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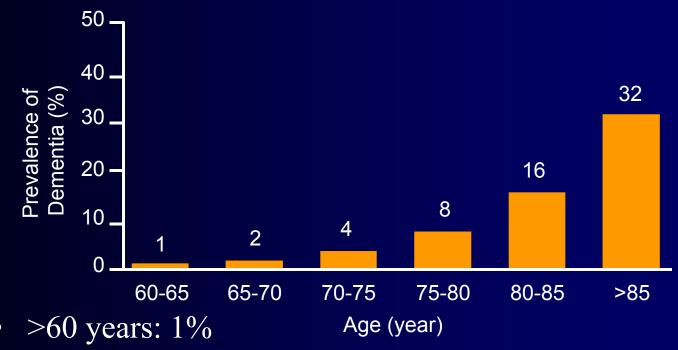
Dementia and PASRR

Timothy R Malloy, MD, CMD

Overview

- Impact of Alzheimer's Disease
- Diagnostic criteria
- Dementia-related behaviors
- Interface of dementia with MI/ID
- When dementia becomes the "primary diagnosis"

Prevalence and Impact of Dementia in the US



- >85 years: 32% to 47% (fastest growing pop.)
- Today: About 5 million have Alzheimer's Disease
- Fourth leading cause of death in elderly
- Third most expensive disease
- Incidence in MI/ID populations

Diagnostic Delays

- "Mom's just getting old"
- Fear of diagnosis (families and clinicians)
- Usually 3 years of symptoms before diagnosis
- Over 50% of AD sufferers are undiagnosed
- Dementia symptoms might be mistaken for MI/ID exacerbation and cause further delay

Consequences of Delayed Dx

- Compliance with medications and appointments
- Unreliable symptom reporting (undetected, treatable medical conditions)
- Safety issues, auto accidents, environmental exposure
- Financial victimization
- Social isolation and neglect (until crisis situation)
- Missed opportunity to begin treatment at early stage

Consequences of Delayed Dementia Dx in pt.s w MI/ID

- MI/ID patients would be even more vulnerable to the harms mentioned earlier
- Doses of common psych meds may need to be much lower in dementia patients
- Dementia pt.s are more vulnerable to side effects of common psych meds
- Meds such as cogentin can make dementia related cognitive impairment worse

Risk Factors For Developing Dementia

- Advancing Age
- Family History of Dementia
- Head Injury/Concussion/ TBI
- Poorly controlled HBP, DM, and Lipids
- Stroke(s)
- Alcoholism/Drug Abuse (esp in MI)
- Low Intelligence, Education, Job Level

A.D. Diagnostic Criteria

Progressive Memory Impairment

And

Impairment in at least one other cognitive area:

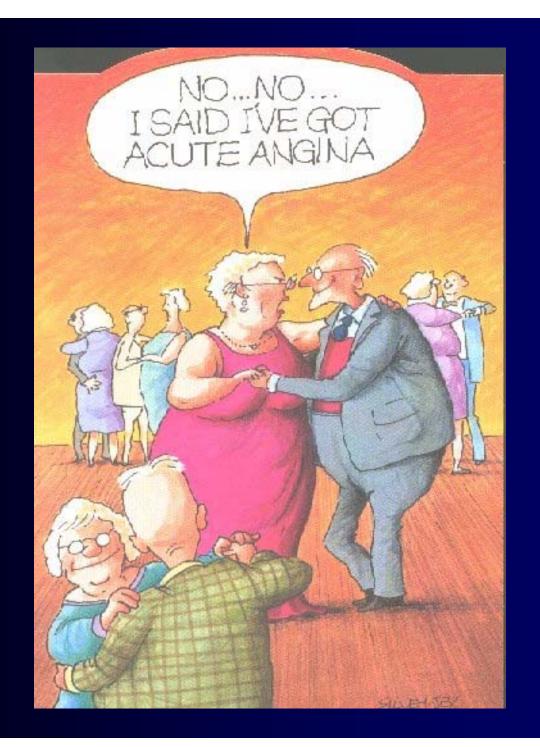
- Aphasia
- Apraxia
- Agnosia

Or

 Executive Function (esp apathy and procrastination vs ED is MI/ID)

Diagnostic Criteria (cont'd)

- Must be progressive and at least of 6 months duration
- Must not be due to delirium
 - Must not be due to MI/ID
- Must not be due to other medical condition (eg. brain tumor)



