Ethical Issues Faced by Families Living with Sickle Cell Disease

Introduction:
The purpose of this presentation is to describe how families living with Sickle Cell Disease (SCD) define and manage the ethical issues that emerge during their interactions with nurses and other 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 nurses, 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 a) the ability to gain access to high quality care, especially pain management, in a timely manner, b) the availability of appropriate education and genetic counselling, c) freedom of choice in reproductive decision-making, d) discrimination, and e) stigmatization. Families who had established 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 the ethical issues that did emerge. Typically, these families were families who were receiving some or all of their care through a SCD clinic. Emergency departments and urgent care clinics were the most commonly reported settings where ethical issues emerged and these were usually related to the inability of the individual with SCD to have their pain managed effectively in a timely manner.

Discussion: 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.

Research Completed: Yes

Financial Disclosure: Have a financial arrangement or affiliation with commercial companies whose products may be mentioned in this material?
FDA Disclosure: No
Non-Exclusive License: Cleared: Yes
Submitted By: Accepted Terms: Yes
vanriper@email.unc.edu