

Supplementary File 1: Detailed description of the domains of the Sickle Cell Disease Burden Interview (SCDBI)

The response options from the individual stressors had a score of 0 to 3. The scores were added for each of the domains and the total score was categorized and interpreted as follows:

Hospital factors:

Score – 0 = the stressful event never occurred

Scores 1 – 8 = stressful events occur occasionally or had an insignificant impact

Scores 9 - 16 = stressful event occurs frequently or had a moderate impact

Scores 17 – 24 = event occurs regularly or had a severe impact

Family/social life factors and interactions:

Score – 0 = not (none) at all

Scores 1–15 = occasionally

Scores 16–30 = frequently and

Scores 31 – 45 = All the time

Physical/health factors of caregivers:

Score – 0 = No impact

Scores 1–6 = occasional or insignificant impact

Scores 7–12 = frequent or moderate impact and

Scores 13 – 18 = severe impact.

SCD-affected children's life factors:

Score – 0 = not at all

Scores 1–7 = occasional or insignificant impact

Scores 8–14 = frequent or moderate impact and

Scores 15– 21 = severe impact.

Family finances impact

Score – 0 = No significant loss of income

Scores 1–7 = Minor loss of income

Scores 8–14 = Moderate loss of income and

Scores 15 – 21 = Severe loss of income.

Caregivers'/parents coping ability and disease factors:

Score – 0 = none at all

Scores 1–6 = mild difficulty

Scores 7–12 = moderate difficulty

Scores 13 – 18 = severe difficulty

SCD scoring system was determined using the SCD disease severity score (22). The severity score assessed a total of 8 parameters that reflected the patient's present state, their state during the previous 12 months and lifetime complications. Based on their state, categorized as follows:

Mild = total score is < 8

Moderate = total score is 8 – 17

Severe = total score is >17

The weight of psychosocial burden scores was assessed qualitatively by measuring the percentage of participants' various responses per individual question i.e., % "none at all", % "mild difficulty or impact", % "moderate difficulty or impact" and % "severe difficulty or impact". The quantitative scores were computed as follows: 0 points, if there is no difficulty/no stressful event/no income loss, 1 point if there is mild difficulty/occasional stressful event/minor loss of income, 2 points if there is moderate difficulty/frequently stressful event/moderate loss of income, and 3 points if there is severe difficulty/severe stressful event/occurs all the times/severe loss of income. These scores were then analysed in two ways:

1. The scores of the individual stressor per participant were added to give the total score
2. The mean score of categories of stressors was derived by dividing the sum of individual scores by the number of items in each category e.g. the weighted hospital score was obtained by dividing the total scores of individual stressors in this category by 8 (i.e., the number of items assessing hospital factors). The value gotten was then rounded up to the nearest whole number and grouped as follows:

Scores 0 – 1 = No/ mild difficulty or impact

Scores 2 and 3 = Moderate/ severe impact or difficulty

The scores of the psychosocial stressors were then re-categorized into:

No/ mild difficulty or impact = Not stressful or impactful or difficult events

Moderate/ severe impact or difficulty = Severely stressful/ impactful/difficult events.