Differential Diagnosis of Alzheimer's Disease

- Delirium
- Vascular dementia
- Dementia with Lewy Bodies & Parkinson's
- FrontoTemporal Dementia (FTD)
- Normal pressure hydrocephalus
- Tumor (meningioma)
- Subdural hematoma
- Hypothyroidism
- Vitamin B₁₂ deficiency
- Depressive pseudodementia
 - *reason for neuroimaging

Diagnostic Work-up

Goal: To rule in Alzheimer's Disease while excluding other causes of cognitive impairment

- History
- Neurologic Exam
- MMSE
- Lab: CBC, Chemistry/electrolyte profiles, TSH, B_{12,3}
 drug levels
- CT brain (non-contrasted) unless MRI warranted
- 85-90% diagnostic accuracy

Neuropsychiatric and Behavioral Manifestations of A.D.

- Apathy
- Affective symptoms
- Agitation/Aggression
- Psychosis
- Pacing/wandering
- Disinhibition
- ADL loss

Order of Loss of Functions in Alzheimer's Disease

Normal Childhood Development . . .

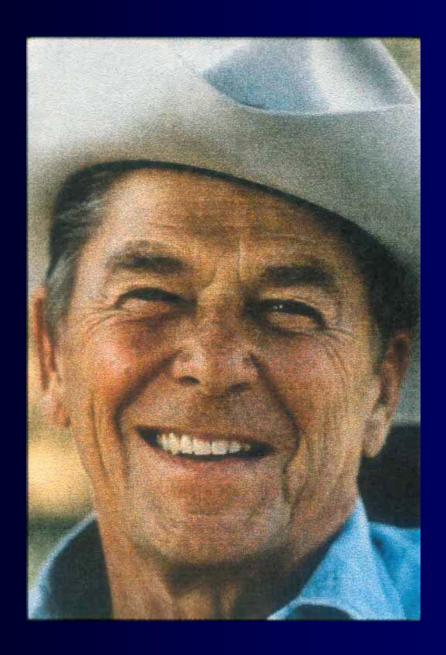
Alzheimer's Disease Clinical Landmarks

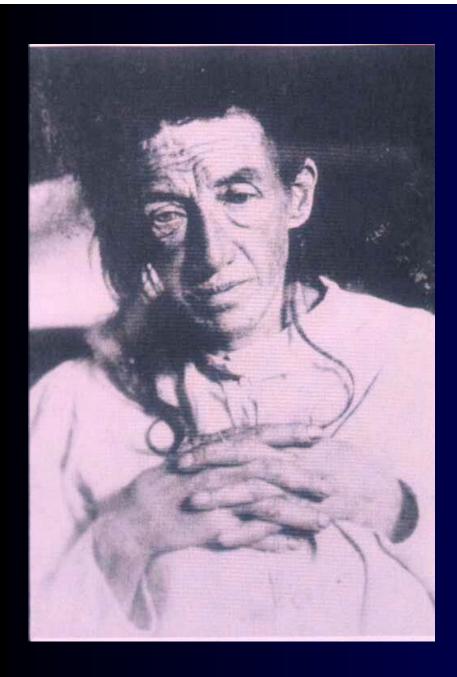
- 9 year life expectancy (3-20 years*)
- 1-3 years initial symptoms until diagnosis
- 3-6 years dx until ADL dependency
- 6-9 years ADL dependency until death
- * Range affected by comorbidities, social support systems, disease aggressiveness, etc.

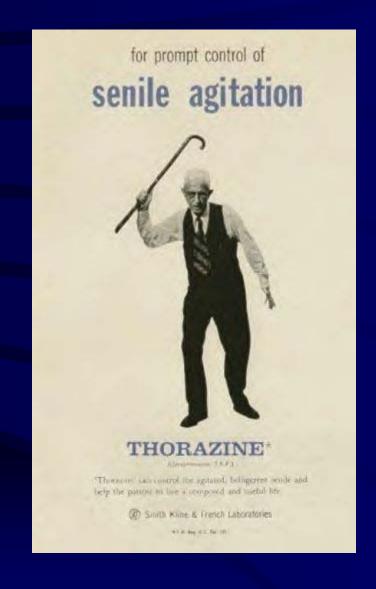
A. D. Treatment: Cholinesterase Inhibitors and

