The Ethics of Consent

Texas Council of Community Centers
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Michael A. Gillette, Ph.D.
(434)384-5322  mgillette@bsvinc.com
http://www.bsvinc.com
Disclosure to Participants

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A Review of Core Concepts
The Structure of the Argument

Liberty vs. Beneficence

We begin with an assumption of respect for autonomy

Restrictions on liberty must be justified,

a right to liberty is assumed.

Restrictions can be justified on two grounds:

Paternalism

Distributive Justice

*Staff Must Uphold Relevant Standards of Care*
Ms. A is a 49 year old woman presently living in a group home who has been diagnosed as operating at the mild level of intellectual disability. Ms. A possesses excellent verbal skills and is oriented X3. Her problem list includes cerebral palsy of unknown origin, spasticity, and moderate quadriplegia. Most importantly, Ms. A has recently been diagnosed as suffering from breast cancer.

When Ms. A’s cancer was first diagnosed by biopsy, chemotherapy was initiated. Ms. A’s attending physician also recommended that a mastectomy be performed but Ms. A refused surgical intervention. Although surgery was a viable option at that point, the physician did not believe that Ms. A’s refusal of mastectomy was unreasonable, as he did not believe that the provision of such treatment would be likely to appreciably alter the course of her illness. Concern was voiced, however, over the possibility that as the tumor was treated by chemotherapy, an ulcer on Ms. A’s breast might form that would be uncomfortable, odorous, and subject to infection. Mastectomy is now indicated for these reasons, but Ms. A opposes surgical intervention.
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.

• Justified paternalism requires that the intervention is consistent with the basic or religious values of the individual whose liberty is restricted.
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.*
The Ethics of Intervention

• Capacity is Local and Not Global
• Capacity is Analog and Not Digital
• The Burden of Proof is on the Usurper
• 'Risk' is a Threshold Property at the Lower Level
• 'Capacity' Relative to 'Risk' is a Threshold Property at the Upper Level
• The Relevance of 'Complexity' is Contingent on 'Risk'
Several residential programs have experienced bedbug infestation, and while most of these situations have been resolved, some clients have refused to adhere to eradication protocols. The cost associated with battling bedbugs is extensive, and even if specific individuals are not bothered by living with infestation, the spread of bedbugs to others is impossible to prevent. Therefore, a client’s refusal to eliminate a bedbug infestation in his own room or apartment has a clear impact on others who live with him/her or others with whom s/he has contact in CSB programming outside of the home. Ethical questions have now emerged surrounding the extent to which the CSB may insist on participation in bedbug eradication protocols as a stipulation of continued placement in settings operated by the agency.
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

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)
Mr. D is a 53-year-old individual who operates at the profound level of intellectual disability and is non-verbal. Mr. D carries a diagnosis of autism and has a long history of extreme difficulty with transitions. At times he will refuse to leave an area for hours, and he has been known to sit down outside in inclement weather and refuse to move. These behaviors have become worse lately, and attempts to find motivators or alterations in staffing that will increase Mr. D’s willingness to transition have produced only very short-lived success. If Mr. D is pressed to move when he doesn’t want to, he can become aggressive and physically assaultive. Staff has attempted to use a wheelchair to aid with transitions if Mr. D does not agree to transition within 30 minutes. This technique has not had any success in altering Mr. D’s behavior, and his intransigence seems to be increasing. Staff is concerned with Mr. D’s health, safety, and the loss of opportunities for increased community involvement and potential discharge if his difficulty with transitions cannot be improved.
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)
Case Studies
Ms. N is 69-year-old patient who carries Axis I diagnoses of Schizoaffective Disorder, bipolar type, depressed and Cognitive Disorder not otherwise specified. Her Axis III problem list includes hyperlipidemia, glaucoma, hypertension, hypothyroidism and anemia secondary to chronic renal insufficiency. Ms. N is often anxious and exhibits specific anxiety surrounding ADLs. She finds it upsetting to shower, but her most severe difficulties arise from refusal properly to toilet. Ms. N has often refused to change dirty Depends, sometimes stacking multiple layers of wet diapers over each other or hiding the torn out wet material from a diaper in her bra. Ms. N is mostly compliant with her medications, including Cymbalta, Ativan, Zoloft, and Resperidal. Since she experiences significant anxiety around bathing, a standing order to utilize Ativan prior to twice-weekly bathing was written and this strategy has been successful in reducing emotional trauma and facilitating bathing. This ethics consultation was requested to investigate reasonable ethical responses to Ms. N's refusal to allow diaper changes.
Mr. C is a resident in assisted living who has requested to return to independent living. Staff indicate that Mr. C was admitted to assisted living based on concern surrounding his documented suicidal ideation and a desire to closely monitor his medication management, even though he did not meet UAI criteria for assisted living. It is unclear how Mr. C scores on the UAI currently but his physical function has not deteriorated since admission. However, Mr. C does have a history of depression and there is some concern that we will be less able to monitor his mental health status in independent living. The primary ethical issue is based, therefore, on whether or not depression, without associated losses of physical function, creates a legitimate basis for ruling out an individual for living independently.
The Ethics of Risk

