

The Brain Trust Podcast

Ep 16 Dare To Care about Early Detection ADRD

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 IASP 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 Education to provide continuing medical education for physicians. Information on how to receive credit can be found on the Brain Trust Project website. Thank you for joining us as we empower each other and provide training on the early detection of Alzheimer's disease and related dementias. And now today's episode.

Raj Shah, MD

Host

01:08

Hello, this is Raj Shah, family physician and geriatrician from Rush University Medical Center and welcoming our audience to a really special show today that combines the work of the Illinois Academy of Family Physicians and their Brain Trust series of podcasts with the Dare to Care work that's been done for a long time. So we made a special trip as co-moderators me and Dr Yukesh Ranjit to visit Dr Elaine Jorowski, who runs the Dare to Care program and is a graduate program director and professor of social work in the College of Health and Human Sciences at Southern Illinois University. So we really appreciate the opportunity to drive down today morning and make it in time for this wonderful episode today where we'll be talking about the synergies between the Dare to Care project and the Brain Trust. And thank you, Elaine, for having us here today and could you tell us a little bit more about your work with Dare to Care?

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

02:06

Oh, you're welcome, Absolutely so. Dare to Care is a show that's actually been running for many, many years. It began by a colleague of mine, Kit Maddox, some time probably 30 years ago In 2014,. He was about to retire and I even a frequent guest of his, so I inherited the show, and the focus of the show is

really to promote health literacy amongst our communities, and so we choose just a variety of topics that go from cradle to grave, that have an interest for folks that have health or mental health or human service interest, and we host guests in various facets, locally and also nationally, with all sides of international guests. Because of technology, we're able to do that now and we just try to give people a sense of information about specific content areas and the challenge stuff to Dare to Care for those that they're close to or those in their communities. And we air over five state area. We air in Illinois, Kentucky, Tennessee, Missouri and Indiana.

Raj Shah, MD

Host

03:29

Wow, that's an amazing reach and a program that's been going on for over a decade or more, and that's terrific. I'm just really curious about the name Dare to Care. How did that come about? Because it's such a powerful term.

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

03:40

Well, that actually is not my brainchild, that was Kit Maddox's brainchild. Kit is a social worker and he ran caring counseling ministries for about 25 years before his retirement. This is an agency that he started up by his own steam along with church groups in the southern Illinois area and he found a need to just educate people on human service kind of human interest topics, just to make them aware of, you know, some of the kinds of programs and services there were in the community. It's again people's hope, really instilled hope for folks.

Raj Shah, MD

Host

04:22

Yeah, that's definitely terrific, because, I mean, I think that's what we also are trying to do with the brain trust, working with primary care physicians, family physicians in the state of Illinois, and really for showing in the early detection of Alzheimer's disease, that primary care physicians are not alone, right, it's not just them working with their patients that have to go through this process and journey, but there's an entire world out there, right, like the community partners, others that have been engaged for a while in trying to make their communities more dementia friendly and to reduce stigma, and that's why I think Dare to Care is so powerful.

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

05:00

Well, thank you, thank you.

Raj Shah, MD

Host

05:02

Yeah, and then I know that you also know our co-presenter and moderator on our brain trust program and that's Dr Yukesh Ranjha, because you're connected by your work at Southern Illinois University. So I just want to give Dr Ranjha an opportunity to say hello to you and also add if you had any comments, or maybe, yukesh, if you can give us a little bit about introducing Desma Razovics from the Illinois Academy of Family Physicians, to tell us a little bit more about what is the Illinois Academy of Family Physicians and then what is this brain trust that they've been working with the Illinois Department of Public Health on?

Eukesh Ranjit, MD

Co-host

05:36

Absolutely. Thank you for the introduction. Razovics Hi, razovics Lane and Desma it's wonderful to be a part of this collaboration. So, desma, would you like to talk a little bit about the brain trust initiative?

Speaker 5

Host

05:49

Sure, we're very lucky.

05:50

At the Illinois Academy of Family Physicians, we recognized that with all of the aging population, we have over 5,000 family medicine physicians caring for individuals across the state and with the aging population, it's become an increasing importance to have early detection of dementias and management of Alzheimer's.

