Why and Early Dementia Diagnosis Matters

Applications from the GSA KAER Toolkit for Primary Care Teams

GSA Momentum Discussions Podcast from The Gerontological Society of America

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Jen Pettis:

Welcome to this GSA Momentum Discussion podcast episode titled Why an Early Dementia Diagnosis Matters. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We are grateful to Genentech, Lilly, Eisai, and Otsuka for their support of the GSA KAER Toolkit for Brain Health and today's podcast episode. My name is Jen Pettis, and I am the Director of Strategic Alliances at the Gerontological Society of America, or GSA. I am pleased to serve as a host for today's Momentum Discussion podcast episode. I am delighted to be joined by my friend and colleague, Dr. Bonnie Berman, who is also a member of the Expert Advisory Panel for the GSA KAER Toolkit for Brain Health. Bonnie is the President of the Ohio Council for Cognitive Health where she is working to change the culture of aging in Ohio. Bonnie, thank you for taking time to share your insights about why an early dementia diagnosis matters.

Dr. Bonnie Burman:
Jen, I'm thrilled to be here today and I'm looking forward to our conversation.

Jen Pettis:
In their 2023 Alzheimer's Disease Facts and Figures, the Alzheimer's Association reported some alarming statistics around kickstarting brain health conversations in primary care. Specifically, they reported that only 4 in 10 Americans will talk with their doctor right away when experiencing symptoms of mild cognitive impairment such as memory loss or thinking problems. The Association went on to report that 97% of primary care providers wait for patients to raise concerns about their cognition before talking with them, the patient about their brain health. We recognize in the GSA KAER Framework that Kickstarting a brain health conversation is a vital first step in early detection of dementia. Bonnie, let's start with talking about the barriers. What are the barriers to step one of the KAER Framework, Kickstarting brain health conversations, and to step two of the Framework, Assessing for cognitive changes to determine if an evaluation for dementia is indicated? Let's start with patient and care partner barriers.

Dr. Bonnie Burman:
I’m going to focus on what I consider the top six reasons, although everyone is different, and there are many more we could add. I'm going to start with the second half of your question, which is the barriers to assessing cognitive change to determine if an evaluation for dementia is indicated, then I'm going to go back to end with the barriers to Kickstarting the brain health conversation. The first barrier is the narrative or the frame. We should reframe the discussion and understanding about brain health and dementia. Right now, most people think of the dementia narrative as one of tragedy. We need to help people understand that there’s much more to the person than dementia and that, with an early diagnosis and care, they can continue to live a purposeful and engaged life in the community.

With the current declinist view of aging, we don't think about how we can help people retain their strengths and live well with dementia. The PCP and their team see patients at all stages of the life journey, allowing them to help individuals impacted by dementia understand that there's more we can do to improve the lives of those living with dementia. That is the first barrier. The second barrier is that people honestly don't know what dementia is. Most people think of dementia as an actual disease and not a term that's used to describe a range of neurological conditions that affect the brain that will worsen over time. Since Alzheimer's disease is the most common time type of dementia, many people think that those are interchangeable, that Alzheimer's and dementia are the same. Many people think that cognitive changes are just a normal part of aging, which they are not.

Dr. Bonnie Burman:
There is a widespread misunderstanding about what dementia is. I think the biggest misunderstanding is that people think that dementia is all about memory loss, but, depending on the type of dementia, the symptoms are far reaching, for example, personality change. The third barrier is the image. This refers to your original question of why so many people are not diagnosed. When most people think of someone with dementia, they visualize or imagine someone who is at the later stage, perhaps in a memory care unit. They don't realize that about 70% of the people who are living with dementia live in the community, not in a shared residential setting.

During these early stages, we can provide the support people need to be able to continue to thrive in the community. If more people were aware of community support systems, then they would want to receive the early diagnosis, which would give them the support they need to continue to live with meaning, purpose, and joy allowing them to live their best lives possible. The fourth barrier is stigma. Just last week I was at an event where I asked an elder if he would like some information on brain health and dementia, he responded, “I don't need it. I'm not crazy yet.” I think that is one stereotype that people can relate to.

As we move into Kickstarting the brain health conversation, it appears that most people are not familiar with what brain health is, and they don't know that they have many options and actions to take. The greatest barrier from a brain health perspective is that people may wait to bring up the topic when they are facing concerns, rather than thinking about brain health throughout the entire lifespan. What we now know is that many of the same lifestyle changes and common practices that prevent or delay other chronic illnesses also have a positive impact on brain health. People should consider the brain as part of the whole body when they come in for a physical. It is integral to include both the patient and their care partners, but we must remember that the estimates are about 30% of people who are living with dementia live alone. About 50% don't have an identifiable caregiver. Folks who are living alone are at a much higher risk for many things including malnutrition, not getting needed services, lack of transportation. The final barrier is that people who live alone with dementia are far less likely to be diagnosed than people who have active care partners.

