Restricted Permissibility for Procuring Solid Organs from Infants with Anencephaly

Brian S. Carter, MD\textsuperscript{a,h,c} and Michael J. Deem, PhD\textsuperscript{d,e}
\textsuperscript{a}Division of Neonatology and Fetal Health, Children’s Mercy Hospital; \textsuperscript{b}Children’s Mercy Bioethics Center; \textsuperscript{c}University of Missouri – Kansas City School of Medicine; \textsuperscript{d}School of Nursing, Duquesne University; \textsuperscript{e}Center for Healthcare Ethics, Duquesne University
Kansas City, MO; Pittsburgh, PA

Anencephaly is a lethal malformation of the central nervous system (CNS) in which the forebrain, cerebellum, cranium, and scalp do not fully develop, leaving an open and exposed rudimentary CNS. Brain stem structures are typically functional. Most cases of anencephaly result in still-birth or death within 7 days of live-birth. When it is diagnosed prenatally, parents might inquire about the possibility of voluntarily making their child’s organs available for donation after birth. Such requests are declined by fetal health centers and organ retrieval services on ethical and policy grounds. Since 1999, only rare cases of solid organ procurement have been documented, occurring in the UK. In this presentation, we argue the traditional normative framework used to assess the ethics of pediatric organ donation is ill-suited for determining whether and when organ donation by anencephalic infants is ethically permissible. We will briefly review this framework and how it has shaped policy. We then will argue that two key elements of this framework cannot be readily applied in cases involving parental request for organ donation involving anencephalic infants: (a) the rule of Donation after Brain Death (DBD), and (b) the best interests standard as a guide to pre-mortem interventions. Specifically, we argue that (a) is not applicable to cases of anencephaly, and that (b) is an inappropriate normative guide for assessing pre-mortem interventions and benefits for infants who have a lethal condition like anencephaly. We conclude by sketching narrow parameters within which solid organ donation by anencephalic infants may be ethically permissible.