B1-9: Ethical Issues for Families Living with Sickle Cell Disease

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Abstract:
Introduction: The purpose of this poster presentation is to describe how families living with Sickle Cell Disease (SCD) define and manage the ethical issues that emerge during their interactions with health care providers. SCD affects millions of individuals and families throughout the world. Currently, little is known about the ethical issues that emerge for these families during their interactions with health care providers. Moreover, it is not clear how well genetic specialists and other health care providers are meeting the counseling and support needs of these families.

Method(s): In this study, which was guided by the Family Management Style Framework developed by Knafl and colleagues, in-depth interviews were conducted with one or more family members from 40 families living with sickle cell disease.
Results: The most common ethical issues reported by participants included concerns about the ability to gain access to high quality care in a timely manner, the availability of appropriate education and genetic counselling, freedom of choice in reproductive decision-making, discrimination in school and work settings, stigmatization, and insurance discrimination. Families who had been able to establish an ongoing relationship with their health care providers reported fewer ethical issues and they were more likely to report that their health care providers helped them to manage any ethical issues that did emerge. Typically, these families were families who were receiving some or all of their care through a SCD clinic.

Discussion & Conclusions: Findings from this study suggest there is an urgent need for more dialogue between families and health care providers concerning ethical issues that emerge during family-provider interactions.

Abstract History:
This abstract has not been presented or accepted for presentation in whole or in part at the SNRS or other scientific meeting.

Financial Disclosure:
No, I (or a member of my immediate family) have not received something of value* from or own stock (or stock options) in a commercial company or institution related directly or indirectly to the subject of my presentation.

FDA Disclosure:
I will not be describing any pharmaceutical and/or medical device.

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