



Show Me the Money:

Financial Considerations in Responding to Parental Requests for Medical Interventions

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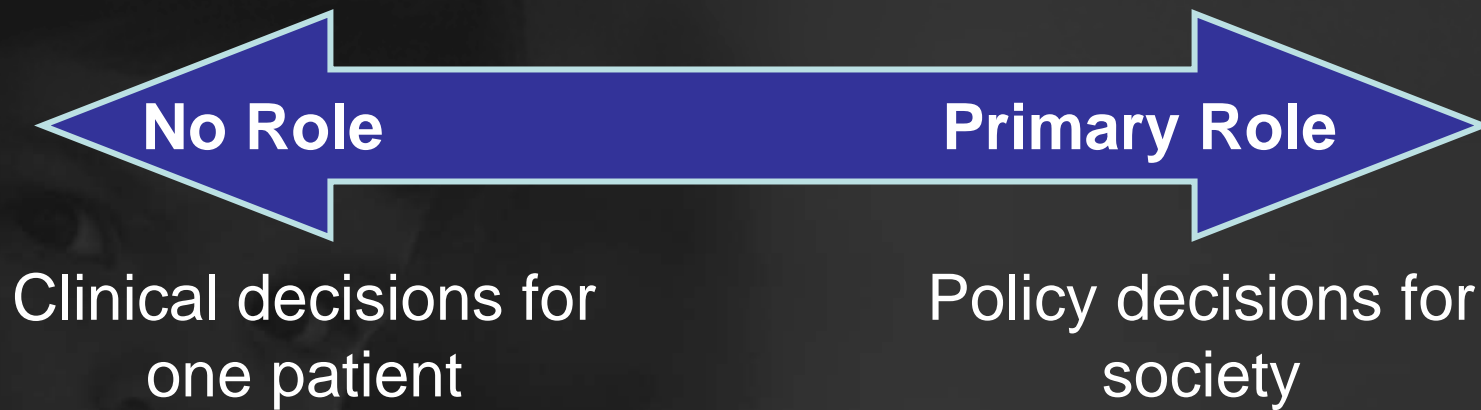
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Raphael – Chapter III

- 6 mo old boy with Campomelic Dysplasia
 - Severe chest wall restriction
 - Short stature
 - Profound developmental disability
 - Ambiguous genitalia
- At “special care” unit in hospital
 - Trach, g-tube, ventilator
- Pediatric residents would ask on rounds:
 - Is this in Raphael’s interest?
 - Aren’t there limits on how we should use available technology?
 - Why are we spending so much money on this child?
 - Wouldn’t the money be better spent on immunizations?

Role Of Cost In Health Care Decision-making



What's Cost Got To Do With It?

- Cost remains an important factor even in clinical decisions
 - “bump on the head”
- Cost may not always be the determinative factor for policy decisions
 - Erectile dysfunction
- In either setting, we should be careful not to conflate cost with the assessment of benefits

Psychosocial Benefits of Medical Interventions

- 6 year soccer player
 - MRI for ankle sprain
 - Ritalin for soccer practice

- 6 month old ex-30 week premature infant
 - Apnea monitor for reflux related choking spell
 - Orthotic helmet for flat head

Is It Appropriate To Use Medical Interventions To Address Psychosocial Problems?

- Places the child “at risk” instead of addressing the social problem
- Reinforces the social reasons for the problem
- Should not spend money on medical fixes for social problems rather than spending the money on the social problems
- Not “medically necessary”

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Psychosocial Benefits Are An Integral Part Of Medical Practice

- Historically, the primary value of medicine has been to provide diagnosis and prognosis
 - Absent treatment, these are psychosocial benefits
- Currently, health technology assessments prioritize “patient related” outcomes
- “Quality of life” is a psychosocial issue





Impact Of Medical Interventions On Quality Of Life In Children With Developmental Delay

- 6 week old with Trisomy 18
 - VSD repair
 - Cleft palate repair
- 6 month old with campomelic dysplasia
 - Assisted ventilation
 - Dialysis/Kidney transplant

Balancing Benefits And Burdens

Benefits & Risks

Clinical

Psychological

Social

Resources

Financial

Time

Facilities

Personnel

Equipment

Opportunity costs

Organs

Perspective

Child

Family

Health care providers

Health care
institutions

Private Payers

Public Payers

Society

Balancing Benefits To The Child With Burdens

- Benefits to the child is not worth the burdens to the child
- Benefits to the child is not worth the burdens to the family
- Benefits to the child is not worth the burdens to society

Raphael – Chapter I

- Two week old boy with Campomelic Dysplasia
 - “lethal dwarfism”
 - Parents refuse to withdraw ventilator
- Parents only speak Spanish
 - Are very religious
 - Are waiting for a miracle
- Care conference to help parents come to a reasonable decision about this child with a *lethal* condition

Parental Requests For Treatment Of “Lethal” Condition

- Which diseases are lethal?

- Asthma
- Diabetes
- Cystic Fibrosis
- Down Syndrome
- Trisomy 18
- Tay-Sachs
- Campomelic dysplasia
- Anencephaly

- What is lethality?

- Likelihood of death
- Duration of life
- Impact of treatment on survival
- Quality of life before death
- Ability to have children (Genetic lethality)

“Lethality” Is A Normative Concept

- “Lethality” medicalizes a normative statement about “quality of life”
- Providers may not be comfortable stating views about “quality of life” and the “value” of children with profound developmental disabilities
- Other surrogates for “quality of life” include “suffering”, “family burden” and “cost”
- Unexamined normative views about children with profound developmental disabilities can influence
 - Provider attitudes
 - Information conveyed to parents

Answering Raphael's Residents Who Worry About The Cost Of Care

- Collective decision-making
 - “Bedside” rationing does not usually result in reallocation of resources to others in need
 - Insurance coverage decisions (esp. medicare/medicaid) are a form of collective decision making
- Vulnerability and dependency
 - Financial cost of care on society may be less than the social cost of withholding care on vulnerable populations
- Justice
 - “Doesn't this child deserve the same care that you would expect for your own child?”

“Don't Want No Short People Round Here”

- Financial concerns are more acceptable than saying that this child's life is not worth living
- Most of society has little contact with children with permanent dependence due to profound developmental disability
- Attitudes of the public and doctors about such children may not be as progressive as we might believe
- We may evaluate such a life from our own cognitive perspective and not from the perspective of the child or the family who loves them



**A productive
member of
society**

Raphael – Chapter II

- Care meeting to discuss whether continued assisted ventilation (and tracheostomy) was appropriate
- Parents asked if assisted ventilation would cause suffering

What are the limits for costs?

- What resources should be provided for children who need assistance with ventilation?
 - A home ventilator?
 - A portable home ventilator?
 - Home Nursing?
 - How much nursing?
- Fiscal policy decisions should be made through a deliberative process
 - We just haven't figured out how to do it well

Raphael – Chapter IV

- Discharged from hospital at 9 months
- Weaned from ventilator at 4 years
- Trach removed at 6 years
- Trach/vent resumed at 8 years
- Raphael is an important member of his extended family

Parental Decision-making For Children With Permanent Dependence Due To Profound Developmental Disability

- Strong social interest in supporting the wishes of parents to provide care
 - Respects their role as parents
 - Respects the value of their children
- Special commitment to care for the most dependent children in our society
- Even with cost constraints, we should be careful about using cost as a primary justification for how we decide about the care of children with profound developmental disabilities