

**Detecting and Addressing Agitation in Alzheimer's Disease:
Improving Lives for Older Adults and Their Caregivers**

Applications from the [GSA KAER Toolkit for Primary Care Teams](#)

GSA Momentum Discussions Podcast from The Gerontological Society of America

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Announcer:

The Gerontological Society of America, meaningful lives as we age.

Jen Pettis:

Welcome to this GSA Momentum Discussion podcast episode titled, Detecting and Addressing Agitation in Alzheimer's Disease: Improving Lives for Older Adults and Their Caregivers. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. I'm delighted to be recording this podcast episode from the podcast booth at GSA 2023 in Tampa, Florida. We do have a lot of background noise here at GSA 2023, but that's exciting. It's because there's 3,700 people in attendance. We're grateful to Otsuka for their support of today's podcast episode. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America. I'm delighted to serve as the host for today's Momentum Discussion. My guests for today's podcast are great members and good friends of GSA, and they are Dr. Carolyn K. Clevenger, professor at the Nell Hodgson Woodruff School of Nursing at Emory University and the Clinical Director and a practicing nurse practitioner at Emory Integrated Memory Care, a nurse-led primary care practice for people living with dementia. Dr. Clevenger is joined by her colleague, Laura Medders, a licensed clinical social worker, and the Administrative Director of Emory Integrated Memory Care. Dr. Clevenger and Laura, thank you for taking time out of your busy schedule here at GSA 2023 in Tampa to share your insights around the common neuropsychiatric condition of agitation in Alzheimer's disease and how it impacts individuals living with Alzheimer's and their caregivers.

Laura Medders:

Thank you so much for having us.

Dr. Carolyn Clevenger:

Always a pleasure, Jen.

Jen Pettis:

Dr. Clevenger, would you explain the condition of agitation in Alzheimer's in general to our audience?

Dr. Carolyn Clevenger:

The word agitation is something we've thrown around for a long time in the care of people with dementia. The classic story for nurse practitioners like me is, in long-term care, you receive a call from the staff, the frontline workers, and the report is agitation, which is this global word. What does that mean? I've evolved my practice over the years by asking either direct care staff who are in maybe senior living communities or families to paint me a picture, what does this look like? What are they doing? What are they saying? I'm trying to get at the root cause of what exactly we're talking about because it's so global. It's been used as a label to describe almost anything, although I will say none of it is pleasant. You clearly know it's a negative connotation.

We've got a problem with this person, and we're really trying to untangle all of that. Our colleagues in geriatric psychiatry and the International Psychogeriatric Association formed a definition informed by clinical experts. They mapped out what does it mean when we say agitation from a clinical perspective if you're making that diagnostic label for someone. A couple of things to consider include that this person does have to have in the setting of dementia, specifically Alzheimer's disease, because we're talking about agitation in Alzheimer's disease. Therefore, there's not something else acute going on like delirium. This would be separate from that.

Dr. Carolyn Clevenger:

They also have active psychosis. It is its own neuropsychiatric symptom and requires its own evaluation and treatment plan. Agitation is something that's been present for a period and it's significant enough that it's causing a negative interaction with their social wellbeing and their ability to interact with their caregivers, in particular. This is literally in some of the risks of agitation, which we'll talk about in a little bit.

Once you establish that context and understand the scenario in which you find yourself, then you have these three categories. We would group the first symptoms under excess motor activity. This is the person who's restless, maybe they're pacing, may or may not be exit seeking, but they're restless, they're rummaging. I have several people who are packing bags, going through closets, and so forth. The next is verbal aggression. This is possibly being disinhibited, but generally negative and difficult in terms of their verbal responses too many times to people who are caring for them or who are trying to provide care. We would group physical aggression as well. That can be anything from pinching, biting, kicking, throwing objects, and so forth. If you're really paying attention and you get a good history, you often find that these symptoms begin with either restless motor activity or excess motor activity and things escalate through verbal aggression and then to physical aggression. Therefore, it's helpful to support people while they're still at that initial category of symptoms to try to get ahead of it.

Jen Pettis:

Laura, at Emory's Integrated Memory Care, you and your colleagues provide primary care to individuals living with dementia, including Alzheimer's. How might a caregiver, either a paid caregiver, maybe in a congregate living setting, or a family caregiver describe agitation to you as a member of their care team? Then can you talk a bit about how it impacts those family givers, how they might really talk about the experience to you?

