

The Cultural Construction of End of Life Decisions in Biomedicine: Anthropological Perspectives

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Betty Wolder Levin, PhD

City University of New York (CUNY)
Department of Community Health and Social Sciences

IN THIS PRESENTATION:

- Introduce the concept of culture and biomedical culture(s) construction of treatment choices
- Ethnographic research in the NICU, 1977-1986
- A Model for Treatment Choice
- Other examples of biomedical culture and end of life
- **Can the model be adapted to explicate MAID?**

DEFINITION OF CULTURE

“that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by [humans] as a member of society”

Tylor, Edward. 1871. *Primitive Culture: Research into the Development of Mythology, Philosophy, Religion, Art, and Custom*. London: John Murray. Volume 1, page 1.

CULTURE

- Shared among a group of people (e.g., members of a nation, religious or ethnic group, profession, or institution)
- All human groups have culture; people in complex societies belong to multiple cultural groups
- Provides a framework for interpretation of phenomena and shapes patterns of behavior
- Includes taken-for-granted, tacit assumptions
- Variations exist between among members of cultures
- Culture changes over time in response to changes in technological, social, political, economic, and physical environments

BIOMEDICAL CULTURE AND END OF LIFE CARE

- Increased ability to prolong life:
of benefit?
prolongation of suffering?
- Clinicians -- complex understanding of treatment choices
- Developed within broader societal context – law, ethics, religion, politics, economics, etc.
- Variations between individuals, institutions, professional groups, nations, etc.

MY ETHNOGRAPHIC RESEARCH IN THE NICU 1977 - 1986

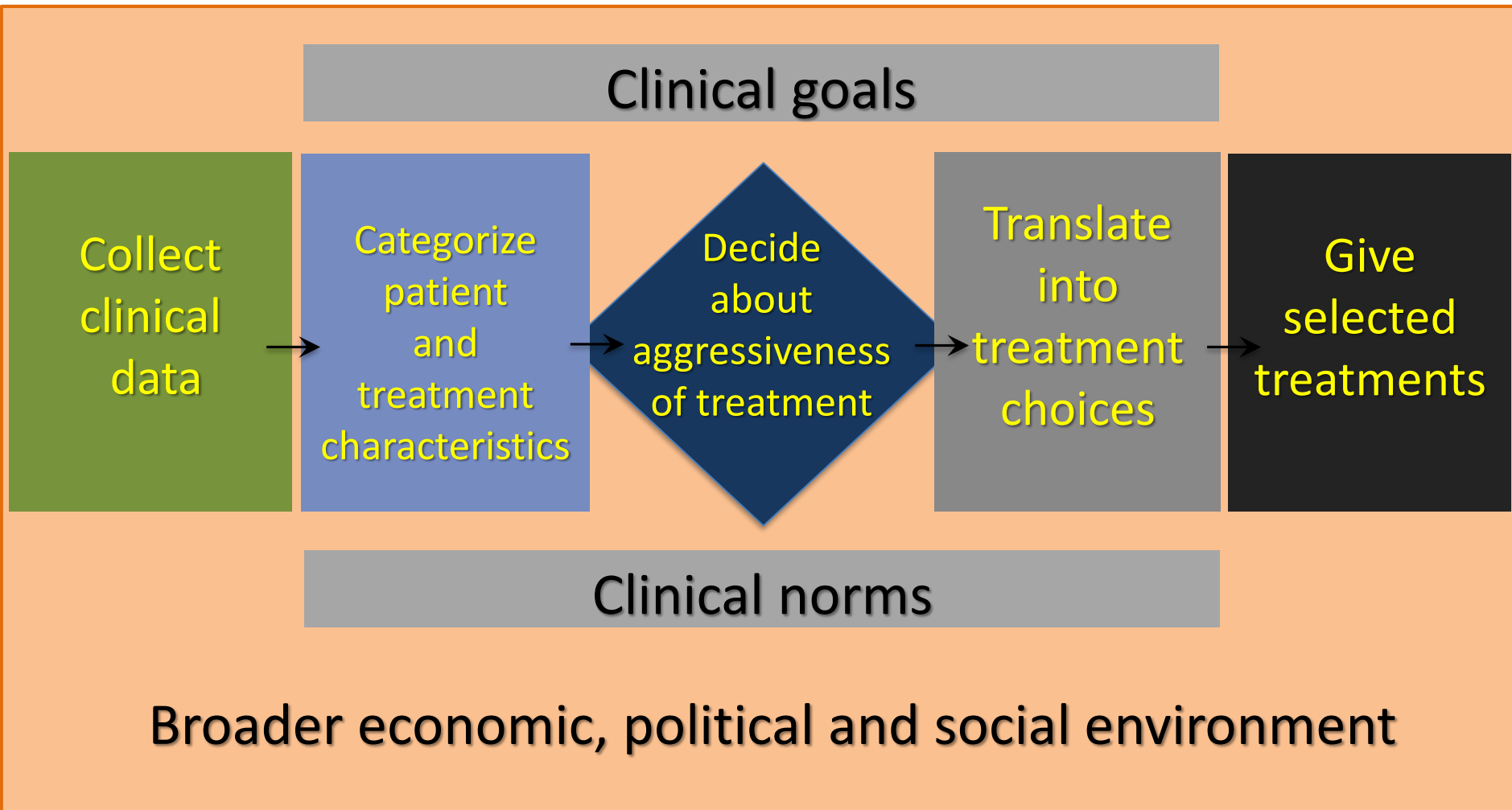
- Columbia -- Task Force on Ethics in the NICU
Scholars – personhood
Clinicians – respirator settings
- Bioethical questions at the time
Who should live and who should die?
Who should be treated?
Should we pull the plug?

