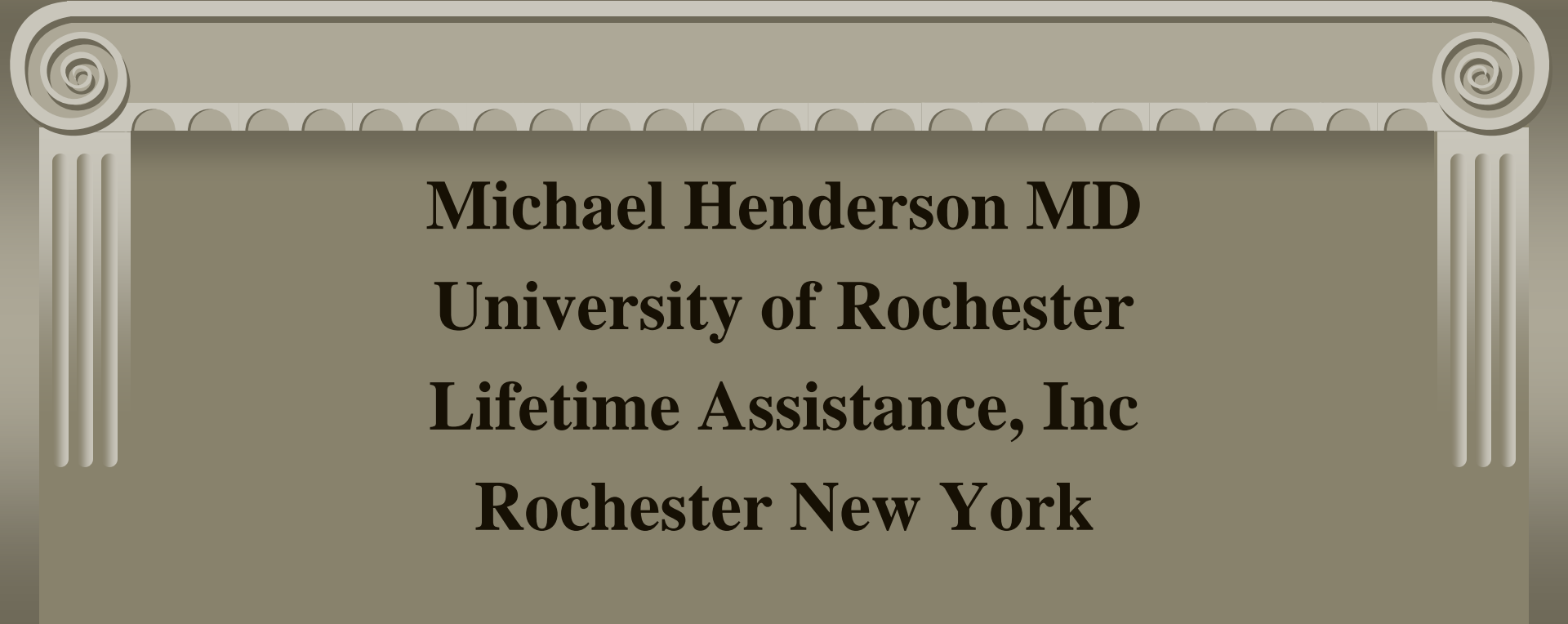


# **Principles of Medical Ethics in Health Care Provision for People with DD: A Case-Based Approach**



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# Medical Ethics

- ◆ **Medical ethics could be considered one example of what could be termed “caregiver ethics”**
- ◆ **Caregiver ethics are built on same bed-rock principles**

# Medical Ethics

## ◆ Principles:

- ◆ **Relationship- resting on trust**
- ◆ **Autonomy- accounting for choice & liberty issues**
- ◆ **Non-maleficence- doing no harm**
- ◆ **Beneficence- acting in best interest**
- ◆ **Justice- doing what's fair**

# Medical Ethics

- ◆ **Holistic person-centered stance- in any given case, several of the ethics principles may overlap (and sometimes contradict each other) to varying degrees**
- ◆ **In DD field, there is often the issue of “substituted judgment” due to inherent problems of communication and understanding**
- ◆ **Other agents: guardians, relatives, agency staff persons- from CEO to direct care- may have important roles in the ethics arena (especially substituted judgment – beneficence)**

# Medical Ethics

- ◆ **Historical background- a people with I/DD have been a vulnerable population within the healthcare sector**
  - ◆ **Institutionalization**
  - ◆ **Deprivation of resources i.e. withholding treatment**
  - ◆ **Active abuse i.e. experimentation, sterilization, etc**

# Medical Ethics

## ◆ Health care decision making - *default positions*

- ◆ **1<sup>st</sup> step: *presumption of capacity*- if lacks capacity, then:**

- ◆ **2<sup>nd</sup> step: *preservation of health and life***

**Plus**

- ◆ ***Undue burden arguments or medical futility-arguments: extremely high standards of proof***