06:13

So the Illinois Department of Public Health has put out, recognized this as well and put out a grant opportunity, and we, of course, with over 5,000 family medicine physicians in the state, it was right, in our importance in our wheelhouse, to say let's go for it. So we have come up with the concept of the brain trust and it's a three prong educational approach for primary care providers, with an accredited podcast series, the online resource center and a one hour CME webinar that's live and also online, enduring. So, yeah, all of the work is being made possible through this grant through the Illinois Department of Public Health and through our two wonderful hosts, which are you, dr Raj Shah and Dr Nakesh Rangit. So I'll let you talk a little bit more about it, but, on behalf of the Illinois Academy of Family

Physicians, it's actually wonderful to partner with Dare to Care and we, I guess, challenge everyone out there to dare to care a little bit more about early detection of Alzheimer's and related dementias.

Raj Shah, MD

Host

07:21

Thank you, desmo, yep, and then Elaine. I think you wanted to say something.

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

07:25

I was going to ask. So tell us a little bit about the podcast series you know, and what are the topics that are in the series and how does this all work.

Raj Shah, MD

Host

07:34

And so, yukash, if you wanted to take a first pass at that, and then I can add components if necessary.

Eukesh Ranjit, MD

Co-host

07:39

Absolutely so, raj and I we had been brainstorming about you know, both of us with the common background of being family physicians or pediatricians as well. We had been brainstorming about what can we do better about provision of care for older adults in Illinois. One of the things that we come across frequently and so for me in specific, like I worked both in Springfield in Illinois as well as in Carbon in Illinois, I worked primarily with primary care providers. What's the things that I find frequently is that a lot of primary care providers have difficulty with working with people with dementia. I looked into the numbers and Alzheimer's Association had this data from a report which found that 82% of primary care physicians said that you know they're in the front line of providing care for dementia care, but nearly two in five of them reported that they're never, or only sometimes comfortable with making a diagnosis of dementia and also, like nearly one third of them said, like you know, they're never or only sometimes comfortable asking patients questions about Alzheimer's or other dementia, and this is something that goes across the board.

08:53

A lot of primary care providers think it's a neurologist who have to manage dementia and that there's a lot of things that are missing out in the community and we thought, you know, it would be better to come up with a program where we could, you know, just talk at the level of primary care, what we could

do about dementia and you know how we could help and empower other primary care providers to take care of patients with dementia. So that's how this came into being from my end. Rajan, would you like to add on?

Raj Shah, MD

Host

09:18

to that. Yeah, no, that was great and I think you know part of it was also not about just, you know, the need to support our primary care physicians in helping our patients and our communities and making an early diagnosis, as Yukesh mentioned, and getting increased comfort in that. But I've also thought about this always as a supply and demand issue. So we have to improve, you know, the supply of our physicians that can handle this and detect and work through the early diagnostic phases and for them to feel supported and that they can do this. But the second piece is really about the community and I just wanted to give something maybe for the dare to care audience that you know, every year or two of the state of Illinois and I think other states do this they do a survey that's part of the Centers for Disease Control around behavioral risk factors and in that survey, where they random digit dial, call people at home and ask them questions about their health, there's a module there about sort of if you're noticing any difficulties with confusion and if it's affecting your day to day life. And they find in Illinois and that's what always wanted me that we could as a state do better together.

10:32

Is that approximately about. You know, 40 to 50% of people over age 50 end up saying they've had episodes of worrying about increased confusion and about 20% of those so you know, about 10% of the total population being evaluated says that these confusion episodes are interfering with their day to day life. But when they're also asked, have you talked with a physician about your concerns? It's less than it's about a third of people say they've talked to their physicians, right? So if we're going to do better and create a dementia friendly communities and reduce stigma and to diagnose early, we have to help people to understand that it's.

11:12

If you're noticing something, if you see something, say something and you should say that to your primary care doctors and then your primary care doctors should be ready to know that more people may be coming to them with these concerns and be prepared to be able to you know, ask questions about it, to listen and to do some of the early diagnostic work up. And I think it's that fusion that we were trying to get across in our training in the podcast. These like short 30 minute pieces that people can hear, you know, on the radio and learn from as primary care physicians, where they hear from other primary care physicians about what can be done, what they're trying, where they're succeeding, where they're not succeeding. It's really trying to help them to gain more comfort, to be there for their communities and for the communities to believe and to understand that there is a resource in their primary care physicians who can help them in the initial diagnostic phase.

