Risk-Based Strategies for referrals to Community Services for Older Adults with Dementia and their Care partners

Applications from the GSA KAER Toolkit for Primary Care Teams

GSA Momentum Discussions Podcast from The Gerontological Society of America

Aired February 1, 2023

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Welcome to this GSA Momentum Discussion podcast, addressing how primary care providers can use risk-based strategies for referrals to community services for older adults with dementia and their care partners. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, and Otsuka for their support of the GSA KAER Toolkit for Brain Health and today's program. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America, and I'm delighted to serve as the host for today's Momentum Discussion. Joining me today are Dr. Carolyn K. Clevenger, a professor at the Nell Hodgson Woodruff School of Nursing at Emory University, and the Clinical Director and a practicing nurse practitioner at the Emory Integrated Memory Care Clinic, a nurse-led primary care practice for people living with dementia. Dr. Clevenger is joined by her colleague Laura Medders, a licensed clinical social worker and the Administrative Director of the Emory Integrated Memory Clinic. Dr. Clevenger and Laura, thank you for taking time out of your busy schedule to share your insights around interdisciplinary care teams and primary care and how they can use risk-based strategies to refer older adults with dementia and their care partners to appropriate community services.

Dr. Clevenger:

Thanks for having us, Jen. Always good to be here.

Jen Pettis:

Great. Well, let's jump right in. Today we're talking about the fourth step of the KAER Framework and that's referring for community services. A person living with dementia has many other health needs that need to be addressed through referrals to professionals who've experienced treating people with dementia for their condition, for example, for treating their hearing loss or their arthritis or perhaps diabetes. And failure to attend to these needs will increase the apparent severity of a person's dementia. Dr. Clevenger, to start can you share some basic tenants about referrals that drive your team's work at the Emory Integrated Memory Care Clinic?

Dr. Clevenger:

Of course, this is a great topic. It's so critical in dementia in particular, broader than in a primary care geriatrics practice, because in this dementia syndrome patients and their families need help really navigating what we call a system. But it's pretty disjointed cluster of services that are related to their healthcare. But sometimes they're considered sort of outside of the healthcare system, those community service agencies in particular. But those are the services and supports that can make the difference between their ability to age in place or at least the place of their choice and between a family caregiver lacking support or burning out. So, they're really critical to keep in mind. This is, I think, about the broader world of long-term services and support and that system is finite, right? We don't have endless services available to people, although many times when people come to us, there are more resources and services out there than they realize because they've never needed to access that world.

But their ability to use those services is directly related to their socioeconomic status or ability to pay, and also their health literacy. So, on the one hand, we can't refer everyone to everything, right? The system is finite. Those resources are finite. They are at capacity in some cases, and it wouldn't necessarily be appropriate for everyone to have every agency available to them. So, in all things dementia, including in this case of referring to other specialists and community services, at Integrated Memory Care, we really believe in tailored or person and family centered care, and that includes referrals. So, we try to think about this under this risk stratification approach. When I was thinking about this the last time we spoke about the KAER Toolkit and making these referrals. I thought about this in placing people in you know, largely in buckets of this low, medium, or high risk.

And that risk category is not continuous, it is where they are right now, what this family needs right now. So, in nursing we think a lot about the five rights for things like medication administration. So, I'll say in the case of referrals, it's about matching the right service to the right family at the right time and for the right price. The other thing I will say is there's a larger conversation happening now about navigation for people living with dementia and their family caregivers and care partners. So, we talk about care navigation in other chronic and complex illnesses. I think cancer care probably has the most conversation about health navigation. Navigating in dementia is going to include specialists and care providers within healthcare systems. It also includes levels of care in terms of residential care. It includes navigating the legal system or elder law world. It includes navigating financial institutions in cases where things like power of attorney not only for healthcare, but for finances. And the last system we think about navigating for these folks might be the most complex, and that's navigating family systems. So, those are kind of the basic ways that we think about this larger world of dementia care and care beyond our clinic.

Jen Pettis:

Well, we heard, Laura, we heard from Dr. Clevenger about this risk-based approach. So, how does your team determine the patient and the care partner, or as Dr. Clevenger alluded to the family system, which could be their support or perhaps not, right? Their level of risk, how do they determine, how does your team determine that when looking into referrals or that the person may need?

