The Unseen: Palliative Medicine with Mental Health Disorders & Special Needs

Tom Allen MD
Michelle Greene PhD

2/26/2016
Objectives

• How to identify and address issues related to mental illness

• How to know when to refer a patient to a specialist

• How to facilitate team communications and avoid falling into maladaptive patterns when working with complex patients
Outline

• Pre-Existing Mental Illness

• Substance-Use Disorders

• Personality Disorders

• Anxiety Disorders (case presentation)

• Intellectual Disability (case presentation)
Pre-Existing Mental Illness
Definition

• Severe and Persistent Mental Illness (SPMI)
  – Occurring in adults, characterized by prolonged or recurrent symptoms, resulting in impaired functioning, and requiring long-term treatment
  – Schizophrenia
  – Bipolar Disorder
  – Recurrent major depressive disorder

• Anxiety Disorders
  – Generalized Anxiety Disorder
Prevalence

• Approximately 6% of the population has SPMI (National Institute of Mental Health)

• After receiving a diagnosis of cancer
  • 39% fulfilled criteria for a major psychiatric disorder or used mental health services for psychological distress
  • 12% met criteria for MDD
  • 3% met criteria for GAD
Clinical Presentation

• Longitudinal pattern of relapsing and remitting symptoms (e.g. BPAD, MDD)

• Progressive decline in functioning (e.g. schizophrenia)

• How to diagnose
  • Pre-existing diagnosis
  • Diagnosis of exclusion
  • Personal and family history
Challenges

- Increased morbidity
- Reduced life-expectancy
- Co-occurring substance-use disorders
- Difficulty engaging in treatment
- Cognitive and functional impairments
- Social factors
- Limited resources
Psychiatric Illness vs. Normal Psychological Reactions to Stress

- Diagnostic Challenges
  - Threshold of clinical significance
  - Diagnostic criteria (DSM)
  - Overlap of symptoms

- Assessment Tools
  - HADS (Hospital Anxiety and Depression Scale)
  - BDI-SF (Beck Depression Inventory Short Form)
  - PHQ-9 (Patient Health Questionnaire)
Treatment

• Multidisciplinary approach

• Depression
  – Trial SSRI and/or SNRI
  – Consider augmentation with a stimulant
  – Referral for psychotherapy

• Anxiety
  – Trial of SSRI and/or SNRI
  – Consider augmentation with a benzodiazepine
  – Referral for psychotherapy
When to Refer Out

• Major Depressive Disorder and Anxiety
  • Lack of response to 1-2 trials of SSRIs or SNRI +/- psychotherapy
  • For depression
    • Mixed mood presentation (i.e. depression plus mania)
    • Psychotic symptoms
    • History of recurrent MDD or treatment-resistant MDD

• Bipolar Disorder and Schizophrenia

• When to consider hospitalization
Advanced Care Planning

• Challenges
  • Symptomatology
  • Cognitive Impairment

• Assessment of Decisional Capacity
  • MacArthur Competence Assessment Tool (MacCAT)
  • Assistance of Family
  • Substitute decision-maker or guardian
Substance-Use Disorders
Prevalence

- 6-15% in the U.S.
- Limited studies in patients with advanced illness
- One study found 3% of consultations at Sloan Kettering Cancer Center
Definition

• Substance Abuse

• Substance Dependence

• Difference from Physical Dependence

• Pseudo-addiction
Challenges

- History of abuse of substances
  - Concern of reactivation of abuse
  - Higher tolerance of prescribed opioids

- Co-occurring mental illness

- Current abuse of substances

- Suspected abuse of prescribed medications
  - Aberrant behaviors
  - Diversion
Management

- Assessment of history
- Screening assessments
  - SOAPP (Screener & Opioid Assessment for Patients with Pain)
  - ORT (Opioid Risk Tool)
- Multidisciplinary approach
- Prescribing guidelines +/- written agreement
- Referral for substance abuse treatment
Guidelines for Prescribing

• Dosing schedule of opioids
• Use of non-opioid adjuvants
• Use of non-pharmacological adjuvants
• Consider methadone
• Limited supplies and frequent follow-up visits
• Use of pill counts
• Use of toxicology screens
Written Agreements

• Samples are at www.drugabuse.gov

• Clearly state the rules and expectations of both provider and patient
  • For example, use of one prescriber, one pharmacy
  • What to do regarding loss/missing doses, etc.

