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Identifying and Assessing Agitation in Alzheimer's Dementia

Announcer:

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Dr. Vega:

Hello, and welcome to this webcast entitled, Identifying and Assessing Agitation in Alzheimer's Dementia. I'm Dr. Chuck Vega, and I'm a Clinical Professor of family medicine at the University of California, Irvine. I'm delighted to be joined today by Dr. Tom Heinrich. Would you mind introducing yourself?

Dr. Heinrich:

Yeah, thanks for that introduction, Chuck. I'm Tom Heinrich. I am a family medicine physician and a psychiatrist at the Medical College of Wisconsin where I'm a professor both in psychiatry and family medicine. And it's great to be here. Thanks.

Dr. Vega:

Yeah, absolutely great to have you. So in this webcast we will be continuing to discussing agitation in Alzheimer's-associated dementia, and look at best practices for identifying and assessing agitation.

Before we get started today, let's look at our learning objectives. We're going to be summarizing the impact of agitation on individuals with Alzheimer's disease, their care partners, and clinicians in the healthcare system. We're also going to be defining agitation based on criteria established by the International Psychogeriatric Association Agitation Definition of Working Group. And then we'll spend some time describing the approach, the identifying, diagnosing, and the ongoing assessment of neuropsychiatric symptoms in individuals with dementia. And finally, we'll be identifying some validated neuropsychiatric assessment tools for use within primary care.

So in my module, earlier, I described that 98% of individuals with Alzheimer's dementia will develop behavioral and psychological symptoms. And that increases over time as the severity of Alzheimer's disease or other dementia is worse, as well as patients grow older.

So let's begin to understand what agitation is and what it looks like by reviewing the consensus definition from the International Psychogeriatric Association. The IPS Agitation Definition Working Group originally published a provisional definition in 2015, but just recently removed the word provisional, and presented the following is a final definition.

So first of all, let's start with Criterion A, I think it's the most obvious, the patient must meet criteria for a cognitive impairment or dementia syndrome.

And then B gets into the behaviors themselves. So they have to have at least one behavior associated with agitation. And it has to promote some level of emotional distress. And the patient has to have that behavior persistently or frequently for a minimum of 2 weeks, or it's a notable change from the patient's usual behavior. And what are the behaviors? It's the behaviors we see all the time in folks with





dementia, as it gets more advanced, it's successive motor activity, it's verbal aggression, and it's physical aggression as well.

Now, the behaviors at least have to promote excess to stress or excess disability beyond what the patient is experiencing due to their cognitive dysfunction. This is Criterion C, for this definition. And so there's impairment, either it's interpersonal relationships, social functioning, or activities of daily living.

And then finally, importantly, Criterion D states, the agitation isn't due to another psychiatric disorder, not due to a medical condition. That includes delirium, which is always important to consider, not due to a suboptimal care conditions. And that brings up the issue of potential abuse or neglect. And so that's always something to think about when we have patients who - with dementia, who have a new change in behavior and are experiencing agitation, we have to screen for that. And then finally, we also screen for substances, usually medications that we're prescribing that could potentially cause the agitation as well.

So, Tom, we'll bring you into the conversation around this definition. Is there anything you feel like there's wanting in this definition? Or does that fit with your clinical practice? And you know, what you think is important to really understand for folks with agitation in dementia?

Dr. Heinrich:

Yeah, that's a great question. I think it's a really well-rounded criteria for agitation in patients suffering or experiencing dementia. It really hits a lot of the high points from the ruling out other potential causes for that agitation, but also qualifies the type of behaviors in that, you know, it's looking at the motor activity, it's capturing the concept of verbal aggression as well. So it's a pretty well rounded and frankly, clinically useful criteria.

Dr. Vega:

I agree. I think it's very pragmatic. It's something that I can use in my practice, it makes sense to me. I think that one point that might be a pearl for clinicians is the fact that it has to cause some distress. We see, you know, particular behaviors as folks advance through dementia that may be distressing to caregivers, but the patient's, you know, quite content with. There's things like just repeating behaviors or repeating questions. And if - I think that there's - those cross a line where the caregiver may be feeling burned out by that, and that's something that can get addressed, but I wouldn't necessarily say that that meets the criteria for agitation, because it doesn't necessarily create that burden of distress either on caregiver or patient. So I think that that's one thing. And I think that line can be crossed, actually. It may not start out as a as a symptom of agitation, but gradually, it grows into one because it's causing some distress on someone's part.