Laura Medders:

Sure. There's a couple of different ways our team assesses a patient or family’s level of risk when they come to us. We have the benefit of having a social worker embedded in our team, and she is able to do an assessment of those psychosocial factors that are impacting the patient and the family's ability to provide care and sort of how ready they are for the disease progression. The other thing that we do, we have an interdisciplinary team within our clinic. And so, it sometimes is a matter of knowing who's coming up, who are all of the different team members talking to frequently. So, we start, we huddle every day, and so, we start noticing that the registered nurse talked with this person, the social worker has talked with this person, the nurse practitioner has talked with this person. They've been calling our scheduler over and over again. And so, we sort of get a sense of something is changing and there needs to be some sort of intervention there. If we break people down into sort of this low, medium, and high risk, what does that look like?

So, low risk, I think of the people who are just sort of chugging along, right? They are in the steady state. They probably have a high functioning support system, so family or friends who are heavily involved in the person's care regardless of stage. So, the risk stratification doesn't directly correlate with where the person is in the disease progression. This could change at any point depending on the family systems readiness or the family of choice systems readiness to sort of respond to these needs. Medium risk, these are people that I, people that fall into this bucket for me or people who are noticing the disease progression, right? So, whatever they have been doing is not going to continue to work as the disease is changing a person's ability and thinking, right? So, what has gotten you to this point is not going to continue to get you through the disease progression.

And so, it's sort of exceeded what the family is currently capable of providing, in the environment that they're in. And then the high risk is really sort of the high crisis. We might affectionately refer to them as the hot mess express in clinic, right? So, these are the patients and families that are coming in a real hot crisis. They have got a lack of support system. Maybe, they have too much support system, people in their support system that don't agree on what the plan of care is. There's a lot of infighting in between the family systems or there is just a lot of complex medical things happening and that things are changing quickly, and families aren't sort of able to get their feet underneath them to respond to that. I think when we're thinking about what are some of the critical pieces that we're looking for that sort of are red flags for us, like Carolyn mentioned, it's that socioeconomic status, those social determinants of health that may be barriers to accessing the care that they need, when they need it, and how they need it.

And there are resources, community-based resources, particularly through the area Agency on Aging that families can access, but they typically are not immediate, right? So, there is a runway of an application period. There is approvals that need to happen. There's forms and documents that need to be filled out, in order to be eligible for some of these programs. And so, really being able to help families identify that early on can be helpful. It is the people with either no clear decision maker, right? So, maybe those elder orphans who are coming to you and they don't have a lot of family support or people who have no clear decision maker because there is too much family support, that is also a risk for us as well. So, that high level of conflict within a family, highly litigious families, those are going to be a risk for our patients as well.

Jen Pettis:

And so, in follow up to that, when you consider community referrals, is there something, is there kind of a standard bucket that you guys would recommend for everyone who's newly diagnosed with dementia and what does that look like?

Dr. Clevenger:

So, I think it is a couple of different resources that could be really helpful. I think regardless of sort of what they're coming with, having those conversations around legal planning is critical for families and can really avoid a lot of crisis situations in the future. So, making sure that there is an advanced directive with a clear decision maker, making sure that there is a financial power of attorney in place or whatever the documents are in your state, that's what they happen to be in Georgia, but having those documents in place, if they have the capacity to execute them, is critical. The other piece that, depending on the age of the person when they're diagnosed, making sure that we're talking to them about Social Security Disability and applying for that, a really clear, good diagnosis and workup can help families and patients access services and benefits faster. A lot of the dementia diagnoses are compassionate allowances, and so those get pushed forward a lot more quickly than some other disability cases if that’s a really clear case. We want to make sure everybody is accessing those quickly and as soon as possible.

Jen Pettis:

Dr. Clevenger, tell me about your team's approach to referrals for a low-risk patient or a patient and care partner dyad. What would goals of referrals as part of their plan of care be for them? And then what are some examples of some services you might connect them with?

