Suffering in Neurological Illness: A Palliative Approach Beyond Medications

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Disclosures

- Nothing to disclose

Case Example: Background

- Mr. X is a 78yo male s/p CAR-T therapy for multiple myeloma
- Developed grade-3 ICANS (Immune Effector Cell-Associated Neurotoxicity Syndrome)
- Neuropsychiatric syndrome characterized by
  - Encephalopathy
  - Aphasia
  - Motor dysfunction
  - Behavioral changes
- Already established with Palliative provider for his MM
- Referred to PCMH clinic because wife felt he was "very depressed"

Case Example: Evaluation

- Mental Status Exam
  - Appearance: well groomed; poor eye-contact
  - Behaviour: NAD, minimally engaging; +abulia
  - Motor: bradykinesia; shuffling gait
  - Speech: poverty of speech
  - Mood: depressed (mostly related to QoL change)
  - Affect: flat
- Minimal anhedonia, hopelessness, or pervasive negative thinking
- Occupational, functional, or social impairment attributed to symptoms of neurological illness
- Differential diagnoses
  - Mood disorder due to medical condition
  - Adjustment disorder with depressed mood

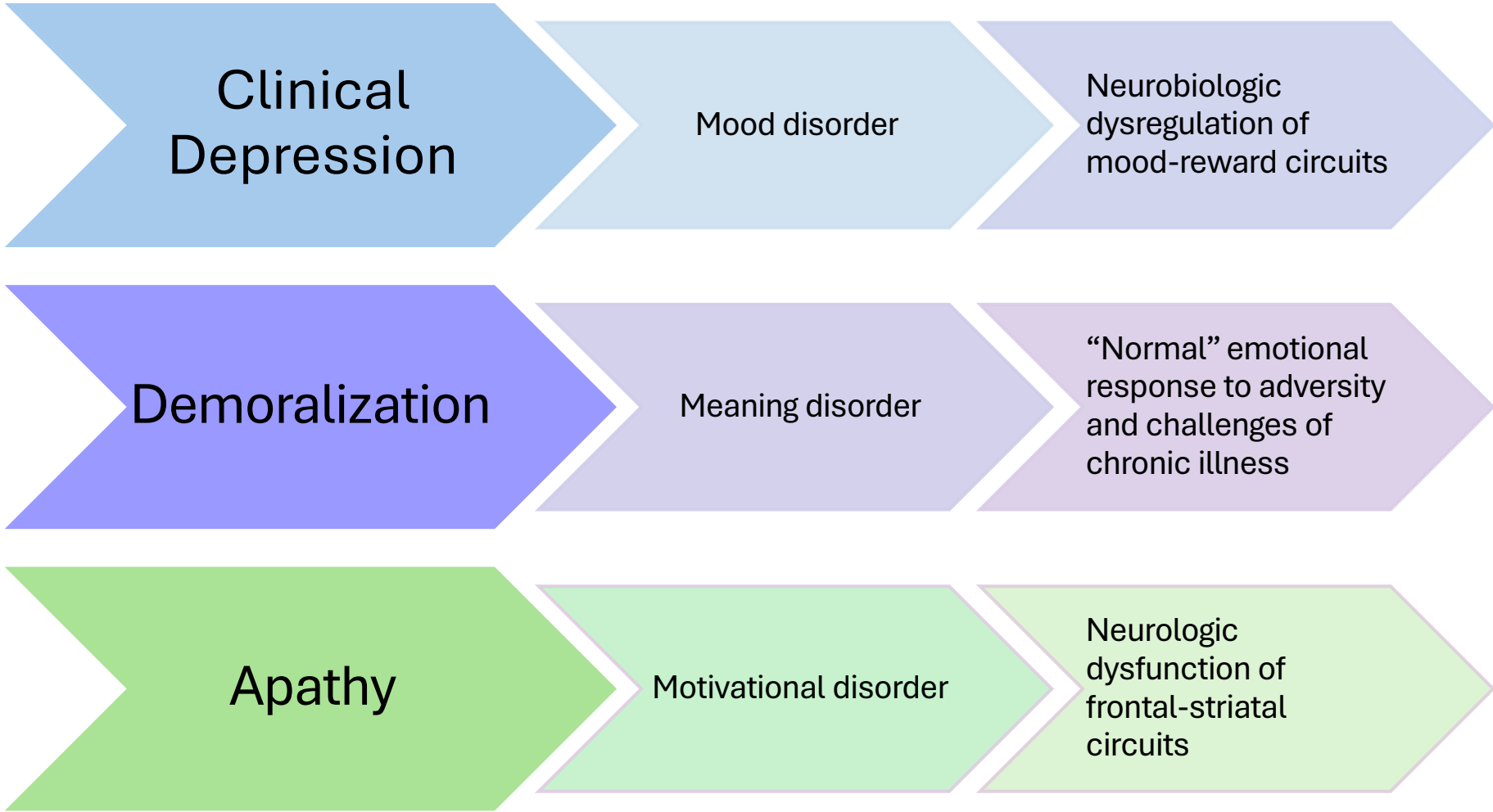
Clinical Case: Treatment

- Discussed concern antidepressant treatment may be ineffective
- 2x antidepressant trials with minimal response
- Private pay symptom-targeted TMS
- Focus psychotherapy using supportive and behavioral activation techniques
  - No further psychotropics were recommended at this point
- Despite psychoeducation, wife kept messaging other providers to start him on an antidepressant

Clinical Case: Conclusions

- What are we actually treating?
  - Clinical depression
  - Depressive-like syndrome
    - Apathy
    - Demoralization
  - Neurotoxic manifestations of his condition misattributed as depressive symptoms
  - Caregiver distress
- No single diagnosis fully explains his presentation or his wife's concern