Jen Pettis:
There are lots of barriers from the individual and care partner perspective, but what are some that are really coming from the health system provider or societal barriers? You mentioned the stigma but there are other societal barriers as well that really impact these conversations that we need to overcome.

Dr. Bonnie Burman:
One of my favorite quotes, which focuses on societal barriers, is from Wendell Berry who said, “I believe that community in its fullest sense, a place in all its creatures is the smallest unit of health. That to speak of the health of an isolated individual is a contradiction in terms.” I believe that community or society is key when we consider how that would impact the physician and the health system. If we estimate 70 to 80% of people who are living with dementia are living in their communities, we need to think about how different sectors of the community view people with dementia so that people living with dementia don't feel isolated, don't feel misunderstood, and don't feel excluded.

Dr. Bonnie Burman:
People around the country and the world are working to create what we call dementia-friendly or dementia-inclusive or dementia-competent communities. A dementia-friendly community would be a place where you have allies throughout the community so that clinicians feel comfortable diagnosing people because they would know how to refer them to appropriate resources. Having access to resources would allow people to feel more comfortable accepting the diagnosis. The dementia-friendly community is a place where people feel comfortable having meaningful social interactions. They have support as their needs change, and they can be engaged in the life of the community. They also have control over their lives and can make choices.

The most important thing in a dementia-friendly community is that people understand that we can build on people's strengths so that they can live meaningful lives. If it's really going to be a dementia-friendly community, residents need to be aware of and have learned about dementia. Education is one aspect of being supported. It is equally important that health professionals are educated about dementia so they may help with the needed services and offer a proper diagnosis. Businesses have folks who understand dementia, and outdoor spaces are accessible so people can get the exercise they need. If you're in a community that is striving to become an inclusive community, you can see how that could have a positive impact on the clinician's ability to provide early and appropriate diagnosis in a timely and person-centered way, for people to want the diagnosis.

This transformation within a community is what will help reduce the barriers that health systems and clinicians feel. We estimate, that only 40% or 4 out of 10 Americans speak to their doctors if they're experiencing early memory or cognitive loss. Consider how that would increase if patients and families felt more comfortable getting the diagnosis, if they understood the symptoms, and they knew the resources would be there, and that they understood that there was so much that could be done to help them live meaningful lives. The typical barriers that clinicians consider are the lack of time, feeling uncomfortable with the tools, being unclear about reimbursement tracks, the lack of up-to-date understanding about how much can be done. They have the sense that they need to refer patients to specialists when they suspect cognitive change.

These barriers really lead to significant challenges and a pose a real problem, which is that if you're only sending someone to a specialist, they are no longer receiving patient-centered care that they need because the specialist doesn't have the relationship with the patient that the PCP has. The only way you can really live your best life with dementia is if we honor what matters most to the individual, which is what guides the development of the person-center approach. The relationship matters. If we're going to Kickstart the conversation, there must be that level of trust and there must be that person-directed approach. As an example, if a staff member in a PCP’s office asks the pertinent questions, they're more likely to get the information they need to assess cognitive change over time.

For example, if somebody says, how's your granddaughter’s swimming going? Or what's her name again? If the response is a blank stare, you've learned something because on the last visit she talked about her granddaughter and she spoke about her swimming and she knew her name. As with everything else, the relationship is key.

Dr. Bonnie Burman:
Finally, from a health system standpoint, the barriers are both significant and challenging. If we change the frame and we have the whole community involved, then more people will be diagnosed and the care that's provided across the system will assess cognitive changes. Staff will know how best to communicate and what the behaviors are all about. But if we don't have a dementia-friendly community, it will be very difficult to have the education and training to ensure a dementia-capable taskforce. The current paucity of staff training is one of the key barriers we can overcome.

Jen Pettis:
Unfortunately, when we speak with individuals, we often inform them that it's important that there's an early diagnosis and frequently they will question, why that is since they deem that there is no solution anyway. Let us answer the question of why it matters. Why is early diagnosis so important with people with dementia? Let's continue the conversation about support and services.

Dr. Bonnie Burman:
One of the first things that an early diagnosis would address is the fear of thinking, what's wrong with me or a care partner or a family member? Fear is not healthy, and it can be eliminated or reduced through an early diagnosis. The second reason an early diagnosis is important is it allows for person-centered care planning strategies. If you are getting the diagnosis early, you can have a conversation with your clinician about what matters most to you. What matters most is not only about the big things like end-of-life decisions, but also about day-to-day life.