Dr. Clevenger:

Well, so like Laura said, someone who we would consider fairly low risk is, you know, things are pretty steady state, and again, it's regardless of disease state. So, it might be someone who is an early stage, it might be someone who's a moderate stage, but they have a high functioning support system around them and maybe they've been steady at that state for a little bit of time. So, for these folks, what we like to do is we like, like to put support around them to really optimize both that patient and their family caregiver's quality of life and optimize the care that they're accessing and getting today. We want to gather resources that we would be appropriate for them to really support them because we know this is a long journey, it's a long haul ahead of them, and it's good, as Laura said, to get ahead of some of these things so that they can continue to stay at this steady state for as long as possible.

We know things will change, but we like to stay here. So, I think a good place to begin is to understand what your resources are in your local area. And every area around the US has an Area Agency on Aging and that will have a whole database of resources. Sometimes it's as simple as understanding that this, this resource exists, whether or not there are needed services through that agency today. It may also be your Aging Disability and Resource Center. So, these are two areas, two agencies that everyone has access to. To understand what services, fall under that group in your particular area is very helpful. I also think, and, you know, a lot of my research is in family dementia, family caregiver education. To prepare them for this job that they are now finding themselves in, which is a very intensive and long-term caregiving scenario and more skills and hands-on than other caregiving scenarios.

So, I want them to learn, I need them to get some training both for their own ability, for their person's quality of life, and also, frankly, to be a better partner to me as the primary care clinician. So I'm going to connect them with some type of educational format, and that depends on the format that they're comfortable with that they will access and it's appropriate for them. So, in our practice, we offer internally caregiver classes, and we have some that are stage based. So, for early-stage folks, we have some courses that are really better for the moderate stage, and we have a late stage group as well that's helpful for a variety of reasons. You know, you don't want to put a patient and or family caregiver in a class that is really about late-stage symptoms when this person maybe has just recently gotten a diagnosis and is experiencing irritating forgetfulness, but not, you know, quite so dependent on their day-to-day abilities that can be very overwhelming.

Laura can tell you we have one course that we offer, I think goes really well for people in moderate stage. And if you put in front of them something that is too advanced in terms of the disease state, we find they don't come back to the next class. So, tailoring it to the right timing is good. And then of course there are preferences, right? So, I, you know, you have to sort of ask people and there's a, a parallel here to the diagnostic process and communicating with people about, as we get this, how much information do you prefer, right? What, so we ask people like, what's your preferred learning style? I think Joint Commission expects us to do those kinds of things. What's your preferred learning format? Are you a visual or auditory learner? That kind of thing. In the caregiver space, I want to know, are you someone who likes all the, the information so that you show up as prepared as possible?

Or you, someone who says, you know, out just in time is about what I can handle and are you someone who's going to listen to a podcast? We've got those resources. Are you someone who will attend a class? I really want you to do that because they're evidence based. The content builds on itself. We know that it reduces anxiety, depression, burden and increases your sense of mastery for this role. So, I want you to do that. But really, I want you to do whatever you're willing to do. I want you to identify who your support system is around you. And if you have what we call a village, right, who is in your village that's meaningful? And sometimes it takes some coaching to get you to sort of build out who are these people and what are the ways in which maybe they've already offered to help you, but they may be helpful.

So, for example, if in your village you have a sibling, an adult sibling, maybe you're an adult child of someone as a caregiver and the person lives at a distance. They can, you know, online bill pays very helpful. They can manage those kinds of finances and legal documents. They don't have to be here in person to do that the same way that you would need someone to take your person to the grocery store. So, thinking about those kinds of things, and if you don't have that, but even if you do, a support group can be very meaningful as well, if that's something that you're open to. I've got, you know, people are all over the spectrum on their preference around that type of group. A lot of our support groups can also be offered by our advocacy organizations such as the Alzheimer's Association and many faith communities offer these kinds of support groups and services as well.

