Quality Improvement Organizations
Sharing Knowledge. Improving Health Care.
CENTERS FOR MEDICARE & MEDICAID SERVICES

QIN NCC
Quality Innovation Network
National Coordinating Center

This transcript is intended to provide webinar content in an alternate format to aid accessibility. We apologize for any inaudible or unclear content as a result of audio quality.

Role of Geriatric Psychiatry in Caring for Persons with Dementia

An interview of Ramesh Sairam, MD (recorded 07-17-2014)
(50 minutes)

Kelly O'Neill: Hello, this is Kelly O'Neill with the National Coordinating Center, and we are pleased to have Dr. Ramesh Sairam with us today to talk about the role of geriatric psychiatry and caring for people living with dementia.

Dr. Sairam is the medical director of the Department of Mental Health with United Hospital in St. Paul, Minnesota since 2012. Prior to that he was the medical director of the Geriatric Psychiatry unit at United Hospital from 2003-2012. His residency was in general psychiatry and he completed his Fellowship in Geriatric Psychiatry at the University of Texas Southwestern Medical Center in Dallas.

Dr. Jane Pederson will facilitate the discussion today. Jane is a practicing geriatrician and the Director of Medical Affairs at Stratis Health in Bloomington, Minnesota.

Dr. Pederson: **Dr. Sairam, I wonder if you could just start today by giving us a little bit about your current role in practice just to let everybody know what you're doing on a day-to-day basis.**

Dr. Sairam: Good afternoon, everyone. I'm currently in a transition mode after being the medical director for 10 years essentially running a very acute care geriatric psychiatry unit. About two years ago I transitioned to the role of the medical director for the whole department. But in the area of geriatric psychiatry, one of the big gaps is the coordination between geriatric psychiatry services and primary care because the bulk of the patients are under the care of geriatric teams or primary care physicians. Many of those patients eventually experience symptoms and problems that are beyond the scope of a primary care physician, but there aren't enough geriatric physiatrists to go out and attend to the needs of those patients individually. So a big, passionate, energy of mine now and for the next year or two would be to try and build some bridges between the few geriatric psychiatric providers that are there with the primary care and geriatric teams out in the community.

Dr. Pederson: That leads into my second question. We don't have an abundance of geriatric psychiatrists.

When do we call? When's the best time for us to be calling in a geropsychiatrist if we're a member of a healthcare team or we're giving advice to an organization how best to use our limited resources of geriatric psychiatry?

Dr. Sairam: I'll tell you what happens and then what should be happening, what is hopefully my dream not a fantasy. Right now what happens is there is a crisis and the folks at the ground level are trying to take care of a patient with dementia with psychiatric or behavioral symptoms. They do what they can, they don't have access to any subspecialty care and then the patient gets sent to the emergency room and then they come to one of our geriatric psychiatry units.

Sometimes those of us who have had outpatient private practices or have outpatient practices and the primary care physicians that I've worked with closely in the past have access to me through a separate secure line so I can their patients preferentially. But in regards to the general primary care physician population they really don't have access to a lot of geriatric psychiatrists, so right now the geriatric psychiatrists often end up seeing patients in kind of crisis-like situations. A small number of us do rounds in long-term care facilities, but again given how busy we can be in our outpatient practices and hospital practices and also consultations in hospitals there aren't a whole lot of us who do the long-term care work.

Ideally, what should be happening and I'm beginning to pilot some of this at our organization is that two or three geriatric psychiatrists can act as consultants and be available either on the phone or e-consults or some other modality and interface with advanced care practitioners like CNSs or nurse practitioners who do the bulk of the rounding in care facilities and who can then identify the problems before it becomes a crisis. Along the way, also we have the opportunity to do some education on a case-by-case basis so that the nurse practitioners can then eventually take on the management of mild to moderate cases on their own initiative.

Dr. Pederson: Thank you. One of the things that we've talked about is this whole concept of the resident's quality of life and quality of choice.

