Autonomy, Control, and the Ethics of Person Centered Planning

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Michael A. Gillette, Ph.D.
(434)384-5322    mgillette@bsvinc.com
http://www.bsvinc.com
The Dignity of Risk

“Why Risk Matters”

• Intrinsic Value: The Thrill of Taking Chances

• Instrumental Value: The Ends Justify the Means
The Ethics Process
The Ethics of Individual Choice

“I Can See Fine”

Mr. G is a 65-year-old individual with Axis I diagnoses of Adjustment Disorder with Mixed Disturbance and Anxiety Disorder NOS. He also carries an Axis II diagnosis of Moderate Intellectual Disabilities. The most immediate clinical issue for Mr. G is his degenerating cataracts in both eyes. Dating back at least for two years, staff has worked diligently to explain to Mr. G that he will likely suffer permanent loss of vision if he does not undergo cataract surgery, but he is unwilling to consent to the procedure. When refusing surgery, Mr. G refers to his own experience with previous surgery along with family history, and he does not seem to fully appreciate the irreversible nature of his vision loss or the fact that in the near future all clinical options to prevent total blindness will be lost. Staff believes that Mr. G understands what surgery is, and what blindness is, but they are unsure that he understands that he is actually likely to lose his own sight. This ethics case consultation was requested to explore the ethical implications of attempting to force cataract surgery over Mr. G's objections.
The Structure of Ethical Argument
The Process of Moral Reasoning

The Default Assumption
The Burden of Proof
Casuistic Exploration
Application to the Current Case
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 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
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 on 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
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.
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.
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) or
- The client forfeits his/her right to liberty by transgressing a clearly defined social expectation (punishment)
The Standard of Care
Ms. V is a 31-year-old client who has been residing in a CSB group home for several years. Ms. V was born in Puerto Rico and moved to Florida in her teens. She developed an online relationship with a man who lived in Virginia and she eventually had a child with this man and remained in Virginia. Ms. V no longer has custody of her child and continues to develop online relationships. She has been diagnosed with Dysthmic Disorder and operates at the level of Mild ID. Ms. V has been in mental health facilities on a number of occasions and was determined by the court to be incompetent. She currently has a legal guardian that is charged with making all decisions for her except for the sale of real property. Recently, Ms. V has developed a long-distance relationship with a woman in Puerto Rico, and she indicates a desire to move there to live with this woman in the woman's parent's home. Staff has very little information about the prospective living arrangement, and Ms. V is unwilling to allow a more thorough assessment of her discharge plan. This ethics case consultation was requested to determine whether or not staff have an ethical obligation to assist Ms. V in moving to Puerto Rico to move in with a woman whom she claims to love.
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
Additional Cases
Mr. G is a 46-year-old resident of a group home who refuses to bathe, sometimes for as long as two weeks. After only a few days, Mr. G produces a remarkably bad odor. He does not have skin breakdown or any other health risk associated with failure to bathe and since he is a large and powerful man, none of the other residents challenge him regarding his odor. When he is in the common living area, other individuals move to the far end of the hall because Mr. G’s odor is so bad. Efforts to cajole bathing have worked intermittently, but now the smell is so bad that it disrupts life in the home. May staff forcefully bathe Mr. G? If so, how?
Honesty and Beneficence

“You Oughta Have That Checked”

Mr. Q was recently seen by the agency nurse because he was concerned about his blood pressure. Mr. Q has moderate ID and has become fixated on his blood pressure, although it is normal. On his most recent visit to the nurse, the nurse noticed a large nodule under his arm while applying the blood pressure cuff. She suggested that Mr. Q have the suspected tumor checked by a physician, but Mr. Q dismissed it as being unimportant. He made it clear, however, that he did want to see a doctor if his blood pressure is high. The nurse contemplated telling him that a doctor did need to check his pressures, knowing that the physician would then discover the suspicious swelling.
What He Doesn’t Know…

Mr. A is a 23-year-old client who is significantly overweight but who loves to drink non-diet soft drinks. He will often ask for specific drinks by name, but staff have found that he isn’t able to taste a difference between them. They recently emptied the contents of a Coca-Cola bottle and refilled the bottle with a low-fat substitute. Mr. A drank the “Coke” without complaint. Would it be ethical to offer Mr. A a “Coke” when he asks for it, but to substitute the healthy alternative?