So in addition, in module one, we talked about the impact of agitation in dementia. And let's start with patients that is associated with a higher risk of mortality, but also injury. And injury for these individuals can be severe. We're talking about older individuals, many with comorbid conditions, and they're more frail. So an injury, a fall say, can result in hospitalization. And that in and of itself can lead to greater institutionalization, certainly a loss of independence as well.

Do you want to speak to a little bit about what the impact is in terms of the impact on caregivers for folks with agitation in dementia?

Dr. Heinrich:

Yeah, I mean, talk about a disorder that has impact kind of across the spectrum. You have, as you alluded to, you have the patient who's impacted by these disorders that are often amazingly distressful to them. And then you have the caregivers, the support givers, the individuals that are trying to make good off if. And to see somebody have these problems, having the inability to function, could really wear on them. You try these interventions, you try what you may see on the internet and they're not working, it tends to wear on you. And you know, your safety may be put in risk. As the individuals' insight tends to decline, they may not recognize you. There's a lot of potential distress associated with this disorder in the individuals that are caring for them. So it is one of those conditions where measuring the distress, asking about the distress, is really key to the treatment of the disorder.

Dr. Vega:

I certainly have treated more depression and anxiety among individuals who are caregivers once the agitation starts. So it's really something to be aware of.

But it takes time. And so we shared some data, how clinicians recognize that this takes more visits, longer visits, they don't feel very comfortable with treatments or even recommending maybe some of the behavioral techniques. And I feel the same way. It is very important, though, I think, to identify it. And because there are management techniques that are important that we can use, and by taking care of it together, between the patient and the caregiver will reduce the risk of institutionalization, which in my practice, personally, is an outcome that almost nobody wants. You know, here, with a with a folks I see in my practice, I see incredible caregivers who go to extraordinary lengths to continue to take care of an older adult, even towards severe stages of dementia with agitation.





Dr. Heinrich:

Yeah, I mean, I think you mentioned in your talk, I mean, the risk of institutionalization with these behaviors is huge. So - and that's not where anybody wants to go, so the more we can do to address those behaviors and address the distress associated with those behaviors. I mean, you have a loved one who's dealing with an individual that has a chronic deteriorating condition, there's nowhere to go but down usually with these conditions. So they're coming to grips with that. And then you add these behaviors onto the picture, it can be - I mean, talks about a weight on the shoulder.

Dr. Vega:

Absolutely. And - but I will say, and I thought your point about the risk to the caregiver is quite valid. So there's certainly the mental health risk, which I mentioned. Then the physical risk, which you were alluding to, absolutely is there. And there does come a point where it's - we have to consider institutionalization for the safety of everyone because the risk of either physical harm or neglect is so is either very present or perhaps you've actually crossed the threshold where it's actually happening. That's the point where you have to have a, you know, a meeting where everybody comes to an agreement in some kind of reality.

Dr. Heinrich:

Yeah. You talked about how caregivers are often willing to tolerate so much in an effort to keep somebody at home, and that comes to the point of these kinds of spectrums of behaviors we see often in patients with dementia. When they are getting agitated, we often focus on the physical agitation, the aggression potentially towards others or towards inanimate objects. But there can be physical aggression, there can be physical behavior that's not aggressive, that's - such as pacing and wandering, that can weigh on somebody a great deal, almost as much as the physical aggression. And then there's those verbal outbursts, where it can be the muttering or screaming at somebody. And how hurtful is that potentially towards a caregiver when somebody's screaming and not knowing what's going on?

So I really try to make sure that caregivers recognize that this is part of the disorder, it's not their personality, it's not who they are, and really try not to take these behaviors personally. And that can be somewhat helpful in relieving their distress.

Dr. Vega:

Well, let's pull back for a minute and think about, Gosh, because I don't think I'm the best at identifying agitation in the first place. And we know that, you know, oftentimes, their first contact will be in primary care, oftentimes, they're not seeing a specialist. So can you give us some tips about how we can better identify agitation in dementia?

