Non-Pharmacological Strategies to Support Behaviors Experienced by People Living with Dementia

Applications from the GSA KAER Toolkit for Primary Care Teams

Momentum Discussions Podcast from the Gerontological Society of America

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Guest:
Kalisha Bonds Johnson, PhD, RN, PMHNP-BC
Assistant Professor, tenure track
Nell Hodgson Woodruff School of Nursing Emory

Host:
Jennifer Pettis, MS, RN, CNE
Director of Strategic Alliances
Gerontological Society of America

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

Jen Pettis:
Welcome to this GSA Momentum Discussions podcast episode titled Non-Pharmacological Strategies to Support Behaviors Experienced by People Living with Dementia. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of The GSA KAER Toolkit for Primary Care Teams and today's podcast. 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'm so happy to be joined by a terrific GSA member for this podcast episode. Dr. Kalisha Bonds Johnson is an assistant professor tenure track at the Nell Hodgson Woodruff School of Nursing at Emory University and a board certified psychiatric mental health nurse practitioner at Emory Integrated Memory Care. Welcome Dr. Bonds Johnson. I'm so glad that you could join me.

Dr. Kalisha Bonds Johnson:
Thank you for having me, Jen. I'm delighted to be here today.

Jen Pettis:
To begin our discussion, Dr. Bonds Johnson, would you share a few insights into the common behavioral symptoms associated with dementia? What are the symptoms and how might they present to care partners and others?

Dr. Kalisha Bonds Johnson:
That's a great question. Symptoms vary depending on where someone is in their disease process when we think about dementia. There are also different types of dementia, but there do seem to be common symptoms that we see. Typically, early in the disease process, it's common to experience some depression and anxiety, especially around the diagnosis, recognizing that right now there is no cure for dementia. People wrestle with their new diagnosis. As the disease progresses for some dementia and even early in the disease for other dementia, sometimes people will hallucinate or see things that aren't there, hear things that aren't there, occasionally feel things on their skin that aren't there, or have what we call fixed beliefs or delusions. The hallucinations and delusions fall under this category of psychosis, and so we do sometimes see that with dementia. The last common behavior I'll mention is mood instability or irritability or agitation, whether that's verbal or physical outbursts that sometimes are associated with individuals living with dementia.

You asked me how they present. For depression, sometimes you see sadness, people are more tearful. Sometimes individuals don't exhibit those typical sad symptoms and they become angry or upset. With anxiety, there's usually a lot of worry or fear. For the care partner, they're noticing in this person more concerns about different things that maybe didn't bother them before, more concerns about the future or what that will look like, not wanting to be a burden to that care partner. An example of the psychosis piece is in a spousal relationship when the person with dementia might accuse their spouse of cheating. We've seen clients thinking someone is taking something from them, stealing from them, worried about the future, feeling like they won't be financially stable. Seeing terrible things hanging or outside. With irritability, sometimes it's more verbal aggression with the care partner and even physically aggressive at times.

Jen Pettis:
How common are these behaviors? You mentioned already that the stage influences what behaviors they have. What is the likelihood of having those behaviors change as someone progresses in their disease? How common are they and how does the stage really influence the likelihood of symptoms?

Dr. Kalisha Bonds Johnson:
The commonality of these behaviors really depends on the type of dementia. Oftentimes when we hear dementia, we often think it's Alzheimer's disease. There are also different types like Lewy body dementia. I know frontal temporal dementia is getting a little more publicity due to an actor having that diagnosis. With different types of dementia, there are different behaviors we see based on each type. Alzheimer's disease has what we call an early onset, which is where it happens for people that are younger than that typical older adult. Sometimes we see that in people in their 40s and 50s. When you think about the age of someone, the type of dementia they have, these symptoms are common.

I'm going to lay out a blanket statement. There's always caveats. Typically, if someone has not dealt with anxiety or depression before, receiving a diagnosis like this can trigger depressive thoughts and anxious thinking in the early stages. They need to have strategies to support them as they're going through that.

Dr. Kalisha Bonds Johnson:
As the disease progresses, individuals will start to be less aware of their environment, less aware of what they are losing in the disease process. We don't always see as much anxiety and depression later. In some of our clients and some of our patients that I see, we can see that happening later, but I would say that is less common.

With the psychosis piece and sometimes with agitation and irritability, those tend to happen later except in Lewy body dementia. Someone with Lewy body dementia will hallucinate in the early stages of the diagnosis. One of the key hallmarks of that diagnosis is individuals who have Alzheimer's disease and other types of dementia will often hallucinate later in the disease process or have delusions in the moderate to late stages of the disease process. Agitation and irritability can happen at any point. It depends on what's going on in that person's life and how well they're able to communicate and how well they're able to deal with the diagnosis.

Jen Pettis:
Why is it so important to detect behavioral symptoms and empower care partners and others with non-pharmacological strategies to address them?