Memantine

- AD meds are not disease pathology modifying and certainly not a cure BUT
- They improve and slow rate of deterioration of:
 - Cognition
 - Function
 - Delays nursing home placement
 - Lessens the emergence of behavioral problems







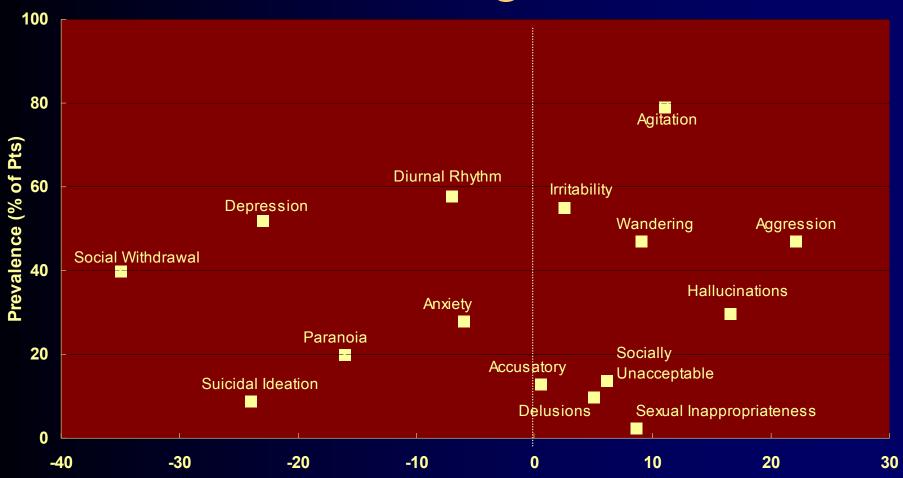
Psychotropic Meds and Dementia

- None are FDA approved for dementia indication (all off-label)
- Some have explicit warnings
- Non-pharm measures get overlooked
- PASRR recommendations might have a major role
- Even if meds necessary, "one size fits all" is a bad idea

Types of Behavioral Disturbance

- Withdrawal / Apathy
- Agitation
- Aggression (provoked / unprovoked)
- Pacing / Wandering
- Depression related symptoms
- Disinhibition

Peak Frequency of Behavioral Symptoms as AD Progresses

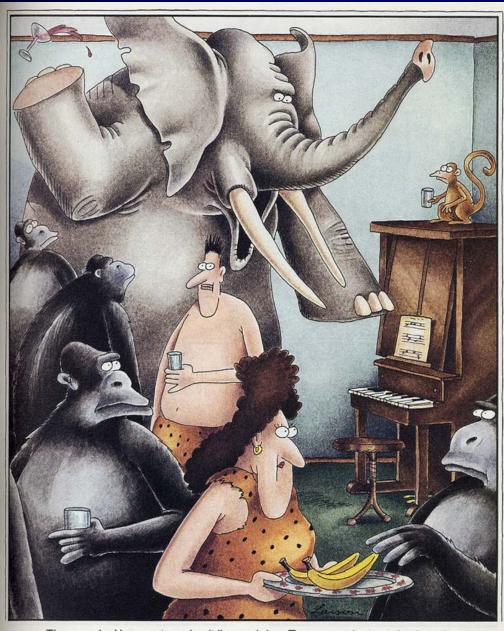


Causes of Agitation

- Physical causes
- Situational causes
- Psychiatric comorbitities
 - depression
 - mood lability/disinhibition
 - psychosis

Physical Causes of Agitation

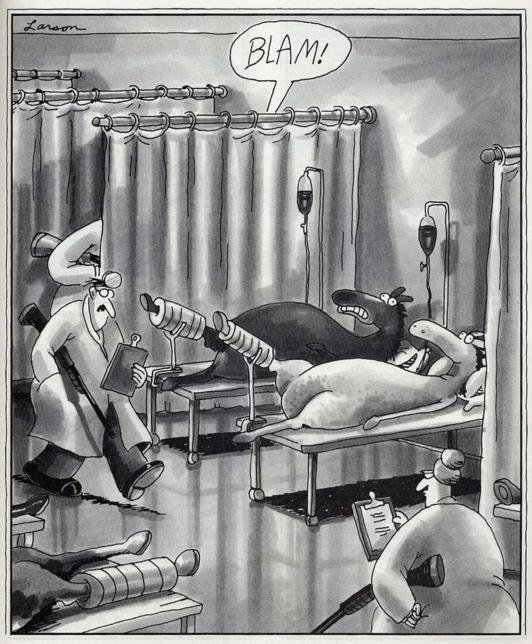
- Pain inadequate control
- Temperature too cold
- Hunger
- Toileting need urgency, constipation
- Noise level
- Acute illness (including delirium)



The party had been going splendidly—and then Tantor saw the ivory keyboard.

