Appendix S1

SICKLE CELL DISEASE KNOWLEDGE AND HEALTH BELIEFS QUESTIONNAIRE
Demographic Questionnaire

1. Age of respondent (years) ___________

2. Marital Status ___________

3. Do you live with your spouse?
   1. Do  2. Do Not  3. No Spouse

4. How many children do you have? ___________
   0  1  2  3  4  5

5. The highest level of school I have finished is _____.
   1. No formal education
   2. Adult and Quranic Education
   3. Primary
   4. Junior Secondary
   5. Senior Secondary
   6. Post-secondary but not University
   7. University

6. The highest educational level of my husband
   1. No formal education
   2. Adult and Quranic Education
   3. Primary
   4. Junior Secondary
   5. Senior Secondary
   6. Post-secondary but not University
   7. University
Assessment of knowledge and health beliefs of Sickle Cell Disease.

The following are some questions about sickle cell disease. Please read each question very carefully and then circle one answer that is the best. Choose only one answer for each question.

1) **Sickle Cell Disease is caused by**
   a. dirty needles
   b. a virus
   c. inheriting genes from both parents
   d. bad blood
   e. none of the above

2) **How many genes must someone inherit to have Sickle Cell Disease?**
   a. zero, it is not caused by genes
   b. one from their mom
   c. two, one from their mom, and one from their dad
   d. three, one from mom, and two from dad
   e. none of the above

3) **Sickle Cell Disease can cause**
   a. severe debilitating pain
   b. strokes
   c. infections
   d. organ damage
   e. all of the above

4) **Sickle Cell Disease occurs most often in**
   a. boys
   b. girls
   c. people of African descent
   d. people not of African descent
   e. all of the above

5) **Sickle Cell Pain can feel worse than**
   a. toothache
Knowledge and Health Beliefs Assessment of SCD

9. At what age does sickle cell disease usually start manifesting?
   a. At birth
   b. from 6-9 months of age
   c. after one year of age
   d. after 2 years of age

10. Which of the following are common features in persons with sickle cell disease
    a. yellow eyes (jaundice)
    b. Bone pains
    c. low blood level requiring blood transfusion
    d. All of above

11. which of the following are forms of sickle cell disease
    a. Haemoglobin SS
    b. Haemoglobin SC
    c. Haemoglobin AS
    d. options (a) and (b)

12. which of the following combinations of hemoglobin genotypes in marriage will not result in a child with Sickle cell disease?
    a. AS/AS
    b. AS/AA
    c. AS/AC
    d. AC/SC

Health Belief Questions.
Please rate your level of agreement with each of the following statements on a 5-point scale where 1 means “strongly disagree” and 5 means “strongly agree.”

Severity
1. Sickle Cell Disease is a serious disease.
   Strongly Disagree 1 2 3 4 5 Strongly Agree
2. Having a child with sickle cell disease would be very scary.
   Strongly Disagree 1 2 3 4 5 Strongly Agree
3. My life would change if my child had sickle cell disease.
   Strongly Disagree 1 2 3 4 5 Strongly Agree

Susceptibility
4. My children are at risk for sickle cell disease.
   Strongly Disagree 1 2 3 4 5 Strongly Agree
5. Sickle cell disease could happen in my family.
Knowledge and Health Beliefs Assessment of SCD

6. My spouse may be a carrier of sickle cell trait.
   Strongly Disagree  1  2  3  4  5  Strongly Agree

Benefit
7. It is useful to know if I have sickle cell trait.
   Strongly Disagree  1  2  3  4  5  Strongly Agree
8. It is useful to know if my spouse has sickle cell trait.
   Strongly Disagree  1  2  3  4  5  Strongly Agree
9. Knowing the risk of having a child with sickle cell disease would change how I plan a pregnancy.
   Strongly Disagree  1  2  3  4  5  Strongly Agree

Barriers
10. Testing for sickle cell hemoglobin is painful and difficult.
   Strongly Disagree  1  2  3  4  5  Strongly Agree
11. My spouse would be hard to convince to have testing.
   Strongly Disagree  1  2  3  4  5  Strongly Agree
12. Screening a child for sickle cell disease would be expensive.
   Strongly Disagree  1  2  3  4  5  Strongly Agree

Acceptability and Barrier of Neonatal Testing
13. What is your hemoglobin genotype?
14. What is your husband’s hemoglobin genotype.................................................................
15. Do you have any child with sickle cell disease?
   1. Yes  2. No  3. I do not know
16. If the answer to Q15 is yes, how many children with sickle cell disease do you have?
   ............
17. Have ever heard that sickle cell disease can be diagnosed in the newborn period
   1. Yes  2. No
18. Would you accept testing of your newborn baby for sickle cell disease?
   1. Yes  2. No  3. I am not sure
19. If yes, please state why?
   ........................................................................................................................................
   ........................................................................................................................................
   ............
20. If No to Q.18, please state why

21. Would you be willing to allow your child have genotype test at birth?
Knowledge and Health Beliefs Assessment of SCD

22. Will you be willing to allow your newborn baby remain in the birth health facility for more than 24 hours to allow for sickle cell disease test

23. Will you be willing for your child to have sickle cell disease test when you bring him/her to the immunization centre?
   1. Yes  2. No  3. I am not sure

24. Will your husband be happy if you permit haemoglobin genotype (sickle cell disease test) on your baby in the newborn period or 1st 28 days of life?
   1. Yes  2. No  3. I am not sure

25. Will your husband be happy if you permit sickle cell disease test on your baby during an immunization visit?
   2. Yes  2. No  3. I am not sure

26. Would you need the permission of any family member to test your baby’s haemoglobin genotype (for sickle cell disease)?

27. If answer to Q.25 is yes, please state who?

28. When is the best time to diagnose sickle cell disease?
   1. When the child becomes sick  2. At 9 months of age  3. In the newborn period

29. Do you think that testing a baby in the newborn period for sickle cell disease is beneficial?
   1. Yes  2. No  3. I am not sure

30. If yes to Q.29, please state the benefit of diagnosing it early?

31. Do you think there is any disadvantage of testing for sickle cell disease in the newborn period?
   1. Yes  2. No  3. I am not sure

32. If answer to Q.31 is yes, please explain

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