Dr. Kalisha Bonds Johnson:
When it's someone you care for, it's hard to separate the disease from that person. Knowing that these symptoms and behaviors happen as a part of the disease can hopefully give them the opportunity in those moments to be a little more objective and say, "I still love you, mom, (dad, brother, sister, aunt, cousin), but I recognize that this is a part of the disease process." It's important to learn what strategies and tools I have to either help minimize these behaviors and symptoms or maybe to even sometimes prevent them from happening. For example, either I'm going to ask something a little differently, or I'm going to say something a little differently than I would normally if I was unaware. These non-pharmacological strategies can help support the care partners.

Jen Pettis:
Dr. Bonds Johnson, what you just replied really makes me think about the philosophy of care. I've heard so much from you and your colleagues at Emory about how you care for a person with the disease and their care partners. That really resonated in what you shared.

Dr. Kalisha Bonds Johnson:
It's true. I tell the care partners all the time, "You all are the experts. You are with this person day in and day out. You knew them before this disease process. You are learning them now." The observations that the care partners make are how I make my decisions and how we develop a treatment plan together. I'm glad it resonates because it truly is what the Integrated Memory Care is about and what the work that I am doing is about. It really is honoring their relationship, recognizing that they are the experts, and we are just here to support them as best as we can.

Jen Pettis:
I understand that detecting and treating behavioral symptoms associated with dementia can be complex. What accounts for that complexity?

Dr. Kalisha Bonds Johnson:
Older adults are often taking other medications and have other disease processes. There are things that happen, even if they don't have any other diagnoses beyond dementia. As we age, we tend to move a little slower and it might take us a little longer to do things. We aren't necessarily as cognitively sharp as we were. Whether or not there is a dementia diagnosis, individuals might have other diagnoses like hypertension or diabetes. They may have other chronic illnesses that they are managing as well as trying to manage the behaviors and symptoms associated with dementia. I look at families all day long, the family dynamics matter. Whether you like this person before this diagnosis of dementia, whether you all got along well or you couldn't stand each other, matters when we're thinking about dementia because it's a debilitating chronic disease that will end in death at this point. Not wanting to be a burden on the family but recognizing that you might need some help from care partners. It's just a lot to navigate.

Jen Pettis:
What are general strategies that care partners and others can use to manage behavioral symptoms associated with dementia?

Dr. Kalisha Bonds Johnson:
Self-reflection is important and both the care partner and the person living with dementia, while they still can, must determine how they're going to navigate these new behaviors. If it's anxiety or depression or depressive symptoms; what is it about this diagnosis that makes that person anxious and/or depressed? Are there things we can do now while that person hopefully has been diagnosed early enough that will help alleviate some of those depressive symptoms and that anxiety? Is there a trip that that person always wanted to take but never felt like there was enough time? Is it that I don't have my affairs in order and that's making me anxious? Then sitting down, figuring out who will do what within the family, where things will go, thinking about advanced care planning and getting that all set up while you can.

If it is psychosis and not recognizing if what I'm seeing is real or not, how does that care partner then have the conversation with that person? We often say, sometimes it's just okay to go into their world if the person living with dementia sees and hears things that aren't there if it's not distressing to them. For example, they see a cat crawling on the floor. As the care partner, you might ask, "what color is the cat?" or "what is the cat doing?" rather than saying, "oh no, I don't see a cat, do you? There's no cat there." Sometimes it's about reframing how we engage with that person living with dementia. It takes a lot of practice. I've been doing this for a while, and it sometimes feels like you're lying to that person.

I'm still hoping God forgives me for the little white lies I tell individuals. I'm thinking of a particular scenario when I worked in a long-term care facility and this, this lady was there for rehab. She did have a diagnosis of dementia and she came up to me and my shift was ending. I was working as a psychiatric consultant in this long-term care facility. She said, "do you have a car? Because I need to get out of here." I said, “Oh, no ma'am, I don't have a car.” She asked how I got there, and I replied that I walked. She asked me again about walking and then continued to ask about a bus station and a cab. Every time she asked about a way to leave, I told her the options weren’t available.

I know it's terrible, but she was so smart, she had all these great questions, and I could not help her leave. To say to her, “I'm sorry, you have to stay here because you need rehab, and this is what is best for you.” I did try that initially was not working. In that scenario, I did lie. I do hope I'm forgiven for it.

Dr. Kalisha Bonds Johnson:
It eventually was enough for her to say, I guess I'm here for the night. I said, “yes ma'am, I think you will be, but I'll see you tomorrow.” I don't always get it right, but we do have to be okay with trying to have that dialogue and that conversation with people living with dementia because they're still smart and they still have a lot of great ideas.