Situational Anxiety as Cause of Behavioral Disturbance

- Weekly bath
- Catheter change
- Visits by dentist, podiatrist, etc.
- 0.5 mg Ativan or Xanax 1 hour before situation



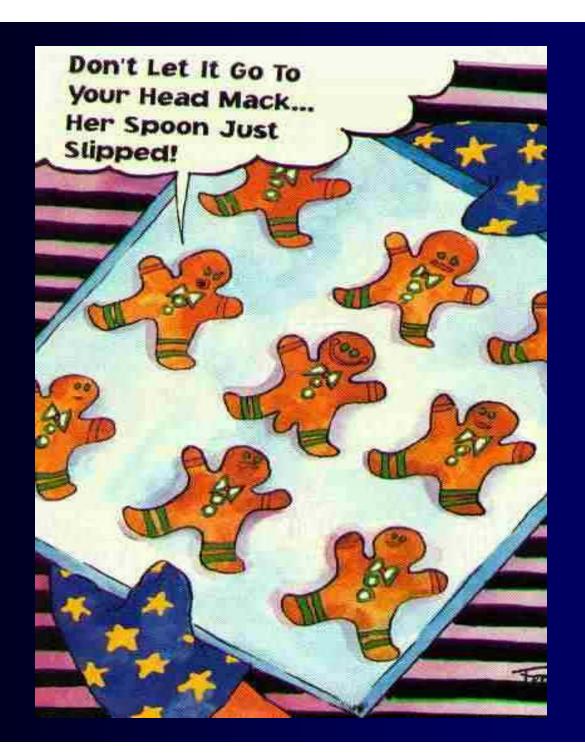
Horse hospitals

Depression as Cause of Behavioral Disturbance

- Affects 1/4 to 1/3 of long term care residents
- Pervasive or prominent dysphoria or anhedonia
- The dementia patient with depression tends to be less animated about affective sx.s. with more somatic focus esp pain c/o; whereas,
- Depressed pt.s w/o dementia will often be more descriptive about the sadness, feelings of guilt, loss, anhedonia, suicidal ideation etc

Frontal Lobe Disinhibition

- Mood lability or inappropriate affect
- Poor impulse control
- Episodically aggressive
- Perseverative
- Restless/grabbing
- Sexually inappropriate



Psychosis in Dementia as Cause of Agitation

- Dementia psychosis usually delusional in nature and rudimentary/simple:
- Spousal infidelity
- Fear that people out to hurt them (poison)
- People are stealing my things (losing things)
- Strangers are in my house
- Visual hallucinations uncommon (except DLB and PD)
- In contrast to MI related delusions being more elaborate, grandiose, and complex

Medication Should Be Directed at Specific Target Behavior

- Depression antidepressant, mood stabilizer
- Mood lability mood stabilizer
- Situational anxiety scheduled anxiolytic
- Psychosis antipsychotic

The more obvious the behavior fits a target, the easier the choice of treatment

Keys to Diagnosing Dementia in folks with MI/ID

- There must be a clear decline from a previously established baseline level of
 - Cognitive abilities
 - Functional abilities
 - Behavioral issues
 - Not necessarily all of the above

Diagnostic Challenges when Comorbid MI/ID occurs

- Is the Executive Dysfunction due to MI/ID or to an evolving dementia?
- Are the psychotic symptoms due to MI/ID or an evolving dementia?
- A well defined baseline is essential
- Sometimes only time will tell because dementia always progresses

Diagnosing Dementia in Down's Syndrome might involve

- Loss of ability to perform job duties
- Difficulty learning new information or tasks
- Exaggeration of personality traits (disinhibition) or a decrease (apathy)
- New onset incontinence or other ADL dependency
- New onset seizures (10% of dementia pop.)

Diagnosing Dementia in Down's Syndrome (cont'd)

- Deterioration of language and social skills
- Deterioration of personal hygiene
- Loss of ability to experience pleasure and take part in fun activities
- But the question should always be "is this a change from baseline"?
- Baseline knowledge is therefore essential

Whether a resident is appropriately placed in a NF?