Depression in Neurological Illness



Clinical Depression (Major Depressive Disorder)

- Mood disorder
- DSM-V diagnosis
  - >5 symptoms (SIG E CAPS)
    - Core feature: anhedonia
  - >2 weeks duration
  - Causing social, functional, or occupational impairment

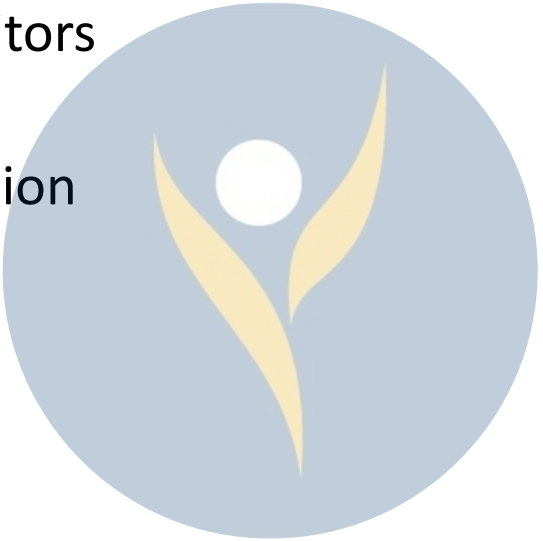
- Represents dysfunction in mood and reward circuits
- Treatment:
  - SSRI/SNRI
  - Atypical antidepressants
  - ECT / TMS
  - NMDA antagonist (Esketamine)
  - Psychotherapy

Demoralization

- Meaning disorder
- Psychological state characterized by feeling
  - Helpless
  - Hopeless
  - Loss of meaning or purpose
- Differentiating features:
  - No anhedonia
  - Context-driven
    - Diagnosis, prognosis, etc.
  - "What's the point?" as opposed to feeling worthless
- Specifically associated with
  - Increased symptom burden
  - Decreased QoL
  - Desire for hastened death
- Minimally responsive to antidepressants
- Treatment:
  - Meaning centered psychotherapy
  - Dignity therapy
  - CBT

Apathy

- Motivational disorder characterized by
  - Deficit in goal-directed behaviour
  - Emotional blunting
- Seen in PD, Alzheimer's, TBI, Huntington's
- Differentiating features:
  - Not persistently sad or depressed, but perceived by others to be
  - Still able to experience pleasure
- Reflects motivational salience network failure
- Antidepressants can worsen symptoms
- Treatment:
  - Methylphenidate
  - Cholinesterase inhibitors
  - TMS
  - Family psychoeducation



Approaching Suffering as a Primary Clinical Problem

- Differentiating between depressive syndromes is important to guide treatment

- Despite their clinical differences, they converge on the same clinical reality: **suffering**

What Do We Mean by Suffering?

- Suffering ≠ depression
- Multidimensional experience of distress and turmoil
- Cannot be captured by a symptom checklist
- Best assessed using a structured framework
- Total Pain Model
    - Physical
    - Psychological
    - Existential
    - Social

Clinical Parallels: "Pain" and "Suffering"

Palliative Care	Neurological illness
"Uncontrolled pain"	"Refractory depression"

• What we see:
  • Refractory 10/10 pain
  • Escalating opioid requirements
  • Minimal or temporary relief
 	
• What is often driving it:
  • Psychological distress
  • Existential distress
  • Social stressors
	• What we see:
	  • "They're still depressed" "Nothing seems to work"
	  • Multiple antidepressant treatment trials with limited benefit
	
	• What is often driving it:
	  • Physical impairment
	  • Existential distress
	  • Social stressors

Suffering in Neurological Illness

Total Pain Domain:	Core Features:	Patient Experience:
Physical	Pain Motor dysfunction Fatigue Sensory loss	"I am in pain all the time" "I'm too tired to do anything I enjoy" "I no longer have control over my body"
Psychological	Depression Anxiety Grief	"This isn't a way to live" "I'm constantly afraid of what's coming"
Existential	Loss of identity Demoralization Loss of purpose	"What did I do to deserve this?" "Who will I be when I lose my memory?"
Social	Role loss Financial strains Caregiver burden	“I’m no longer able to help my family" "I feel like a burden to my family"

Revisiting Case Example

- Physical
  - ICANS associated with cognitive slowing, motor dysfunction, abulia
  - Perceived as loss of agency
- Psychological
  - Wife convinced negative symptoms as signs of clinical depression
  - Grieving dramatic change in quality of life
- Existential
  - Loss of self
  - Questioning how this happened to him
- Social
  - Family distress
  - Change in relationship dynamics

Palliative Approach to Suffering

- Comprehensive assessment of all areas of potential suffering
- Multidisciplinary approach to care centered around Total Pain
  - Physical (providers)
  - Emotional (psychotherapist +/- psychiatrist)
  - Existential (chaplain)
  - Social (LCSW)
- Not replacing, but working *alongside* Neurologist to improve quality of life and alleviate suffering throughout treatment
- Promoting message that while pain may be inevitable, suffering is not

When to Consider Palliative Involvement

- Distress feels disproportionate to symptoms
- Incomplete response to standard depression treatments
- Medications alone are not going to "fix the *problem*"
- Anticipated identity crisis from disease progression
- Significant caregiver distress

- When you suspect **suffering** is the primary clinical problem

Key Takeaways

- Suffering in neurological illness is multidimensional experience
- Not all suffering is best treated with an antidepressant
- Recognizing subtle differences between depressive syndromes can help guide treatment
  - But addressing someone's suffering requires a wider lens
- Our goal in Palliative Care is to improve quality of life and alleviate suffering
- While we often use medications in our practice, our approach to suffering in patients with neurological conditions goes beyond medication management alone