So certainly, Jewish Family Community Services has been a wealth of resource in our area here. As Laura mentioned, understanding the need for elder care law I think is helpful. And then at this point I also want to know, and she sort of touched on this, what is your eligibility for these services? So, like a VA aid and attendance, like Social Security Disability, even to understand maybe we're not about to pull the trigger affiliates applications out today. Some we do because it's a long pathway, but let's sort of know at what point will we pull that trigger and what would be the milestone that would sort of indicate it's time to do those sorts of things. But early on we want to at least kind of know what are our resources around this person? What do we have access to today and how do we strengthen and bolster and really prepare them for what's ahead?

Jen Pettis:

I loved your comment about what is that milestone we're going to pull the trigger. What is that point when the care partner maybe needs some help and, and you begin to recognize that ahead of time, that that's certainly helped to avoid the crisis.

Dr. Clevenger:

You know, what might be helpful, I think also for primary care practices or clinic practices like ours is I think sometimes we think, you know, if you don't, if you're not fortunate enough to have an embedded social worker in the team or you don't feel like this is part of the way, you can work this into your workflow. The reality is this is advanced care planning. We are having a conversation about what's ahead and what we might need. Advanced care planning is not just about completing your legal documents for advanced directives. So, that might be something for folks to think about in terms of how they might take the time, time to at least start these conversations.

Jen Pettis:

Exactly. Well, Laura, I have kind of a similar question for you, but I'd like to ask you about the medium risk patient or patient and family. What are the goals of referrals for them and what are some other examples of services you might connect them with?

Laura Medders:

Yeah, so medium risk, again, as often those people that are find themselves in this bucket because of changes in the person's disease progression, they’re exhibiting new symptoms that are overwhelming or frustrating to the patient and family. It, there's often, you know, increasing caregiver burden and a decrease in the person's abilities to sort of orient and initiate things on their own. Training and education may be very critical in this stage as well, but you have to make sure that the caregivers are ready and able to do it. And so, what we may think is if they just understood that this symptom was a normal part of the progression, they would, you know, this wouldn't be such a crisis for them. But it, you have to sort of alleviate some of that burden before they'll be ready to learn and apply some of what you were trying to teach them.

So, this stage, I would say typically there's this increased caregiver burden. The caregiver is being asked to take on additional tasks on behalf of this person. This may start impacting the caregiver's ability to hold down a job. You know, they're having to leave work earlier, they're having to take a lot of calls during work because the patient is continuing to call them and it's really starting to impact their job performance or it may be inter encroaching on some of their other caregiving responsibilities. For those people that find themselves in the sandwich generation, you know, do I focus on my child or my adult parent? And so, we see a lot of people in this bucket sort of with this increased caregiver burden, there's increased safety concerns. Oftentimes, they start realizing maybe my person is not safe to be alone. Maybe it's not safe for them to be operating so independently.

What do I need to have in place for my person to be able to be able to operate independently? And they start facing some decisions about care. This is usually when a trigger has to be pulled, right? There is some change in the disease progression. The patient may have increased care needs as well, right? So, this is, they're needing more assistance with prompting for eating and meals. They may need start needing assistance with toileting dressing and things like that. And so, there is this sort of increased tasks that go along with this. And so, depending on what the challenges really depends on which recommendation our team will make, right? It's that the right care for the right price at the right time. But a lot of that is having that relationship with the family to know what they can afford doing some of that pre-work when they're not in crisis.

So, that, that there is a plan can really go a long way. But this is often where we see families initiating that family medical leave so that they can take some time off of work to handle these responsibilities. This is where we often say, have you considered an adult day program that may be able to provide some of that oversight, provides some of that supervision, sometimes help with those ADLs, if it is a medical model. And sometimes it is, let's have a family meeting to really talk about getting everybody on the same page about how do we move forward and avoid further crises, right? How do we talk about who is pulling the trigger and when we're pulling the trigger? So, getting all of the players involved for a discussion can be really helpful as well.

Jen Pettis:

Dr. Clevenger, let's move on now to those high-risk patients. Tell us a maybe scenario or two of them and how you can support them with referrals.