- Is altogether different than if "primary diagnosis" status per PASRR is appropriate
- PASRR did not intend for the dementia diagnosis to eclipse co-morbid MI/ ID
- MI/ ID might continue to prominently impact the resident with dementia in the NF
- NF placement is often a function of the social support systems and financial status of the dementia patient and has little to do with PASRR and "primary diagnosis"

PASRR Definition of "Primary Diagnosis"

- When the dementia had advanced to such a degree that the resident is unable to benefit from specialized services
- How is that determined?
- At what point in the progression of dementia?
- Easy to determine at the extremes of dementia
- There aren't clear cut answers for the grey area that exists between extremes (only clues)

How to Determine when Dementia as "Primary Diagnosis" has occurred

- A cut off point on the MMSE?
- Functional decline to the point of basic ADL dependence?
- The level of aphasia?
- The level of apraxia?
- The level of agnosia?
- Are any chronic symptoms of the MI still present or have they been eclipsed by the dementia?

Has Dementia become the "Primary Diagnosis"? (cont'd)

- When the answer is elusive, the solution might be to have a trial of specialized services
- Reevaluate at a later date

Case Example

- 68 yo with schizophrenia and Diabetes in ALF
- Cognitive decline over past year characterized by
 - Apathy
 - Hygiene deterioration
 - Incontinence
 - Reclusiveness
 - Language skills deterioration
- Developed foot ulcer and refused to take off shoes to allow cares
- Exceeded scope of ALFs ability to provide care so transferred to NF

Case Example (cont'd)

- Was NF placement appropriate?
- Is Dementia the "primary diagnosis"?
- Doesn't she still have Schizophrenia?
- Would specialized services improve her Quality of Life?

Case Example (cont'd)

- Is she aphasic to the point of no longer being able to communicate? No
- Is she so apractic that she can no longer carry out some tasks alone or even with assistance? No
- Does she recognize familiar people or things (agnosia)? Yes

Case Example (cont'd)

- Does she have paranoia related to her MI that isn't optimally addressed?
- Is undiagnosed depression or delirium a contributor to her decline?
- A hard look at some of these questions might help make the determination.
- A trial and a periodic re-look might be appropriate.

Clues that MI/ID still there?

- The presence of coexisting delirium further clouds the picture
- The characteristics of psychosis might offer a clue that mental illness is still relevant

Is Delirium Part of the Picture?

- Important evidence of delirium: Lethargy and Inattentiveness.
- Delirium is common in folks with dementia and often unrecognized.
- Co-existing delirium will make screening even more difficult.
- Better to screen patients once delirium resolved and new baseline achieved.

Psychosis in MI/ID vs Dementia

- Visual hallucinations are uncommon in AD but common in DLB/PD.
- Auditory hallucinations are uncommon in all dementias.
- Both auditory and visual hallucinations are common in folks with mental illnesses.
- The usual psychosis seen in Dementia is delusions of a paranoid type (not complex or grandiose).

Psychotropic Medication for Persons with both Mental Illness and Dementia

Some medications typically given for MI may need to be used differently for persons with a cooccurring dementia.

- Use lower doses of....
- xyz class of meds harm this and that in persons with dementia

Conclusion

Folks with MI/ID get Dementia.

Dementia doesn't necessarily eclipse the MI/ID.

Sometimes hard to discern whether the MI/ID is still relevant.

Knowledge of the cognitive, functional, and behavioral symptoms of dementia can help you make that determination.

Networking with NAPP

(National Association of PASRR Professionals)

http://www.pasrr.org/about.aspx



- Networking with NAPP is a follow up discussion on the webinar.
- The next Networking with NAPP session is:

Tuesday, January 27th, 2014 1 PM EST

To register for the session, please contact Betty Ferdinand: (bferdinand@cii.us.com).

A reminder invite will be sent to all webinar participants.