From your perspective, what are the things that you focus on when supporting a nursing home resident living with dementia to promote that best quality of care and best quality of life?

Dr. Sairam: I think there comes a stage with dementia that the patients themselves, tragically, cannot articulate for themselves and state what their wishes are. The big push over the last few years is really everyone beyond the age of 50 should have a document indicating their wishes regarding healthcare treatment. Especially anyone over the age of 70 should be strongly encouraged by their primary care physicians to have a document in place. That will be the final arbiter of what we should or should not do for the patient.

Until such time that happens, a lot of my focus has been to work with families to explain, number one, that dementia is a terminal illness. It's like some of the more serious cancers where it's not something that we have a cure for, it is a progressively declining illness and they will be an end and so how to prepare them for it. I'm repeatedly surprised at how often I come across families that haven't heard that it is a terminal illness that will take their loved ones life, so when they hear then, concepts like, we'll have to start preparing for the end it takes the families by surprise.

My contact with families is an inefficient way of spreading this information and the best approach would be to start working with the staff at the care facilities at every level, nurses, social workers and also even the patient care assistants. If they can understand the nature of this disease, the relentless progressive aspect and then also comfort and alleviating distress is a big part of the care of this disease then, hopefully, we'll all be speaking the same language.

Dr. Pederson: That's a good segue-way into my next question.

The progression of dementia changes, and so as our brain continues to change, how do you approach management of symptoms? How do we avoid starting something and saying well, that's fixed?

Dr. Sairam: Dementia makes it particularly difficult because the standard terminology to describe the progression of a disease is mild, moderate, severe. That leads to a couple of problems in the setting of dementia because there are two parallel processes that are going on. One is there is a cognitive decline and then there is the functional and physical decline and there's a lag time between the two.

Cognitive decline usually precedes functional decline and eventually the physical decline part, which leaves many family members definitely, but also I've found many professionals with the impression that psychiatric and behavioral symptoms are correlated with the stages of the disease. Meaning, that it's only in the severe stages of the illness that someone will have severe behavioral systems as opposed to the mild stages.

Unfortunately, that's not the case. Someone in very early stages of dementia if they have the belief that they should be allowed to drive, that nobody should be taking away their wallet, nobody should be telling them anything about changing their lifestyle, then they may end up in a geriatric psychiatry unit with a lot of agitation. They may also be the kind of folks may who end believing that their family just wants to lock them up in a nursing home so they can go off and enjoy their money so they may start sounding delusional.

Even though this person may have fairly mild to moderate stages of dementia, they may have fairly severe behaviors that may even necessitate placement in a geriatric psychiatry unit or a loss memory care unit. On the other hand, I've followed patients in my office where almost until the very end, until the last few months of their life they were able to stay at home because their manifestation was essentially apathy. All they needed was hands-on care, but they never got into trouble.

So one of the challenges in our minds is to disconnect the notion that there is predictability or even a causal relationship between the stage of dementia and the behavioral symptoms and have a more open approach to recognize that this is a very convoluted, complicated illness. Depending on which part of the brain, which pattern of brain pathology, whether it's frontal lobe with the language part of the brain or the visual spatial with the frontal lobe, you can have different manifestations.

Then, of course, dementia is not an illness by itself, it's an illness that occurs in the background of a human being who has his own personality and other characteristics and so that will also impact how they manifest. So the answer to your question, Jane, would be have a very open mind and have no preconceived notions and especially not leave family members with any impression that there is a clear causal relationship between the stage of dementia and behavioral symptoms.

Dr. Pederson: Kind of a piece of that, too, is just because someone is behaving or acting a certain way right now may mean that six months from now they may be totally different. I think that's helpful for us to all think of as we're looking at this. Especially in our community where we're trying to work with helping nursing homes or helping providers best address these symptoms is really keeping our minds open. At least if I'm hearing what you're saying, this is not something that just stays stable. If someone is having issues with certain types of behaviors or they're suffering from certain feelings, that may change six months from now and we need to be prepared for that. Am I on the right track?

