Untangling the Web: Understanding the Relationship Between Dementia and Behavioral Health Conditions
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Special Thanks
• Mary O’Hara, LCSW
  • Rocky Mountain Neurobehavioral Associates

Overview
• Understanding dementia
• Diagnosis
• Relationship between mental health conditions and dementia
• Treatment considerations
• Special considerations around trauma treatment & treatment in later stages
• Working with family members/caregivers
• Barriers to treatment
What is dementia?

- Not a specific disease
- Describes a group of symptoms
- Has multiple causes
- May see the term ADRD (Alzheimer’s Disease and Related Dementias)
- Decline in memory or other thinking skills
- Severe enough to impact daily activities

Facts and Figures: U.S.

- ADRD the 6th leading cause of death
- 16.1 million provide unpaid care
- 1 in 3 seniors dies with ADRD
- 5.7 million people with Alzheimer’s
  - By 2050: 14 million
- Every 65 seconds someone develops the disease

Alzheimer’s Association Facts & Figures
DSM-V Change

- Neurocognitive Disorders
  - Primary clinical deficit is cognitive function
  - Acquired, rather than developmental
  - Represent a decline in a previously attained level of functioning
  - Unique in that underlying pathology and often etiology can potentially be determined.
  - Inclusive of conditions that affect younger individuals, such as impairment secondary to TBI or HIV infection.
  - Less severe level of cognitive impairment, **mild neurocognitive disorder**, also recognized and allowed to be a focus of care.
  - American Psychiatric Association, 2013

Dementia vs. Alzheimer's

<table>
<thead>
<tr>
<th>Dementia</th>
<th>Alzheimer's</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vascular Dementia</td>
<td>Lewy Body Disease</td>
</tr>
<tr>
<td>Frontotemporal Degeneration</td>
<td></td>
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</tbody>
</table>

What is Alzheimer's?

- Most common form of dementia

- [https://www.youtube.com/watch?v=ECbjK4Ra-Ys](https://www.youtube.com/watch?v=ECbjK4Ra-Ys)
DIAGNOSING DEMENTIA

10 Warning Signs
- Memory loss
- Trouble planning or problem-solving
- Trouble completing familiar tasks
- Confusion with time or place
- Trouble with visual images or spatial relationships
- Trouble with words in speaking or writing
- Misplacing things and not being able to retrace steps to find it
- Impaired judgment
- Withdrawing from work or social activities
- Changes in mood or personality

Differential Diagnosis of Dementia
- Substance use or misuse
  - Medication interactions
- Medical conditions
  - Infections
  - Thyroid problem
  - Vitamin deficiencies
  - NPH
  - Sleep Apnea
  - B12 Deficiency
  - Head Trauma
- Mental Health Conditions
  - Depression
Screening Tools for Dementia

- Mini-Cog
  - Minimal language content, reduces educational and cultural bias
  - Give three words, have them draw a clock, have them repeat 3 words

- MMSE, SLUMS, MOCA
  - SLUMS and MOCA available through public domain.
    - Instructions for administering available online.

Delirium vs. Dementia vs. Depression

- How to differentiate:
  - Onset
  - Attention
  - Fluctuation

- Most common cause of delirium for older adults living in the community?
  - Alcohol

<table>
<thead>
<tr>
<th>Depression</th>
<th>Delirium</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>Acute or sudden onset of mental confusion due to result of a medical, mental or other condition.</td>
<td>Progressive loss of brain cells resulting in decline of the ability to reason and think clearly and perform daily activities.</td>
</tr>
<tr>
<td>Duration</td>
<td>May last several months to years, especially if not treated</td>
<td>Years (usually 8 to 20+)</td>
</tr>
<tr>
<td>Thinking</td>
<td>May be incoherent and thoughts are disorganized and inappropriate.</td>
<td>Gradual loss of cognition and ability to perform daily activities.</td>
</tr>
<tr>
<td>Mental status testing</td>
<td>Delirium may result in disorganization of thinking.</td>
<td>Testing may not improve.</td>
</tr>
<tr>
<td>Memory</td>
<td>Disorganization of memory, especially recent and immediate memory impaired.</td>
<td>Memory loss may appear with information or to recall previously learned information.</td>
</tr>
<tr>
<td>Sleep-wake cycle</td>
<td>Disturbed, usually early morning awakening.</td>
<td>Normal to fragmented</td>
</tr>
<tr>
<td>Hallucinations &amp; delusions</td>
<td>Can be present in a severe depression.</td>
<td>Often of a frightening or paranoid nature</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>May be depressed but often agitated and agitated.</td>
<td>Usually diagnosed after the symptoms for depression.</td>
</tr>
</tbody>
</table>
HOW DO MENTAL HEALTH CONDITIONS OVERLAP WITH DEMENTIA?