Laura Medders:

As Carolyn mentioned, most of our caregivers, whether they're paid or unpaid or not, will call the clinic saying this person is agitated, or they're experiencing symptoms of agitation. They're describing a whole lot of other things. I think for family caregivers, they do not understand that agitation is a not uncommon experience and symptom that shows up within the disease progression. They may be hesitant to describe these symptoms that their person is exhibiting because they feel that they should be able to manage this. They are concerned that their loved one is angry with them. This is viewed as a reflection on them as a caregiver, not a reflection of the disease progression. I think some caregivers are not as forthcoming about some of the challenges that they're experiencing on a day-to-day basis because of how they think that reflects either upon them or upon their person and their loved one that they are providing care for.

Family caregivers often describe those symptoms that Carolyn described as my person packing up every day. "They're driving me nuts with the bags that are at the front door trying to leave town. I don't know where they think they're going. They're up all night, trying to exit the house because they think they're trying to go to work. They're disoriented, and they're really frustrated about why I won't let them go to work. They're keeping me up all night." It's their personality changes that they've never seen like this before. "I don't understand why things don't just roll off their back like they used to. This is not a big deal. Why are they getting so upset?" These things are much more frequently presenting themselves in just a venting session instead of, I am reporting symptoms of agitation to my provider.

Laura Medders:

They often don't think to bring it up unless providers are asking about it. I think for paid caregivers in a formal setting, whether it's a long-term care setting or somebody that you're bringing into the home, what they report are different symptoms of agitation. I want to be clear that being uncooperative is not a symptom of agitation. What we get from some assisted living communities and other long-term care settings is paid caregivers who are calling and reporting that this person is really agitated because they didn't want to take a bath today. Well, did you ask them more than once? Did you try different strategies? How did you phrase that question? Who is the person that is asking? There's lots of different ways to understand what the context of these symptoms are to really tease out whether this is agitation or something else. Is there pain that's involved that's been left untreated? I do think it is not something that is well defined to the broader community so that there's a lot of education to be done around how we educate people to report these symptoms to their providers as well.

Jen Pettis:

How common of an issue is this, would you say, for people with Alzheimer's?

Laura Medders:

It's incredibly common. I would say 8 out of 10 patients will experience symptoms of agitation at some point during the disease progression. I think most people associate agitation with the middle stage of Alzheimer's and other types of dementia. I think in the middle stage people are losing some of their cognitive abilities, but they still have the physical abilities to get in a lot of trouble, is what we hear. Caregivers will say they're just getting into things.

It can really happen at any point of the disease progression. In the earlier stages we think of people who are reactive to situations that might not have been a big deal before. In the late stages, there's anger around things that they would not have previously been angry about. If you've worked in a skilled nursing facility or long-term care, you've seen people screaming in the corner, possibly because they are under stimulated or just frustrated with whatever their experience is. It can happen at any point in the disease progression, which is very common.

Dr. Carolyn Clevenger:

I want to add something that Laura was talking about. I was thinking about agitation from the clinician's perspective, and she was adding what the family caregivers report. I was part of a team in the last year that did some social listening and focus groups with both of those parties about the agitation term and how they use it. What we found is that clinicians are more likely to think of it as a symptom, because we're thinking about a disease and disease progression and symptoms also help us think about staging. When I consider if we have transitioned to moderate stage, we are starting to see more neuropsychiatric symptoms including agitation. Family or informal caregivers saw it more as a personality change. I think certainly that reflection for them, was reading into the meaning of the behavior, thinking about behavior has meaning. Is that the form of communication?

It was more about this person's longstanding personality and how similar or different it was from their longstanding personality. It makes sense for families. They have this long relationship with this person and it's very difficult to tease out what is the disease and what is the person.

Dr. Carolyn Clevenger:

Many things may be persistent, maybe we've always had difficult interactions, maybe these are very different interactions and that's sort of a stark change for the person. Families have not necessarily thought about this as a symptom, as a clinical meaningful measure, that we might think about from an Alzheimer's disease management perspective.

Jen Pettis:

That must have been interesting research to be part of. In your practice, Dr. Clevenger, you, and your colleagues often see firsthand the burden of the individual. Would you share a little more about are these symptoms impacting the individual's quality of life?

Dr. Carolyn Clevenger:

For people living with dementia, living with Alzheimer's disease, one of the earliest symptoms and progressive symptoms is memory loss, right? I think we must remember that there are lots of forms of memory. While this person may not remember the actual interaction that happened, those emotional cues or the feeling that an interaction leaves you with tends to persist. Those are stored in different parts of the brain, right? The more emotional or deeper the brain, less of the cortex. For people who are experiencing or expressing agitation, I think there are challenges for their own level of distress. Whether or not they're able to communicate that to you, define it, characterize it, is a whole other question. You will see a negative interaction or feeling of that rummaging, that pacing, that sort of searching for something they can't get to - that stays with people.