• Based on graded agreements (i.e. levels of restrictions based on patient behaviors)

• What to do when transgressions occur
When to Refer Out

• Patients with a history of a substance-use disorder

• Patients with a current substance-use disorder
  – Inpatient (e.g. detox)
  – Residential Treatment
  – Day Treatment (PHP or IOP)
  – Outpatient treatment +/- 12-step group

• Patients with aberrant prescription drug-use behaviors
Personality Disorders
Definition

- Enduring pattern of behavior, beginning in childhood/adolescence, that is inflexible and pervasive

- Includes the following dimensions:
  - Perceptions of self and other
  - Affect (intensity and appropriateness)
  - Effect on interpersonal relationships

- Causes significant distress and impairment in functioning
Defense Mechanisms

Mature
- Intellectualization
- Humor
- Isolation of Affect
- Reaction Formation

Immature
- Denial
- Dissociation
- Splitting
- Projective Identification
Borderline Personality Disorder

- Pervasive patterns of instability of self-image, affect, and interpersonal relationships

- Occurring as a result of real or perceived trauma, abandonment, or chronic invalidation in childhood

- Resulting in a sense of inner emptiness

- Includes frantic efforts to avoid abandonment

- Often leads to alienation by others
Clinical Presentation

- Patients tend to emulate early childhood relationships with medical providers
- Regressive behaviors, rage attacks
- Over-idealization and devaluation
- Splitting of treatment team
- Risky behaviors, self-harm behavior
- Frequent suicidal ideation and attempts
Interventions

• Treat psychiatric symptoms and co-morbid disorders (e.g. substance abuse)

• Establish clear, consistent communication among all providers, and have one clinician in charge

• Set realistic treatment goals

• Have early control of behaviors that interfere with the functioning of the treatment team
  – Establish clear boundaries
  – Set limits
Interventions

• Validate their perspective

• Empathize with their underlying feelings

• Understand their defense mechanisms

• Avoid confronting a patient’s anger or entitlement using emotional language or punishment

• Avoid being blackmailed by the patient’s explicit or implicit demands
Interventions

• Focus on clarifying the reality of the patient’s situation

• Have clear and consistent boundaries and limits

• When behavioral problems emerge, calmly review the therapeutic goals and boundaries of treatment

• Consider using a treatment contract that outlines the roles and expectations of the provider and patient
When to Refer Out

• Symptoms of emotional dysregulation, mood swings, aggression, or self-harm behaviors

• It is recommended to work alongside an psychiatrist and/or psychotherapist

• Use of adjunctive medications

• Consider Dialectical Behavioral Therapy (DBT) for emotional regulation and interpersonal effectiveness

• Need for 24-hr crisis service
Anxiety Disorders
Case #1
Anxiety and Panic in the Context of “Special Treatment”
Anxiety Overview

Cognition:
• Performance, punctuality, catastrophic events, approval, worry over worry, fear about fear

Feeling/Physiological Consequences
• Short-term: sympathetic activation
• Long-term: Muscle tension and headaches, sleep impairment, difficulty concentrating

Autonomic Nervous System (ANS)

Sympathetic NS “Arouses”
(fight-or-flight)

Parasympathetic NS “Calms”
(rest and digest)
Behavioral Cycle of Anxiety

Maladaptive anxiety fueled by avoidance

Things that feel good in the short-term are rewarding i.e., we want to do more of them
Anxiety Disorders

Generalized Anxiety Disorder-
- 3% of population -2X as common in females
- Intensive, pervasive worry that impairs daily functioning

Panic Attacks & Disorder-
- 11% of the population (Panic Attacks)
- 2-3% of population (Panic Disorder)
- Palpitations, sweating, trembling, SOB, feelings of choking, chest pain, nausea, dizzy/faint, chills/heat, paresthesias, de-realization, fear of losing control, fear of dying
Case Presentation: #1