Question and Answer Transcript

Answers provided by Dr. Timothy Malloy,
Director of the Geriatric Department of Family Medicine at Nebraska Medicine

- 1. Are both Mild and Major Neurocognitive Disorders synonymous with Dementia or would Major NCD (only) be considered Dementia? The latest DSM edition is a bit confusing. (Angela Howard)
 - a. The latest DSM definition is very confusing. But the one that is Major Neurocognitive Dysfunction would be considered Dementia. I find it very confusing and frustrating to me, too. I think we've not taken a step forward in this classification.
- 2. Do you believe a CT scan is warranted on most individuals with mental illness to help rule out Dementia? (Rhonda Harris)
 - a. No, I don't because the CT scan in mental illness is normal and the CT scan in Alzheimer's disease is normal. So, that's not why we do a CT scan in people with Dementia symptoms. We do it to try to help rule out three of the more common conditions that mimic Alzheimer's disease, and those three would be a supdural hematoma or hydrocephalus or a benign tumor called a meningioma. That's the main reason for neuroimaging and the workup. I think we'd have an awful lot of normal CT scans if we were to do that in everybody with mental illness. So, in treating Alzheimer's disease, we have the cholinesterase inhibitors and memantine. And I don't want to spend hardly any time about them, other than to say that they are not curative. They do not alter the disease pathology in the brain. People continue to lose brain cells and continue to decline. But what they do for us is they slow the rate of deterioration of important things, such as our cognition, our function. They delay placement in the nursing home and they lessen the emergence of behavioral problems in people with Dementia.
- 3. Are there significant differences between a diagnosis of Organic Brain Syndrome and Alzheimer's disease or Dementia? (Sharon Rushing)
 - a. No. Organic Brain Syndrome is the old-fashioned name for Dementia; it's also an old-fashioned name for Alzheimer's disease. I almost never see it anymore. So, we ought to quit using it, if it's still out there. But it doesn't mean anything special, it's just Dementia.

*Dan Timmel: A reason to ask about Organic Brain Syndrome is the very out-ofdate diagnostic criteria in CFR for PASRR Mental Illness. There is some information on the website about how to translate those old terms into today's criteria.

4. Is that maybe what was happening with Robin Williams? Visual Hallucinations due to Parkinson's disease? (Ann Seanor)

a. It certainly could have been. It's my understanding that Robin Williams had Dementia with Lewy Bodies and he could have easily had the onset, well, he obviously did have the onset of Major depression, that's what I think was probably the thing that caused him to commit suicide, is he had Major depression. And, as I mentioned previously, depression is so much more common in people with Dementia.

5. What does DLB stand for? (Lakisha Hyatt)

a. Dementia with Lewy Bodies. Dementia with Lewy Bodies is the second most common type of Dementia, and it's a Dementia characterized by memory loss and cognitive loss. Also, Parkinson-like symptoms, not Parkinson's disease, but Parksinson-like symptoms of slowness of movement and rigidity and maybe a little tremor. And a striking tendency to have visual hallucinations. And, as I mentioned, visual hallucinations are very rare in Alzheimer's disease. So, it's an important, fairly common type of Dementia.

6. When do you worry about dependence on anxiolytics with Dementia or is not a concern? (Kathleen McKinney)

a. It's not commonly a concern with dependence and Dementia, of these medicines, because Dementia folks don't tend to take on dependence or addictive type behaviors. In general.

7. What exactly is the physiological process that makes up Dementia? (Ann Seanor)

a. We don't know what causes Dementia, really. We do know that what's bad for the heart is bad for the brain, in general. When you abuse your brain you are more likely to develop Dementia. But what is the actual pathophysiologic reason why people get Dementia is really unknown. There are some theories, and the Amyloid theory is the most common one out there, but it's not proven, and it's probably also a major reason why we don't have something that directly stops Dementia. It would be impossible to reverse Dementia because once we lose brain cells they're gone forever. I don't think I can really get into the patho-physiology any more than that. We don't really know.