Having an early diagnosis allows an individual time to plan how they want to spend their days, who they want to see, and where they want to go. An early diagnosis encourages and allows people to let their wishes be known. An early diagnosis is also key because care partners, whether they're paid or family members, can build on the individual' strengths. We want to move from a deficit-based approach to a strength-based approach. There's always something we can do to help them live their best lives and to slow the decline. What we find with an early diagnosis, which is a key part in the KAER Toolkit, is that we're able to identify the resources in the community that can help the care system and the providers so that they don't have to do it alone. It takes allies throughout the community.

Care partners are also impacted by dementia. With an early diagnosis, they will also experience less fear. They're able to figure out a plan, they're able to learn more about what it means to be a care partner before it becomes an overwhelming task. That time also lets them prepare and learn what they need to do to take care of themselves. Self-care for care partners is incredibly important and most caregivers don't understand the importance of self-care. An early diagnosis allows patients to advocate for themselves, which reduces the stigma of dementia. In the early stage, patients become the "soldiers" in the field to help erase the stigma by letting people know, that's they are thriving and still living a good life. They become a positive role model in the dementia community. The bottom line is that the care and medical interventions work especially well during the early stage, allowing an improvement in somebody's quality of life.

Jen Pettis:
You have relayed many benefits from the patient and caregiver side. Are there benefits for a healthcare provider or health system if those early diagnoses are made?

Dr. Bonnie Burman:
Clinicians attend medical school to ensure they can provide the type of care that benefits their patients. Having access to the tools and resources allows physicians to refer their patients appropriately. They know that there's something that they can do to help people live their best lives and slow the decline. They can do their jobs by letting other people do their jobs. It's the resources and the ability to know that there is more that can be done, and the tools are there. That's why the KAER Toolkit is important because it's one thing to want to do it, it's another to know how to do it. Everyone has the best interest of the patient involved in mind, but they may not have the tools, hence the KAER Toolkit is an invaluable tool.

Jen Pettis:
You have mentioned the KAER Toolkit several times. How can primary care teams use that? How can it help the whole team?

Dr. Bonnie Burman:
Ensuring that the whole team has access to tools and resources is integral for a successful diagnosis. The KAER Toolkit is not meant only for the provider, it is meant for everyone on the staff. There are several ways that the Toolkit can help teams. First is the Framework. Having access to many resources is very empowering. We have an incredibly talented workforce, but it takes determination and the KAER Toolkit helps the entire team be determined because it gives them the tools to support their patients. There are several tools worth mentioning that are valuable to the whole team. Firstly, the intended target audience of the KAER Toolkit is for the whole team to be involved. We must make sure everybody has something to do. The Framework is not focused only on the provider; it moved from the PCP to the entire team. Secondly, it's helpful for the team to focus on brain health, not just decline, which has a significant impact throughout the lifespan. Thirdly, it builds on the sense of relationship, which is integral because the only folks that can really make this happen are the people that have the relationship with the patient. Sometimes it's the assistant and, other times, it's other folks that you are working with that you have a relationship with, and they can really help and inform the clinician.

The next thing that the KAER Toolkit does is that it embraces the role of the care partner, which is key here. The KAER Toolkit advances what is called a person-centered approach. It's not a one size fits all. It doesn't say to the clinical team, here's what you should do. Instead, it gives guidance and allows the care team to adapt what they're doing to the needs of the patient, which empowers the team to provide personal care. As the care team thinks about the resources in the KAER Toolkit that they can reference, they realize that they add their own shared resources. For example, if a patient is spiritual, they can talk about some of the faith-based opportunities. If they are someone who belongs to a gym, they can talk about some of the things that they might learn there. It's the adaptable nature and the ability to make it work for your team that is a key component of the Toolkit. The whole team will feel empowered and well equipped using the KAER Toolkit and refer patients and their care partners to tools and local resources, connecting with amazing community-based allies.

Jen Pettis:
Speaking of community-based allies, how can others in the community, like people working in libraries or businesses or other community settings use parts of the KAER Toolkit to raise awareness of brain health and encourage that early detection?

