

# **END-OF-LIFE DECISIONS FOR PRE-TERM INFANTS**

**ETHICS: BIOETHICS (FALL 2014) | LAURA GUIDRY-GRIMES**

# WHY RESPECT PARENTAL AUTONOMY?

✧ *What are some moral reasons for privileging parental decisional authority in medical care decisions?*

## ✧ **Presumptions**

- ✧ Best or “good enough” interests at heart
- ✧ Maintaining family values, identity
- ✧ Privacy rights
- ✧ Who bears the burdens
- ✧ Family-centered care: obligation to facilitate choice, support families, give leeway to decisions

# DECISIONAL LEEWAY?

## ✧ American Academy of Pediatrics:

✧ “because we live in a pluralist society, parents have wide discretion in what they choose for their children”

✧ “parents may ‘compromise the interests of the child [for the sake of a group goal or other family member’s interests], provided that they do not sacrifice the child’s basic needs’”

✧ *What do you foresee as potential moral problems in granting this leeway? Where might the boundary lie between **morally permissible** and **morally impermissible** compromises with parents?*

# BABY DOE & CHILD ABUSE AMENDMENTS

- ✧ **Baby Doe Regulations** (aspects overturned)
  - ✧ Raised concerns about discrimination, contentious quality of life judgments based on disability
  - ✧ Was the infant being denied standard medical care *merely* because of the infant's disability?
- ✧ **CAA** (created standard of care as det. by courts, professional orgs.)
  - ✧ States asked to ensure non-discrimination against infants with disabilities
  - ✧ Exceptions to standard medical care: permanently comatose, near death, futile or “virtually futile”

# ROBERTSON ON *MILLER* CASE

## ✧ **Key issues**

- ✧ Should CAA apply to pre-term infants?
- ✧ Regardless of type, severity of disability?
- ✧ Should CAA always receive more moral weight than parents' wishes?
- ✧ Moral weight of parents' decisions pre- vs. post-birth
- ✧ Slippery slope for denying equal access to medical care, controversial quality-of-life judgments?

# ROBERTSON ON *MILLER* CASE

- ✧ **Should determine POST-BIRTH whether child will have meaningful life**
  - ✧ “some threshold of cognitive ability” (36) – capable of relational activity – sufficient abilities for symbolic interaction
  - ✧ No prenatal DNRs; emergency stabilization required
- ✧ **Shift burden of proof to hospitals to challenge parents’ non-treatment decision**
  - ✧ Given authority based on threshold consideration

# PARIS ET AL. ON *MILLER* CASE

## ✧ **Key Issues**

- ✧ What is in the child's best interests? How and when should this determination be made?
- ✧ What moral authority should parents' decisions have in cases of low-weight, pre-term infants?

## ✧ **Analysis largely relies on statistics for survival and morbidity & mortality**

- ✧ Most heavily weigh quality-of-life factors

# PARIS ET AL. ON MILLER CASE

- ✧ **“ventilation is not necessarily justified simply because it offers a modest chance of survival” (F210)**
- ✧ **Should inform parents of child’s prospects PRE-BIRTH and incorporate their wishes in decisions**
  - ✧ Against giving as much discretion and authority to physicians, especially in unclear cases
  - ✧ Avoid imposing physicians’ values on parents



# DISCUSSION

- ✧ *What are the strengths and weaknesses in the arguments presented by Paris et al. on the one side and Robertson on the other?*
- ✧ *If you were on the Texas Supreme Court in this case, what would you have decided and why?*
- ✧ *Are there some crucial caveats to the overall judgment that need to be clarified, specified?*

# ADDITIONAL REFERENCES

**Ladd, R.E. and E.N. Forman. “Ethics for the Pediatrician: Pediatrician/Patient/Parent Relationships.” *Pediatrics in Review* 31, no. 9 (September 2010): e65-e67.**

**L.F. Ross, qtd. in McDougall, R. J. and L. Notini. “Overriding Parents’ Medical Decisions for Their Children: A Systematic Review of Normative Literature.” *Journal of Medical Ethics* 0 (2013): 1-5.**



**QUESTIONS? COMMENTS?**