17 year old teen

No siblings, parents married

Straight A student

Volleyball player

“Worrier,” “homebody,” rule-follower, some history of panic attacks

Best friend but enjoyed spending a lot of time w/mom

Initial diagnosis localized Ewing’s Sarcoma
Case Presentation: #1
“Special Treatment”

Special privileges-sitting at nurses station

Special food

Consistently given the message, “tell us what is wrong immediately, and we will ‘take care of it’”

Consistently receiving the message, “we will fix it.”
Case Presentation: #1
Reinforcing Panic

Frequent SOB, trembling, sweating, heart palpitations

Panic attacks

Treated \textbf{aggressively} with benzodiazepines, began to demand benzos more immediately at stronger doses with fewer physiological symptoms
Case Presentation: #1 Reinforcing Panic

Multiple relapses with progressive metastatic disease in lungs

S/P bilateral thoracotomies and lung resection for persistent mets and radioablation

Physiologically primed for panic attacks

Panic attacks and disorder greatly exacerbated
Case Presentation: #1
Reinforcing “Special Treatment”

Multiple relapses with progressive metastatic disease in lungs

Message of “we’ll fix it,” continued

Very aggressive benzo regimen continued, requesting IV Benadryl pushed “fast”

Psychiatry consulted, suggestions allowed to be declined by patient

Accommodation of drop-in schedule

Accommodation and immediate response to very frequent text messaging seeking re-assurance
Case Presentation: #1
Reinforcing Anxiety & “Special Treatment” through Reassurance Seeking

Avoidance Reinforced

Fear and Anxiety of Fear and Anxiety

Avoid Feelings of Anxiety

Reassurance Reinforced

Fear and Anxiety of Bad Medical News

Seek Immediate and Convincing Re-Assurance

Reassurance Brings Relief

Avoidance Brings Relief

Re-assurance is experiential avoidance
Case Presentation: #1

At time of her death

• No formal psychiatric services

• No formal psychological services

• Select nurses asked to not be assigned

• Patient had “cherry picked” medical team

• Texting other select members of medical team very frequently

• Heavy benzo use, high anxiety/frequent panic

• Starting to have difficulty with avoiding school work (above and beyond expectation given medical symptoms and expected psychological symptoms)
## Case Presentation: #1

<table>
<thead>
<tr>
<th>Contribution to Maladaptive Pattern</th>
<th>Helpful Alternate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Treatment</td>
<td>Be aware of your pull towards special treatment to certain patients. Be honest with yourself about implications for the team</td>
</tr>
<tr>
<td>Message of “we’ll fix it”</td>
<td>Message of investment in symptom management without promising to eliminate distress</td>
</tr>
<tr>
<td>Steadily increasing benzo use with increasing anxiety</td>
<td>Adherence to consultants suggestions—even if unpopular</td>
</tr>
<tr>
<td>Extensive pattern of texting</td>
<td>Schedule in-person meetings</td>
</tr>
<tr>
<td>Contribution to an avoidance model</td>
<td>Contribution to an approach model</td>
</tr>
</tbody>
</table>
Intellectual Disability
Case #2

Protective and Avoidant Parenting in the Context of Cognitive/Intellectual Disability
Intellectual Disability (ID)

~2% of the population

Definition: IQ <70 + impaired adaptive functioning (conceptual/academic, social, personal)

- Mental Age (MA)/Chronological Age X 100 = IQ
- Mental age helpful to guide conceptual understanding
<table>
<thead>
<tr>
<th></th>
<th>Conceptual</th>
<th>Practical</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mild</strong> (IQ 69-50)</td>
<td>Acquisition of conceptual skills requires support. In adults abstract thinking and executive functioning impaired. Somewhat concrete approach</td>
<td>Needs support for complex ADLs (ex. banking). Generally need support for health and legal decisions. Support to raise a family, vocational support</td>
</tr>
<tr>
<td><strong>Moderate</strong> (IQ 35-49)</td>
<td>Conceptual skills/abstract reasoning markedly impaired relative to peers. As adults academic functioning near early elementary school</td>
<td>Extended time and significant support needed to learn ADLs. Independent employment may be possible with significant support. Self-injury or maladaptive behavior present in significant minority.</td>
</tr>
<tr>
<td><strong>Severe</strong> (IQ 20-34)</td>
<td>Conceptual skills/abstract reasoning is limited. Understanding of numbers, time and money limited. Require extensive support for problem solving.</td>
<td>Requires support for ADLs. Very limited ability to make responsible decisions regarding well-being. Self-injury or maladaptive behavior present in significant minority.</td>
</tr>
<tr>
<td><strong>Profound</strong> (IQ 19 and below)</td>
<td>Usually involve physical rather than conceptual skills. Some matching or sorting may be possible.</td>
<td>Dependent on others for full execution of ADLs, but may participate in ADLs. Some limited vocational possibilities with high support. Self-injury or maladaptive behavior present in significant minority. Physical disability present in significant number</td>
</tr>
</tbody>
</table>