Dr. Heinrich:

Actually, if you're not thinking about it, you're not going to ask about it. So it really has to be forefront in your mind when you're interacting with patients suffering from dementia, even at early stages of dementia. And you have to be thinking about these behavioral and psychiatric manifestations of dementia, if you're not thinking about it, you're guaranteed to miss it until it's probably too late, until that distress has occurred or something bad has already happened. So you need to be thinking about it.

And it comes in all shapes and sizes and all types of presentations. It comes with a caregiver that says, you know, frankly, this is what's going on, do something about it. That's not too hard to pick out that something going on.

Dr. Vega:

Right. One would hopefully catch that one.

Dr. Heinrich:

I mean, but I mean, think about your practice. How many, if you're fortunate enough to care for multiple generations in your practice of one family, you may be seeing a caregiver in your clinic, and they're talking about depression and insomnia and loss of weight. And then you kind of make that connection of what's going on in their life. And that they're caring for a family member who's suffering from dementia, you can pick up behavioral disturbances in dementia in that visit with a patient not even in the room. And prompt a visit of that patient to come see you with dementia to start addressing that and do that.

So again, think about it, and ask about it. And potentially think about screening for it with some of these instruments we may be talking about in a bit.

Dr. Vega:

Yeah, maybe you want to share and just do a quick review on a couple of the instruments because I thought that was really valuable for me to hear.

Dr. Heinrich:

Yeah, in my module, I talked a couple - about the couple of neuropsychiatric instruments that can be really helpful in a primary care





practice. One is specifically related to agitation, and that's the Cohen-Mansfield Agitation Inventory. And the other is maybe a little bit more applicable for screening. And that's the Neuropsychiatric Inventory Questionnaire, because that not only looks at agitation, but looks at other potential neuropsychiatric sequelae of dementia, like depression and apathy, like you mentioned in your talk, or anxiety, or even psychosis, which can really confound a lot of people, and quite frankly, be scary for some people.

Dr. Vega:

Yeah, I thought that you had me at the neuropsychiatric inventory when describing 5 minutes filled out by the caregiver, and can give you that broad range of symptoms. Because absolutely, we don't want to just treat agitation, we want to identify apathy, depression as well. And you can certainly have multiple neuropsychiatric symptoms, comorbid in the same patient, and until you treat the depression more effectively, the agitation will probably be less well controlled, not ideally controlled. So yeah, I think that that is something that absolutely we can do in primary care. And again, not just as a screening tool, but then you can follow it along kind of like we would do with like Patient Health Questionnaire-9, which a lot of I think primary care practices are doing in terms of following patients with depression. Screen for it with a PHQ-2 or PHQ-9, and then you've got a nice score, which you can follow over time. It gives you something actionable. We know when you follow neuropsychiatric symptoms like that, generally, patients tend to remit easier and maybe that will take some of the burden and some of the mystery about treating agitation in dementia away so we feel more confident in making treatment recommendations.

Dr. Heinrich:

Yeah, I'm actually so glad you mentioned that PHQ-9 and GAD-7, that whole concept of depression and anxiety about treating towards a target, treating towards remission by using these objective measures. I mean, I think we're early in using these types of tools in the management of agitation or the other kind of psychiatric sequelae of dementia, but the tools are there to allow us to do it. And they're pretty flexible and easy to utilize. We talked about the Neuropsychiatric Inventory Questionnaire, that's the shorter one. You know, there's also that Cohen-Mansfield Agitation Inventory that measures 29 agitated behaviors, and really breaks them down like that - the International Psychogeriatric Association does into those types of behaviors, you have the physical aggressive, you have the verbal aggression, you have the physical non-aggression, and kind of breaks those behaviors down into domains. And you can utilize that tool for a longitudinal assessment to see if, what in your primary care practice or me and my practice, if what we've done is actually effective.

Dr. Vega:

So say you use one of those instruments, and the caregiver is filling it out, and it comes back as a positive screen. And so you want to address it with, you know, the caregiver and patient together. And the patient just denies that these behaviors exist? Because this is not an uncommon scenario. We want everybody kind of rowing in the same direction here, caregiver, patient, and provider, how do you manage that kind of situation?

