

Arsht Research on Ethics and Community Grant

Medical Professionals' Decisions to Report Medical Neglect Following Positive Newborn Screening

2008-2009

Faculty: Sakina Butt, M.A., Nicole Cano, B.S., Susan Dandes, Ph.D., Jason Jent, Ph.D., Walter Lambert, M.D., Melissa Merrick, M.S., Lee Sanders, M.D., M.P.H.

Students: Ana Chapman and Daisy Ciener

School of Medicine

Abstract

Preventative medicine has recently begun to focus on newborn screening (Kenner & Moran, 2005; Ross, 2008). The principal ethical justification in support of mandatory newborn screening is that society's obligation to promote child welfare through early detection and treatment supersedes parental prerogatives to refuse such services (Almond, 2006; Nelson et al., 2001). As such, the ethical conversation as it relates to newborn screening has focused mostly on informed consent issues. However, there has been no empirical evaluation of the ethical issues related to perceived refusal on follow-up with recommended treatment and intervention following a positive newborn screening. Further, no studies to date have examined the factors that medical professionals consider when making decisions to report parents for medical neglect following positive newborn screenings.

The proposed study aims to examine demographic and case-specific factors as potential areas of bias that impact medical professionals' reports of medical neglect following a positive newborn screening and perceived family noncompliance with subsequent treatment. Medical professionals (e.g., faculty, medical residents, nurses) working in three different pediatric practices within the Departments of Pediatrics and Genetics at the University of Miami, Miller School of Medicine and the Jackson Memorial Hospital (N ≈ 150) will be invited to participate in the proposed study, which involves reading 8 case vignettes with varied family medical insurance statuses, screened genetic disorders, notification types of positive screenings, and intervention/treatment prognoses, that may be related to whether a medical professional decides to report medical neglect. Participants will be asked to decide based on the information provided in the vignettes whether the incident represents grounds to report suspicions of medical neglect to Child Protective Services, which is the dependent variable for the study. Results from this study will inform training protocols for medical professionals who have an ethical obligation to protect children and families. Reduction in biases will allow medical professionals to make more objective and consistent decisions when conducting newborn screenings and will assist in their decision-making processes regarding reporting medical neglect to the authorities.

Please do not copy or quote without permission. For more information, please contact the University of Miami Ethics Programs at ethics@miami.edu.