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

12:07

It's really very important to me and I think we need to neglect. You know how important it is, not only for physicians, but for just people in general public to understand that these are things that they can both ask their physician and recommend to their physician in terms of your series and your resources. You mentioned the tool kit. What is available in the tool kit and how could that be of help to your colleagues and how can it be of help to our community? Thank you general public to know about so they can recommend that to their physicians.

Raj Shah, MD

Host

12:45

Yeah, I think the toolkit is a work in progress, right, it's a living sort of document on the website that anybody can type in. They can type in the brain trust in Illinois, or just even brain trust, and they will get to the website. And then we're trying to build resources on the toolkit that will help primary care physicians get the added information around what are sort of best practices and guidelines around evaluating and diagnosing individuals at an early stage and then to also start to get to know the resources in their community. Who else is there with them that can provide services and support? You know, it's never easy to build these sort of items, but we're trying to find information that's trustworthy, that's been vetted, that's been peer reviewed, that can then help, as physicians want to learn more than just listening to that 30 minute podcast.

13:37

And now we have somewhere, you know, approaching 20 of these podcasts in the works, and now we're just, you know, want to build the other resources so people can use the podcast as an early introduction. But then they say, oh, I want to find out a little bit more about something you talked about in the podcast as far as the tool, and that is something that we can do to help people over time. So, yeah, I think where it's a work, it's going to be a continuous work in progress and something that will keep adding and becoming richer over time to support things and you know, screening and detection and then how to manage people that you've diagnosed over time, and to also deal with caregiver support. How do you help the caregivers over time?

Eukesh Ranjit, MD

Co-host

14:17

And the tool kit provides like very broad categories of different services that are provided there, that's, the sections for screening. Assessment is a section for practice management, for education, caregiver support, community resources and things of that nature. It's also a very good learning tool for medical students, residents, fellows who are in the training, also for new physicians where they're starting out and you know they find themselves in a new community, do not know much about the community resources that are available. So has a lot of resources related to the things that are helpful for basically primary care physicians, but also for the patients and other caregivers and providers.

Raj Shah, MD

Host

14:59

Yeah, the final piece, just to kind of close out.

15:02

You know, what we've been putting together on the brain trust and sort of building as a living resource is been this one hour CME webinar or continuing medical education webinar.

15:13

And the reason behind that is that the state of Illinois passed a law around training of licensed health practitioners that they needed a required one hour of training on dementia to be met on a regular basis to maintain their licensure. So you know, because IAFP has been a trusted resource of continuing medical education, we built a brain trust one hour CME to meet that requirement for our members and primary care physicians and other health professionals to learn a little bit more about where we were at when we put that together about a year ago as far as early diagnosis and detection. So it becomes a resource to train you know physicians to meet some of their licensing requirements along with other health professionals. So it's been a great experience. I think we've been learning a lot and we just wanted to be able to share with broader audiences that you know the brain trust resources there. It's growing. Seek feedback from different stakeholders about you know what else we can do to improve the content and help our primary care physicians as much as possible.

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

16:17

That's great, thinking about the concept of dementia and related disorders, alzheimer's disease and related disorders. Just how prevalent is this within both the area and, you know, nationwide, like the two of you are specialists in this area, so to what extent do we see this happening amongst people in the community?

Raj Shah, MD

Host

16:40

Yeah. So maybe, yukesh, if you want, I'll talk a little bit about what's happening nationally just as far as numbers and our estimates. But we do get estimates by the Alzheimer's Association, facts and FIGERS report pretty much every year and maybe you can break it down for the state of Illinois and what our numbers are. Then we can both talk about where we practice I mainly in northeastern Illinois and sort of in Cook County at Rush University and then your practices that are based outside, you know, encompassing Springfield and Carbondale and the surrounding communities, and sort of what are the things that are similar, what are different in those spaces? So just for the audience, elaine, alzheimer's

disease I've always felt because I've trained as a family physician, then a geriatrician and then a practice in a tertiary care center and a memory clinic that specializes in Alzheimer's disease and related dementia diagnosis at Rush is. I've always felt that Alzheimer's disease is the prototypical condition for primary care in older adults because it just doesn't affect the person that's developing the memory troubles, but it affects their family members because many of their family members become those informal caregivers and there's usually about six informal caregivers for every one person living with the condition and then it also impacts, you know, the community, the businesses that are provided in the community, the librarians, the police departments and the fire departments, so it's broad ranging. It truly fits what sort of the broad aspects of primary care and for family physicians.