Depression & Dementia

- People with dementia often experience depression
- Depression can mimic dementia
- Depression may happen in response to early cognitive decline
- Depression may put someone at risk for dementia, or be an early sign of dementia
  - Earlier life depression potentially a risk factor
  - Later life depression potentially an early symptom
  - Byers & Yaffe, 2011

Anxiety & Bipolar Disorder

- Anxiety is also a risk factor for developing dementia
  - Gimson, Schlosser, Huntley, et al., 2017
- As number of episodes of depression or bipolar disorder increase, so does risk of dementia
  - Vessing & Andersen, 2004
Schizophrenia & Dementia

- Schizophrenia also associated with increased presentation of dementia
  - de Vries, Honer, Kemp, et al, 2001
  - May be due to the fact that people with schizophrenia have other adverse health outcomes that increase their risk of dementia
    - Rohde, C., Agerbo, E., & Nielsen, P. R., 2016

Trauma & Later Life

- 70 – 90% aged 65 better exposed to at least one traumatic event
- 7-15% older adults have sub-clinical levels of PTSD symptoms
- 70% older men; 41% women
  - May not always identify as having experienced trauma
- Vets with PTSD have 2x the risk of developing dementia
  - Yaffe et al, 2010

Substance Use and Dementia Risk

- Excessive alcohol use linked to dementia, especially early-onset
  - Schwarzinger et al, 2018
- Other drugs such as tobacco, benzodiazepines, and cannabis linked to cognitive impairment, but association with dementia is less clear
  - Hulse, Lautenschlager, Tait, & Almeida, 2005
- One study out of the UK showed a slightly increased cognitive ability among former recreational drug users
  - Dregan & Gulliford, 2011
**Medications and Dementia Risk**

- Certain anticholinergic drugs (such as Benadryl, bladder medications, and tricyclic antidepressants) were shown to lead to an increase risk of dementia.
  - Gray et al, 2015
- Benzodiazepines also associated with an increased risk of dementia.
  - Takada, Fujimoto, & Hosomi, 2016

**Dementia and Suicide Risk**

- Unclear if dementia increases suicide risk
  - Rohde, Agerbo, & Nielsen, 2016
- Concern of suicide should not be a reason to withhold a diagnosis.
- Important to assess for suicide risk, particularly for:
  - Men...
  - ...in the early stages of dementia...
  - ...with symptoms of depression or anxiety...
  - ...who have access to firearms.
  - Rohde, Agerbo, & Nielsen, 2016

**DIFFERENT TYPES OF DEMENTIA**
Behavioral and Emotional Concerns with Alzheimer’s Disease
- Early Stages
  - Depression
  - Anxiety
  - Poor Sleep
  - Decreased Activity
  - Increased Isolation
- Feeling Ambiguous Loss

Behavioral Symptoms of Lewy Body Disease
- Increase risk of depression
- Rapidly fluctuating cognition
- Acting out dreams: REM sleep disorder
- Recurrent, complex visual hallucinations that are well-formed and detailed
- Delusions
- Movement symptoms—similar to PD

Behavioral Symptoms of bvFTD
- Lack of Insight
- Disinhibition/Impulsivity
- Apathy and lack of initiative
- Emotional Blunting
- Compulsive or Ritualistic Behaviors
- Hyperoral Behavior
- Deficits in Executive Functioning
- Abrupt mood changes

*www.theaftd.org*, 2018
**Wernicke-Korsakoff Syndrome**

- Most commonly caused by heavy, prolonged alcohol use
- Early presentation:
  - Confusion
  - Nystagmus ("dancing eyes")
  - Ataxia (stumbling, lack of coordination)
- Later stages:
  - Agitation
  - Anger
  - Hallucinations
  - Confabulations

**Chronic Traumatic Encephalopathy (CTE)**

- Associated with repeated blows to the head
  - Dementia pugilistica or "punch-drunk syndrome"
- Causes problems with thinking & memory
- Causes Personality & Behavioral Changes
  - Agression
  - Depression
  - Suicidal thoughts

- Alzheimer’s Association

**Other behavioral presentations**

- Vascular dementia
  - Behavioral symptoms may vary based on the parts of the brain affected
- Pseudobulbar affect (PBA)
  - Associated with many neurological conditions
  - Often mistaken for a mood disorder
  - Uncontrolled crying or laughing that is out of proportion with the context of the situation.
  - Often a significant impact on social interactions

- Ahmed & Simmons, 2013
TREATMENT CONSIDERATIONS: MEDICATIONS

Medications for Dementia
- Namenda (memantine), NMDA receptor antagonist, approved for moderate to severe Alzheimer’s.
- Cholinesterase inhibitors (e.g., donepezil) improve memory.
- Dopamine agonists (e.g., bromocriptine, amantadine) and CNS stimulants (e.g., methylphenidate, modafinil) improve cognition, concentration and focus.

