
Alzheimer's Related Psychosis: Personal and Clinical Perspectives for Understanding and Responding to Delusions and Hallucinations

Applications from [The GSA KAER Toolkit for Brain Health](#)
Momentum Discussions Podcast from the Gerontological Society of America

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Announcer:

Welcome to a Gerontological Society of America Momentum Discussion podcast, where we explore groundbreaking topics in the field of aging.

Jen Pettis:

Welcome to this GSA Momentum Discussion Podcast episode titled *Alzheimer's Related Psychosis: Personal and Clinical Perspectives for Understanding and Responding to Delusions and Hallucinations*. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Bristol Myers Squibb 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 (GSA). I'm pleased to serve as the host for today's Momentum Discussion.

I am delighted to be joined by two guests for this podcast episode: Dr. Kalisha Bonds Johnson, a clinician-scientist and psychiatric-mental health nurse practitioner whose work focuses on dementia care, caregiving, and family support, and Maureen Morrison, whose husband, Angus, lives with Alzheimer's disease. Kalisha and Maureen, thank you for taking time out of your busy day to talk with me about Alzheimer's-related psychosis and how interdisciplinary person-centered approaches can help improve quality of life for people living with Alzheimer's dementia and their caregivers.

Welcome.

Maureen Morrison:

Thank you. Happy to be here. Thank you.

Kalisha Bonds Johnson:

Yes, thank you for having us.

Jen Pettis:

Great. Dr. Bonds Johnson, let's start with you. Alzheimer's related psychosis affects many people living with Alzheimer's dementia and often includes delusions and hallucinations that can be distressing for both individuals and caregivers. To start, how do you define Alzheimer's-related psychosis?

Kalisha Bonds Johnson:

I think just how you did, right? It's someone living with Alzheimer's disease who has, typically, what we see are delusions or hallucinations. Sometimes, it's hallucinations. Sometimes it's together, but delusions are these fixed beliefs. Someone's trying to harm me, someone's out to get me, someone stole from me. Hallucinations are typically where you, or where the individual will see things, hear things, feel things that aren't there.

Jen Pettis:

All right. Thank you. How common of a problem is Alzheimer's-related psychosis?

Kalisha Bonds Johnson:

It's more common than we probably give it credit. Typically, we don't see that in the early stages, but often in that middle, moderate stage of dementia is where it ramps up.

I think that because it doesn't happen to everyone and it happens a little later in the disease process, we as clinicians often don't speak about it, right? I don't want to scare people into what might happen. I think sometimes we're nervous about the idea of that. If you've seen one person with dementia, you've seen one person with dementia. I don't want to tell you too much, but sometimes I wonder if we don't tell families enough about it.

Jen Pettis:

Okay. My next question was going to be where in that continuum of Alzheimer's it's most common for hallucinations and delusions. You said really middle stage?

Kalisha Bonds Johnson:

If it happens early, that typically often is not Alzheimer's dementia. With the psychosis associated with Alzheimer's disease, it's typically in that kind of middle phase. People are starting to notice that they may be having some issues. We may actually have a diagnosis at this point. We think we know what's coming, and then bam. It's a new level, oftentimes, for families, and one that is sometimes really hard to talk about, again, because I don't think we've put out enough information about it.

Jen Pettis:

I suspect when a family comes to you, talking about their loved one, they don't say, "my loved one has Alzheimer's-related psychosis and these symptoms of delusions and hallucinations." Instead, what might they say to you?

Kalisha Bonds Johnson:

One case that I found really interesting is a family I had been seeing for a while. She said, "My mom's not sleeping at night." As the clinician, I'm thinking, "Okay, maybe she needs a sleep aid. Maybe we need to make sure she's more active throughout the day." However, what actually happened when we started talking was that the daughter shared with me, no, her mom is hearing a baby cry, and she can't go to sleep because she keeps hearing this baby crying at night. We needed to fix the hearing of the baby crying, which again is an auditory hallucination, to get her to sleep. Sometimes with the more distressing cases, and I say distressing just because anytime there's aggression or irritability, sometimes those are just tough for both the person living with dementia and the family care partner. I've heard things like, "they become really, really agitated or really irritable."

