Processing Ethical Issues: Autonomy, Paternalism and the Limits of Staff Responsibility

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The Structure of Ethics

MEDICAL ETHICS CASE STUDY

THE CASE OF MS. G

4 YEARS OLD
PRESENTS WITH MOTHER/LEGAL GUARDIAN
THREE DAYS STATUS POST GREENSTICK FRACTURE TO THE RIGHT RADIUS, BONES ARE UNDISPLACED.
BACKGROUND INFORMATION

- The forearm was previously placed in a fiberglass cast which is now wet.
- The mother initially requested that the cast be removed because it got wet.
- The physician indicated that the cast was in good condition and could be dried without first being removed.
- The mother then demanded that the cast be removed as she desired to treat the fracture with herbal remedies including hot compresses.
- A brief orthopedic consult resulted in the opinion that the cast should remain in place.

The Process of Ethics (Casuistry)

Methods of Doing Ethics

“Theory and Casuistry”

Theory

Casuistry

Top-Down

Bottom-Middle-Down

PRINCIPLES

EASY CASES

HARD CASE

EASY CASES

THEORY

EASY CASES

HARD CASE

EASY CASES
Casuistry takes place in a three dimensional conceptual space involving multiple data points and is not restricted to two analogues.

We become wiser as we get older because our bank of experience is broader.

Think about Pong vs. a modern video game. As resolution improves, detail becomes visible.

The Structure of Ethical Argument
The Process of Moral Reasoning
The Default Assumption
The Burden of Proof
Casuistic Exploration
Application to the Current Case
MEDICAL ETHICS CASE STUDY

THE CASE OF MS. G

4 YEARS OLD

PRESENTS WITH MOTHER/LEGAL GUARDIAN

THREE DAYS STATUS POST GREENSTICK FRACTURE TO THE RIGHT RADIUS, BONES ARE UNDISPLACED.

BACKGROUND INFORMATION

• THE FOREARM WAS PREVIOUSLY PLACED IN A FIBERGLASS CAST WHICH IS NOW WET
• THE MOTHER INITIALLY REQUESTED THAT THE CAST BE REMOVED BECAUSE IT GOT WET
• THE PHYSICIAN INDICATED THAT THE CAST WAS IN GOOD CONDITION AND COULD BE DRIED WITHOUT FIRST BEING REMOVED
• THE MOTHER THEN DEMANDED THAT THE CAST BE REMOVED AS SHE DESIRED TO TREAT THE FRACTURE WITH HERBAL REMEDIES INCLUDING HOT COMPRESSES
• A BRIEF ORTHOPEDIC CONSULT RESULTED IN THE OPINION THAT THE CAST SHOULD REMAIN IN PLACE
THE ARGUMENTS

- PARENTAL AUTHORITY
- PHYSICIAN AUTHORITY
- BEST INTEREST OF THE CHILD (PATIENT)
- BEST INTEREST OF THE FAMILY
- LEGAL AND POLICY ISSUES

THE STRATEGY

- LEGAL/POLICY ISSUES: INCONCLUSIVE
  APPROPRIATELY, THESE GIVE INSUFFICIENT GUIDANCE
- BEST INTEREST OF THE FAMILY: IRRELEVANT
  THE WELFARE OF THE FAMILY (NON-PATIENTS) IS OF SECONDARY OR INDIRECT CONCERN ONLY
- BEST INTEREST OF CHILD (PATIENT): DIVERGENT EVALUATIONS
  ALL PARTIES INVOLVED HAVE AN OBLIGATION TO SECURE WHAT IS IN THE CHILD’S BEST INTEREST
- PARENTAL VS. PHYSICIAN AUTHORITY: WHOSE JUDGEMENT SHOULD PREVAIL IN THIS CASE?

