

The Brain Trust Episode 24: Primary Care Summary: Early Detection and Diagnosis of Alzheimer's Disease

Transcript

Kate Rowland, MD - Announcement

00:03

Welcome to the Brain Trust, a physician's guide to diagnosing Alzheimer's disease and related dementias brought to you from the Illinois Academy of Family Physicians. I'm Dr Kate Rowland, family physician, member of the IAFP and faculty at Rush University. Funding for this podcast series was provided by a grant from the Illinois Department of Public Health. The goal of the Brain Trust and this podcast series is to educate and empower the primary care clinician in the early detection, diagnosis and management of Alzheimer's disease and related dementias. Clinical resources, free CME and other educational materials are available online at thebraintrustproject.com. Cme credit is available for each podcast. The Illinois Academy of Family Physicians is accredited by the Accreditation Council of Continuing Medical. Welcome everybody on the early detection of Alzheimer's disease and related dementias. And now today's episode.

Raj Shah, MD Host

01:08

Welcome everybody to the Brain Trust podcast series sponsored by the Illinois Academy of Family Physicians with a grant from the Illinois Department of Public Health. It's hard to believe, but today marks our 24th episode, and so today we're going to come back to the team, the moderators, dr Yukesh Ranjit is with me, dr Raj Shah, and we're here to talk a little bit today about what we've reflect on, what we've learned and what we've talked about in the prior 23 episodes that we have done as part of this series and then lead to you know what might be next steps or conversations that we have to continue to have to encourage and advance the early detection of Alzheimer's disease and related dementias. So our goals today are really going to be to share again some of the early diagnosis and detection in primary care and what are some of the key lessons that we've learned, and then follow up by maybe going through some of the potential future developments that might occur and we have to prepare for in the family physician and other primary care specialty groups in the state of Illinois. So yeah, yukesh, it's hard to believe, right Like we're on our 24th episode and it was so nice to have this opportunity to really have these 30-minute podcasts with multiple different speakers.

02:28

When I was looking over the list, it's hard to believe, after we did our welcome session with the IAFP leadership describing what we were going to do as part of this project, that we spent the first four episodes three to four episodes just kind of laying the groundwork about what we understood from

our experiences as geriatricians working with individuals with dementia and helping to make those diagnoses and supporting their caregivers, and maybe what we could start out with is just a little bit of your sense of what were some of those universal things we were talking about in the beginning that we felt all primary care physicians that are going to have to be part of this experience should be approaching. How do we get to early diagnosis and detection?

Eukesh Ranjit, MD Co-host

03:14

Absolutely.

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Time flies, raz, and we have a lot during this time in these different episodes.

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So some of the earlier things that we started out with was we started with the basics.

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We started with learning about clinical examinations.

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We started with learning about what to look out in the history when a patient has issues with cognition and memory, and then maybe doing basic lab works and imaging imaging primarily to rule out other diseases that can mimic dementia, such as hypothyroidism, anemia or depression or, you know, vitamin deficiencies or any other or non-pressure hydrocephalus or any other diagnosis that can mimic dementia.

04:03

And once we rule those out, basically you know, to move forward with the diagnosis of mild cognitive impairment or dementia per se. That is the cookbook, basically. We've learned about it in the med school, we've learned about in our residency and in the first few episodes we talked about that as well, as we talked about the ecosystem of Alzheimer's and dementia and how things are done in the state of Illinois, and we started with that background and we then went on this adventure to see how they are implemented throughout various parts of our state and how it affects not just us physicians but caregivers, you know, other members of our team, the multidisciplinary team and other members of society as well, and that is what we started off with.

