

Supplemental Materials

Appendix I) Demographic Survey

We are currently studying the prevalence of vaso-occlusive or “sickle cell pain” during menstruation or your period. The goal of this anonymous questionnaire is to collect information so that we can treat pain during menstrual periods more effectively. This questionnaire is divided into three sections. The first set of questions will ask you about your sickle cell disease and pain episodes. The second section will ask you specifically about “sickle cell pain” experienced either the week prior to or during your last menstrual period. The final section is called the Menstrual Distress Questionnaire and this will ask you more specific questions about symptoms during your menstrual period. We appreciate you answering these questions and if you have any questions during the questionnaires, please ask the study coordinator.

Section 1: Questions about your sickle cell disease

1. How old are you? _____
2. What type of sickle cell disease do you have?
 - a. Hemoglobin SS disease (HbSS)
 - b. Hemoglobin SC disease (HbSC)
 - c. Hemoglobin S Beta Thalassemia +
 - d. Hemoglobin S Beta Thalassemia zero
 - e. Other (please specify:_____)
3. On average, how often do you have pain from your sickle cell disease?
 - a. 1-2 times per month
 - b. 3-4 times per month
 - c. > 4 times per month
 - d. Daily
4. Have you been admitted for a pain episode from your sickle cell disease?
 - a. Yes
 - b. No
5. How often have you been admitted for a pain episode from your sickle cell disease?
 - a. Never admitted for pain
 - b. Rarely admitted for pain

- c. 1-3 times per year admitted for pain
 - d. 4-6 times per year admitted for pain
 - e. > 6 times per year admitted for pain
6. On average, how long do your pain episodes last?
- a. < 4 days
 - b. 5-7 days
 - c. > 7 days
7. When you experience pain from your sickle cell disease, where do you usually have pain? (Please circle all that apply and if legs or arms are circled, please indicate right, left or both)
- a. Back
 - b. Chest
 - c. Arms
 - d. Legs
 - e. Headache
8. Do you have a pain action plan?
- a. Yes
 - b. No
9. Do you know how to use your pain action plan?
- a. Yes
 - b. No
10. How often do you use your pain action plan when you have pain?
- a. Never
 - b. Sometimes
 - c. Always
11. Have you been able to identify any triggers for your pain?
- a. Yes
 - b. No

12. If you answered yes to question 11, what triggers your pain? (Circle all that apply)

- a. Cold weather
- b. Seasons changing
- c. Dehydration in the summer time
- d. Exercise
- e. Menstrual periods
- f. Stress
- g. Illness
- h. Other: _____
- i. Not applicable

13. Do you take hydroxyurea?

- a. Yes
- b. No

14. Do you receive chronic transfusions?

- a. Yes
- b. No

Section 2: Questions about your menstrual period

1. How old were you when you first had your period?

- a. 8-9 years old
- b. 10-11 years old
- c. 12-13 years old
- d. > 13 years old
- e. Other, specify age: _____

2. When was your last period?

- a. Within the last month
- b. Within the last 2 months
- c. I can't remember

3. How many days will your period last on average?
- a. < 4 days
 - b. 5-7 days
 - c. > 7 days
4. How many maxi-pads or tampons do you use each day of your period?
- a. 2 pads or tampons per day
 - b. 3 pads or tampons per day
 - c. 4 pads or tampons per day
 - d. More than 4 pads or tampons per day
5. How often do you get your period?
- a. Every 2 weeks
 - b. Every 3 weeks
 - c. Every 4 weeks
 - d. Other, please specify: _____
6. Can you distinguish your “sickle cell pain” from your menstrual cramps?
- a. Yes
 - b. No
7. If yes to question 6, how can you tell that you’re experiencing your “sickle cell pain” during your menstrual period? Please describe below.
- _____
- _____
- _____
- _____
8. If yes to question 6, how can you tell that you are experiencing only menstrual cramps and not “sickle cell pain”? Please describe below.
- _____
- _____
- _____
- _____

9. Answer only if yes to question 6. If you experience both “sickle cell pain” AND menstrual cramps during your menstrual period, how can you tell the difference between both types of pain? Please describe below.