Family Authority

Parental authority over minor children is powerful, but not absolute:

- The burden of proof rests with those seeking to overrule parental authority.
- Parental authority does not empower a parent to be negligent in the care of a child.
- Parental authority does not empower a parent to be abusive in the care of a child.
- Parental authority does not empower a parent to demand that care providers offer sub-standard care.
Three Responses to Conflict Between Providers and Families

1. If it can not be shown that the family’s choice is abusive, negligent, or inconsistent with the standard of care, the care must be provided.
2. If it can be shown that the family’s choice is inconsistent with the standard of care, but not abusive or negligent, then care can be refused but transfer must be allowed.
3. If it can be shown that the family’s choice is abusive or negligent, judicial relief is appropriate.

The Ethics of Patient Refusal

“The Limits of Provider Support”

Optimal Care

Sub-Optimal/Super-Standard Care

Sub-Standard Care

Staff never have an obligation to commit malpractice

The Ethics of Patient Refusal

Three Resolutions to Conflict

When care provider A and care recipient B are involved in a dispute whereby B refuses (or demands) care that A believes is (in) appropriate, three options are available:

- A May Give in to B’s Demands (if A is unable to show that B’s choice would involve negligence, abuse or sub-standard care)
- A May Forcibly Overrule B’s Choice (if A can show that B’s choice would require A to engage in negligence or abuse)
- A May Legitimately Refuse to Satisfy B’s Demands, But B May Receive the Demanded Services Elsewhere (if A cannot show that B’s choice would entail negligence or abuse, but A can show that B’s choice would involve A in the provision of sub-standard care)
EXAMINATION OF THE CONFLICT

QUESTIONS:
• IS THERE A CLEAR MEDICAL INDICATION?
• WOULD FAILURE TO CAST THE ARM BE NEGLIGENCE OR ABUSIVE?
• ARE THERE ANY OTHER OPTIONS THAT ARE LESS INVASIVE OF THE FAMILY’S VALUES?

ASSUMPTIONS:
• FAMILY AUTHORITY REMAINS INTACT UNLESS THE PARENT IS ACTING NEGLIGENTLY OR ABUSIVELY TOWARD THE CHILD
• THE BURDEN OF PROOF RESTS WITH THOSE WHO WOULD INTERVENE AND USURP PARENTAL AUTHORITY

CONCLUSION

• UNLESS THE PHYSICIAN CAN CONFIDENTLY SUPPORT THE VIEW THAT THE FAMILY IS ACTING NEGLIGENTLY OR ABUSIVELY IN THIS CASE, SHE MUST RECOGNIZE AND ACCEPT PARENTAL AUTHORITY

• IF THE PHYSICIAN FEELS THE FAMILY’S CHOSEN COURSE OF ACTION IS NOT ABUSIVE OR NEGLIGENT BUT IS INCONSISTENT WITH THE STANDARD OF PRACTICE, SHE MAY REMOVE HERSELF FROM THIS CASE

• A COMPROMISE OPTION OF SPLINTING AND FOLLOW-UP OFFICE VISITS SATISFIES ALL CONCERNS

Casuistry In Action
Methods of Doing Ethics
“Theory and Casuistry”

Theory
Top-Down

Casuistry
Bottom-Middle-Down

The Ethics of Refusing Treatment
“Listen To Me Or Else…”

Ms. I was recently assigned a new physician to the practice who advised her that she needed to lose 20 pounds and quit smoking. The physician repeated the same recommendations on two subsequent office visits, but after 18 months Ms. I has neither lost weight nor quit smoking. Her physician recently called for an ethics consult to determine if he could discharge her from his practice for noncompliance.

The Ethics of Refusing Treatment
“Cocaine or Coumadin”

Mr. J is a 61-year-old individual who receives services from PACE which include the provision of Coumadin for treatment of a cardiac blood clot. Mr. J suffers from CHF, COPD, Renal insufficiency, Hypertension, Chronic Thrombosis and he is S/P CVA. Mr. J’s most serious risk factor presently is his admitted continued use of crack cocaine. Mr. J lives in his own apartment, although he is currently at risk of eviction, and receives in-home ADL and medication management support from PACE. Staff has become increasingly uncomfortable with continuing to provide Mr. J with Coumadin given his ongoing use of crack cocaine which counteracts the clinical efficacy of warfarin, but ethical question has emerged regarding the withdrawal of Coumadin from an individual with a known thrombosis.
The Ethics of Refusing Treatment

“Infection By Injection”
Ms. K is a 20-year-old recurrent patient at the local hospital who has been hospitalized on an almost monthly basis for IV antibiotic therapy of a recurring infective endocarditis. After receiving antibiotic therapy, the bacterial infection generally resolves. However, providers believe that Ms. K’s IV drug abuse is the source of the recurrent infections. Ms. K refuses to stop using heroin and on her most recent hospitalization she is suspected of having introduced illicit drugs by means of her IV line. She developed a new infection in the hospital which staff believe was introduced by injection of less than sterile substances.