Raj Shah, MD Host

04:56

Yeah, and maybe, if you know, some of the things I remember from those original discussions is we, you know, we also talked about some of the like, the basic like tips and tricks of you know how to approach these in a primary care setting. You know, one was maybe using things like the annual wellness visit that's provided by Medicare as an opportunity to ask a person coming in if they have

concerns about their memory, just so that it can help. We know right now there's no recommendation on an evidence basis to say we need to screen everybody that's over age 65 for memory loss. We're just not there yet right now. Or dementia, more than memory loss, because dementia can encompass other things. But using that wellness visit, it's just a check, right, because people feel stigma. They might not bring it up on their own. It could be a way to get a conversation started. We talked a little bit about looking for clues, right, like listening to your office staff because they might be saying, oh, this person is missing their appointments or asking for their medications multiple times when we just refilled it. That might give us clues that we have to bring up this conversation. Listening to when a caregiver calls or says you know, hey, you know, or pulls us aside and says, you know, can you ask about memory? Or that would help. And then we talked about like doing that evaluation of the memory right, Like once we get the clues there in that annual wellness visit or somebody signals to us something might be going on, is really listening and depending on that history, to kind of get that story about how long something has been going on, what is it affecting in their function, what kind of cognitive problems are they're having, looking at sort of their medication list, if there's any medications that might be causing this, checking their mood, you know, making sure that's not part of the picture.

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And then doing some very basic like blood work and imaging studies, like you mentioned. Right, but then being okay and being confident in most cases, if you've done that workup, that you can make the diagnosis in primary care and as a family physician, to say, you know, based on what I'm seeing right now, this is my working diagnosis. But if you get some red flags right, like something's just not right with the story, like people are hallucinating early on or falling, or you know there's something that doesn't fit, sort of a dementia due to Alzheimer's pattern, or or they're very young or it's a complex case with behavioral changes. That's when you want to use your other resources and the community to engage and get support whether it be neurologists or geriatricians or psychiatrists to support that work over time. So I think we learned a lot, right, like, based on our prior knowledge and what others have heard, and we try to give a couple tips there about how people can approach it by using the annual wellness visit, keeping the ears open, but it's definitely not easy, right, like that's what we heard by talking with primary care doctors. Right, because they have to keep adapting that to their daily setting.

08:00

And you had this great chance, you know, talking with individuals that were practicing in rural settings, which is a large part of where practice occurs in the state of Illinois, and we can't forget about that and what were some of the things people were doing? As you were remembering those conversations with, you know, practitioners, primary care practitioners, providing services to rural communities, what were the things they were having to adjust their context of that formula, of that universal pathway.

Eukesh Ranjit, MD Co-host

08:30

The rural population by itself is a very special population. We tend to think about rural more often as a slow-paced urban population, but one of the findings that I've had was that it is not necessarily the case. Basically, the kind of occupation that they do in the rural areas are different. The level of education is different, their perception and their cognition of the world is slightly different as well. Basically now also the other things that are very common in rural areas are that primary care providers in the rural areas they have much closer bonding with their patients. So, like you know, if you are serving in a smaller town, let's say in Southern Illinois, you're more likely to run across your patient while you're shopping at your local grocery store and the community is much closer knit because of that reason. So you can find other clues about, you know, cognitive decline just based on you know your findings outside of the clinic setting as well. So those things play a big role.

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The patient population you know like there's a seasonality to agricultural population. So, like you know, if it's harvest season it wouldn't come to you. And you know, sometimes just asking them about seasonality and you know whether they can recognize what season it is is a big one in the rural population. Also, there are a number of community organizations you know, not just the medical organization, but the community organizations just because they're slightly more close-knit that actually learn about patients' declining memory and cognitive issues even before the patients themselves often find out. So getting these community organizations involved, community healthcare workers involved, engaging our social worker, is a big part of early detection in rural communities. One other thing is you have to talk the rural talk. Oftentimes you talk to the rural population. We cannot go in there and just offload them with all this information, and doing that part was something else that facilitated conversation as well as early detection in rural communities.

Raj Shah, MD Host

10:58

Yeah, no, I mean you bring up a fascinating point because sometimes we view all the downsides of a particular community like a rural community, like things are far apart. There might not be of a fascinating point because sometimes we view, you know all the downsides of a particular community like a rural community, like you know, things are far apart. There might not be enough specialty care, but some of that there's actually advantages too, right, because the post-nit and less the ability for you, if you live in that community as the doctor and are integrated in the community, to see these different patterns because you could just get more exposure to people and hear stories than just waiting until they come to your clinic, you know, every six months or a year. So yeah, there's always that balance and I think you bring up a really good point. You know about what you were learning and the networks that are available in those spaces.

