Uncertain End of Life Trajectory:

Care implications for patients with severe psychiatric illness

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Learning Objectives

- Through case-based discussion, examine the complexity of caring for people with life-threatening complications of mental illness
- Identify and explore ethical challenges in end-of-life care for patients with serious mental illness
- Discuss barriers to palliative interventions experienced by patients with serious mental illness

Case Overview

- Man in late 50s presenting with mild-moderate hypernatremia asserting he cannot speak, eat, or drink, and hasn’t for many weeks
- PMC 5d; 4 weeks later UVMMC 3d; 2 weeks later PMC 2d to UVMMC 34d
- Labs sufficiently concerning for medical admission, but not consistent with his asserted history of no food/fluid intake for weeks
  - Hypernatremia, no AKI, minimal ketones for first three admits
  - Final presentation with more significant abnormalities
  - Substantial weight loss over the last year
- No physiological etiology for his concerns identified
  - Ability to speak spontaneously returns
  - Observed eating/drinking without difficulty
  - Willing to passively receive treatment, refuses active participation, demands BZD
- Long history of various mental health diagnoses, CRT client of CSAC

Final Hospitalization

- Arrives with same complaints – can’t eat, drink, or speak
  - Sodium max 171, with kidney injury
  - Admitted, electrolytes stabilize
- Psychiatry assesses repeatedly
- Now consistently refusing most interventions, most food/fluid
- Palliative care and clinical ethics consulted
- Capacity questions are mooted – found to retain DMC
- Transitions to CMO, transfers to hospice, and dies a few weeks later

Case, Psychiatry Perspective

- Psychiatry consulted – found to have probable factitious disorder in the context of somatization disorder and dependent personality disorder
  - History of multiple similar presentations to several OSH over the last several months identified – BBR x2, RRMC Psych x1
- Diagnoses historically have included bipolar illness, several personality disorders, polysubstance use (BZD, alcohol, opiates), various anxiety disorders, and self-reported PTSD
  - OP team notes he is given to behavior that draws substantial attention to himself, which has been the case for many years
  - Chronic SI, but without attempts in recent years
  - Declines to participate in psychotherapy or intensive work

Case, Psychiatry Perspective

- Complex dynamics
  - Asserts suicidal ideation, at or near baseline
  - Adamantly requests assistance yet refuses it when offered
  - Generally declines psychotropic medication
    - BZD are exception to this, and he attempts to bargain for them
  - Clearly needs intensive psychiatric care, but his refusal to eat/drink precludes placement at a psychiatric hospital regardless of being voluntary or on an involuntary status
    - OP care also cannot be accessed as he becomes too physically decompensated due to refusing to walk or engage with PT
    - Consultative psychiatric care in hospital is inadequate to meet his needs
    - Medical psychology works with him but cannot make headway
    - ECT is offered, but he refuses

Case, Palliative Perspective

- Patient with severe malnutrition without a viable road to treatment given he declined recommended psychiatric interventions and tube feeding, and cannot treat over his objection in Vermont regardless of capacity
- All providers in agreement he appeared to be rapidly nearing the end of his life
- Patient requested to allow death and optimize comfort in the dying process

Case, Palliative Perspective

- Capacity
  - He named psychiatric illness as cause of his minimal PO intake and malnutrition (understanding)
    - He endorsed knowing there was no physical reason he could not swallow but stated anxiety around oral intake was unbearable
  - Stated he knew he would die without nutrition (appreciation)
  - Endorsed understanding there were treatment options being offered for psychiatric disease but did not believe they would be effective (reasoning)

“Terminal Psychiatric Illness”

- Long debated idea which posits that the direct or indirect consequences of severe and persistent mental illness may be terminal in a similar sense to somatic illness
  - Key principles include “intolerable suffering” and “irremediability”
  - Decision-making capacity critical
  - Some parts of the world, such as the Netherlands and Switzerland, allow medical aid in dying for terminal mental illness
- HOWEVER – substantial medico-legal issues exist in the US due to some regulatory bodies not recognizing the existence of the concept
  - Many psychiatrists recognize the validity of the construct while also being unable to freely discuss in clinical documentation

Implications of VT Mental Health Law

- Involuntary Psychiatric Hold ("EE")
  - Evidence of illness
  - Dangerousness
  - Lack of alternative
- Context
  - Full adversarial process
  - "Level 1" placements
  - Limited ability to treat medically compromised patients
- Application of law
  - Limited diagnoses accepted as being "mental illness"
  - Department of Mental Health with discretion to dismiss EEs without judicial review or clinical oversight

Implications of Diminished Capacity

- True informed consent
  - Patient’s health beliefs mediated by delusional intensity precepts, and at obvious odds to fact
  - Patient unable to integrate learning of the facts into his decision making
  - Within psychiatry, suicidality due to mental illness impairs DMC related to mortality de facto
- “Presumption of Capacity”
  - Psychiatry is compelled to presume our patients have capacity to make decisions about their mental health regardless of clinical fact
  - For all other concerns, this means that the patient must have some reason they lack capacity (other than mental health)
    - Sustained lack of nutrition impairing cognitive functioning

Psychiatry Upshot

- Voluntary/Involuntary
  - Theoretically meets involuntary criteria – symptoms of mental illness are directly leading to starvation and dehydration, placing him at imminent risk
  - HOWEVER, imminent in this context is interpreted as meaning “within 24h” and by that point, he is too medically unstable to go to psychiatry
  - THEREFORE, his EE would be thrown out due to there being no appropriate placement for the patient
  - Without an EE, there is no way to get a court order for psychotropics over objection
- Capacity
  - Although he cannot truly have informed consent or adequately process/integrate information, and his choice to die is informed by longstanding suicidal ideation, he does have capacity within the autonomy-driven construct used in Vermont
  - Reality of a lack of viable alternative treatments given his refusal, and our legal system constraining our ability to render treatment

Palliative Upshot

- What would treating over objection have looked like for this patient?
  - Sedation/restraint in order to administer artificial nutrition?
  - If presentation truly primarily due to factitious disorder, somatization disorder, and dependent personality disorder, psychotherapy is the primary intervention -- not medication or ECT
    - How would he ultimately undergo intensive psychotherapy? Would discontinue sedation/restraint and admit to Psychiatry without a plan for nutrition?
    - Note he had repeatedly sought out, but not fully engaged in, psychiatric help in the past
    - His diagnoses are notoriously challenging to treat in the best of circumstances
    - Note that even when anxiety around oral intake was treated with benzodiazepines at the end of his life, this did not increase his oral intake
  - *Acknowledge this is a moot point given this option was not on the table*

Palliative Upshot

Thinking upstream…

- Would waiver of right to object to treatment, documented at a time when the patient was not expressing suicidal ideation, have changed this outcome?