

Neonatal opportunity to educate parents and other



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Neonatal screening provides an opportunity to not only identify sickle cell disease but also the opportunity to educate parents and other caregivers about the disorder before a child starts to develop symptoms. Educating on sickle cell disease focuses on the genetics, the basic pathophysiology, and the importance of regularly scheduled health maintenance visits. Parents and caregivers need to be educated on such matters because they are the child's first line of help, with doctors and other medical professionals being next in line. Parents and caregivers can be taught how to manage pain crises by understanding possible triggers for pain crises, such as dehydration and exposure to extreme temperatures. Immunizations and other medications are other health maintenance steps that can be taken to ensure relief. All of this would be regarded as impossible if it were not for genetic counseling. The purpose of genetic counseling is to guide people through the meticulous decision-making process concerning reproducing.

Because sickle cell disease is a genetic disease the primary means of pathology is reproduction. Therefore, genetic counseling for carriers of the sickle cell trait is of utmost importance because it was created to help solve their inheritance problems (Silva & Ramalho, 1997). Counseling for sickle cell disease deals with the occurrence or risk of the disease in a family and helping to understand how genetic heritage contributes to the disease. Genetic counseling is ideal because it guides a family on decisions about procreating while defending the family's interests in mind. According to some authors "individuals are aware of the problem without being deprived of their reproductive decision-making rights" (Ramalho & Silva, 1997). Genetic counseling is based on five ethical principles. Autonomy, privacy, justice,

equality, and quality all constitute genetic counseling for not only sickle cell disease, but genetic counseling for all other genetic diseases. The principle of autonomy declares that genetic testing should be voluntary.

The principle of privacy says that the findings of genetic testing cannot be exchanged to any person without express consent. The principle of justice supports the protection for the rights of susceptible individuals. The principle of equality provides equal access to tests. And lastly, the principle of quality requires that all tests that are administered are carried out in labs are done with professional and ethical supervision.