I had one client who would run out of the house. If the door were open, she would run out. What we found out is that she was seeing things in the home that were really distressing to her; she was leaving. Sometimes, with the agitation, it's often about thinking someone has taken something from them, or that you're not really the spouse you say you are. Again, these beliefs happen. I think what I would tell clinicians is that we have to be curious and that we often can't. I recognize that visits with a healthcare professional are quick. They're short. I mean, you may get 15, 20 minutes with someone.

I think families are like, "Let me just give them the cliff notes. Let me just tell them the really quick things that are happening." I found that if you tell me the full story of what's happening, I can pick it apart and pull back layers. You have to have time to do that. You have to be curious, because you'll miss something. The example was sleep. Like if I'd have just said, "Okay, let me just give her something from sleep. Here's some melatonin," I'd have totally missed the fact that she was staying awake because she was having this auditory hallucination.

Jen Pettis:

Okay. You've alluded to this a bit, but why is it so important that we identify these symptoms and diagnose Alzheimer's-related psychosis when it exists?

Kalisha Bonds Johnson:

Because I found that it doesn't go away; it doesn't just tend to go away on its own. Oftentimes I've found it to be extremely distressing for not only the person living with dementia, but also for the family. And I've found that it typically exacerbates and gets worse over time if not treated. We have medications that can treat this pretty well, in my opinion, if we give the right medicine at the right dose. Sometimes finding that is a bit of a task, but I think, for quality of life, the ability to have more good days, better days, to keep that person at home longer, to keep them in assisted living longer. These are the behaviors that have someone removed from the home, that have someone I don't want to say kicked out, but asked to leave a facility.

These are the behaviors that are just challenging. They're challenging to manage, and we do have medications that can help.

Jen Pettis:

Great. Dr. Bonds Johnson gave us a bit of clinical insight, and we're going to turn to Maureen now. Maureen will share with us some personal insights about her and her husband Angus's journey with Alzheimer's disease. Maureen, can you share with us a little bit about Angus's initial diagnosis when he was diagnosed with Alzheimer's disease and the signs and symptoms that led to that diagnosis?

Maureen Morrison:

Sure. He was diagnosed with early-onset Alzheimer's in 2016, so about 10 years ago. I personally saw signs I hadn't understood before then. My husband is a brilliant man, very social, and a scratch golfer, right? I noticed changes in his personality. He was withdrawing from any place with multiple conversations going on. I later realized that he couldn't follow them anymore. He was paying our bills. He would pay the same bills three, four, and five times. I would open the bills and find these huge credit balances because he had been doing something. My husband's a CPA, so he knows how to balance books, and he would do things like that. I knew something was wrong. Ultimately, Jen, he came to me, and he said, "You know, I think something's wrong. I think I need to go to the doctor."

When he went to his physician, at first, they said, "No, it's not. It couldn't be. You're just too young." They thought it was a vitamin deficiency. Ultimately, they sent him. When it didn't go away, they sent him for neurological testing, and it turned out to be early onset. That's when everything seemed to change.

Jen Pettis:

I understand that he did experience psychosis related to that. Kalisha described for us the delusions and hallucinations from a clinical perspective. I'd love to learn about your experiences with how Angus was living with these signs and symptoms.

Maureen Morrison:

Kalisha is absolutely right when she said it normally happens sort of in the middle of the journey. Angus began to get hallucinations and delusions probably about three months after his diagnosis. Everything from, the neighbors are out to get us. The neighbors are trying to take our home away from us. The one that was very difficult to deal with was that he was convinced that people were trying to harm him physically, and they were following him in a black pickup truck. Now, I live in Georgia. There are a lot of black pickup trucks in Georgia. Every time I took him out, either to the doctor's or to adult daycare, he would see a black pickup truck and become very agitated and upset. It seemed to prove to him that they were following him.