Dr. Bonnie Burman:

There is a greater impact of support by broadening the reach of the Toolkit. Let us put it in the frame of dementia-friendly communities or communities that are considering becoming more dementia friendly. Our first "aha" moment here in Ohio with this approach happened when you, Jen, came up and gave a presentation about the KAER Toolkit at a caregiving conference that was being hosted by Benjamin Rose Institute on Aging and was supported by Ohio's Geriatric Workforce Enhancement Program. In attendance was a woman from the library system who was caring for her mother who had dementia. I believe she was also caring for a sister as well. After the presentation, she said to all of us, "I'm going to take this to my primary care provider and tell them I want to be assessed!" She didn't say, I think I'm going to ask them if I should be assessed. She said, "I'm going to tell them I want to be assessed." From that one experience, Jen, we realized that by sharing parts and parcels of the Toolkit throughout the community, we could empower families and others with concerns to be the soldiers in the field to help make a difference. They can take the Toolkit to their PCPs and ask, "have you seen this?" Here in Ohio, as communities think about becoming dementia friendly or dementia inclusive, we introduce the importance of sharing the Toolkit with all sectors. In addition to the folks learning about early diagnosis from trusted sources, for example, their library, it also gets people thinking about what role they can play. Hopefully, over time they will become a resource in their community. They may run a business, yet they learn about it from the library. They may want to share something about the KAER Toolkit in their business, thus creating a domino effect. I believe that the KAER Toolkit is the secret sauce that will bring the medical community and the various sectors together to ensure that those who are living with dementia in their communities can continue to live with purpose, meaning, and joy. Another example involves the business community. If employers who have increased their knowledge through the KAER Toolkit, knew more and thus were able to have an earlier diagnosis for their family members, their ability to continue their employment has been enhanced. They would have a better understanding of care partner support, respite, and decreased burden. We go as far as to recommend the use of the KAER Toolkit in several different capacities as part of every dementia-friendly initiative. That is our goal here in Ohio, and we hope to spread it nationwide.

Jen Pettis:

This has been a great discussion, Bonnie. I appreciate your taking the time and your wonderful insights. It's always a joy to listen to you, and I always learn something from you. You are such a wonderful champion for this cause. I want to reflect on the list of why early diagnosis matters, as a few of your statements really stuck with me. First, the relief of fear for the patient and their care partner. Second, the person-centered care planning, what matters most in the day-to-day life, not just the end of life. Years ago, when I talked about care planning with folks in nursing homes, I would review their care plan, which might tell me how to give them a bath or how to help them dine, but it didn't tell me what makes life worth living to them. That should drive each person's care plan. Third, I heard that care partners can build on individuals' strengths. Rather than the doom and gloom of a diagnosis, we can look at the strengths. We can build that person's care around what they're still able to do and how they're able to contribute. I love the phrase allies in the community. That's who our resources are, our allies. Fourth, that early-stage patients are the soldiers in the field. One of my colleagues, who's on a work group here in my area, is a physical therapist who has early-onset Alzheimer's, and he certainly is a champion. You also mentioned that people can be referred for medical care, where in this exciting time of disease modifying treatments, folks can get that early diagnosis, and potentially be part of something that can improve quality of life for them. I wanted to mention those, but what are some key points you'd like to leave our listeners with?

Dr. Bonnie Burman:
I think the most important thing I would like to leave folks with is that we need to make sure that people understand that cognitive aging is not the same as cognitive disease or something that is not normal. You're going to find a lot of people that are fearful that they've got dementia and they're going to find out these are just some of the normal changes that happen with aging. There is such a thing as cognitive aging and we aren't going to do something about the cognitive aging, like how I lost my phone this morning. But that's okay because there's other very positive aspects of cognitive aging, like the wisdom for me to say, I don't care where my phone is, I've got something more important to do. We can put things in context. I think that understanding that some of these cognitive changes are okay and to be expected will eliminate some of that fear.

The other part is that there can be an early diagnosis and there are resources and dementia education to know that there's more that can be done, especially in this environment, which should alleviate stress from previously not knowing what was happening to them or their family. The other thing I wanted to add was the KAER Toolkit is about brain health. We need to understand as a society and as clinicians and the whole team, that there are many actions you can take throughout the lifespan to enhance your brain health. They're no different than the things that you can be doing to prevent other chronic diseases. The last thing I wanted to add is you can exercise, get the right amount of sleep, eat the right foods, be social, keep your blood pressure in check, etc. Once you have an early diagnosis, there are always things you can do to help delay the symptoms. The KAER Toolkit empowers the care teams, the care partner, and the individual who is living with dementia. As an organization, it really has changed what we do.

Jen Pettis:
Thank you, Bonnie, for joining me today and for sharing all that you and your colleagues are doing there in Ohio to change the culture, to improve dementia care, and to improve brain health across the state. It's exciting to see the momentum there. Thank you to all those who listened to our episode of the GSA Momentum Discussion podcast. We hope you found it as enjoyable to listen to as I did to talk with Bonnie.

Dr. Bonnie Burman:
Thank you for having me.

Announcement:
To learn more about The Gerontological Society of America, visit geron.org. The Gerontological Society of America was founded in 1945 to promote the scientific study of aging, cultivate excellence in interdisciplinary aging research, and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.