The Ethics of Autonomy

Family Control

“I Want My Shot”
Ms. E is an 85-year-old resident who has a diagnosis of dementia but is oriented X3, lucid, able to converse on complex subjects and scored a 27 out of 29 on a recent mini-mental status exam. Ms. E recently requested an influenza inoculation and clearly indicates that she understands that this is a special injection for the current swine flu outbreak and that she will also want to receive the seasonal swine flu inoculation when the time is appropriate. Ms. E admits to no clinical contraindications for receiving the vaccine. She indicates that she has always received flu shots and secured them for her children, and that she wants this flu shot now. Ms. E’s daughter, who is listed as her responsible party but who does not carry a durable power of attorney for healthcare, does not want the facility to provide the injection on the grounds that this treatment would only prolong Ms. E’s life and that pneumonia is not a bad way to die. Ms. E insists that this decision should be hers alone and that she does not understand why her daughter would not want to her to receive the inoculation.
The Structure of Ethical Argument
The Process of Moral Reasoning

The Default Assumption
The Burden of Proof
Casuistic Exploration
Application to the Current Case

Individual Choice
Basic Assumptions

1) What is the default assumption regarding an adult individual’s right to direct his/her own healthcare?

2) Where does the burden of proof rest? Does the patient have to justify control, or do those who would intervene have to justify wresting control away from the individual?

3) What would it take to satisfy the burden of proof?

Individual Choice
The Burden of Proof

1) All other things being equal, individuals have an autonomy right to control their own care.

2) The burden of proof rests on the party that would restrict an individual’s autonomy right.

3) The burden of proof can be satisfied in on the basis of only two classes of argument: prevention of harm to self (paternalism) and prevention of harm to others (distributive justice).
The Two Paradigms Explained: Harm To Self

The Ethics of Patient Refusal
“There’s Nothing Wrong With Me”

Mr. L is a 60-year-old patient who carries a diagnosis of schizophrenia, NOS with fixed delusions. He has been hospitalized on a number of occasions for treatment of infections associated with a large mass on his right thigh that is suspected to be squamous cell carcinoma. Mr. L has no insight into his illness and refuses surgical intervention to remove the mass. He believes that he can treat the growth with topical salves and nicotine. Given the extent of tumor growth, the surgical intervention being contemplated is an above the knee amputation, but the surgeon is reticent to provide surgery over the patient’s objections. An ethics consult was requested to determine whether or not court authorization for treatment over the patient's objections should be obtained.

Paternalism

An intervention is ‘paternalistic’ whenever the justification for the restriction of an individual’s freedom is calculated to be in their own best interest.
Requirements For Paternalism

Paternalistic interferences with clients' liberty of action are justified only when:

- The client lacks the capacity for autonomous choice regarding the relevant issue
- There is a clearly demonstrated clinical indication for the treatment or restriction under consideration
- The treatment or restriction under consideration is the least restrictive alternative that is reasonably available and capable of meeting the client’s needs
- The benefits of the treatment under consideration outweigh the harms of the interference itself

*Paternalistic interventions must attempt to advance the values of the individual whose freedom is restricted.*

Diminished Capacity

Basic Assumptions

The two most important things to remember at the beginning of any interaction with a patient surrounding capacity issues are:

1) All adults should be presumed to have capacity until they are explicitly found to lack it,

2) An individual cannot be found to lack capacity simply because s/he carries a particular clinical diagnosis.