11:40

I think I had a similar experience like as I talked with providers and communities inP president Emma Daisy, about working at an FQHC or a federal qualified health clinic that was not far from sort of a large immigrant Asian communities close to Devon and Chicago and you know just having to navigate, not only being able to try to understand, like getting a history, but getting a history in like

30 different languages, based on older people, that would come to your practice, knowing full well that the scales, like the MOCA exam or the MMSC in English, may not translate into other cultures, right? I really found that fascinating about how they were trying to then go back to that old-fashioned, like I can't fully depend on the scale and a cut point on the scale, but I just have to be able to listen to where the person was before, right, what are they doing now? Right, and what does the cognition play a role in this? And using her skills as a diagnostician to support those families where there are these linguistic and cultural barriers and we don't have the perfect tools that can be adapted into those spaces. I heard the same thing when I talked with Evelyn Figueroa about the Latino community and some of the ways things are discussed, how it's not only just dealing with the person that has the condition but getting the approval of the entire family to be involved, about that discussion. And then even in the African-American community, with Dr Scott Levin and some of the work they were doing in the Austin neighborhood and the falling populations for a long time, and Tonya Austin, who was working with the community close to the Indiana border for decades in the Southland of Chicago.

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It just brought out all the different ways that people had to adjust as primary care physicians, with this process to the communities they provided services.

Eukesh Ranjit, MD Co-host

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Absolutely, and we fortunately in Illinois. Illinois, we have a diverse community and there are subtle differences in the way cognition is perceived in different communities. Involving family is always a big part, basically also, one of the other things is learning about their activities of daily living and you know whether they are capable of performing their activities of daily living and whether they are capable of performing their activities of daily living and if the decline in cognition is so bad that it is actually affecting their ability to perform daily activities, which is basically dementia. I think navigating through the sociocultural system to get to those conclusions are oftentimes challenging but at the same time, very rewarding as well.

Raj Shah, MDHost

14:42

Yeah, no, definitely. And then we started realizing, like you know, I think it's not just the primary practitioner with the shingle by themselves anymore, right, like they're part of these systems, these health systems, when most experiences and we have this really interesting opportunity, I think, to talk through with a couple of clinicians, practitioners in some of these systems right, va has been approaching older veterans and their families that get care at the VA and using sort of this home-based care services to be able to do the evaluations in the home, to be able to support people as they, you know, go through the experience, and I found that really fascinating to hear about that and some of the activities. And in many ways, like you know, the veterans have their own unique cultures but we can learn from that, right, like there was things that the VA was doing that because of their population, because of the way they're organized, that they were able to offer some broader, more comprehensive services that might be harder for, say, somebody in a rural community getting

it from their local health system, but if they're a vet they could work with the VA, even by Tenelow to get certain services. So I found that interesting. But we also had some discussions around, apart from the VA system around some of these innovations that were going on with health systems in general, by talking with Advocate Aurora soon to be, I think they're called Advocate Health now but their approach with this grant that was given out to multiple institutions to incorporate some of this care navigator mechanisms that the Alzheimer's Association was developing. So there's some really interesting system stuff that was going on that could add value into what was happening. And others were also providing that in healthcare systems at North Shore, now Endeavor Health. These systems all keep changing their name even after we gave our talks here.

16:53

But I found that interesting right To hear how health systems were also trying to support their primary doctors, their patient population, by adding other members of the care team into the scenarios. But that kind of rolls us into some of these community services. Right, you mentioned a little bit about community health workers and some of our conversations with the dare to care group and the social workers and the social network. What do you think we learned from those conversations?

Eukesh Ranjit, MD Co-host

17:23

One major thing that I learned was the role that a multidisciplinary team has in early detection as well, as you know, management of patients with dementia in different settings basically. So there were various groups. There are various groups actually in Central and Southern Illinois who are involved in taking care of various parts of the patient's well-being. Basically, some of them are community health workers who are directly involved with the patients in the communities. Some of those are social services. Some of them provide help for caregiving, for example.

18:06

Basically, especially in rural Illinois, a lot of patients and their family members do not have much knowledge about dementia and once you know, once the diagnosis is made, or even before the diagnosis is made, these organizations teach and train patients and caregivers about the changes that are anticipated and about how the caregivers can play a key role in you know, noticing the changes and providing them with information to find help and teaching them about caregiver resilience as well as caregiver burnouts and basically locating the local resources.