Dr. Sairam: Oh, absolutely. Thanks for bringing that up because one of my pet peeves is this whole notion of vitamin “AD” - which is vitamin antidepressant. We are a very prescription happy society, both as providers and also patients who want prescriptions. What I see quite often is not everyone has insight into the illness, depending again on the pattern of their brain pathology. Tragically, some folks are aware that they have Alzheimer's disease and get a prognosis, but they may have what we call an adjustment reaction. It's a grieving process and preparing, it's like someone being told they have cancer.

Unfortunately, anyone we see who is crying the assumption is that they must be depressed so we give an antidepressant. That may be okay, but as the disease progresses and as their amnesia sets in or as their ability to have an awareness of their illness goes there's no longer a need for the antidepressant. This is one of those medications where in the then distant midst of time medication was prescribed and then nobody knows why it is being continued. It's sort of a trivial medication, but when you start talking about the stronger medicines, especially neuroleptics, you really have to be aware that this is a continuously shifting, evolving illness. It's shifting goal posts, so the brain in January 2014 is not the same brain in July and won't be the same brain in 2015.

Dr. Pederson: That's really helpful for us all to keep in mind as we're both teaching this and working with facilities. Before we get into our next segue, I want to see if anyone has any questions.

Kelly O'Neill: Okay, we do have a question for you Dr. Sairam.

As a physician, how would you suggest a nursing home address their psychiatrist who always uses medications as the first step when they are trying to use less antipsychotics or anti-anxiety meds?

Dr. Sairam: I have to state the obvious, any views I share today are mine. Meaning, I'm a very conservative physician when it comes to diagnosis and prescribing medications and so whenever I give talks or in my practice I really believe that medications are over used and, more importantly, that we equate emotional states to diagnostic labels. We automatically as a culture and as a society have come to see a crying person as a depressed person and depressed has that kind of clinical connotation so a pill follows.

I don't want to bypass that question, but my point is that we've come to see emotional states as symptoms as opposed to a human condition or a human reaction. Let me give you an example of one situation where a presentation is described as paranoia which I believe is not paranoia.

Folks with dementia often misplace objects and, of course, they can't remember where they misplaced their objects and, of course, they don't know how to solve the problem of their missing objects. Many of you may have the experience that when say our child doesn't come home at a certain time our mind jumps to the worst possible conclusion. It's almost like we're hardwired to believe immediately that something awful has happened to our child, but we calm ourselves and then solve the problem of the missing child.

The problem with someone with dementia is that when there's the missing wallet they freak out, they are unable to calm themselves and then the mind jumps to the worst possible conclusion, which is that somebody is stealing my things. If they're in a care facility surrounded by strangers, of course, each of those strangers are coming in and stealing their things and so they start making "paranoid comments" that people are stealing my things and then, of course, they hide objects to prevent people from stealing their things and just perpetuate the problem. To me this is not a psychotic state. To me this is a classic manifestation of a brain that has executive and memory problems and is not able to connect the dots properly and I don't believe this should be called psychosis.

To the question about the psychiatrist, our training is that if someone is making paranoid statements they are psychotic and immediately it should be followed by antipsychotic medications. In some instances I do have to use neuroleptics medications, but it's after other options have been tried. I know there are many providers, both psychiatric and otherwise, who have the symptom/diagnostic/label followed by a pill as the kind of standard mode of practice and it's going to take a lot of education and some pressure from different sources to make that change.

Dr. Pederson: Thank you for that answer. There's another term that often gets used when we look at dementia and behaviors and that's this term of agitation.

This is kind of a vague term, is there a definition for agitation? What does that say to you when you hear someone is agitated?