He was convinced at one point in time that there were two Maureens, one of whom he was married to. He told his brother that he wanted to divorce the old Maureen and marry the new Maureen because he liked the new Maureen better. Just bizarre things that are so counter to his loving personality in the relationship that we've been married 35 years. Just all of this was really hard to deal with. When it came to hallucinations, he saw people in our living room. He was standing in our dining room, and he saw people in our living room. I noticed he was nervous, upset, and agitated. I said, "What's wrong?" He said, "They won't leave." I said, "Angus, what? Who?" He was pointing towards the other room. He said, "They're in there." He was getting more and more upset.

That happened more than once. Then there was a time I walked in and saw him actually talking to no one, but he was in the middle of a conversation. Seeing that no one can prepare a spouse or caregiver to see something like that.

Jen Pettis:

I'm sure. How did all of those things that Angus experienced impact his quality of life, his ability to engage in meals or activities or time with family and friends?

Maureen Morrison:

He became very withdrawn. He stopped playing golf. His social life: there were very few people that he wanted to be around. It, it really, he didn't trust, he didn't trust anyone. He looked. He didn't sleep well because he was always, at least during this time period, concerned about someone coming into the house. It affected multiple aspects of his life.

Jen Pettis:

How about your life as a caregiver? How did it impact you?

Maureen Morrison:

Jen, I couldn't believe it. That is the hardest thing about being a spouse of someone with Alzheimer's. You cannot believe that the person you're married to is going through this. For the longest time, I tried to reason with him. I tried to say, "Honey, no, there's no one there." Or, "Honey, of course not. They're not trying to steal the house." I probably did that for too long. What I ultimately learned was to acknowledge what he was thinking or seeing and then try to help him through it. For example, one day when he saw those people in the living room, I said to him, "Honey, would you like me to go ask them to leave?" He said, "Yeah, would you, please?" I said, "I got it. I'll take care of it, sweetheart. You sit down." I walked into the other room and waited for 30 seconds. Then I came back and said, "They're gone. No worries. I fixed everything." He was so grateful. He was so relieved. I felt like, oh, I've been doing this wrong all along. I should have been doing this earlier.

Once I learned that worked: not to try to deny it, but to accept that he was seeing it and feeling it, then it was easier to deal with him. Because then I could say things like, "Honey, you trust me?" He'd say, "Yes." I said, "All right, I'm going to go out and talk to the neighbors, and I'm going to put a stop to all this nonsense. All right?" He'd say, "Yes, please." I'd come back and say, "That's finished." He was like, "Oh, okay." It didn't solve everything, but it certainly helped in the moment, right? When you're dealing with someone with Alzheimer's, it's just a collection of moments, right? You have to get through each moment.

Jen Pettis:

In addition to joining him where he was and helping him give it with that reassurance, were there other things that you figured out along the way that might help maybe when he saw the black trucks or, or did something, that might help either prevent the problem or help him relax when he had the issues?

Maureen Morrison:

One of the things I would try, with mixed success, was to distract him. This sounds funny, but M&Ms were a great distraction. My husband has the biggest sweet tooth, so if he were getting upset, I would say, "Hey, honey, you want some M&Ms?" All of a sudden, he'd be standing by the candy bowl, and he'd be eating M&Ms. It didn't always work, but it did sometimes. Because he knew he was upset, but very quickly he'd forget why he was upset. He'd forget that he saw that black pickup truck. He'd forget that he saw the neighbors. He just knew he was upset. If I could give him ice cream, M&Ms, or something, he could concentrate on that. I tried all sorts of stuff, but that tended to work reasonably well.

Jen Pettis:

Great. How about in conversations? I know you had a very close care team who you thought an awful lot of caring for Angus.

What were kind of strategies and supports and conversations with that care team that really helped you to understand better and respond to these symptoms?

