Palliative and End-of-Life Care in Individuals With Serious Mental Illness

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No commercial or in-kind support was provided for this activity

Introductions

Our ECHO Team: Planning Committee

Clinical Leadership	Egidio Del Fabbro, MD VCU Palliative Care Chair and Program Director Danielle Noreika, MD, FACP, FAAHPM Medical Director/Fellowship Director VCU Palliative Care
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Support Staff	Teri Dulong-Rae & Bhakti Dave, MPH – Program Managers David Collins, MHA – Telemedicine Practice Administrator Frank Green – IT Support

Learning Objectives

- Recognize characteristics of people with serious mental illness
- Identify challenges and barriers to care for people with serious mental illness
- Discuss opportunities for improving quality of care, outcomes in the case of a patient with SMI

Serious Mental Illness (SMI)

- Mental illness that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning.
- Common examples: Schizophrenia, Major Depression, Bipolar Disorder, Personality Disorders
- SMI is associated with premature mortality across all age groups; the majority due to chronic diseases such as cancer, heart disease, COPD, and dementia

Schizophrenia

- Typically diagnosed in the late teen years to the early thirties
- The dx often follows the first episode of psychosis, when individuals first display symptoms of schizophrenia
- Symptoms generally fall into three categories:
  - Psychotic symptoms (altered perceptions, abnormal thinking, and odd behaviors)
  - Negative symptoms (loss of motivation, lack of enjoyment in daily activities, social withdrawal, flat affect, and difficulty functioning normally)
  - Cognitive symptoms (problems in attention, concentration, and memory)

Personality Disorders

- 10% of the general community, 25% of primary care patients, and at least 50% of psychiatric outpatients
- Enduring patterns of inner experience and behavior that are inflexible and pervasive which cause clinically significant distress or impairment in social, occupational and other areas of functioning
- Four “E’s”:
  - Early
  - Enduring
  - Ego-syntonic
  - Externalization of conflict

Types of Personality Disorders

- Cluster A: odd, eccentric thinking or behavior
  - paranoid personality disorder
  - schizoid personality disorder
  - schizotypal personality disorder
- Cluster B: dramatic, overly emotional or unpredictable thinking or behavior
  - antisocial personality disorder
  - borderline personality disorder
  - histrionic personality disorder
  - narcissistic personality disorder
- Cluster C: anxious, fearful thinking or behavior
  - avoidant personality disorder
  - dependent personality disorder
  - obsessive-compulsive personality disorder

Schizotypal Personality Disorder (STPD)

- Less than 1% of the population have this disorder
- No male to female prevalence differences
- STPD is related to Schizophrenia and believed to be a part of spectrum disease
- A pervasive pattern of social and interpersonal deficits marked by acute discomfort with, and reduced capacity for, close relationships, as well as by cognitive or perceptual distortions and eccentricities of behavior, beginning in early adulthood and present in a variety of contexts

STPD

Five (or more) of the following symptoms:

1. Ideas of reference
2. Odd beliefs or magical thinking
3. Unusual perceptual experiences, including bodily illusions
4. Odd thinking and speech
5. Superstitious or paranoid ideation
6. Inappropriate or constricted affect
7. Behavior or appearance that is odd, eccentric or peculiar
8. Lack of close friends or confidants other than first-degree relatives
9. Excessive social anxiety

Health Implications for people with SMI

VERY LIMITED RESEARCH but….