Dr. Clevenger:

So, these are hot mess express folks. This is, and that's sort of a nice way for our team to sort of decompress by the way, not to make light certainly of the situation. These are people who find themselves in crisis and, and sometimes this is fairly early. So, an example is this is a patient I started seeing a year ago and her husband brought her in, and she was very actively psychotic. She was experiencing really firm delusions, was not sleeping, which means he was not sleeping, very busy person. So, every time she was out of his sight, she was into something she probably shouldn't be into in terms of a from a safety perspective. And if he, if he forgot to lock the car, she would be in the car at three in the morning ready to leave to go to work, fully dressed.

He was finding medicines all over the house. They had a family dynamic that was not a firm foundation to begin with. So, this for the two of them was a second marriage. Her children were not his children and they had a friendly relationship but not a close relationship. And as things began to escalate, tensions began to escalate as well between them. So, family in a bit of crisis. And his mother had lived with them and had been quite a help and honestly, I think hid a number of his wife's cognitive deficiencies from him. So, he actually had, he was surprised at that she had a dementia syndrome. Her adult children knew, didn't tell him. So, he, he's, you know, when his mother passed away, things were in crisis, right? So, two things have happened in this situation. If you think about this, that medium risk person, it can either be a change that has happened for the family caregiver care partner, right?

So, they now have a financial or an employment issue. Maybe now they have a medical issue themselves, but, and so there's that, or it could be that the person, maybe the disease has progressed into some more bothersome symptoms that we don't know how to manage. And I think the high risk probably both has happened. Both the family support system is not there or has really declined for whatever reason. And also, there's been disease progression. I think that sets it up very nicely for the high-risk scenario. So, in, in that case, we probably need, you know, a good bit more support around this folks, these folks, this is not the time to send them to caregiver class or recommend a book <laugh>, right? We've really got to put sort of all hands on deck, and that may include your clinic team as well as the community agencies that you're recommending for folks.

So, our goal here is trying to get them through this on the day-to-day. We're not looking months and years ahead at this point. We really are trying to get from week to week to both support the health and wellbeing of the patient and their support system to typically the family caregiver. So, in this case, we are trying to organize and coordinate and advocate for both of them. And it's going to require a good bit of time, which, of course, is another good reason to engage agencies or referrals and specialists outside of your practice. One particular professional I think that is under-recognized, undervalued, but really is tremendous, are aging life care managers. Because these folks require high touchpoints and frequent touchpoints. So, you can find an aging life care manager in your area, and this is when the family really needs not just someone to coach and support them on the day-to-day, but then also be the advocate to talk with different agencies on their behalf because they are such a crisis or so overwhelmed or don't have a designated person now to make calls on behalf of this person if that's going to involve additional services.

Making a change in a residential living situation, coordinating me with multiple medical special specialists. In other scenario, I had a family patient had progressed, had a lot of other medical comorbidities. It actually, the issues were not so much about dementia progression, but it was that, you know, we had a hip fracture and we had like a vision issue that was kind of acute. Like we had multiple specialties that needed to be attended to. And her son, who was her primary caregiver, traveled every week for work. We live in Atlanta, so you can guess what company this person worked for a lot of flying places and himself had five children. So, you know, things were really overwhelming for him when that happened. And that had been sort of a change in employment, so more travel for him. It's not that there was discord per se. So, in that case, they needed that aging life care manager to make those appointments, take her to those things, coordinate all the documentation, get prescriptions on the same page, and then they've been a wonderful point of contact of course for our primary care team.

Because you have another professional who's involved in the day to day much more than even a practice like ours. And we have pretty frequent support can help with that. So, in these cases, it's not just about what agencies or services are you eligible for, can you pay for? Then it gets into someone's actually probably going to have to call and make those appointments and get you to them. And so, it's not just making that referral, it's actually employing a resource. You're able to get them to those actual other services because even the, you know, sending somebody out of your clinic with a referral like you should call this service like it, it's not, probably not going to happen when they're in this crisis mode.

Jen Pettis:

Well, once again, ladies, a wonderful discussion with you both. Some things that I heard, I actually have two pages of notes I've been writing here. I don't have time to share all my, my thoughts, but I love the idea of right care or service, right price, and right time. And clearly part of your early kind of negotiation with those patients is determining what is that time through that advanced care planning as you go through this journey that you both know so well, what your patients are just learning along with their care partners. What is going to be that time when you know you're going to need some extra support? Let's talk about that now. So, you kind of avoid that train to the hot mess express that you, that you mentioned. And we appreciate the need for your team to have some levity when you're facing all of these, these conditions, you know, tough conditions.