# Medical Ethics

- ◆ What is “substituted judgment”?
  - ◆ The ability to make informed health care decisions *is presumed* in all adults unless otherwise determined
  - ◆ However, in patients *who do not have the capacity to make an informed decisions*, these decisions are made by other, concerned parties who “don the mental mantle of the incompetent”

# Medical Ethics

## ◆ “Substituted judgment”

- ◆ For a person who had capacity at one time, posing what she would want if they could now express themselves
- ◆ For a person who never has had capacity
  - ◆ Making an inference of what she would want
  - ◆ Determining what a “reasonable person” would want



# Medical Ethics

- ◆ **Bases of informed health care decision-making assessment:**
  - ◆ **Effective exercise of self-direction- life history**
  - ◆ **Taxonomy of Applebaum & Grisso (1988)- formal evaluation**
  - ◆ **Unless in guardianship proceedings, capacity is decision-specific**

# Medical Ethics

## ◆ Examples of self-direction

- ◆ **School/literacy**

- ◆ **Residence**

- ◆ **Work**

- ◆ **Finances**

- ◆ **Access community**

- ◆ **Vote**

- ◆ **Previous health care decision-making**

# Medical Ethics

- ◆ **Taxonomy of Applebaum & Grisso**
  - ◆ **Make and communicate a choice**
  - ◆ **Understand facts**
  - ◆ **Grasp personal context**
    - ◆ **Context of facts re: personal health situation**
    - ◆ **In ID, social context re: choice for self and not to please others**
  - ◆ **Perform higher level reasoning (risk/benefit)**

# Medical Ethics

- ◆ **Reversible versus irreversible incapacity**
  - ◆ **Reversible- concurrent mental illness, health care illiteracy**
  - ◆ **Factors- tempo of illness, legal environment**

# Medical Ethics

## ◆ “Substituted judgment”

- ◆ **If lack of capacity is determined, health care decision-making then devolves to others**
- ◆ **Important health care decisions may require intimate knowledge of an individual’s preferences, values, baseline quality of life, prognosis for current and/or other health disorders**
- ◆ **Courts play key roles in final legal review of life-and-death health care decisions**

# Medical Ethics

## ◆ Other issues

- ◆ **Quality of life**
- ◆ **Assent/refusal versus informed consent/refusal**
- ◆ **Wider social arena of health care decision-making “standard of care”**
- ◆ **Societal, especially legal, mandates**

# Medical Ethics

- ◆ Stakeholders in medical decision-making in I/DD
  - ◆ Individual
  - ◆ Involved relatives or guardians
  - ◆ Agency administrator
  - ◆ Agency advocates(s)
  - ◆ Physician
  - ◆ Agency nurse
  - ◆ Lawyer

# Medical Ethics

## ◆ Stakeholders continued

- ◆ **Physicians are often more powerful figures than ones who simply convey medical information; they often insinuate values especially via quality of life assumptions**
- ◆ **Relatives can assume extremely powerful roles: this may be problematic if a relative has been geographically or emotionally distant from the individual**



# Medical Ethics

- ◆ Four medical scenarios will be used to illustrate medical care-giving ethics principles
  - ◆ Renal hemodialysis (in depth)
  - ◆ Alzheimer disease as a life-ending illness
  - ◆ Dysphagia & gastric tube feeding
  - ◆ Psychotropic drugs

# Medical Ethics

- ◆ **Renal dialysis for end-stage kidney is a way of life for 300,000 US citizens**
  - ◆ **Hemodialysis most common**
  - ◆ **Surgery (that confers risk) is required to place the access i.e. AV fistula for hemodialysis**
  - ◆ **Three four-hour sessions per week are required to maintain life and health**
  - ◆ **Complications are common- hospitalizations for shunt infections, additional surgeries for shunt revisions, volume overload, electrolyte imbalance etc**

# Medical Ethics

- ◆ **To consent to or refuse hemodialysis, a person needs to know a complex array of basic facts, including:**
  - ◆ **Kidney function and disease**
  - ◆ **Need for dialysis to preserve life and health**
  - ◆ **How dialysis is performed**

# Medical Ethics

- ◆ The person would need to understand their own personal context:
  - ◆ Facts about *her* kidney disease
  - ◆ Impact of dialysis on *her* lifestyle

# Medical Ethics

- ◆ The person would need to be able to engage in high levels of reasoning, including for a *fully informed* choice:
  - ◆ **Risks and benefits of dialysis**
  - ◆ **Options: hemodialysis, peritoneal dialysis, kidney transplant (in future), deferral of treatment (palliation)**

# Medical Ethics

## ➤ Case #1: Geraldine

A woman receiving hemodialysis with a diagnosis of mild ID- *his sister signed for all procedures*. She had never questioned or not cooperated in dialysis-related activities- she had *never been asked* to participate. In her life, she had:

- 1) **Lived independently in the community (now in nursing home)**
- 2) **(Still) regularly read the newspaper; had voted in elections**
- 3) **Had worked at a variety of jobs**

# Medical Ethics

## ◆ Case #2: Bill

**A 63 year old man with mild ID living in the small town with only service coordination and once a week reshab support. He frequently skipped dialysis sessions.**

- 1) Was formally assessed, and understood the risks (including death) of skipping dialysis sessions**
- 2) Had quality of life reasons for skipping dialysis (“take a break”)**
- 3) No evidence of an active mental health disorder**

# Medical Ethics

## ◆ Case #2: Bill

He had a legal finalization of a divorce and stated that he felt hopeless about life and didn't want to continue dialysis.