  ((Yoder, Norman, & Friedman, 2016))

Medications for NPS of Dementia
- SSRIs are safe and usually well-tolerated.
  - Citalopram may also reduce agitation (Porsteinsson et al, 2014)
- Anticonvulsants are useful for seizure prevention and mood stabilization.
- Atypical antipsychotics are useful for aggression, agitation and irritability.
  - Black box warning from FDA (increased risk of death in elderly people with dementia).
- Andrenergic beta blockers are useful in the most severe cases of aggression, agitation and irritability.

  ((Yoder, Norman, & Friedman, 2016))
Antipsychotics and Dementia
- Largest # of rx for atypical antipsychotics written for neuropsychiatric symptoms (NPS) of dementia.
  - Up to 97% of people with dementia have NPS
- No atypical antipsychotic is FDA-approved for the tx of any NPS in dementia.
- Antipsychotics show a 1.5-1.7 x increased risk of death in those with dementia.
- 2-3 times higher risk of cerebrovascular events.
- Worsen cognition, more frequent infections and falls.
- Recommended they only be used when "nonpharmacological options have failed and patient is threat to self or others."
  - Steinberg & Lyketsos, 2012.

Special Considerations with LBD & Antipsychotics
- People with Lewy Body Disease can have severe reactions to antipsychotic medications
  - Worsening cognition, sedation, increase in parkinsonian symptoms,
  - In rare cases, can cause "neuroleptic malignant syndrome"
  - Fever, muscle rigidity, kidney failure, death
- Typical (first generation) antipsychotics should NOT be used
  - Haldol
- Atypical (Second Generation) antipsychotics should be used conservatively

Anxiolytics and Dementia
- RCTs comparing benzodiazepines with placebo for behavioral and psychological symptoms of dementia are lacking.
- Given serious concerns about adverse events, such agents are not recommended except for management of an acute crisis.
  - Kales, Gitlin, & Lyketsos, 2015.
Cannabis and Dementia

- Research currently being done to examine:
  - If cannabis is effective for tx or prevention of ADRD
  - If cannabis is effective for tx of behavioral symptoms of ADRD

Early Stage Memory Loss

- Based upon work of Robyn Yale, LCSW
- Designed for those who are struggling with how the disease is impacting their daily life, sense of self, relationships and their plans for the future.
- Customized to the goals of each family
- Short-term
- Focus on capacity for resilience in face of hardship
What we know is helpful

- Maintaining a sense of control
  - Structure and routine
  - Remaining active and involved
  - Feeling safe
- Having emotional support
  - Opportunities to feel successful
  - Purpose and meaning
  - Social, physical and mental activity
- Opportunities for expression


TREATMENT CONSIDERATIONS: PSYCHOTHERAPY

Dimensions of Loss in ADRD

- Primary and Progressive Loss of Cognitive Skills
- Secondary loss
  - Identity and Sense of Self
  - Future Goals and Dreams
  - Meaning
  - Relationships
  - Financial security
  - Safety
  - Faith
  - Embarrassment
  - Anhedonia
The Paradox of Pain in Context of Loss

- “The only way to the other side is through”
  - Helen Keller
- Alan Wofelt’s Work around loss: Accepting reality, feeling pain, search for meaning, letting others help.
- In order to heal from pain, we must let ourselves experience pain
- We must create safe spaces for clients to journey through the pain in order to cope.
- The space between diagnosis and the ability to move forward can be crossed

Individual Counseling for Cognitive Changes

- Goals
  - Better understanding the diagnosis
  - Managing worry, stress, sadness, changes in mood
  - Reconnecting with your sense of self and sense of belonging
  - Living a full and meaningful life despite the cognitive changes
  - Moving forward with resilience

Framework for Coping

Emotional Adjustment
Practical Coping skills
Life Style Issues

These domains exist regardless of whether or not a person is ready to face/accept them.
Identifying Goals: Emotional Adjustment

- Understanding, acknowledging and becoming more accepting of my condition.
- Working toward finding new meaning/purpose in life
- Redefining my identity and feeling good about who I am
- Expressing feelings (positive and negative) about my situation
- Having an attitude of being strong and capable
- Letting others know that I want to be treated with respect

Identifying Goals: Lifestyle

- Doing and/or developing new and social and meaningful activities
- Talking about and making future legal, financial, health and care planning decisions
- Acknowledging and working on challenges with my family
- Asking for and accepting help from others
- Using early stage support services
- Taking steps to problem solve safety issues such as driving, managing finances.