Dr. Heinrich:

Yeah, I often will try to talk to the patient and realize that we can have a disagreement about whether these are - whether these behaviors are occurring. But we're going to operate right now on the fact that they are and we're going to explore them. And if you're using an instrument like the Neuropsychiatric Inventory Questionnaire, that actually includes distress scales, so I'll often list - I'll often appeal to the patient with dementia's empathy by recognizing the distress in their care support, their caregivers, and the importance of that. And most demented patients unless they're suffering from pretty significant neurocognitive decline, that sense of empathy is still there, and they still want to do good, they want to do right. So they're willing to want – they're willing to recognize the distress and maybe disagree with the cause of the distress, but address the distress and that's - I get a lot of traction with that.

Dr. Vega:

I think that's great. And I like the term of distress, and using that language versus agitation, which can be inflammatory, people feel like they're acting out and being blamed. And once they get on the defensive, and particularly if they have some limited understanding because of their cognitive decline as to what we're even talking about and the reasoning behind it, you know, it can actually make the situation more challenging and lead to some real tension there that - which is not good for anyone. But using terms like stress, instead of anxiety, or even agitation, talking about stress, talking about fatigue and energy versus talking about depression, I find that those are useful terms, because patients feel very comfortable, particularly in a community like mine, where these symptoms are stigmatized, and have been for generations, it just provides an easier space to enter into the conversation. So we can all kind of understand each other and then come up with some solutions together. I've found that to be very, very helpful.

Dr. Heinrich:

That's great. Yeah, that's good.

Dr. Vega:





So we've been talking about agitation, and we defined it. And I think one of the keys to the definition is that it should not be caused by medication side effects, it should not be caused by another comorbid illness that's not being well controlled. What are the most common things you see that mimic agitation in dementia, but are actually - there's a secondary cause there's something else as you mentioned, agitation is a symptom, but the cause is something quite separate from the dementia?

Dr. Heinrich:

Yeah, I'm so glad you mentioned that. Because again, one of my teaching points is that, you know, agitation is a symptom of something, it's not a disorder in and of itself. So we have to figure that out. And, you know, agitation related secondary to a dementia is really a diagnosis of exclusion, you've got to look for all this other stuff that may be contributing to it. So, you know, you look for - you look at patient factors. And I think, I believe in your module you mentioned, you know, what chronic conditions that the patient may have may be exacerbated that are causing this? Or some of the most common are depression and anxiety. But don't overlook congestive heart failure and shortness of breath. The shortness of breath presenting with agitation, the distress associated with that leading to agitation. We often think about other patient factors, like unmet needs, pain. Pain is a common cause of agitation. So we look to address that. Boredom, stimulating activities, bringing those kinds of things can do it. So you look at those patient-specific factors. But you also have to look at the environment. What's going on surrounding the patient? What's going on in the house where they're residing? Is it a too stimulating environment or not stimulating enough? Is the care manager - does the caregivers' communication style match that of the patient? A distressed, overwhelmed caregiver does not communicate often all that well. And that can escalate the distress. A frustrated caregiver often will communicate frustration in somebody - to somebody who doesn't understand the frustration, leading to agitation.

Dr. Vega:

And yeah, it reminds me of a case just from a couple of weeks ago in my own practice, a patient with severe dementia having more agitation. And what had changed was that a new job for the primary caregiver, now there were multiple caregivers that were linking up during the day. And it is, it's a challenge, I can't dictate to families that, no, you need to have one caregiver there because they need to live their lives. But there were even gaps in care where this person was left alone at times for an hour or two at a time, and was wandering and potential and getting into some, you know, some situations which could be dangerous. And so it really just took a family conference to try to bring everybody together to just, even though there's different caregivers, keep the routine the same at least. So really make sure that it's - that every day at 4 o'clock, at 5 o'clock, the routine is similar so that way we'll minimize the disruption to the patient. And so far, so good. It seems to have worked.

But there is often some root cause. You have to look for it within the patient in terms of their, you know, physiology, pathology, but also in terms of their medication list, other substances they could be using, and then finally, look to their home environment too. It's a lot. How do you move through it efficiently?