Maureen Morrison:

The first thing was that it made me feel like I wasn't alone in this. Alzheimer's can be the most isolating experience, not just for the individual, but even more so for the caregiver. You want to protect the person. Your circle of friends becomes much, much smaller. To have someone who understood the disease, and my group of people really did, and they gave me advice. When I would, I would literally walk into the office in tears sometimes. They would listen and hug me. They would say, "You're going to get through this, and we can help." They gave me ideas, but mostly they were there to listen and say "yeah" to acknowledge how awful this was and to let me know they were there to help whenever they could. That meant the world.

Jen Pettis:

What advice do you have for other care partners whose loved ones live with Alzheimer's and may be experiencing hallucinations or delusions or other troubling symptoms?

Maureen Morrison:

As Kalisha indicated, everyone's journey is different. While you want to educate yourself about what this disease is like, realize that there's no playbook here. There's no map of how this is going to work. Reach out to people, but take what they say, especially if it's someone else who's going to tell you their story, and realize that it may not happen to your person. What happens to your person may be very different, may be much worse. Be willing to open up to ideas. Secondly, you can't do it all yourself. I tried. I tried. I was going to. The minute he was diagnosed, I was going to handle it. That was my new project in life, and I was going to handle this. I couldn't. I did it for years, but I couldn't do it all myself.

I needed my children. I needed my friends. I ultimately needed care partners. I ultimately needed adult daycare. Then finally, he's in a memory care facility, which was so hard for me to acknowledge that I couldn't do it all, but I couldn't take care of him. I probably should have gotten there sooner. It would be a little easier on yourself to accept help and realize that this is a journey you have to take a day at a time.

Jen Pettis:

Okay. Thank you so much for sharing your insights, information, and advice for others. I'm going to go back to Dr. Bonds Johnson for a minute and ask, from your clinical and research perspective, what interdisciplinary care strategies can help individuals with Alzheimer's-related psychosis in their care, in their family caregivers?

Kalisha Bonds Johnson:

That is such a good question. I'm going to get to it, but the one thing I want to say is that Maureen touched on some really great non-pharmacological interventions. As a clinician, my mind often goes to medication first, but we know they can have many side effects. Being able to distract, be in the moment, and go into their world with them is so important.

When you think about it from an interdisciplinary team, you want someone who can prescribe meds because sometimes you need meds. Still, often families are really hesitant to add medications in dementia across the board, regardless of the type of dementia, and especially the types of medications that we use for psychosis and delusions, which are antipsychotics, which do carry a black box warning, which means we shouldn't prescribe them lightly. There is a risk of increased death when someone living with dementia takes these medicines.

You do have to weigh pros and cons around that. Again, you want someone who can diagnose and prescribe, but you also want someone who can see you and meet with you. I love social workers for that. They often know where the community resources are. They're often the ones who'll have the family meetings with you and practice and prepare. Whether it's I want to have this birthday party with the person living with dementia, or I want to take them on a trip, or whatever, I want to work through how we're going to handle Christmas or Thanksgiving. There are so many great resources that social workers bring to the table. Then also our nursing colleagues, to be able to triage and to talk through different things that are happening.

I think Maureen said it beautifully; you really do need a team. It takes a village. I would tell all care partners, caregivers, family members, whatever word you subscribe to that are listening that you can't do this alone. You shouldn't do this alone. It's not safe for you to do it alone. Regardless of when you get to it, because I want to extend Maureen grace, just like she's extending to all the listeners, whenever you realize that is when you realize it. I think we all want to do the best we can for the person we're supporting, especially when it's a spouse. I mean, we didn't take those vows lightly. Just know that you need a team. And if the team is not giving you all the things you need, then seek out resources like GSA, the Alzheimer's Association, or a foundation if the person has a different dementia associated with the type they have.

Support groups can be really helpful to hear what other people are doing and how they're troubleshooting different behaviors. It really does take a village.

Jen Pettis:

You mentioned non-pharmacological approaches, and Maureen shared some great examples. What are some other non-pharmacological, person-centered approaches that caregivers might try?