Identifying Goals: Practical Coping

- Learning and using stress management techniques
- Using memory aids and strategies
- Paying more attention to physical exercise, diet, rest, and general health
- Enhancing my ability to communicate and informing others about it.
- Doing more memory and other cognitive exercises.
- Getting emotional support from others
Adjustments for Therapy Sessions

- Go at a slower pace.
- Avoid covering too many topics during a single session.
- Content may be repeated from session to session—that’s okay!
- Provide written materials and summaries at the end of the session.
- When appropriate, bringing in family members may be helpful.

Criteria for Termination

- Lowered insight into the cognitive changes
- Disorientation
- Increasingly tangential in their conversation
- Discussing termination
  - What will it be like?
  - Fears, concerns, plans
  - Referrals to Alz Assoc. Early Stage Programs
  - What is next?

SPECIAL CONSIDERATIONS FOR TRAUMA TREATMENT AND LATE STAGE DEMENTIA
PTSD & Dementia: Assessment

- Nightmares, trauma hx, and agitation in response to specific cues warrant evaluation for PTSD.
- PCL-5 has preliminary support as an assessment measure
  - (Yoder, Norman, & Friedman, 2016)

PTSD & Dementia: Psychotherapy

- Some individuals with mild dementia can benefit from psychotherapy for PTSD.
  - Case by case
  - PE & CPT
  - Modifications may include using memory aides, adding more structure, longer sessions, increasing the number of sessions per week, and combining group and individual therapy.
  - (Yoder, Norman, & Friedman, 2016)

PTSD & Dementia: Pharmacotherapy

- First line medications are SSRIs and venlafaxine.
- Second line tx are mirtazapine, nefazadone and older antidepressants (e.g., tricyclics (TCAs) and MAO inhibitors
- Prazosin is recommended for traumatic nightmares
- Specific medications contraindicated for PTSD include benzodiazepines, risperidone and most mood stabilizers / anticonvulsants.
  - (Yoder, Norman, & Friedman, 2016)
PTSD & Dementia: Later Stages

- Important to identify triggers:
  - TV shows, movies, or news coverage
  - Being bathed
  - Male or female caregivers for someone who has been physically or sexually assaulted
  - Smells (e.g., bodily smells, wounds, fires, certain foods).
  - Sounds (e.g. songs, foreign languages, loud noises such as alarms).
  - Perceived threats or physical touch.

- Once triggers are identified, the staff can try to problem-solve ways to ameliorate the triggers.
  - Minimizing the patient's contact with specific triggers
  - Interventions such as providing social support or engaging in positive activities may also be effective in reducing stress or problem behaviors.

( Yoder, Norman, & Friedman, 2016 )

Behavioral Changes in Later Stages

- Paranoia, due to confusion
- Frustration with inability to communicate
- Responding to a perceived threat with fear, aggression
- Restlessness, pacing
- Sleep Disruptions
- Hallucinations
- Delusions

Interventions for Behavioral Changes in Later Stages

- Screen for delirium
- Assess for unmet needs
- Routines
- Calm environment
- Exercise
- Natural light
- Art or Music Therapies
- Distractions from cause of concern
- OT, SLP, PT Referrals
- Providing caregiver training: Feelings are more important than facts!
- Medications
WORKING WITH FAMILY MEMBERS AND CAREGIVERS

Working with Family

- Family caregivers at increased risk for:
  - Anxiety, depression
  - Social Isolation
  - Poorer physical health
  - Financial hardship
  - Death

  *63% higher than non-caregivers*  
  Brodaty & Donkin, 2009; Tremont, 2011
10 Symptoms of Caregiver Stress

- **Denial** about the disease and its effect on the person.
- **Anger** at the person with Alzheimer's or frustration that he or she can't do the things they used to be able to do.
- **Social withdrawal** from friends and activities that you used to enjoy.
- **Anxiety** about the future and facing another day.
- **Depression** that breaks your spirit and affects your ability to cope.
- **Exhaustion** that makes it nearly impossible to complete necessary tasks.
- **Sleeplessness** caused by a never-ending list of concerns.
- **Irritability** that leads to moodiness and triggers negative actions.
- **Lack of concentration** that makes it difficult to perform familiar tasks.
- **Health problems** that begin to take a mental and physical toll.

