

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

A decorative architectural border in a light gray color. It features a horizontal top rail with a repeating pattern of small semi-circles. At each end, the rail is supported by a column with a spiral capital. The columns have three vertical flutes.

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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- based on trust
- ◆ Autonomy- choice & liberty issues
- ◆ Non-maleficence- do no harm
- ◆ Beneficence- act in best interest
- ◆ Justice- do what's fair

Medical Ethics

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

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
 - ◆ How is lack of capacity to make informed health decisions care determined?
 - ◆ Unless in guardianship proceedings, capacity is decision-specific

Medical Ethics

◆ Bases of informed health care decision-making:

- ◆ **Effective exercise of self-direction (life history)**
- ◆ **Taxonomy of Applebaum & Grisso (formal evaluation)**

Medical Ethics

◆ Examples of self-direction

- ◆ **School/literacy**

- ◆ **Residence**

- ◆ **Work**

- ◆ **Finances**

- ◆ **Access community**

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

Medical Ethics

- ◆ **Taxonomy of Applebaum & Grisso**
 - ◆ **Make 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

◆ Other issues

- ◆ **Reversible versus irreversible incapacity (mental illness, or improvement of “health literacy”)**

- ◆ **Tempo of the clinical scenario**

- ◆ **“Local” legal considerations**

- ◆ **Quality of life- to extent, defined by lifespan expectations (un-due burden not due to ID?)**

- ◆ **Assent/refusal versus informed consent/refusal**

- ◆ **Wider social arena of health care decision-making**

Medical Ethics

- ◆ **Three medical scenarios will be used to illustrate medical care-giving ethics principles**
 - ◆ **Renal hemodialysis (in depth)**
 - ◆ **Psychotropic drugs**
 - ◆ **Alzheimer disease as a life-ending illness**

Medical Ethics

- ◆ **Renal hemodialysis for end-stage kidney is a way of life**
 - ◆ **Surgery (that confers risk) is required to place the access fistula**
 - ◆ **Three four-hour sessions per week are required to maintain life**
 - ◆ **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**
 - ◆ **Why and how hemodialysis is performed**

Medical Ethics

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

Medical Ethics

- ◆ The person would need to be able to engage in high levels of reasoning, including:
 - ◆ Risks and benefits of hemodialysis
 - ◆ Other options (peritoneal dialysis, transplant) compared to dialysis

Medical Ethics

Case #1: Bill

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

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

Medical Ethics

◆ Case #2: Josephine

A woman with mild ID living in the community with only service coordination and once a week reshab support. She 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: Josephine

She lost custody of her children and stated that she felt hopeless about life and didn't want to continue dialysis.

- 1) **Understood that skipping dialysis could cause her death**
- 2) **Tearful, but would not say that she wanted to do die**
- 3) **Escorted by police to psych ER**
- 4) **Not deemed by psychiatrist to have decreased capacity due to depression**
- 5) **She skipped one dialysis session**

Medical Ethics

◆ Case #2: Josephine

What would an agency do if Josephine lived in an agency-sponsored residence, was deemed to *not* be depressed, 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: ?take her to dialysis in four point restraints against her wishes?)

Medical Ethics

➤ Case #2: Josephine

Non-maleficence- no maleficence in this case

Justice- no discrimination, treatment being offered

Tempo of need for clinical/administrative decisions- fast

Legal/Regulatory issues- many

Medical Ethics

◆ Case #3: John

A 62 year old man with worsening chronic kidney disease, multiple other medical problems, and severe and treatment refractory borderline personality disorder and bipolar disorder. Psychiatric course characterized by cyclical episodes of agitation, non-compliance with health and other care, aggression, and self injury.

Medical Ethics

◆ What would an agency do if it provided residential services to a person with severe ID and autism with severe tactile defensiveness who needed dialysis?

Autonomy/Liberty- physical assent or refusal- not (never) 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

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?

Legal/Regulatory- if anything, compounded by lack ability to make informed decision & living in agency residence

Agency resources (nurse, behavioral specialist administrator)? tempo always fast

Medical Ethics

- ◆ **Care provision in older adults with Alzheimer disease**
 - ◆ **Alzheimer disease is a fatal neurodegenerative condition**
 - ◆ **It is hard to project life expectancy in AD-functional status and the presence of co-morbidities would be used**
 - ◆ **Severe decline in function is problematic in I/DD field (progressive versus static)**

Medical Ethics

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



Medical Ethics



Medical Ethics

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 psychiatrist**

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
 - ◆ Risk to others (dayhab participants, housemates, staff persons)
 - ◆ Injury- preserve safety (beneficence, trust, choice/autonomy)
 - ◆ Climate of fear- ?injustice

Medical Ethics

- ◆ **The myth of pure autonomy**
 - ◆ **Studies of beneficence and substituted justice in general population re: relatives and physicians of person without capacity who need life-sustaining treatment (dementia and life-ending illness)**
 - ◆ **To what extent is the process of decision-making not individual-based, but rather reflects a group consensus**

Medical Ethics

◆ Aggression

◆ 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)
- Long-term unknown effects?