I heard you say that part of your linking community services was allowing that person to age in place or the place of their choice and really to optimize quality of life. I also heard loud and clear that your focus on these connections with that these external sources is really about based on that stage kind of different goals, right? If they're early in their disease and or at low risk even if they're, they're later in their disease progression, it's about making sure that that quality of life and that that kind of stability continues. Where if you're in that really high risk, it's let's get you through the day. Let's not, not worry so much. And I really appreciated your focus on training and education for the caregivers and really looking at as well as the patients. But where are, is there readiness to learn and not just readiness to learn, but ready to apply what they learn.

And that's such an important part of your very comprehensive assessment that I know you do with your patients. I also heard advanced care planning, which of course makes me think of end care coordination and that makes me think of our other recent podcast where we talked about reimbursement as a pathway to quality care. That there is reimbursement available for all of this hard work that you're doing. So, let me turn to you both and just start with you Laura. What's some other key points you want to mention? A couple of things you'd like to mention.

Laura Medders:

I know we talked about identifying different family systems that are in crisis and stratifying that level of risk, but I think one thing that our team also tries to do is not necessarily assume that we know what the families need at which time. Just because the family is not presenting as on fire and in total chaos does not mean that that is how the family is feeling when they go home after presenting their best foot forward in clinic. And so, we really try to offer that, those educational pieces to everyone regardless of whether or not we identify them as somebody who could benefit from it. So, we offer this we offer support groups and various educational opportunities to our patients and families. When there is like if they're appropriate to participate, we want them to come and do it. So, we try not to make that decision or be a barrier to them getting that information if they need it.

Jen Pettis:

Dr. Clevenger, how about you? There's some key points you'd like to recap.

Dr. Clevenger:

I have to give Laura kudos because that is such an excellent point. I do find so many times in especially primary care medical practices where we're used to like, what is your problem? Here's your prescription. And in this case, exactly like she said, you open it up to everyone, you let them decide when they want something and you know, allow the agency to be present for those folks to make those decisions. I love that. Now, as the reimbursement person, I like to think a little bit about, I was thinking a bit about not just advanced care planning and capturing your time, but a couple of things have come to my attention recently. And so, as a bit of background, people may know ICD-10 has added a lot of new diagnoses codes for 23. Many of them actually are related to dementia diagnosis and characterizing neuropsych symptoms. But they also have added new codes that can better capture some of the things we would consider social determinants of health.

Our team was talking about this recently and we were getting pretty excited about it because, in a practice like ours, we're very attuned to the dementia syndrome to the family system. I think we do things and we have that approach, it's on our mind. It's very central. I know not every practice has that luxury. But when you have this shift and this way to actually identify and capture a person's perceived financial hardship or transportation insecurity or housing insecurity, that becomes very helpful. Because you can imagine how having that as part of someone's total picture in the medical record would at least create some awareness that some challenges may exist for this person with a lower threshold than it would happen for someone else. So, I'm really optimistic about that. And then to parallel that, or to build on that, I also looked at the 2023 MIPPS measures, at least for geriatrics practices, which include capturing some of this information.

So, I'm hoping that more health systems, not just practices that are very fairly specialized like we are, but larger health systems will have some motivation to then systematically collect this information, so that we can start to understand what kind of risk category people might be in and to maybe be a bit more proactive about at least making these community services agencies potential referrals available to people so that they know what might be out there or we can actually recommend them as needed. Interesting to see how some of these systems changes happen with our new billing and coding. That's coming for us right now in 2023.

Jen Pettis:

Wonderful. Thank you for your time, ladies and your knowledge and your passion for the great work that you do. You're doing such amazing work for the individuals with dementia, their care partners. Thanks to everyone who's listening to the podcast as well. I'm sure you found it informative and enjoyable as I did with talking with Laura and Dr. Clevenger. Thanks again.

Dr. Clevenger:

Thanks for having us.

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.