I have learned that shutting them down completely or saying things that don't land well can just cause further distress. I've just gotten creative in how I answer questions. If we're not interested in medication or wanting to try other strategies before we move into medications, to think about what we're saying to the person living with dementia and how we're navigating that relationship.

Jen Pettis:
You mentioned several specific behaviors when we began our discussion, including anxiety and depressive symptoms. Clinicians or care partners don't always consider these when they're thinking about behaviors related to dementia. Would you give some insights into how you detect these symptoms and then offer some specific strategies that you find most useful for care partners and others to address these?

Dr. Kalisha Bonds Johnson:
I mentioned one very briefly about not having your affairs in order, but usually it's something as simple as every time I call, mom is crying, or, when I've walked into her room, I see that she's tearful. When I ask her what's wrong, she's upset. Earlier in the disease process, when that person living with dementia is still able to communicate with you, it's in those moments you can find out if it about the disease process, and for some clients it is. I won’t forget one client that I was working with, and she said, "I did all the things right. I ate well, I exercised, and I didn't smoke. I did all of the things I needed to do for my health, and I still have a diagnosis of dementia."

For her it was really distressing. You can understand and empathize with how they feel and what they're going through. She had an amazing husband that would be there and support her. In those moments, just validating their feelings. I would feel the exact same way. I'd be very frustrated and very upset and distraught. Validating someone's feelings is the first thing. The other thing is that the care partners also can't forget their feelings and in validating that person living with dementia also remember that you must validate how you're feeling, what you're going through, and making sure that you have some outlet.

Jen Pettis:
You also listed discussed psychosis and, and mood instability and agitation or aggression. GSA has several resources on agitation in Alzheimer's, and I certainly refer our listeners to those on geron.org/brainhealth. Could you share some insights about detecting and addressing mood instability and psychosis?

Dr. Kalisha Bonds Johnson:
Thank you for mentioning that about the GSA resources. One of the hardest challenges is when it's a family member who is in a long-term care facility and it's the facility staff reaching out with concerns that sound like, "Ms. So-and-So did this, we need medicine, or we need help." One of the hardest things to decipher is what is going on so that I know what to do to help. Anxiety, depression look alike, mood instability, psychosis, depending on what's going on, or agitation can look alike.

Dr. Kalisha Bonds Johnson:
Without the context of knowing what is happening, it is hard to figure out strategies to support them. We're not talking about medication, but this example that I'm going to give is one that might help with that.

I had a daughter who was caring for her mom at home who has Alzheimer's disease and she said, my mom has been up for like four days straight. When I'm hearing the message, I'm thinking, okay, we have to get her to bed early. We need to have her work out a little more in the morning. Can we get her up, get her active, and then she'll sleep well at night? She would occasionally hear voices and see things and we called them her visitors. I said, "Ms. So-and-So, have your visitors been by lately?" She said, "I cannot get my baby to go to sleep." I said, "tell me more." She responded, "My baby has been up crying for four days straight."

I looked at her daughter and I said, "part of the reason your mom is not sleeping is because she believes that her child is awake crying." As a mom, I totally get it. If my child is not sleeping, then I'm not sleeping. The reason this lady living with dementia wasn't sleeping was because in her mind she heard her baby crying. Her baby had been crying for days, and she was not going to go to sleep without ensuring that her baby had gone to sleep. In this case, we did have to do medication management and once we did things were okay. We must figure out the context. Somebody could be aggressive and agitated really because they're depressed. If we could improve the mood, then that agitation and aggression would leave. Someone could be having mood instability because they have this fixed belief that their spouse is cheating on them or that their spouse did something wrong to them. Having the two of them come together and sit down and talk sometimes can alleviate some of those thoughts if we can. Just recognizing that there's always this context that we need to understand and then trying to find strategies that support them once we know the context.

Jen Pettis:
This was a terrific discussion and I really appreciate your time. Some of the things that I heard that really stood out to me were that behaviors are changing over time and that a stage may or might not impact those depending on the type of dementia. I really heard that message of honoring the individual and their care partner and the importance of the context in which behaviors happen. Really understanding that situation is such a vital part of the overall assessment so you can strategize together to hopefully prevent the behaviors or at least address them more appropriately in the future. What are some things that I that you'd like to leave our listeners with, a key point or two?

Dr. Kalisha Bonds Johnson:
I'll add that the one phrase comment we hear often is, if you've seen one person with dementia, you've seen one person with dementia. Really taking the time to get to know the person living with dementia that you are supporting, what is it, what is in there that is still in there that was their personality before? Then one of those things that have changed and how do we work together to still honor that person, recognizing that this disease process has changed them from who they originally were.

Jen Pettis:
That's a great point to end with honoring the person. Dr. Bonds Johnson, thank you so much for joining me and for sharing your insights and sharing those important strategies that care partners and others can use. Thank you also to those listening to the episode of the GSA Momentum Discussion podcast. We hope you found it informative and enjoyable.

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.