CONCLUSION FROM ETHNOGRAPHIC RESEARCH:

Decisions about critically ill newborn are:

- not conceptualized as decisions
“to treat or not to treat”
- they are choices about which treatments to give and which to withhold from a range of possible treatments

MODEL OF DECISION MAKING ABOUT THE AGGRESSIVENESS OF TREATMENT



AGGRESSIVENESS OF TREATMENT

Transplant

Neurosurgery

Intestinal Surgery

Seizure Medication

Antibiotics

Tube Feedings

Food by mouth

BALANCING PATIENT CHARACTERISTICS AND TREATMENT CHARACTERISTICS WITH CONSIDERATION OF THE GOALS OF CARE

PATIENT CHARACTERISTICS

Quality of Life
Uncertainty
Critical Condition
Social Value

TREATMENT CHARACTERISTICS

Aggressiveness
Ordinary/Extraordinary
Withholding/Withdrawing
Active/Passive Euthanasia

GOALS OF CARE

To Cure
To Care
To Preserve Life
To Do No Harm

CHARACTERISTICS OF PATIENTS

- Quality of Life
- Uncertainty
- Critical
Condition
- Social Value

CHARACTERISTICS OF TREATMENTS

- Aggressiveness of Treatment
- Ordinary / Extraordinary Care
- Withholding / Withdrawing
- Active / Passive Euthanasia