Kalisha Bonds Johnson:

It really does depend on what they're experiencing, but, for example, I have had clients who heard babies. Sometimes having a baby doll is helpful. If there were a homemaker, a caretaker who had babies themselves, sometimes that can be helpful. I often distracted individuals by doing laundry. I remember working in an assisted living nursing home. We would mess up the clothes behind the nursing station and bring them back. The lady said, "You sure have a lot of laundry." "Yes, ma'am, we do, but we are so grateful that you are here to fold it with this."

One of the questions I always like to ask is, "What did that person do for a living?" What was the main thing that made them feel important?

Can we incorporate that into the task we have? I had another gentleman I worked with who liked building things. We had this box with various keys and other items you could use to unlock the door. Then, so really figuring out. It's hard, when you ask, like, what pharmacological things do you do? It's hard because it really does need to be tailored to the person living with dementia. The one thing I will say, and the one thing that even Maureen mentioned, is that you try something. If it doesn't work, you try something else. Sometimes you get success, sometimes you don't. The one thing I tell the families is that the neat or the forgiving thing about dementia is that if it's a bad day, guess what? They're going to totally forget it eventually. Then we can try something else, either the next day or in a couple of hours, depending on how their disease progresses. Just be kind to yourself.

Jen Pettis:

Okay. Thank you. Ladies, this was a great discussion. I appreciate so much that you are so generous with your time and your insights. What are some final things you want to leave our listeners with? Dr. Bonds Johnson, let's start with you.

Kalisha Bonds Johnson:

Final things. Do not be afraid to mention this to your healthcare team. I think oftentimes it's easy to say, "I've got this. I can do it. I don't need help." Speak out to someone on the healthcare team. If it's a clinician, sorry, we're probably going to recommend medications. You should feel comfortable saying no. If that's not what you're comfortable with, say no. Try the non-pharmacological options, whether it's driving them around or distracting them with sweets. I have a huge sweet tooth, so I would've been right there with your husband, enjoying all of that. Or, getting them what I- and I feel like I'm blanking. Whether it's getting them a stuffed animal or a baby doll, giving them things to play with, or giving them things to do, like laundry and different things.

Sending them to an adult day care, keeping them active, working in the garden. Whatever it is that you think will work, give that a try. Remember to be kind to yourself. Most importantly, unfortunately, I wish we had a playbook. I wish we had a map that we could give you and say, "This is exactly how this disease is going to progress." We don't. I know that makes it really challenging for families, but know that, as clinicians, we also struggle with wanting to provide you with the right answers while recognizing that sometimes we can't.

Jen Pettis:

Okay. Thank you. Maureen, how about you? Final things you'd like to share with our listeners?

Maureen Morrison:

This journey my husband and I are on has been the most challenging thing I've ever encountered in my life. It continues to be. It's not over yet. I will say that looking back on the last 10 years, there have been moments when people have reached out.

I call it the kindness of strangers, right? When someone I haven't seen in years sends me a greeting card that says, "Thinking of you and praying for you." Or someone will come up and say, "Hey, I'll watch Angus for a half hour. You go take a walk." Those moments have kept me sane throughout this journey. What I would say to the caregivers is accept those moments. What I would say to everyone else is that it seems like everybody I know knows someone who's going through this journey.

Please reach out to them. No one knows what to say to someone who's dealing with Alzheimer's. Just say, "I'm sorry. What can I do to help?" or listen. How was your day today? When someone calls me and says, "How was your day today?" Some days I really need to talk to somebody. That makes all the difference in the world. I think as we, as the population ages and as more and more people have to deal with this terrible disease, we are all going to have to get better at learning about it, hopefully not dealing with it, but helping those that are.

Jen Pettis:

Thank you very much. Ladies, thank you again for joining me. I found this information meaningful, and I'm sure our listeners will find this discussion helpful. For those listening, thanks so much. I hope you found it as meaningful a discussion as I did. Thank you again, Kalisha and Maureen.

Maureen Morrison:

You're so welcome.

Announcer:

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