“He Is Discharge Ready”

Mr. K is a 64-year-old consumer of services from the Permanent Supportive Housing Program. Mr. K has been receiving services from that program for five years but he has refused most of the offered services. Specifically, the DHS case manager has made attempts to work on hoarding issues by providing housekeeping services, but Mr. K refuses those supports. By doing so, Mr. K puts his placement in jeopardy and staff is concerned that he might be evicted. After aggressive outreach, Mr. K continues to refuse all supports except rental assistance. Although Mr. K exhibits symptoms of mental illness and has a history of traumatic brain injury, staff believe that he does have capacity to understand the alternatives, risks and benefits that are available to him and that he does act volitionally. Staff are also in consensus that if Mr. K were to present for services initially, while refusing social work supports, housekeeping, and any other efforts at support, he would not be opened to PSH but would be referred to housing assistance. Ethical questions have now emerged surrounding Mr. K's continued status with PSH. By keeping Mr. K open to this program, staff project a level of support that is not taking place. Furthermore, other clients who have refused services in similar ways have been discharged from the program. Staff now question whether or not it would be ethically preferable to transfer Mr. K from PSH to simple housing assistance.
Comfort and Tolerance

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Truthfulness
“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?
Deceit
Ms. D is an 86-year-old patient at a mental health facility who periodically worries about the welfare of her dogs. If Ms. D did have dogs, she has not seen them for at least three years. However, once Ms. D becomes fixated on her pets, she becomes extremely agitated. Ms. D will repeatedly ask where her dogs are, and will not engage in any activities or treatments until she is satisfied that the dogs are OK. On one recent occasion, a staff member told Ms. D that the dogs were fine, and that they were being cared for at a local kennel. The staff person even provided the name of a particular kennel. Now she feels guilty about lying to the patient.
Mr. U has had a long history of serious mental illness but seems to have done best on one particular psychotropic medication. Mr. U has been determined to have diminished capacity to make his own healthcare decisions, but he is compliant with his meds because he believes that they are good for him (based on delusional thinking). Recently, Mr. U developed some side effects and his attending believes that it would be best to switch to an alternative. Mr. U’s surrogate consents, but Mr. U becomes agitated when he sees unfamiliar pills. He wants his old blue pill, but the new medication is pink. The surrogate requests that staff dye the pink pills blue in order to relieve Mr. U’s distress and successfully deliver the medication.
Medical Ethics Case Study

“Hide The Meds”

Mr. S is a 14-year-old patient who suffers from Bipolar Affective Disorder and who was committed after assaulting a police officer. Mr. S lacks the capacity to make his own health care decisions, and his parents act as authorized representatives. Mr. S's parents have given consent for treatment with mood stabilizers, but Mr. S is non-compliant in his care. It is possible to get a court order to initiate forcible IM medication, but Mr. S's parents ask whether it would be possible to hide PO meds in Mr. S's food.
Silence
End of Life in the CSB

“Is Honesty the Best Policy?”