- Shorter life expectancies (10 years less for people with schizophrenia)
- At least 2x the risk of dying from natural causes at any given age
- 35% have undetected significant medical conditions
- Medical co-morbidity is associated with more serious psychiatric symptoms.
- Later presentations, less aggressive interventions

Special Challenges in End of Life Care for People with SMI

- Little is known about end-of-life care for persons with SMI
  - Specific literature scarce
  - Tools not tested in this population
- Advance Care Planning is complicated
  - Capacity assessment issues
  - Legal guardianship issues
- Shortage of persons to designate as Health Care Proxies

Barriers to Care

Patient Factors

- Poor insight
- Struggle to communicate symptoms
- Psychiatric symptoms that challenge a therapeutic alliance
- Social withdrawal and apathy

Barriers to Care

Healthcare Factors

- Discomfort of staff/lack of training (palliative/psych and psych/palliative)
- Siloed care
- Presumptions of lack of capacity and inability to discuss challenging topics (Advance care planning)
- STIGMA
  - Misattribution of medical symptoms as manifestations of psychiatric illness

Barriers to Care

Sociocultural Factors

- Impact of social determinants of health
- Stable housing
- Social support
- Surrogate decision making
- High risk of social isolation, homelessness, poverty

Case Presentation

- Mr. W- 66yo man w/PMH of metastatic urothelial carcinoma s/p bilateral nephrostomy tubes, chronic anemia, CKD5, HTN, documented hx of paranoid schizophrenia v schizotypal PD.
- Social: lived in a hotel independently, used public transportation, no family nearby
- 1st visit May 2017, presented to the ED with hematuria. Admitted for ~15 d until he left the hospital AMA to “pay some bills”
- Set up for ambulatory care appts with urology, oncology, ophthalmology
- 5/17 – 8/20 Mr. W attended over 135 amb care appts and was hospitalized 11 times. Psychiatry was consulted x 5 during first hosp, 5 additional times in 2019 and x 2 in 2020; Ethics consult x 3; Palliative consult x 2 (late 2019 and prior to death).
- Transferred to Palliative afternoon 8/6 and died early am 8/7

Challenges

- Nearly half of Americans will meet criteria for a DSM disorder in their lifetimes, and a considerable proportion of people entering serious illness care will already carry a pre-existing BH condition or will develop a new one.
- There is inadequate palliative care among individuals with mental illness and the causes are complex: unstable housing, estranged from social support, and unable to form trusting alliances with providers.
- Non-psychiatric providers feel inadequately trained regarding communicating with patients with mental illness and psychiatric providers are often less knowledgeable about palliative care and may be less likely to discuss this.
- Issues surrounding the assessment of capacity are among the most challenging barriers.

Challenges Presented

- Diagnostic challenge: Often, pts with SMI are oblivious to dysfunctional personality traits; people with STPD tend to blame others. Direct questioning is less likely to yield dx information, indirect extrapolation is usually how dx is made.
- Mental health and decision issues: What if the mental illness is playing a significant role and affects whether the patient makes choices that may lead to likely death?
- Patient's beliefs: What should a care provider do when the patient's beliefs conflict with medical evidence or the care provider's experience?
- Patient's goals: How can a care provider respond when a patient's goals are not in his own best interest?
- Beneficence: Are care providers assuming that they know the wishes and best interests of clients without consulting them directly?
- Refusal of care: How can care providers respond to patients who refuse care that would be in the best interest of their health?

Take Aways

- The sooner clinicians realize they are communicating with someone with SMI, the better. What sustains the distorted pattern of communication is the mutual lack of awareness of the other's perception of the relationship.
- Capacity is not static and does not disappear in patients with mental illness. A patient's capacity for decision making is constantly changing and should be assessed regularly by clinicians.
- When a patient has capacity to make decisions for themselves, patient autonomy trumps medical beneficence.
- The core of patient-centered care is a principle of autonomy that allows patients to guide the clinical process. Patient-centered care requires respecting and responding to the patient's values, needs, preferences, goals, and hopes for the future.
- Once someone is labeled 'difficult' (countertransference), we tend to lose our curiosity about what else could be going on; we tend to shut down our brain and dismiss pt concerns, setting up the potential for communication breakdown and power struggles

Good Communication

- There is no definitive model of “good communication”
- Highly complex process
- Vital to the development of a therapeutic relationship
- Predictor of patient outcomes and satisfaction
- Generally agreed that there are two components in health care:
  - Patient-centeredness
  - Shared decision-making
- Misunderstanding and miscommunication are particularly problematic in patients experiencing psychosis/delusions