-Alzheimer's Association, 2018

Other Reactions to Loss

- **Emotional**
  - Guilt or Regret
  - Ambiguity of Loss
  - Shame
  - Not feeling normal anymore
  - Sense of isolation
  - Self-doubt
- **Physical**
  - Sleep Disturbances
  - Somatic Complaints
  - Time distortion
  - Lethargy and fatigue

What we know is helpful

- **Emotional Support**
- **Taking care of themselves physically and mentally**
- **Breaks from caregiving responsibilities**
- **Maintaining relationships with others**
- **Disease Education**
  - Understanding changing behaviors as part of the illness
  - Adapting communication methods to person’s ability
- **Feeling that they have the best medical care**
- **Learning to control guilt**
- **Learning to prioritize differently**

Common goals of therapy for family members/caregivers

- Managing stress, fear, worry and sadness, anxiety, guilt or depression
- Navigating changes in relationships, roles and expectations
- Recognizing and accepting their limitations
- Nurturing their own needs
- Reconnecting with who and what they value most
- Accessing appropriate support and resources
- Focusing on moving forward with resilience

Therapeutic Interventions

- Driven by goals of client
- Normalize grief experience
- Understand reactions to loss
- Concept of ambiguous loss
- Place to name and process their emotions
- Disease education
- Breathing and mindfulness practice
- Cultivating self-compassion
- Exploring forgiveness
- Education about resources

Resources for Caregiver Training

- Bathing without a Battle
  - http://bathingwithoutabattle.unc.edu/
- Teepa Snow, OT
  - Youtube
    - http://teepasnow.com/
- Alzheimer’s Association Online Courses
  - https://alz.org/help-support/resources/care-training-resources
- The Savvy Caregiver
  - http://www.hcinteractive.com/SavvyFamily
Disease-Specific Organizations

- Alzheimer’s Association
  - www.alz.org
  - 800-272-3900
- Lewy Body Dementia Association
  - www.lbda.org
  - 844-311-0587
- The Association for Frontotemporal Degeneration
  - www.theaftd.org
  - 866-507-7222

Support in Colorado

- Alzheimer’s Association offices
  - Denver
  - Fort Collins
  - Greeley
  - Colorado Springs
  - Boulder (Louisville)
  - Pueblo
  - Durango
  - Grand Junction
  - https://alz.org/co/about_us/office_locations

BARRIERS TO TREATMENT
Barriers to Treatment

- Stigma
- Cost or Insurance issues
- Logistical
  - Transportation
  - Privacy
  - Coordinating multiple medical appointments
- Memory Loss
  - Forgetting appointments
  - Following up on “homework”
  - Ability to carryover between sessions
  - Can the person benefit?

Key Components

- Train individuals and professionals in the community to become Community Partners and identify and refer seniors in need

Community Education & Outreach

- Elder friendly, telephonic, single point of entry
- Receives referrals from community and reaches out to seniors
- Provides screening, information and referral
- Links to behavioral health and/or care management services

Screening

- Home-based intake to determine individualized needs and services
- Brief, solution-focused, behavioral health treatment
- Care management
- Referral to additional community resources as needed to support the wellness and independence of seniors

Services

Key Takeaways

- Relationship between dementia & mental health is complex
- Emotional well-being of the person with dementia should always be monitored & prioritized.
  - Assessment and available interventions will change as the disease progress
  - Interventions are possible at any stage!
- Support for caregivers is critical, and improves outcomes for everybody.


https://doi.org/10.3949/jalz.7-4-607


Resources
https://www.alz.org/national/documents/topicsheet_dementia_depression.pdf
https://www.alzheimer.org/alzheimers-disease_MO.aspx
https://www.alzheimer.org/alzheimers-disease_MO.aspx
https://www.ptsd.va.gov/professional/Maximizing_Effectiveness/Assessment_and_Treatment_for_PTS_with_CO-occurring_Neurocognitive_Disorder.asp
https://www.alzheimer.org/alzheimers-disease_MO.aspx
https://www.lbda.org/go/treatment_behavioral_symptoms_when_consider_antipsychotic_medications.html
https://www.lbda.org/go/symptoms-0
http://www.minicog.com/minicog-instrument/administering-the-minicog/
https://www.lbda.org/go/behavioral_symptoms-0
https://www.lbda.org/go/behavioral_symptoms-0