- 8. What are some helpful non-pharmacological interventions we can recommend in our PASRR evaluations, to help reduce behavioral problems with Dementia diagnoses? (Sharon Stremel)
 - a. PASRR might recommend something in the form of pharmacologic management. And I think that might be a recommendation that someone see a, be followed by a psychiatrist, if that's available. PASRR might recommend, in the non-pharmacological realm, that somebody be seen by a therapist of some sort, a psychotherapist. And then, all the different nonpharmacologic things that sometimes get overlooked. Such things as simply avoiding. The individual may do very poorly in crowds, and they've done poorly in crowds their whole life, so therefore a fun activity for that person might not be to go to a crowded dayroom and enjoy a group activity. I think, maybe, recommending a more individualized form of therapeutic exercise for someone. Avoidance of certain things that tend to historically set people off and escalate behaviors. Things such as, and this drives me nuts at nursing facilities, is how televisions are blaring from so many people's rooms. And, maybe somebody never liked to watch television and they're now sharing a room with somebody who's got their television blaring all the time. Well, that would drive me crazy, too! Or, having people sit in the day room at the nursing facility in wheelchairs parked in front of the television is not, in my opinion, a group activity. So, those sorts of things. I don't really fancy myself an expert on nonpharmacologic measures but I think maybe, in terms of Dementia, trying to get inside a of person's world rather than asking that person to come into our world is a theme that I see over and over again, is helpful in terms of trying to limit medications. Also, understanding, if you want to limit medications, understanding what is a normal behavior in Dementia versus what is a behavior that could result in a person's harm and warrant medication. I think pacing is a classic example. People with Dementia who pace are just being normal Dementia folks. That doesn't mean that they need anxiety medicines to calm their anxiety. Sometimes, pacing is relieving to people and it's OK. And pacing into other people's rooms. Now, it can be problematic, but that's just normal Dementia behavior. That's not something that can be treated with a medication, or should be treated with a medication.
- 9. Minimizing sensory overload in general? Or looking at that per individual? (Anne Seanor). Rephrased: Would sensory overload be common to most persons, or would you say "Oh if this person is disrupted by sensory things, then recommend minimizing sensory overload?"
 - a. Well, I would certainly recommend it if that's their history prior to living in a nursing home. I think people are mixed. There are some people that don't seem to mind it and there are other people who clearly don't care for group environments or excessive noise, especially Dementia folks.

- 10. Please comment about your experience with the use of OT assessments and prescribed sensory diets for individuals with intellectual disabilities and Dementia. (Lakisha Hyatt)
 - a. I don't have any experience with that. I'm not afraid to say I don't know.
- 11. Would you discuss the staffing level interplay with the ability to appropriately attend to these residents? And, could you discuss community integration possibilities for such residents? (Dean Lerner).
 - a. I'm not sure I'm qualified to answer that, to be honest with you. My gut impression is that staffing needs would increase for this dual diagnosis of mental illness and Dementia. I think these people would require more attention. It's probably not relevant once someone gets to primary diagnosis level of Dementia, but specialized services are not just going to drop out of the air. So yes, I agree with you.

12. Is there anything in standard mental health treatment that you think would lead to a poorer result for a person with co-occuring Dementia?

a. Oh, yes, especially pharmacologic treatment. For example, many of the medicines that are used in mental illness. So many people with a mental illness, especially with an anti-psychotic, and they could well need that anti-psychotic, but do they need that degree of a dose now that they have Dementia? My guess is no, they don't need as high of a dose. Realize that Dementia folks are also very sensitive to medication side effects. And, I think in the mental illness world, medicines like Artane and Cogentin are really common, but that's anti-matter to someone who's got Dementia. People who have Dementia have deficiencies in some of these neurotransmitters, such as acetylcholine, and when you make the matter worse by giving an anti-acetylcholine drug to treat extrapyramidal side effects, I think you're going to hurt that person's cognition. And so there are many different anti-cholinergic medicines and anti-histaminic medicines. etc.

13. Is onset of seizures not previously noted in an older person specific to Dementia for a person with an intellectual disability? Or is that generalizable to Dementia for all persons?

a. I think it's generalized to all people with Dementia. It's really terribly underdiagnosed because it would be easy to diagnose if people actually had major motor grand mal seizures. But they don't. They have these little space out spells. And, one of the things that doesn't enter into clinicians' minds is this little space out spell is not a TIA, they often get attributed to TIAs, the most over-diagnosed thing in the world, when actually what they're having is complex partial seizures and a lot of their lethargy is from being postictal from a complex partial seizure. Those people, functionally, they just do terrible.

14. I feel the Dementia diagnosis is given too readily to older folks with mental illness. (Laura Block)

a. I agree. I do agree. I think sometimes it's given too readily to other folks, too. And I think, conversely, there are a lot of people with mental illness who have Dementia but their Dementia is not diagnosed until much later than it ought to be.