You can watch them get escalated. For that reason, I think sometimes families will say they're anxious. What does that look like? What it looks like are these behaviors of agitation, but they're reading into like they're upset, they need something. You can tell they are in that moment certainly in some distress, which is not short-lived. We distract, we redirect, we try to engage people in something more stimulating. In time you can get past that. For example, sometimes we may start our day off with a terrible meeting; the rest of the day you have that feeling sitting with you and lingering in the back of your mind. Even if I didn't remember the actual interaction itself, I just have that bad feeling. Similarly, that distress is there for those people who are experiencing it. Some of my patients who have less amnesia can recall some things. They will acknowledge that they've been blowing up at their family or caregivers. They say, "I know I've been mean" and they feel guilty about it when they're sitting in the exam room with me. While we offer both caregiver only visits and patient and caregiver visits together, if they're doing that together and the caregiver's telling me this is happening and this is what they're saying and doing and they hear those behaviors about themselves, and they have some acute guilt in the moment.

Jen Pettis:

Laura, caregivers often think of dementia as memory loss and don't consider that their loved ones may experience symptoms like this. How do you and your colleagues at Emory Integrated Memory Care help to prepare families for the possibility or perhaps the probability that their loved one will experience these symptoms?

Laura Medders:

Education is important for families to understand that this is not an abnormal part of the disease progression. That often comes through a lot of education. We offer formal educational training for family caregivers. We have one-off training with a social worker to prepare families for these symptoms that may occur, and here are strategies to help address those behaviors. If this is happening to you, our nurse practitioners do a really good job of providing that anticipatory guidance.

We're entering the middle stage of this disease progression and here are things that we would not be surprised to see showing up with your person so that family members are not surprised when they're agitated. If they've done any of the educational classes, they have a plan for how to manage that, but hopefully they're not bringing their loved ones to the hospital or at least know that there is a plan, there are resources that we can do something about that within the clinic.

I think that's helpful. I will say that family members feel very isolated because this is not who their person has been. This agitation, this conflict that they're getting into is a difficult burden for them just psychologically and emotionally because they come to caregiving because they have this relationship with the person. The caregiver has a job to do. There are tasks that go with caregiving, but they are in this relationship with the person, like Carolyn said, for several decades. It's your spouse, it's your parent, it's your sister. The interactions for caregivers are something that they are also carrying for a long time. Very similar to the patient.

I had one caregiver who was talking in a group recently where the noise that the dog food made in the dog food bowl was just very upsetting to a person who was living with Alzheimer's disease, and he got very angry at his spouse. "Why would you do this? I can't believe you did this." It was very uncharacteristic response to who this man had been his whole life. The caregiver is talking about it months later. She has all this guilt about it. "I don't know, I'm walking around on eggshells all the time because I don't know how to respond to him. I don't know what's going to set him off." They're carrying a lot of this frustration and burden and just discomfort and the caregiving relationship. They have the memory as well of what this experience has been like. The husband has no idea that dog food was ever a problem, and he has no remembrance of this. It hasn't been an ongoing issue. This is something that many caregivers think is only happening to them. They feel it's their fault if they're not responding in a different way. Normalizing that information for a lot of caregivers I think provides a lot of support. They discover that they are not the only ones going through this experience of living with someone with Alzheimer's. We have support groups through the clinic where caregivers can share these experiences and then we also have a clinical social worker who does individual and family psychotherapy so that we can help families process these changes that they're seeing in their loved one and how that impacts them.

Dr. Carolyn Clevenger:

I think this is the power of having a practice that's all three in one, which includes primary care, dementia care, and caregiver services. Even if somebody's not going to take advantage of a class or a support group or even some of our one-time or just-in-time lecture series, they're still going to be meeting with that dementia care specialist, the nurse practitioner, who's going to say, here's where we are today, this is where we're headed. I anticipate these things. If I'm not surprised, you shouldn't be surprised. For people who would never access a dementia specialty practice, you're going to come to primary care if you're living with any chronic conditions probably. Even in that space, you're still going to have this condition addressed.

Dr. Carolyn Clevenger:

You're still going to get whatever amount of education and coaching you're able to access today. We want to make sure you have that education and coaching in whatever form and in whatever length that you're willing to access or have the capacity to access. Even if it's the shortest we can make it as far as integrated into the visit. I know if I hear something in a visit, I can say to Jenny, the social worker, hey this came up. I'm going to have them do therapy individually with you. Someone mentioned something in the group, I know about it when I see the patient again. That's the value of having all those things in one location.

Jen Pettis:

In our KAER Toolkit, we talk about using quick screening tools for cognitive impairment. Are there such tools for agitation and Alzheimer's disease?