18:52

One thing I would say is that finding resources in Central and Southern Illinois is much harder than, say, in a bigger city, than when I practiced in a bigger city previously, and just getting people connected to the resources oftentimes makes a key difference in the outcome that a patient has, and the fact that we have a network of these organizations throughout the state was something that was very exciting. Organization throughout the state was something that was very exciting and that is an information that a lot of our primary care providers could, you know, take into consideration

whatever they're dealing with their patients, and just to know that they're not by themselves, and to have this whole ecosystem of other health care providers who can help them out.

Raj Shah, MD Host

19:34

Yeah, and I thought that was great that we had those voices, because I do think it's a little bit isolating, right. That's what sometimes concerns primary care physicians is like I can bring this up and talk about this diagnosis, but if I don't feel like I've got support right or other people in the community to help me or make those connections, I'm a little bit, you know, hesitant to make those diagnoses right without the right care support teams in place, the right care support teams in place. But it's really clear that these are systems that are developing. There are people there. We just have to make the right connections with individuals like community health workers or care navigators. I think the other thing that was something that came up, which I'm glad we did and you were sort of heading there you know, the community health workers can act as a bridge between the healthcare system or and the physicians working, you know, in in, in providing the diagnosis and treatment, and the caregivers. And I think we have this wonderful like mini series part that I moderated with Susan Frick, who's a social worker, oversees some of the without warning group at Rush, where we actually talked with caregivers about five of them about their experiences.

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I think the thing that got me from that discussion was just how long the process is that a family goes through to get to a diagnosis, and it's not just about, like I can't get an appointment with the primary care doctor.

21:02

There was time and time again when we heard these stories from the caregivers about when they noticed things happening and then by the time it got brought up with the primary care doctor, you know, sometimes it'd be like 18 months to three years would have gone by, and a lot of that was because the person was noticing these things as a caregiver.

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But they were asking the person who was in an early stage of these memory and cognitive changes to talk with their doctor at their appointment with them, and that person would not bring it up right Like either because they were afraid of bringing it up or they didn't remember to bring it up, and so there was always this like game going on, right.

21:41

And so the thought was is, like you know, in especially in primary care, where we might be taking care of caregivers, right Like we take care of entire families, how do we maybe put our signals on when somebody comes to us and ask if they're doing a caregiver role right and if they're noticing some changes or experiences with their loved one that's stressing them out. You know, maybe that can be the opening to start the conversation earlier. And then, in the process of even once it got brought up and the clinician was made aware of it, it took about 18 months before the diagnosis

was made. And you know how can we work on continuing to move that process along so that it can get shorter, because if you think about it, if you get something and somebody says look, I think you might have cancer, right, we don't waste 18 months.

Eukesh Ranjit, MD Co-host

22:30

No, we do not. I had a conversation with Dr Smaga, Heather Nutt and Becky Salazar along the same lines as well. Some things I think we can do from our end is one is our team members. Basically, if my MA is telling me that, like you said earlier, they haven't noticed something different about one of my patients, we should encourage them to come and tell those things to us directly and just say, hey, we've noticed that he's been asking the same question over and over again when we asked him to fill out the form.

23:05

The other thing is empowering our community health workers, basically so that whenever they are in the community with our patients, if they notice something, let us know about it sooner. The other thing is also, like I said, if there's a diagnosis of cancer, we don't sit on it. If this person has an MRI or if this person has a suicidal ideation, we have an action plan already, you know, ready and set to go. Basically. Now we should have something similar when it comes to memory issues as well, basically. So whenever patient, the caregiver or anyone around them are concerned about memory, we should delve into it sooner than later and cut down the time. 18 months is a long time, yeah.

