Appendix II. Quantitative Survey

Do you have other children with sickle cell disease YES NO

Did you find out your child had sickle cell prior to your first clinic visit YES NO

Did you try to learn about Sickle Cell prior to you first clinic visit YES NO

**Learning about Disease**

Prior to seeing the Sickle Cell doctor, I learned about sickle cell disease from:

1. Pediatrician Learned alot Learned some Learned little Did not ask

2. Family Members Learned alot Learned some Learned little Did not ask

3. Friends Learned alot Learned some Learned little Did not ask

4. Sickle Cell Foundation Learned alot Learned some Learned Little Did not ask

5. Internet Learned alot Learned some Learned little Did not use

6. Books Learned a lot Learned some Learned little Did not use

How/who would you like to teach you about sickle cell. Circle one for each

Doctor talks about disease Yes No

Talk to family members with disease Yes No

Talk to friends with disease Yes No

Read educational pamphlet from doctors office Yes No

Look up information on internet Yes No

Read book on sickle cell disease Yes No

**Source of information**

Should educational material be sent to you prior to the first visit Yes No

If yes, what educational material would you like

Recommend websites Very important Important OK Would not use

Recommended books Very important Important OK Would not use

Pamphlet about disease Very important Important OK Would not use

Link to videos about disease Very important Important OK Would not use

Names of parents to talk to Very important Important OK Would not use

**Parent emotions**

When I found out my child had sickle cell, I was concerned about: Circle answers you agree with

Will my child live a normal life Will I be able to take care of my child

Will my child be treated differently by friends How will I know when my child is sick

How will other people (teachers, relatives) know how to take care of my child when I’m not there

Will my child live a long life Will my child live a life of pain

**Educational Videos**

Have you watched the sickle cell educational videos at Clinic YES NO

Would you rather watch the videos : In clinic DVD at home Video on the internet

Are the videos helpful Very helpful Somewhat helpful Little help Not really

Would you prefer to: Watch the video in clinic Watch the video at home Both