Dr. Carolyn Clevenger:

There are now. We're excited to be part of the team that really started this journey, listening to how people were defining agitation and coming from different viewpoints. With that newer definition from the International Psychogeriatric Association, now we have a well-defined, much better defined than it has been tool that we can use to screen. The audience, in particular people who see this symptom but don't recognize it as a symptom, are family or informal caregivers. We now have the AASC tool and that is to be used as part of your process for doing check-in. Many practices who do dementia specialty are probably doing a form of a screener for neuropsychiatric symptoms. Some of our challenges in using the broader tools is that particularly agitation was not well-defined when those were created.

That's sort of one limitation and you're sort of getting a touch on everything and sometimes when you're asking a list of 12, 13, 15 things, the definition for people to understand what you mean by some of these symptoms is just really depends heavily on the way the question is worded. The AASC tool is really designed for family caregivers. It uses language that is more family or informal, individual specific. I think you'll gather again information about something that otherwise may never have been mentioned unless you intentionally ask for it, which is the idea of doing screening tools like this. In our primary care practice, that means we're going through volume in a day just like most primary care practices, although we do have longer appointments by intention. I won't say we're running 15-minute appointments here, but it's still primary care.

We're doing all the things. We're making sure your pneumonia shots caught up right now and your RSV vaccine at the pharmacy. That's what's happening in Georgia in terms of our, how we're getting those to patients. We use tools like this as part of our e-check-in process. This is to gather the information that you need. We know that the care measures or quality measures for dementia care require that you're assessing or screening for neuropsychiatric symptoms every six months. We can time them that way. We can do them intentionally with something like your cognitive assessment and care planning visit. I will say the AASC tool is one of the shortest, I think we worked hard as a team to keep that brief and it's certainly not going to overwhelm people in terms of the volume of questionnaires you can get in terms of e-check-in sometimes.

Jen Pettis:

I have two questions and follow up. The first is you're saying the AASC tool, what does that stand for?

Dr. Carolyn Clevenger:

AASC is Agitation in Alzheimer's Screener for Caregivers (AASC).

Jen Pettis:

I understand you are the lead author on sharing that information here at GSA 2023. Can you tell us about that?

Dr. Carolyn Clevenger:

I have such a robust and excellent team of experts who have worked on this, and I'm delighted to be the primary author for GSA this year to talk about this screener. The team includes geriatric specialists, geriatric psychiatry specialists, and neurologists. We pulled this tool together. We have done a little bit of testing, which I'll be presenting on some of our earliest testing in qualitative feedback from folks. Then, we were able to sort of refine the tool from what we initially built. When you're using a new tool or a new measure, the measure development is like its own science. We're really delighted to have Dr. Jack Cummings as a part of the team who is very experienced in screeners and measures. You can expect, I think, some ongoing validation of studies going on after this. But we'll be talking about what we've done so far, how we've refined it, and launching the new website where you can download it.

Jen Pettis:

Well, that's terrific that it's happening here with GSA's Annual Scientific Meeting. This was a great discussion, exciting stuff. Some wonderful information in our podcast. One about how common this symptom is and how significant the impacts are on the individuals. It's wonderful that there is a new tool that's available for clinicians that family caregivers can just answer a couple of questions and really give that valuable insight. I'll ask you each to leave me with one final point. A last word from you, Laura?

Laura Medders:

I would like families to realize that this is a normal part of the disease progression or can be a very normal part and it is common. I think it is important that they understand that this is something that they can report to their practitioner, their provider, to say that my person is experiencing these things. It's exciting that now there are things that can be done. I want people to understand that these are symptoms that are a normal part of the process and should be talked about instead of suffering alone from that process experience.

Dr. Carolyn Clevenger:

I would add from the practicing clinician, this is one of those symptoms that can be embarrassing to talk about. People feel like they're telling on their person or saying negative things about their person because they don't realize that it is a symptom. They don't realize that it's part of the disease. They really are suffering in silence. As I mentioned, those symptoms of agitation do tend to escalate. As a clinician or running a busy practice, you certainly want to identify a symptom early in its stages and get ahead of it because none of us like to go from crisis to crisis. Otherwise, if you allow something to escalate to crisis level where someone is not physically aggressive, we are dealing with insecurity in the home and identifying caregiver safety. Let's get at this when we are at an earlier stage so that we can address it sooner. Both improve and protect, preserve the quality of life for the person experiencing it and for the person who's caring for them.

Jen Pettis:

Thank you both so much for joining me here. Thanks for all your great work and your wonderful contributions to our work at GSA. Enjoy the rest of the meeting.

Announcer:

The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.