling or stooping			0.61
Q3A Health Limitation: Vigorous exercise			0.60
Q3C Health Limitation: Lifting or carrying groceries			0.48
Q3J Health Limitation: Bathing or dressing yourself			
Q11C I expect my health to get worse			

which related to general health did not load on any component.

**PCA on original SF-36 items: sample two ('Main')**

The PCA using data from 'Main' patients generally paralleled those from the PCA of the 'Cohort' group. While the initial PCA of the data (based on Kaiser's Rule) yielded seven components, this solution lacked both simple structure and psychological meaningfulness. Five, four and three com-

ponents were also explored. Of these PCAs, the three component solution best met the criteria established for determining the number of components to keep (Table 4). This

Table 4: Varimax rotated component loading matrix for the 'Main' patients

SF-36 Item	Component		
	1	2	3
Q4B Physical Health: Accomplished less than you would like	0.90		
4D Physical Health: Had difficulty with work or activities	0.90		
Q4C Physical Health: Limited in kind of work or activities	0.89		
Q4A Physical Health: Cut down on time at work or other activities	0.88		
Q8 Interference of pain on normal work	0.79		
Q7 Body pains	0.67		
Q10 Interference of health with social activities	0.67		
Q5A Mental Health: Cut down on amount of time at work or activities	0.62		
Q6 Interference with social activities	0.61		
Q5B Mental Health: Accomplished less than you would like	0.61		
Q5C Mental Health: Did work or activities less carefully than usual	0.60		
Q2 Health in general since last year			
Q9F Felt downhearted and depressed		0.76	
Q9H Have you been happy		0.74	
Q9E Have a lot of energy		0.74	
Q9D Felt calm and cheerful		0.73	
Q9A Feel full of life		0.73	
Q9G Felt worn out		0.67	
Q9I Feel tired		0.66	
Q9C So down in the dumps that nothing could cheer you up		0.66	
Q9B Have you been very nervous		0.60	
Q11B I am as healthy as anybody I know		0.51	
Q11A I get sick a little easier than others		0.50	
Q11D My health is excellent		0.49	
Q1 In general what is your health?			
Q11C I expect my health to get worse			
Q3H Health Limitation: Walking several hundred yards			0.81
Q3I Health Limitation: Walking 100 yards			0.79
Q3E Health Limitation: Climbing one flight of stairs			0.77
Q3C Health Limitation: Lifting or carrying groceries			0.75
Q3J Health Limitation: Bathing or dressing yourself			0.69
Q3B Health Limitation: Moderate activities			0.69
Q3G Health Limitation: Walking more than a mile			0.67
Q3D Health Limitation: Climbing many flights of Stairs			0.62
Q3F Health Limitation: Bending, kneeling or stooping			0.61
Q3A Health Limitation: Vigorous exercise			0.48
Q3C Health Limitation: Lifting or carrying groceries			
Q3J Health Limitation: Bathing or dressing yourself			
Q11C I expect my health to get worse			

three-component solution accounted for approximately 54.5% of the total variability in the SF-36 items. These three components were quite similar to those found within the 'Cohort' group. The first component, which accounted for 36.1% of the total variability in SF-36 items, appeared to assess interference with physical, occupational and social activities. The second component, which accounted for 11.5% of the total variability in SF-36 items, appeared to measure a combination of sad affect and general health. The third component which accounted for 6.9% of the total variability in SF-36 items appeared to assess physical health. Consistent with the PCA for 'Cohort' sample, several very general items which related to past and future perceptions of health did not load on any specific component.

## DISCUSSION

In psychosocial and medical sciences, many psychosocial constructs are measured by means of health status questionnaires. Principal components and factor analysis are one of the most commonly used procedures in the development and evaluation of psychological measures (23). The aim may be either pure data reduction, assessment of the structure (dimensions) underlying the questionnaire or investigating whether the questionnaire shows the same dimensions across different groups (structural reliability). When no clear-cut ideas about the factor structure (number of dimensions and their mutual associations) exist, the factor structure of an instrument can best be investigated by means of exploratory factor or principal components analysis (26).

In this study, exploratory principal components analysis was applied to study the component structure of the SF-36 in two distinct subgroups of the Jamaican sickle cell disease population.

The first step of this process was to follow the steps set out by Ware *et al* (21). In both samples, these criteria were clearly rejected. Only one component was seen to underlie the SF-36 subscales within the 'Main' sample. Even though the 'Cohort' sample showed a two-component structure, the subscales loading on to each component were clearly different than what was proposed by Ware *et al*.

The next step was to conduct the PCA on the original items of the SF-36. Whereas the initial solutions showed eight and seven components for the 'Cohort' and 'Main' samples respectively, these were not the most parsimonious solutions. For each sample, the subscales initially defined as 'role physical', 'bodily pain' and 'social functioning' clustered together on one component and 'vitality' and 'mental health' clustered together on the second. The last few components had items from the original 'physical functioning' subscale and it made no intuitive sense for those items to load separately on three components. Hence a three-component model was defined as the most parsimonious solution for each sample.

These three components were labelled “Role limitations”, “Mental health” and “Physical health”. The veracity of these findings was strengthened as the results of the initial PCA were replicated by using two independent samples of sickle cell patients. These findings were in opposition to other research on the dimensional structure of the SF-36. While other studies have found two underlying dimensions (19) in this population, three clear dimensions were seen. One possible reason for this discrepancy is that many of these previous studies have subjected scores on the SF-36 sub-scales to principal components analysis (PCA) or factor analysis (FA) rather than the individual SF-36 items. Use of sub-scale scores in PCA or FA may be questioned as such a strategy assumes a clustering of items on sub-scales which have not been empirically verified.

Keller *et al* (27) applied structural equation modelling techniques to the SF-36 identifying three second order factors which are subsumed under a single third order factor. This can be seen to be quite similar to what has been shown in this study.

Despite the similarities between the PCAs for the two samples, there were two notable differences. First, three of the SF-36 items (5A, 5B and 5C) which loaded on the ‘mental health’ component in the ‘Cohort’ sample loaded on the ‘role limitations’ component in the ‘Main’ sample. These three SF-36 items related to either limiting activities due to problems or taking less care with work or activities. It is possible that the ‘Main’ patients did not distinguish between the impact of physical and emotional problems on their work and daily activities. Alternatively, this switching of components may simply be due to small variations in the magnitude of the inter-correlation of items between specific samples. Second, three items related to general health which did not cluster on any component of the ‘Cohort’ sample fell on the component which assessed ‘mental health’ in the ‘Main’ sample.

In summary, the data presented here indicate that the SF-36 has a component structure which is quite distinct from that initially proposed by creators of the SF-36. Whether this difference is due to differences in cultural and social norms or due to an effect of sickle cell disease will need to be explored in future research.

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