10. Have you ever experienced “sickle cell pain” in the week prior to or during your period?
- a. Yes
 - b. No
11. If you answered “Yes” to the question above (question 10 in Section 2), when you think of your last menstrual period, when did you start to have “sickle cell pain?” If no, please skip this question.
- a. 0-7 days prior to the start of your menstrual period
 - b. During your menstrual period
 - c. 0-7 days after your menstrual period
 - d. I did not have sickle cell pain associated with my menstrual period
 - e. Not applicable
12. If you answered “Yes” to question 10 in Section 2, how often do you have your “sickle cell pain” during your periods? If no, please skip this question.
- a. Every now and then
 - b. Almost every period
 - c. With every period
 - d. Not applicable
13. When you experience pain from your sickle cell disease during your menstrual period, where do you usually have pain? (Please circle all that apply and if legs or arms are circled, please indicate right, left or both)
- a. Back
 - b. Chest
 - c. Arms
 - d. Legs
 - e. Headache

f. Not applicable

14. Do you find that you are more likely to experience “sickle cell pain” during your period or in the week after your period?

- a. During your period
- b. Week after your period
- c. Not applicable

15. Do you need to use your pain action plan for “sickle cell pain” during your period?

- a. Yes
- b. No
- c. Not applicable

16. If you had pain during your last menstrual period, what medications, the dose and how frequently did you use to control your pain?

17. Have you been admitted for pain control for “sickle cell pain” and had your menstrual period at the same time?

- a. Yes
- b. No

18. Have you found any medicines or therapies that help your “sickle cell pain” during your period?

- a. Yes
- b. No
- c. Not applicable

19. If you answered “Yes” to question 13 in Section 2, please share with us what medicines or therapies have helped during your “sickle cell pain” with your menstrual period. If you can, list the dose and how often you have needed these medications.

Answer:

20. Are you sexually active?

- a. Yes
- b. No

21. Are you using birth control methods?

- a. Yes
- b. No

22. If you answered yes to Question 16 in Section 2, can you specify what you are currently using? Circle all that apply.

- a. Combination oral contraceptives (contains both estrogen and progesterone)
- b. Depo Provera (the shot)
- c. NuvaRing
- d. OrthoEvra (the patch)
- e. Intrauterine device
- f. Condoms
- g. Intradermal (it's implanted under your skin)
- h. Other, specify: _____

23. Did you notice a change in sickle cell pain around your period after starting birth control?

- a. Yes, the pain worsened
- b. Yes, the pain improved
- c. No, the pain did not change

Appendix II) Modified version of the Sickle Cell Disease Pain Burden Interview-Youth (SCPBI-Y)

I want you to think about your sickle cell pain experienced 7 days prior to or during your last menstrual period:

1. How many days have you had any sickle cell pain during this menstrual period?
None A Few Some Many Every
2. How many nights have you slept poorly (trouble falling asleep or waking up during sleep) because of sickle cell pain during this menstrual period?
None A Few Some Many Every
3. How many days have you had trouble taking care of yourself (dressing, going to the bathroom, showering) because of sickle cell pain during this menstrual period?
None A Few Some Many Every
4. How many days have you missed from school/work because of sickle cell pain during this menstrual period?
None A Few Some Many Every
5. How many days have you left school/work early because of sickle cell pain during this menstrual period?
None A Few Some Many Every
6. How many days have you been unable to do things you enjoy because of sickle cell pain during this menstrual period?

None A Few Some Many Every
7. How many days have you felt sad, mad or upset because of sickle cell pain during this menstrual period?
None A Few Some Many Every

Scoring System: “None” = 0, “A Few” = 1, “Some” = 2, “Many” = 3 and “Every” = 4

Scores ranged from 0 to 28, i.e. no pain burden to severe pain burden.