Diminished Capacity

The Definition of Capacity

In order for a patient to have diminished capacity, s/he must meet at least one of three criteria:

1) The inability to understand information about the decision that needs to be made (ARBs)

2) The inability to use the information, even if understood, to make a rational evaluation of the risks and benefits involved in the decision

3) The inability to communicate by any means
**Diminished Capacity**

**Incapacity Determinations**

There is an important difference between a clinical finding of incapacity that can be documented by the attending physician, and a legal adjudication of incompetence.

A determination that a patient has diminished capacity can apply to a particular healthcare decision, a set of healthcare decisions, or all healthcare decisions.

It is essential that a clinician making a determination that a patient has diminished capacity be able to define the scope of the finding and its basis. A note must be set forth in writing to indicate something like “This patient is unable to make decisions of type X because of deficit Y.”

**Diminished Capacity**

**Important Concepts**

- Capacity is task specific, so incapacity must be assessed relative to the particular decisions at hand.
- Patients can maintain capacity in certain decisional areas while simultaneously lacking it in others.
- The amount of capacity necessary to make any particular decision is relative to the complexity of the decision and the risks associated with the decision. Therefore, clinicians should be very careful when assessing the inability of patients to make complicated high-risk choices and to verify that the patient lacks a sufficient level of capacity to take responsibility for those choices.

**The Two Paradigms Explained: Harm To Others**
**Ethics and Dementia**

**“The Silver Fox”**

Mr. S is an 82-year-old gentleman who presented in his primary care physician's office requesting that his Foley Catheter be removed. When asked why he wanted the Foley removed, Mr. S replied that he "wanted to have sex". The attending believes that Mr. S could tolerate the removal of his catheter for a short period of time, and agrees that Mr. S has the right to engage in a sexual encounter if he desires to do so.

The attending asks Mr. S with whom he intends to have sex and Mr. S replies that "there are any number of women on the third floor who would be happy to oblige". The attending knows that Mr. S is correct in his assumption, but she also knows that the third floor of the nursing home where Mr. S resides is the Alzheimer's unit. Many of the women on that unit are married, but don't remember that information. Furthermore, they are women who would not have consented to a casual sexual relationship prior to onset of their illness, but they have lost many of their inhibitions secondary to their dementia.

**Distributive Justice**

An intervention is justice-based whenever the justification for the restriction of an individual's freedom is that it is calculated to protect a victim of the individual’s action other than him/herself.

**Requirements For Justice**

Justice-based interferences with clients’ liberty of action are justified only when:

- The client behaves in some manner that places others at risk and
- Those placed at risk have not provided valid consent to be placed at risk (either by choice or incapacity) and either
- The risk of harm to others is more significant than the harm generated by restricting the client’s freedom and is not protected by an identified right (deterrence)
- The client forfeits his/her right to liberty by transgressing a clearly defined social expectation (punishment)
Additional Case Studies

Nursing Ethics
Unsafe Working Conditions
Ms. D is a 61-year-old patient who carries a diagnosis of Type II diabetes. She suffers from urinary incontinence and has a Foley Catheter. At present, Ms. D lives at home and receives once monthly visits from Home Health to provide catheter care. The trailer in which Ms. D lives is poorly kept and extremely dirty. On a recent visit to the trailer, the home health nurse fell through the floor and injured her back. The dangerousness of the environment has been well documented and multiple attempts have been made to arrange for fixing the floor. Home Health staff members have even gone so far as to locate alternate housing, but Ms. D refuses to move to a safer environment. Staff are now concerned that visiting Ms. D in her present living arrangement is too risky. This ethics case consultation was requested to help staff consider the ethical implications of withdrawing on-site support from Ms. D in order to protect the safety of the home health practitioner.