15. Can you address the early onset cases? (Sandra Sinz)

a. Yes. Early onset Dementia represents, early onset Alzheimer's disease represents probably <3% of all Alzheimer's disease. The rest of Alzheimer's disease is called sporadic Alzheimer's disease or, I like to call it just old age Alzheimer's disease. These people typically have a family history, or often have a family history of AD. And it may onset in the late 40s or 50s--classically before the age of 65. 65 is this arbitrary cutoff of when we say people are old, even though I think that's become obsolete now to make 65 the old age cutoff. It's a similar, pathologically identical disease that's going on in the brain. It used to be called pre-senile Dementia or pre-senile Alzheimer's disease, commonly called now early-onset Alzheimer's disease, as the question implies. I don't have anything special to say about it, other than that.

16. In terms of Primary Dementia with the PASRR definition, you would advocate that unless you are absolutely certain, assume that the person belongs in PASRR population and that your recommendation may help.

a. Yes, I agree. If you don't know, I don't see what it would hurt to assume and then re-look later.

*Dan Timmel: I wanted to say to most of our listeners, if you're in a state agency, you know the part of PASRR that does Level II evaluations and determinations, I would say that this webinar and some others like it, but this one particularly should be required training for your evaluators. This kind of level of differentiation of people's needs on a highly individualized level that speaks to the nursing home and makes a difference in the care-planning that the nursing home staff will do, almost none of whom have training in this area, at least at this level. A Level II that understands all these issues and takes these into account will change people's lives. I would really encourage you to incorporate this webinar in training that section's staff or vendors.

17. Can you talk about overdiagnosis of psychosis not-otherwise-specified in patients with Dementia as the primary diagnoses? (Kathleen McKinney)

a. Yes, I think it is overdiagnosed. I think people do tend to use antipsychotics and anti-anxiety medicines as their sort of go-to drug. And, it's clearly not a one-size-fits-all. I mean, not every behavior will benefit from an anti-psychotic. Sometimes a behavior might benefit from an antidepressant. Many times, a behavior might benefit from avoidance of the trigger that sets off the behavior. So, I don't know how to otherwise speak

of it, but I see it. If you're going to justify using an anti-psychotic, you always have to put down "psychosis." You have to write down "psychosis" as a reason why you're using it. And I think that's done too often. That's my guess, that's my experience.

18. Have you seen early onset more prevalent with individuals with intellectual disabilities? (Ali Stanley)

a. Yes, definitely with people with Down's syndrome. In fact, Dementia is not the exception, it's more the rule of people with Down's syndrome as they approach their 50s and 60s. Other forms of intellectual disability, I can't say that I've seen an excess of that.

19. For PASRR, if someone has any diagnosis of Dementia either primary or secondary, should these folks all have a level II assessment done? (Ruth Anne Barnard)

a. Nancy: The answer is a combination of Dr. Malloy's skill and then what the requirements are. And the requirements are, if you're not certain that the Dementia is so advanced that the person would never or not again benefit from mental health services, Specialized Services, then you should keep them in the population and refer for a Level II so that recommendations to help that person can be written. If someone's at either extremes of dementia, you know the answer. If they are early Dementia, you know you have to do a Level II. If they are very late-stage Dementia, that's when it's okay, they're probably not going to benefit. But everywhere in-between, PASRR still applies because that person may benefit and because your expertise in knowing how their mental health or their intellectual disability might even change the way common Dementia medications are used. Or, the presence of their Dementia may change the way common mental health medications are used, I think, is what Dr. Malloy talked about. Incorporating that into your recommendations would be very important.

*Dan Timmel: In the past, I think, CMS did not do a very good job of helping states interpret PASRR, and you were kind of left with the CFR, which gives you kind of a sense that there's an algorithm. If this, then that. You know, gives you a compass of the rules so you're complying with the federal requirement. In reality, what you need to be doing with PASRR is way more individualized and not a formula. Almost no part of your PASRR process can just have a simple "if this, then that." So, and some of you are sick of me saying this, but any time you have a question like this, you should ask yourself, "what would help people?" Well, would it help people if we just always or never included people with Dementia? Well, no. You need the Level II expertise to figure that out, person-by-person. And then, when you get to Level II the question is not "is Dementia everything we just heard, not some simple level of threshold of how bad is the Dementia" but, "in what way does the Dementia and the mental illness interplay so that it affects their care-planning?" Which is a really different question than "what's the cutoff?" I don't think there should be many cutoffs. I think there should be "how can we

give individualized assessment and then care recommendations for each person?" It really can't be about algorithm.

*Frank Tetrick (comment) The regulations address the ability to "terminate" the Level II "evaluation", based on the guidelines regarding primary Dementia, thus the decision should be done during the Level II process, not before.