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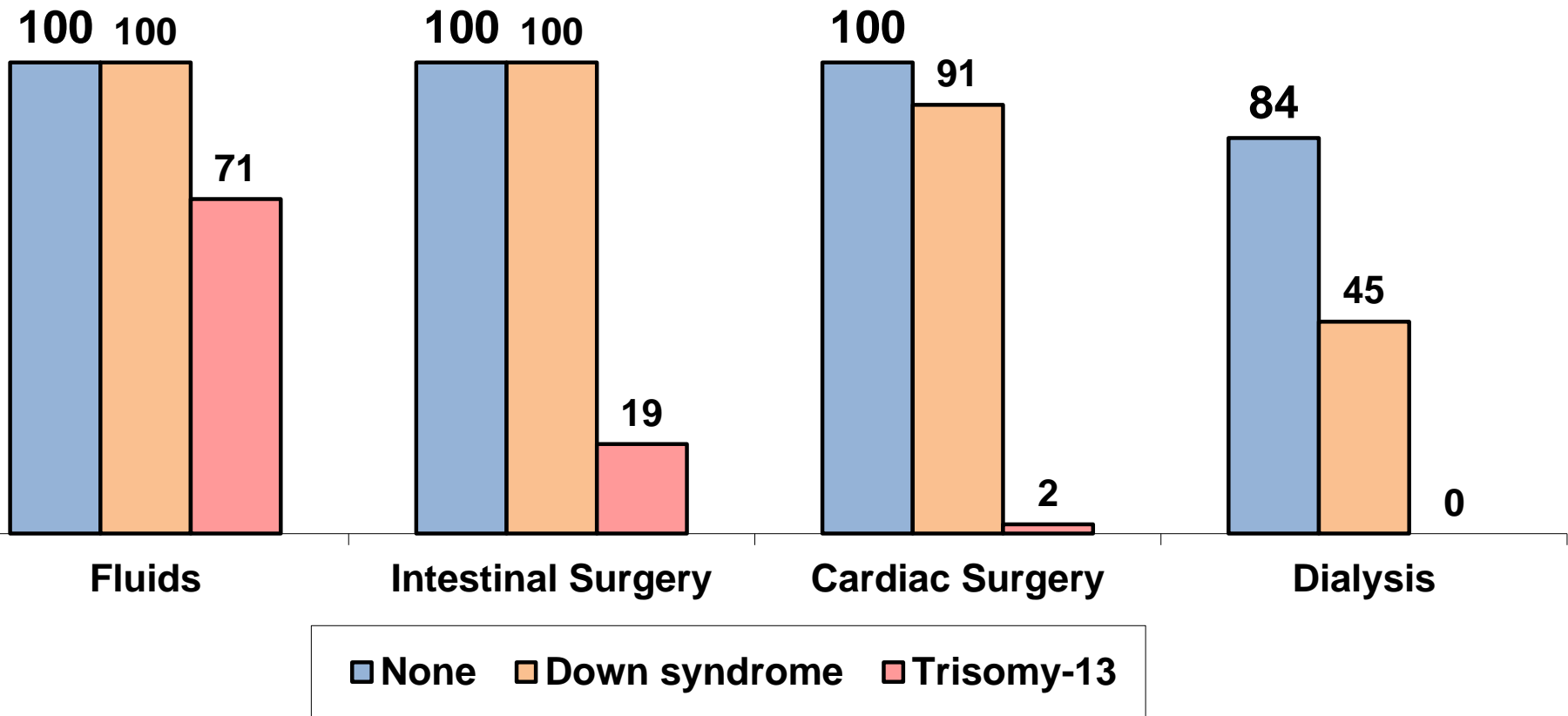
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