Communication tips for people experiencing delusions

DO	Calmly ask objective questions about their delusion
Do not	Dismiss their delusion as inconsequential
Do not	Verbally assault them or call them 'crazy'
Do not	Play along with their delusion

- Calmly ask the individual pertinent questions in a nonjudgmental manner so as to better understand why they believe what they do. How did they arrive at their belief? How long have they held their belief? What do they plan to do in response to it? Address the emotional underpinnings of the delusion (paranoid = fear)
- For people with STPD, they are MORE COMFORTABLE being socially detached so avoid excessive emotion and attempts at creating a solid relationship. Validate their concerns and try to aim for a collaborative treatment plan to support their investment and autonomy.

Compassionate Communication

Based on the above assessment, pt's presentation is unchanged compared to the prior consultation. He is notably NOT demonstrating signs consistent with schizophrenia. His statements are indicative more of an ego-syntonic personality disorder in the cluster A family, with the mostly likely presentation being that of Schizotypal Personality Disorder. With this in mind, he also carries a rather low health literacy and is rather concrete with his thought processes. This makes speaking to him about health care decisions difficult but not impossible. With regard to the question asked in this consultation, he is deemed to HAVE capacity to determine whether to leave AMA. Dx: Schizotypal Personality Disorder

Plan

1) Patient deemed to HAVE capacity to determine whether to leave AMA or not

2) Would recommend speaking with the patient in the following manner:

i) Give plans in clear, concrete fashion (i.e. we need 3 more doctors to come talk to you and weigh in to see if they have any ideas)

ii) Give progress in clear, concrete fashion (i.e. our palliative doctors need to see you so they can help out with some of this distress you're having)

iii) Procedures/plans need to be described in a simplified fashion consistent with his low health literacy (i.e. your tubes are bleeding so we need to have the doctors that deal with your kidneys, where the tubes are connected, come see you and talk).

iv) Gently redirect patient away from his topics of conspiracies and other delusions. This will require patience on the part of both patient and providers but can be done, allowing patient to receive the best possible treatment.

v) Avoid stigmatizing patient. While he does have these bizarre ideations, they are normal for him and would be no different than suggesting to him that his name is not actually Mr. W. Writing things such as "Hangry" into medical charting is less than productive.

Best Practice Recommendations

- Cross training in Psychiatry/Palliative Care
- Frequent (and compassionate) capacity assessments
- Involve Psychiatry/Behavioral health early on in Palliative care
- Assess and address social needs
- Challenge stigmatizing assumptions
- Increase integrated care

References

- Bauer, R. (2017). Ethical Considerations Regarding End-of-Life Planning and Palliative Care Needs in Patients With Chronic Psychiatric Disorders. Published Online:1 May 2017https://doi.org/10.1176/appi.ajp-rj.2016.110503
- Cheung, S., Pincus, H., & Spaeth-Rublee, B. (2020). A model to improve behavioral health integration into serious illness care. J Pain Symptom Management, 58(3), 503-514.
- Fond, G., Salas, S., Pauly, V. et al. (2019). End-of-life care among patients with schizophrenia and cancer: a population-based cohort study from the French national hospital database. Lancet Public Health, 4(11), 583 – 591.
- Liu, N., Daumit, G., Dua, T. et al. (2017). Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy, and research agendas. World Psychiatry, 16(1), 30–40.
- Shalev, D., Brewster, K., Arbuckle, M., & Levenson, J.A. (2017). A staggered edge: End-of-life care in patients with severe mental illness. Gen Hosp Psychiatry, 44, 1 – 3.
- Shalev, D., Fields, L., & Shapiro, P. (2020). End-of-life care in individuals with serious mental illness. Psychosomatics, 61(5), 428–435.
- Sheridan, A.J. (2019). Palliative care for people with serious mental illness. Lancet Public Health, 4(11), 545-546.

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