Understood that skipping dialysis could cause his death

Tearful, but would not say that he wanted to die

Escorted by police to psych ER



# Medical Ethics

## ◆ Case #2: Bill

Not deemed by psychiatrist to have  
decreased capacity due to depression

Then skipped one dialysis session

What if he had skipped two sessions?

What if he had become ill-appearing, but still did  
not want dialysis?

*The tension between promoting autonomy and  
providing protection.*

# Medical Ethics

## ◆ Case #2: Bill- Questions

What would an agency do if Bill lived in an *agency-sponsored residence*, was deemed to not be depressed or psychotic, and still refused to comply with dialysis?

**Autonomy/Liberty- crux of matter**

**Relationship/Trust- not clear (patient's perception)**

**Beneficence- not clear (trumped by autonomy: ?should he be taken to dialysis in four point restraints against his wishes?)**

# Medical Ethics

## ◆ Case 2: Bill

**Non-maleficence- no maleficence in this case in informed, voluntary non-cooperation**

**Justice- no discrimination, treatment being actively offered**

**Tempo of need for clinical/administrative decisions- extremely fast**

**Need for documentation- high**

**Legal/Regulatory issues- many**

# Medical Ethics

◆ **Case #3: Sam, a 34 year old man severe ID with autism with severe tactile defensiveness who needs dialysis**

**Autonomy/Liberty- physical assent or refusal- not only- not (can never be) informed**

**Relationship/Trust- the agency wants to do the right thing**

**Beneficence- make sure the non-consenting person gets to dialysis to preserve life**

# Medical Ethics

## ◆ Case #3: Sam

**Justice- transplant list**

**Non-maleficence/Injustice- would apply only if intentional neglect (not dialyze)**

**Un-due burden/Quality of life- no QOA if dead? or lifetime of “intermittent physical assaults” to maintain life**

# Medical Ethics

- ◆ **Care provision in older adults with Alzheimer disease**
  - ◆ **5,000,000 people have Alzheimer disease- it is a fatal neurodegenerative condition**
  - ◆ **It is hard to project life expectancy in AD- functional status and the presence of co-morbidities are often used to do this**
  - ◆ **The medical decision being posed are important**
  - ◆ **Quality of life questions are important**

# Medical Ethics

- ◆ **Care provision in older adults with Alzheimer disease- end-of-life questions**
  - ◆ **Should individuals with I/DD and Alzheimer disease be full code for resuscitation? Should individuals with I/DD and AD given a “trial” on the ventilator?**
  - ◆ **If No to above, why?**

# Medical Ethics

## ◆ Gastric feeding tube for dysphagia

### ◆ Context-

- ◆ Neurodegenerative disorders versus cerebral palsy
- ◆ Video-pharyngogram findings
- ◆ History of aspiration pneumonia
- ◆ Other measures i.e. food textures, sedation

### ◆ Efficacy

### ◆ Complications

### ◆ Patient-specific issues

### ◆ Wishes of others i.e. parents



# Medical Ethics

- ◆ **Psychotropic drugs for agitation and aggression**
  - ◆ **Background- agency resources/strengths**
    - ◆ **Strong nursing support (“think medical first”)**
    - ◆ **Highly expert behavioral services- motivation assessment routinely done for aggression- BSPs implemented**
    - ◆ **Conservative psychiatrists**

# Medical Ethics

- ◆ **Aggression-** not a DSM-IV diagnosis (“intermittent explosive disorder”)
- ◆ **Ethical parameters for med use: *pro***
  - ◆ **Risk to self due to injury (beneficence)**
  - ◆ **Agitation decreases quality of life (beneficence)**
  - ◆ **Risk to others (dayhab participants, housemates, staff persons)**
    - ◆ **Injury- preserve safety (beneficence, trust, choice/autonomy)**
    - ◆ **Climate of fear- (?injustice)**

# Medical Ethics

## ◆ Aggression

## ◆ Ethical Med use: con

### ◆ Side effects (do no harm)- example Risperdal

- Weight gain, metabolic syndrome, type 2 diabetes, hypertension, heart disease
- Tardive movement disorder
- Sedation (decrease attention, participation, falls)
- Commitment to med: ?easier to start than to take off- withdrawal phenomenon)
- Long-term unknown effects?

# Medical Ethics

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# Medical Ethics

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