18:15

In the United States the estimate right now is that there's over 6 million people that have Alzheimer's disease or related dementia. And when we say related dementia there's over 100 different causes of chronic thinking problems that affect people's day to day life. Chronic thinking problems that affect people's day to day life is dementia. The causes of the dementia are things like Alzheimer's disease is the most common you know factor but it's mixed with other factors such as vascular disease or blockages of blood flow to the brain through vessels that eventually somebody has a stroke. It can reduce the amount of oxygen to some tissue and cause some brain cells to die sooner.

18:55

It's associated with Parkinson's disease and something we call Louis Body dementia, something called frontal temporal dementia, and most people have a mixture of the different causes to explain their own particular dementia. But we think it's about 6 million in the country. You know, because of the caregiver needs and the burdens right now, it costs a significant amount of money for us as a society to really support our individuals with dementia and to make sure they get the best quality of life as possible along with their caregivers. Now in Illinois we're one of the top 10 states of people because of our population in general and our aging population that have dementia and Yukes, what is sort of the number in the state of Illinois that we predict that kind of has Alzheimer's disease?

Eukesh Ranjit, MD

Co-host

19:44

Well, according to Illinois Department of Public Health their data from 2020, there were 230,000 people over the age of 65 who are living with Alzheimer's disease or related dementia With aging population. They say this figure is projected to actually go up to 260,000 from 230,000 by 2025. So that's about a 13% increase in that number, also with the increasing number. One thing that's common is the amount of caregiving. Short is that we have. So the data according to 2021 shows that there is about 386,000 caregivers in Illinois and they were providing 486 billion hours of care for patients with dementia. That's a very big number. They estimate that the unfit value of caregiving is more than 8.8 billion dollars basically, so that's a very huge number.

20:44

Also, the thing that I wanted to talk a little bit about the cure of dementia is that Illinois is not one monolithic state. It comes in various shades and the care that the patients receive, at least in medical part, is very different from Chicago to Springfield and to Cogmedale. Basically, it's a surprising the level of difference you can have for every 50 or 60 miles that you move away from Chicago, and that is the part that is very interesting to me and that is the part where we need to do more work on. The more rural you go, the less services are there, and oftentimes people do not even have services for basic diagnosis, for example, and they would have to wait months and years sometimes, just to know what is happening with them, and there's a lot that can be done in that field as well.

Raj Shah, MD

Host

21:39

Yeah, and similarly, I think in general, we're all recognizing we need to do more at our various diverse communities across the state and in northeastern Illinois, where the largest population of the state of Illinois is, in areas like Cook County and around Chicago, the challenges are slightly different.

21:58

I think this is some of the things we've been learning as we've been talking with primary care physicians in the different areas of practice, whether it be in rural settings, whether it be in suburban or small urban settings, and then large-scale urban settings is you have to tailor the early diagnosis of dementia to local needs.

22:18

So I remember like one program we had with a physician who practices in a federally qualified health center based close to Devon Avenue in Chicago, which is sort of the little India of Chicago, and there's such a diverse population in the community, but the older adults tend not to speak English and have a little bit less of an education level, so they even struggle with things like using the tools that have been designed in English that we commonly use and teach people about, such as the mini mental status exam or the mocha Montreal cognitive assessment, as screening tools because they're developed in English and and developed in a culture that's mainly based in the United States or North America that they have to adapt to those resources for a population that's coming from diverse communities and I'm sure we heard the same things you gosh like when you were talking with physicians practicing in rural areas there's no cookie cutter way of going about the diagnosis of dementia early, because it always has to use that flexibility of the primary care physicians to adjust to the local community needs and resources and capacities.

Eukesh Ranjit, MD

Co-host

23:29

Absolutely.

23:31

We do tend to talk about the diversity as and then we need that a world of things.

23:36

That often gets missed out in the diversity is the rural population as well, because most of the data that come into this study, that they develop a toolkit, are done in urban setting and they know they have a slightly higher educated population and also some of the questions are not very relatable to the rural population.