Dr. Heinrich:

We use the term cognitive reserve. We all have a certain degree of cognitive reserve that allows us to deal with stressors, to deal with chaos, to deal with schedules that go out of whack. Patients with dementia have very little, if any, cognitive reserve to deal with those curveballs life throws us. So that structure is so important for those patients. So one of my instructions to caregivers is, you know, to minimize the distractions and to maximize what cognitive re - to maximize what cognitive reserve the patient has. Don't stress it.

Dr. Vega:

Right. Yeah, because the results can be bad. Yeah.

Dr. Heinrich:

Yeah, and distressing can be environmental, it could be medications, it could be a urinary tract infection. These stressors could really be any number of things.

Dr. Vega:

Okay. Well, you know, I think this takes us to kind of our take-home points for today's session. And I'll focus on the impact overall, because if this didn't have, you know, a strong impact on patients, their caregivers, the healthcare system, you know, it wouldn't be so important. It has a major impact. So we're talking about an increased risk of death for folks with agitation in dementia. They have more clinic visits, the clinic visits tend to take longer. And clinicians oftentimes don't feel prepared and they don't feel like they've got the adequate tools to treat individuals. And then for caregivers, higher risk of burnout, which can lead to institutionalization.

I think it's also very important, from my perspective, to identify agitation and then get the diagnosis right. So remember, it has to be at least 2 weeks of symptoms, they have to be causing distress to the patient or the caregiver. And they can be caused, as we just went over, by extrinsic forces that are causing stress to the patient, which can be many different types. But if you find them, you can really do a lot of good for patients, because you could correct those without necessarily having to, you know, go to pharmacotherapy right away for agitation.





What are your take-homes?

Dr. Heinrich:

Yeah. So I mean, I would start, you know, if we've identified that there are neuropsychiatric sequelae of the dementia, it starts with defining those and characterizing those. It starts by not accepting just the term agitation, but what does that agitation mean? Give me concrete examples for that. It's by establishing those behaviors and the severity of those behaviors, ideally, through the use of some neuropsychiatric assessment tools like the Cohen-Mansfield, or the Neuropsychiatric Inventory Questionnaire. By establishing those firm baselines, we're actually knowledgeable about what we're going to treat.

And then once we know what those baselines are, we come up with a plan and how to manage it. Again, using those kinds of tools we talked about, looking at the patient, looking at the environment, and looking at the caregiver. Once we assemble that care plan, we want to monitor that care plan longitudinally, kind of going forward to the follow-up, ideally, by the use of subjective measures, how are things going, having those conversations, but by also using these neuropsychiatric instruments that we mentioned before.

One of the other really nice things about those neuropsychiatric instruments is they can - they bring value to the visit with the patient. We've talked about how time-consuming these patients are for your very short 15, 20-minute assessment, the patient's caregivers can come with these forms filled out to you, and you can - and that gives them a sense of involvement, a sense of caring for their loved one in a different manner. But it also gives you something that you can kind of sit down and look at and can guide the conversation through that piece of paper, and really do a focused, efficient type of interview with that. So it's really - we like win-wins in medicine, this is a win-win. It's an evidence-based tool that can hopefully make your job in primary care a little bit more efficient.

Dr. Vega:

Absolutely. And then that questionnaire becomes by history of present illness, actually. So there's another way to make it more efficient. Essentially, it's incorporating the medical record, which is, you know, great for continuity of care for the patient, but also just creates another sense of efficiency.

That said, I think that this is, you know, it's a tough job. You know, as a primary care physician, I think it is a tough job, but it is one of the most important jobs you can have, because you can help slow the progression of dementia, you can slow some of those negative outcomes that nobody, including you as a clinician, want for patients, and I think overall yields good things.

Dr. Heinrich:

I couldn't agree more.

Dr. Vega:

Alright. Well, hopefully our audience feels the same way and got some good use and some clinical pearls out of this discussion. Tom, it was great. Thank you for taking the time to speak with me today. And I hope everybody stays well. Join us for the next modules in the series. We're going to be focusing more on the management of agitation in dementia.

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