The CSB Ethics Committee recently received an ethics consult regarding an individual who lives in an ID group home but is able to read, write and converse on complex subjects. His mother died of cancer years ago, and the individual remembers that event quite well. He was recently diagnosed with bladder cancer and his sister, who serves as his legal guardian, prohibits staff from telling the client that he has cancer. She is concerned that he would not handle the information well. How should staff proceed?
Person Centered Planning

“He Is Dangerous”

Mr. F is a 52-year-old Training Center resident who, on two separate occasions, caused the death of other residents. Details regarding the episodes are unclear, but it is believed that Mr. F stomped an individual to death pushed another resident who hit his head and died. Both of these events took place decades ago. Mr. F has not exhibited violent behavior in the last 15 years, although he has verbalized the concept of killing someone. Mr. F has done well in a competitive work environment and has gone on extended trips without incident. Mr. F was recently accepted for a trip that will involve air travel. Staff are concerned that this trip will place Mr. F in an unknown environment – an enclosed airplane for several hours — and that the distance and time away from the Training Center make this trip different from others that he has attended. Staff have not communicated details about Mr. F’s history of violence to the trip-sponsoring agency, and have requested this ethics consult to determine if such disclosure is ethically necessary.
Persuasion
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 MR 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.
Person Centered Planning

“You’ll Have A Ball”

Mr. N has a history of becoming very anxious about transition from one activity to the next, but he usually enjoys himself once the activity begins. The group home has planned a special dinner and Mr. N has worked with others to prepare the festivities. On the day of the event, however, Mr. N complains that he does not want to go. He has already spent money on the dinner reservation and staff have already been paid to escort him to the party. Knowing that Mr. N is likely to be happy once at the party, should staff encourage/persuade/force him to go?
Additional Case Studies (Paternalism)
Ms. X is a 71-year-old patient who carries an AXIS I diagnosis of delusional disorder. Reports indicate that she has lived in her mini-van for the past ten years. Ms. X showers at the YWCA, cooks on a camp stove, and while she does move the van from place to place, she parks at night in particular locations that are well-lit. Ms. X was detained by police after she called regarding a stalker but she has stabilized and is approaching discharge readiness. She indicates a desire to return to her mini-van but staff members are concerned that this placement might be unsafe. Ms. X insists that she needs to move back to her mini-van for delusional reasons (she indicates that she is safer from internal parasites and stalkers in the van). An ethics consult was requested to determine the ethical implications of either supporting her choice to move back into her van or paternalistically intervening.
Ms. S is a long-time client of the State system who originally lived at a Training Center. Ms. S was moved into a group home, and initially did well. After several efforts to support Ms. S in her own apartment, it has become clear that she is not capable of living independently. Plans have been made to move Ms. S back into a more closely supported living arrangement. Ms. S has looked at several group homes and rejected all of them. Once before, when Ms. S had run away from her apartment, she had spent several days in a homeless shelter. Ms. S apparently made some friends at the shelter, and enjoyed the environment. She has been diagnosed with moderate ID and has no plans to accept support services from the CSB. Ms. S just wants to go back to the homeless shelter where she can relax with her friends.
Additional Case Studies (Justice)
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?
“With regard to the question of whether or not restrictions in dining locations are justifiable, we recommend that mere annoyances are insufficient to justify forcible intervention. We believe that the behavior in question must rise to the level of a disturbance in order to justify restrictions. In making this recommendation, we are cognizant of the fact that special social responsibilities exist for individuals living in a communal setting like a long-term care facility. Residents in the dining hall are not eating in a private room, and therefore they must demonstrate a level of tolerance that is greater than what might be expected in one’s private residence. At the same time, the disrupting individuals have an obligation to respect the social nature of the dining hall and to behave according to reasonable expectations. We recommend that it is necessary to balance the burdens associated with multiple personalities sharing an eating space. That is why we recommend that annoyances must be tolerated, but disruptions may be restricted.”
Additional Case Studies (Standards of Care)
Mr. N is a 47-year-old patient who carries a diagnosis of schizoaffective disorder and has been living in correctional and in-patient mental health environments for the past quarter century. Mr. N is now a mandatory parolee. Mr. N's psychogenic polydipsia has progressed and his sodium levels have dropped substantially. Staff has instituted a treatment plan that limits the amount of liquid that we provide, but it is very difficult to prevent Mr. N from accessing additional liquids. An ethics discussion took place to determine whether or not we could, ethically, enforce fluid restrictions.
Mr. M carries a diagnosis of Borderline Personality and has been hospitalized for the past three months. Mr. M has a long history of voicing discontent with the services that he receives and he recently announced that he would go on a hunger strike. He has not eaten for the past week and he is beginning to lose weight. Mr. M also states that he believes that the facility is not responding properly to his hunger strike. How should the hospital respond?
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.