Ethics At the End of Life
“It’s Just A Little Lie”
Mr. H is an 82-year-old patient with moderate dementia who has been determined to lack capacity to make her own healthcare decisions. Ms. H suffers from a variety of health challenges, and has been determined to be terminally ill secondary to stage four lung cancer. Her family has enrolled her in hospice, but they are adamant that she not be told her diagnosis or prognosis. They demand that if Ms. H asks whether or not she is in hospice, staff should lie to her and tell her only that she is receiving home health services. How should staff handle the potential disclosure of information to an inquisitive patient with diminished capacity?
Withholding Treatment
To Treat or Not To Treat…
Mr. J is a 40-year-old patient with schizoaffective disorder, dementia NOS and has a history of poly-substance abuse. Mr. J became progressively more disoriented and is now being treated with Aricept. The Aricept is achieving marked results and has improved Mr. J’s alertness and orientation, to the point where his is able to act on his delusions. Is it ethically better to treat Mr. J with Aricept, which increases his autonomy, or to withhold Aricept so that, although clearly less oriented, Mr. J will not engage in confrontational behavior and will experience reduced agitation?

Ethics in Long-Term Care
“She Knows What She Wants”
Ms. M is an 88-year-old resident who has been diagnosed with dysphagia by MBS and a recommendation has been made that she receive only a mechanical soft diet and thickened liquids. Ms. M adamantly opposes the restriction to thickened liquids and desires to drink water and ginger ale. She is capable of voicing her desire, and she is also able to ambulate and secure liquids for herself. Ms. M has been determined to have diminished capacity to make health care decisions regarding her diet. Her diagnosis is senile dementia with delusions. Ms. M does not have a written advance directive, as she indicated no need to complete one since she wanted her son to make all decisions in the event that she lost capacity, and he is the next of kin. Ms. M’s son has been made aware of the health risks associated with allowing his mother access to thin liquids and he has requested that she be allowed such access. Given the fact that Ms. M is deteriorating secondary to advanced age and an irreversible disease, the son wishes that her quality of life be maximized by allowing her to eat and drink as she pleases.

The Ethics of Intervention
“The Future Looks Bad”
Mr. G is a 34-year-old client who has been diagnosed with Schizophrenia, Paranoid type and who has delusional thinking around worldwide conspiracies to do him harm. Mr. G lives with his parents, who are very worried about his condition. He demonstrates poor compliance with treatment – accepting only clonapine and refusing all other medications – and he exhibits poor hygiene. Although he is agitated and states that his neighbors harbor ill-will towards him, he has never made any threats to do harm to others. Mr. G was hospitalized briefly in 2010 secondary to suicidal ideation, but he never formed a plan to harm himself and he is not known to ever have engaged in any suicidal or self-injurious behavior. All staff concur that Mr. G does not currently meet criteria for civil commitment, but they are concerned that his condition is likely to deteriorate and that he could pose a threat of harm at some non-specific time in the future. Mr. G currently receives case management and medication management support from the CSB and he sees a local psychologist privately. This ethics consultation was requested to clarify any ethical responsibilities that might attach to the management of services for a client who is not currently dangerous, but could become so in the future.
Distributive Justice
“Children Beware”

Ms. R is a 23-year-old client who carries diagnoses of Depressive Disorder with Psychotic Features and Autistic Disorder. Ms. R lives with her parents who have worked hard to control her dangerous reaction to the sound of young children crying. Ms. R attempts to choke children and babies when they cry or scream, and she reacts similarly to adults who have communication challenges that cause them to vocalize in primitive ways. Ms. R’s behaviors in this regard have been noted on several occasions and she verbalizes an intent to “choke their guts out” when asked why she acts as she does. Although a behavioral plan has been developed for Ms. R, the team is concerned that she does pose a risk when in public. This ethics consultation was requested to analyze the team’s responsibility in maintaining public safety.

Hoarding and the Ethics of Intervention
“He Is Out Of Compliance”

Mr. B is an 88-year-old individual who lives in an apartment with a housing voucher. The property manager states that Mr. B pays his rent on time, and that he is sometimes cordial and friendly and at other times irritable and irrational. At the time of his annual inspection with the county housing department to ensure continued eligibility for a voucher, Mr. B refused to allow staff entry into the apartment. According to the property manager, Mr. B has saved every piece of paper from his adult life, resulting in an apartment cluttered with boxes and loose papers piled up in every available space including closets, in front of windows, and in the oven. The housing department is planning to execute an eviction notice as Mr. B is not cooperating with the rules of the program and they are unable to conduct the inspection of the apartment.