Raj Shah, MD Host

23:51

Yeah, and I think you know it's a work in progress and you know, in some ways you know we've covered today in our reflection a little bit about. You know what are those universal tips and tricks and things we need to do in the evaluation process as primary providers. What is it that has to be contextualized by primary care physicians, depending on where they're practiced? How can systems that we work under help to support this effort? How can we build teams and connect with community partners to make this a better process? And then how do we listen to those caregivers right and the clues that they're sending so we can reduce that time? But I thought maybe in our last couple of minutes, if we could spend some time talking about what we might be seeing coming down the horizon, that might be innovations in this space. My feeling is that even though we are getting some new treatments coming to the market, they're just not ready to meet the full needs of everybody. They're very specialized, right, and how they need to be delivered and who has the right risk benefit ratio, and that takes a lot of work. But some people are saying like, okay, even though we have 6 million people, or 250,000 people in Illinois that might have dementia 6 million in the United States. You know that we can handle this in a just without any primary care involvement, because it's too. You know the we can handle this just without any primary care involvement because it's too. You know the primary carers are too busy. You know the specialists can take care of all of this, maybe with some mid-level providers, and I'm not sure that model holds in my mind right.

25:21

I still think that primary care physicians are the biggest population that provides care. Patients trust them the most. That they're going to have to be part of these journeys going forward. But what are some of these innovations that can maybe help those primary care physicians? One lecture that kind of started that topic was our discussion around, you know, using artificial intelligence, machine learning from electronic health records, and I think that kind of gives a clue that maybe our day-to-day notes and the way that they're formatted in some of the techniques can help us. But I actually think there might be other things that will come into the pipeline. What are your thoughts about? Maybe like some of the diagnostic tests, like right now we need to do these PET scans or some of these more detailed testing, but do you think we're going to get to the day where we might have a blood test that might help us.

Eukesh Ranjit, MD Co-host

26:15

That's a really great question. I mean, starting off with AI. Pattern recognition is a great tool. We have not had something similar in the past and if we utilize the pattern recognition tools properly, I think with passing time we will have greater sensitivity and specificity as well as predicting value or detecting or at least learning about potential dementia or mild cognitive impairment or any of the other parts of the EDR spectrum. One of the things that I think and I believe you focus on this a lot rather than using artificial intelligence, using human intelligence, basically, a lot of it is just seeing the patient and learning about the patient, and I disagree with the primary care providers not being a part of it, because primary care providers are the ones who see the patients on a consistent basis over years and if there's a decline, they are the ones you know among the people in the healthcare system who would know about it the most. Basically, so definitely have to engage primary care providers.

Raj Shah, MD Host

27:25

I do think the future is going to be exciting as far as some more innovations to help primary care providers, and we've got to kind of demand it as primary care providers too right based on the contextual issues we're having and the systems we need to support it. But I think it's been great that we've had this opportunity in our session today to kind of reflect on what we've talked about up till now, what we've learned from our different conversations and 23 other broadcasts, and a little bit of that hope about. You know, the primary care physician can do this work and can make it successful and can really be that good partner in the early diagnosis and detection. And you know I'm hopeful that we can have future conversations as part of the brain trust series, you know, to advance some of this understanding and to help keep that momentum going. But with that I'll let you Rukesh if you have any last words, but I'm really glad to have had this opportunity to work with you on moderating some of these sessions to date.

Eukesh Ranjit, MD Co-host

28:23

Absolutely Likewise. This was an excellent journey for me. It was an amazing journey. I learned so much about the whole ecosystem of Alzheimer's disease and related dementia in our state and I'm looking forward to doing something similar in the future as well, where we could help our primary care providers in the state to learn and practice medicine especially with the gastrointestinal dementia better.

Raj Shah, MD Host

28:46

All right, and with that we'll wrap up for today and really appreciate the opportunity and you listening to this podcast. I hope you've learned from the series and are willing to share and if there's something really innovative you're seeing in your experiences as a primary care or family physician in Illinois, please let us know and as part of the brain trust, because I'm sure there'll be other opportunities for us to keep sharing and learning together. So thank you again and we'll talk to you soon.

Kate Rowland, MD Announcement

29:20

Thank you to our expert faculty and to you, our listeners, for tuning into this episode. If you have any comments, questions or ideas for future topics, please contact us at podcast@thebraintrust.com. For more episodes of the Brain Trust, please visit our website, thebraintrustproject.com. You'll find transcripts, speaker disclosures, instructions to claim CME credit and other Alzheimer's resources as well. Subscribe to this podcast series on Healthcare Now Radio, spotify, apple, google Play or any major podcast platform. Thank you again and we hope you tune in to the next episode of the Brain Trust.