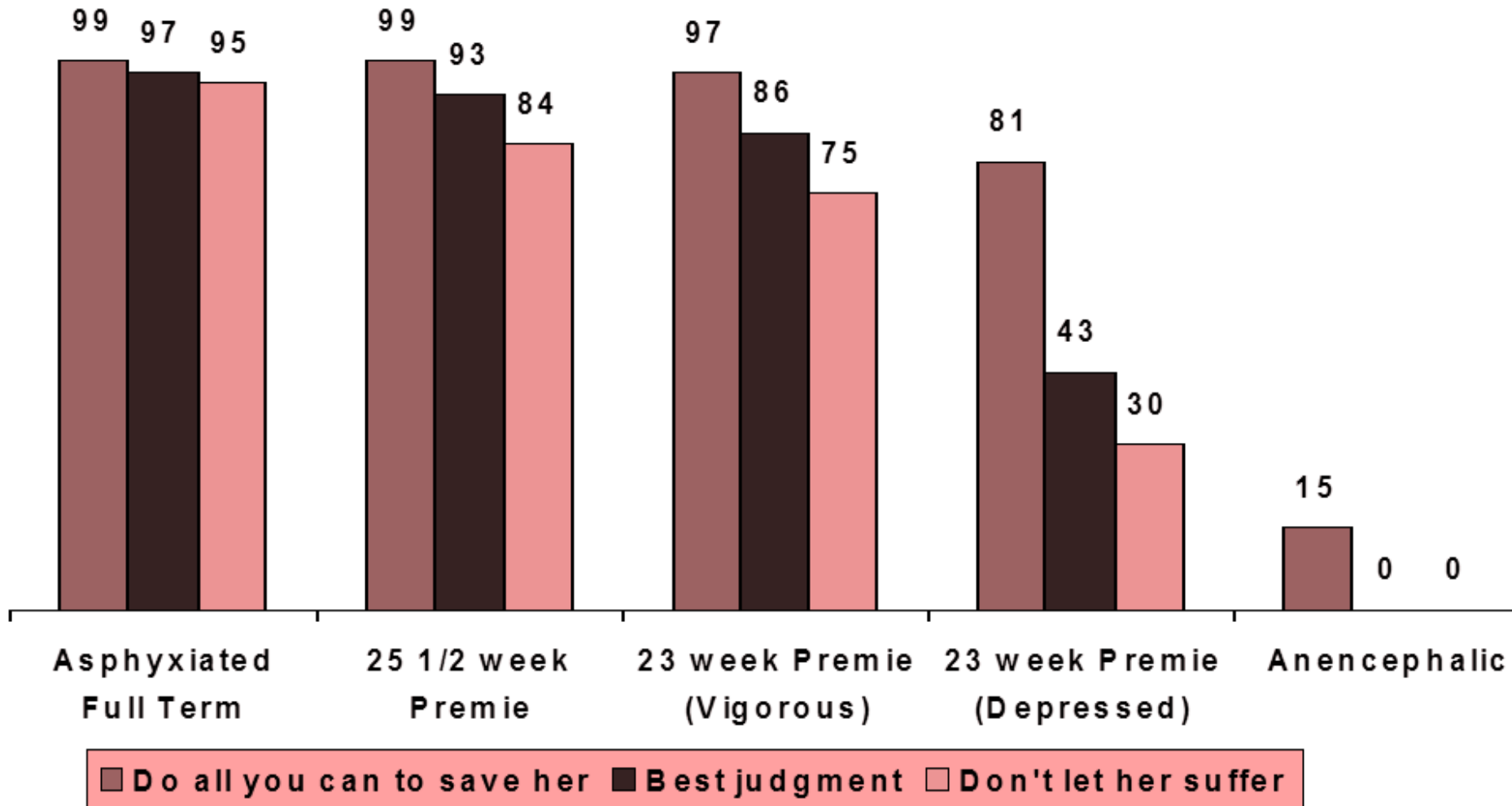
SURVEYS with clinical vignettes conducted with John Driscoll, MD, Alan Fleischman, MD, Paul Yellin, MD & David Krantz, PhD