23:55

Basically, and the way you ask questions. Also, like you know, sometimes when you have a rural patient who is there in a clinic which is an absolutely new setting for them and you know they would have driven like 40, 50 miles away from their home they've lived in their farm throughout their life and it's an exciting, provoking place and you have now two or three people they're asking them questions. Sometimes they tend to get intimidated and then when you ask them to subtract seven from a hundred and keep on going, it's it's something that they find not just hard to do, just that question, but the question is following that, that you can see the level of anxiety and there's a number of things that well primary care providers do to help the population that they're surveying.

Raj Shah, MD

Host

24:44

Yeah, maybe, Elaine, I was curious from you know your side and from the dare to care audience. You know we're trying to engage primary care physicians to understand why early detection is going to be important, you know, to just give people peace of mind, to recognize what's happening earlier, to connect them to resources. And then there are new medications that are getting FDA approved in the last year or two that are focused on trying to help people at a milder stage of the condition. So that's why early detection is important. But you know from your interaction either in the social work realm or you know from you know working on dare to care and working with various communities, what do you think are the sort of the feelings about early detection that community members think about it? Do they do they value it? Would they value it if they knew, like, what it would lead to if you could get an early diagnosis?

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

25:37

you know that is such a great question and I I think I think Dr Ranji stated on the head when he talked about you know, in rural areas there's a lot of kind of fear and misconception, and so I think early detection is important, but probably more important is also education about you know what to expect and what are some of the sorts of things that we could be doing in order to help both the caregiver and the individual with dementia, or was on the road to seeing that dementia become, you know, full-blown into other areas that will affect their lives.

26:18

I think that the care which was originally part of caring, health and light ministries.

26:24

We got into this because the agency was really not understanding how to deal with older adults and they were receiving calls from caregivers with loved ones who did have dementia and they were asking about what resources are there, how it could be enough to meet, etc. We're also we've also partnered with a pioneer coalition in Southern Illinois and we do a lot of education for caregivers and people working in long-term care facilities. And then, in addition to that, we are involved with Ketchum, which is a project upstate which you've been involved with through Rush University, so we've been doing any education through their modules that they have to educate people in the community on caregiving as well as dementia, alzheimer's and related disorders. And then, lastly, dementia friends has been an initiative that we've been promoting in the area as a way to both educate social workers and other helping professionals to know that there are, there is folk and there are ways that we can make our communities more friendly and have an impact to include those people who are developing dementia and play sports.

Raj Shah, MD

Host

27:41

Yeah, and I know this has been a great starting conversation and introduction. You know, between the Dare to Care program and the Brain Trust and you know I'm so glad you're working on the Dare to Care education side and that we can be part of it and even if it's just to share with the audiences that we understand the need around Alzheimer's disease and related dementia and early diagnosis, we are working hard to train primary care physicians to be more comfortable and confident in handling these problems and I guess my ask, you know, for the Dare to Care audience is sort of threefold, you know. Number one please share this resource or this podcast or this radio show with primary care physicians in your area so they can learn about this as something that can help them to advance their understanding and delivery of services around early detection. Number two, if there's a way that, if you know resources in your communities that you think would be helpful for primary care physicians to know about, let us know on the Brain Trust so that we could put those resources in our toolkit. And number three, I would ask if you know a primary care physician who's doing really good work in your community in addressing the needs around Alzheimer's disease and early detection you could share.

28:57

I would love to talk with them, so I really appreciate this opportunity to come down and visit with you, elaine, today, with the Desma and you cash. I hope that you know we learned a lot together by just talking with each other, even in this short session. But, elaine, I'll let you have the final word. Anything else you wanted to talk about?

Elaine T. Jurkowski, PH.D, M.S.W.

Guest

29:15

I want to just say thank you so much for being guest today on our show. It's been great having you. I know I've learned a few more things about the Brain Trust and some of those advantages, and I hope that my listening audience has also learned something. In order to help, the better dare to care. So please join us next week on Dare to Care.

Kate Rowland, MD

Announcement

29:41

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 at thebraintrustcom. For more episodes of the Brain Trust, please visit our website, thebraintrustprojectcom. 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 for any major podcast platform. Thank you again and we hope you tune into the next episode of the Brain Trust.