DSM-V
Intellectual Disability & Decision Making

Need for surrogate decision making varies across spectrum of intellectual disability

Guardianship vs. Power of Attorney (POA)
• Guardian legal proceeding
• POA more fluid

Assisted Capacity (Friedman, 1998)

“Best Respect or Best Interests”

Stein, 2008
Case Presentation: #2

14 year-old Latina teen
30 year-old brother, 15 year-old sister, parents married
History of “developmental delay”
Family very “tight-knit,” family mistrustful of MDs
Family viewed and treated patient as particularly vulnerable
Receiving significant special education instruction
Per IEP mild developmental delay (IQ=65, 1st percentile)
• Age-equivalent of ~ 9 year-old, 3rd/4th grade
• MA helpful to guide conceptual understanding
• Don’t use MA to guide tone of voice, general approach

Initial diagnosis metastatic Osteosarcoma
Case Presentation: #2
Reinforcing Avoidance & Protection

Very challenging treatment course

Previously ‘tight-knit’ family growing increasingly insular

Increasingly protective against any emotional discomfort, negative news

Viewed one doctor as main source of information

Belief that discussing prognosis or anxiety causes poor outcome

Extreme protection from emotional discomfort is experiential avoidance
Case Presentation: #2
Impact of Avoidance & Protection on Teen’s Anxiety

View of Child as Particularly Vulnerable

Fear and Anxiety of Fear and Anxiety

Avoidance Brings Relief

Avoidance Reinforced

Avoidance/Blocking of Discomfort Brings Relief

Discomfort with Child feeling Discomfort

Blocking of Discomfort Reinforced

Avoid Feelings of Anxiety

Discomfort with Child feeling Discomfort
Case Presentation: #2
Impact of Parental Avoidance & Protection on Staff

Exceedingly difficult situation for staff

Staff see increasing anxiety, deteriorating health and feel helpless

The “Big Squeeze” ensues……tendency to avoid follows
Case Presentation: #2

At time of her death:

• Incorporating as many other family members as possible, father, aunts, older sister (phone and family meeting)

• Providing education about the power of avoidance of anxiety

• Earning mother’s trust, permission/welcoming of relaxation exercises and broad questions about patient’s thoughts and feelings

• Powerful use of Chaplaincy, Child Life, Palliative Care
## Case Presentation: #2

<table>
<thead>
<tr>
<th>Contribution to Maladaptive Pattern</th>
<th>Helpful Alternate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making assumptions about patient or her overall social functioning given her IQ</td>
<td>Understanding conceptual understanding and social and emotional functioning</td>
</tr>
<tr>
<td>Treating patient as a particularly vulnerable teen— not including her in discussions, no discussion of any emotions with her</td>
<td>Respecting guardians, encouraging guardians to respect patient’s wishes. Providing patient a venue/opportunity to discuss her feelings. Praise less vulnerable behavior</td>
</tr>
<tr>
<td>Respond to “Big Squeeze” by more forcefully applying team member’s beliefs, or, by avoiding family</td>
<td>Respond to “Big Squeeze,” by making effort to build rapport with family and understand their values and rationale</td>
</tr>
<tr>
<td>Contribution to an avoidance model for family and staff</td>
<td>Contribution to an approach model for family and staff</td>
</tr>
</tbody>
</table>
Summary

- Pre-Existing Mental Illness
- Substance-Use Disorders
- Personality Disorders
- Anxiety Disorders
- Intellectual Disability
Questions