- 1983 Convenience sample of nurses, pediatric residents, neonatologists and obstetricians, NYC, n=249
- 1989 Neonatologists and pediatric residents in 6 hospitals, NYC, n=247 (78%)
- 1991 Perinatal Section of the American Academy of Pediatrics, n= 951 (63%)
- 1995 Perinatal Section of the American Academy of Pediatrics, n=1186 (71%)

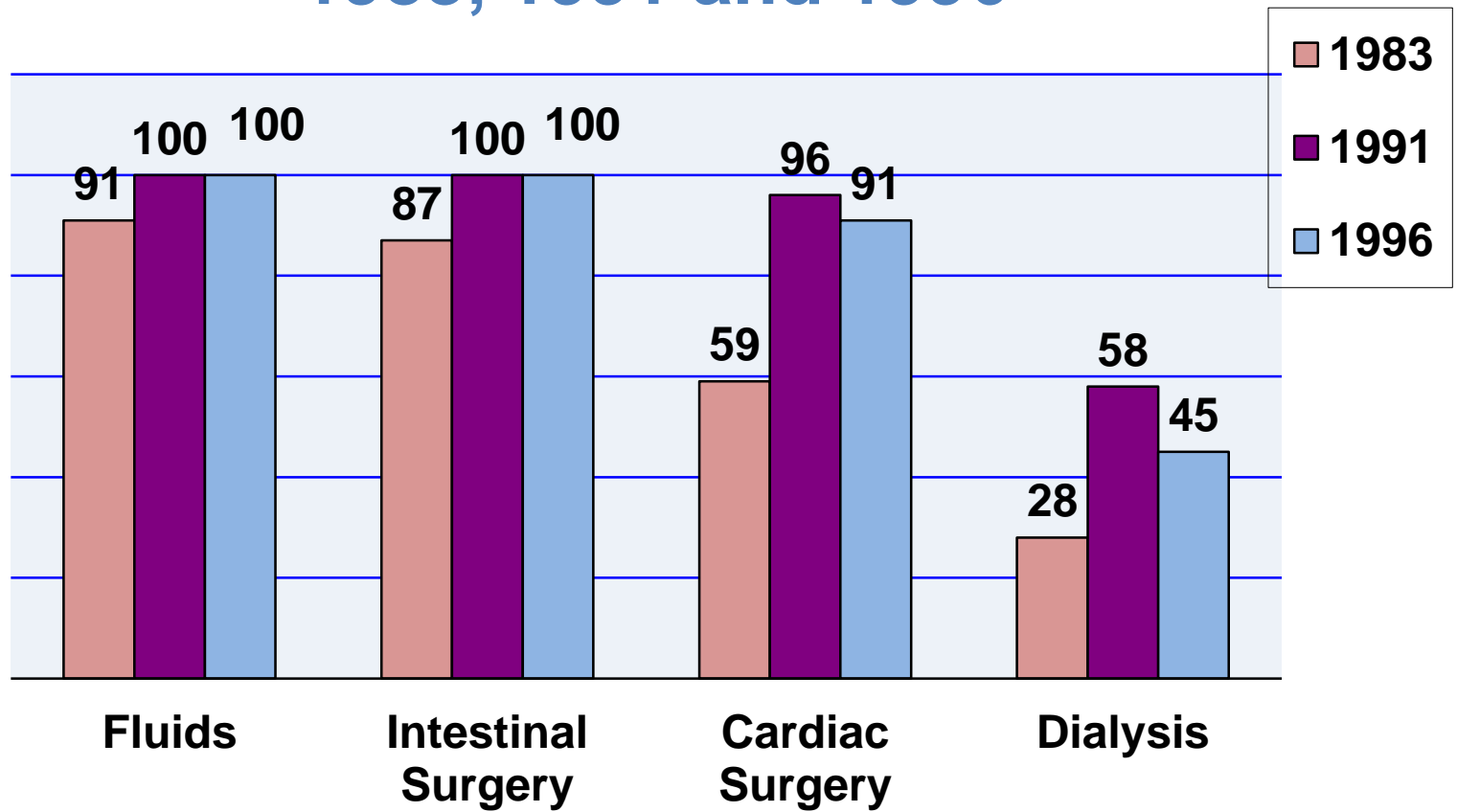
MODEL ILLUSTRATED BY TREATMENT CHOICES FOR INFANTS WITH GENETIC CONDITIONS (1996)



MODEL OF TREATMENT CHOICE AFFECTS RESPONSES TO PARENTS WISHES



Comparisons of survey responses concerning treatment for infants with Down Syndrome 1983, 1991 and 1996



OTHER EXAMPLES OF THE CULTURE OF CLINICIANS AND END OF LIFE

- Model useful for explicating treatment decisions for adults
- Model useful for identifying reasons for variations between individuals and groups (e.g. as part of Ethics Committee discussions)
- Cultural differences help explain discomfort and debates related to donation after cardiac death (DCD)
- Changes over time in moral distress about treatment choices for brain dead patients

COULD THE MODEL BE EXTENDED OR ADJUSTED TO ELUCIDATE MAID?

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**Thank you for your
attention!**

**I am looking forward to
your questions and
comments!**