Dr. Sairam: Well, the symptoms I see, within me, is "what is agitation?" when I hear people say a patient is agitated. That's my short answer. The problem is agitation is like saying a patient has pain or a patient in the medical setting would be a patient has fever. It really doesn't tell us anything other than a very vague notion of something is off from baseline. The reason why this is part of the core education process is that we can start off by saying I have a patient who is agitated. But then we have to go beyond that, to be clear in our minds not just as providers, but I'm starting with the PCA level and the people who take care of the patient hands-on, to be able to learn the language to describe what's going on.

It could be someone who is in pain. It could be someone who wants to go pee. It could be someone who is missing their spouse. It's someone who is looking for their car keys. Someone who believes they are trapped or locked in a place, all kinds of emotional distress. Anything other than a calm patient is often described as an agitated patient. Again, there's nothing wrong in using that so long as then they proceed to the next step and have some sense of what's going on. From the physician side, we should also not take the term agitation at its word and then prescribe a medication, but also get some information from the person reporting to get an idea of what this agitation means.

Dr. Pederson: Let's now move into this topic of antipsychotic medications, psychotropic medications and especially antipsychotics.

Could you talk a little bit about what is the role of psychotropic medications and symptom management? In regard to antipsychotics, are they overused? Is there actually an appropriate role for them?

Dr. Sairam: The answer to the last question is absolutely, there is an appropriate role for those medications despite the black box warnings. To those in the audience if you're not familiar with the black box warnings, a few years ago based on a few small studies the FDA applied black box warnings to all neuroleptics, the old ones and the new ones because of an increased risk of strokes. This went up like from 1.5 to 3%, so 1.5% in controlled groups and 3% incidences of new stokes in those who received these medicines. Then just in nonspecific increased mortality, 2% in the controlled groups and 4% in the patients who received them.

So the first message is yes, there's definitely some medication-related effect, but unlike what was portrayed in the television media especially is that these medicines double the risk of patients dying. It's a gross exaggeration because it's not like the risk is doubled from 30% to 60%, it's from 2% to 4%. Having said that, I'm more concerned about some of the other effects of the medications than the black box warning which get most of the publicity.

These are powerful medicines, they are designed for powerful illnesses like mania, bipolar disorder and schizophrenia and they have to be used with respect. Being powerful medications, they come with fairly strong side effects and so we are giving these medicines to all of these frail, vulnerable, restless, unsteady elderly and we can create new mobility (problems) from the use of these medications. My concern about the overuse of these medications is more in this area than specifically the black box warnings, even though I don't discount them.

This is the part where this talk can get a little rambling. So, Jane, feel free to just interrupt if I get a little too longwinded. There are a couple of situations where there is a very clear, obvious need. Despite what I described earlier about the paranoid patient, there are patients who experience true psychotic symptoms in the setting of dementia. They feel the food is poison, they stop eating. They refuse medications. Some of them from their confusion can reach a place where they are really frightened. It can still be from their disorientation and not being able to make sense of where they are, but when they find themselves completely lost and helpless they can truly have a paranoid sense of I'm being held a prisoner and they don't sleep.

For those situations, after having tried some of the milder medications, the non-neuroleptics, it is perfectly appropriate to use neuroleptics. Depending on how severe the symptoms are, I may go to the neuroleptics straightaway if the level of distress justifies it. For example, if someone has post-operative pain I'm not going to go giving them just Tylenol. I will use a narcotic, even though narcotics come with side effects because the severity of the pain justifies the stronger medication. It's the same if somebody is having a very severe level of distress from their paranoid fears, using a neuroleptic is perfectly appropriate.

Some of you may be familiar with a unique kind of dementia called Lewy body disease. It's an unusual kind of dementia that accounts for about a quarter of all the cases of dementia, where psychosis is a very early presentation along with a couple of other unique features. These patients' psychotic symptoms can be very distressing. They can see certain things like fire, blood, scary animals. They can have really persecutory fears for themselves or their families. So for them you have to use a neuroleptic medication, but very cautiously because only two or three neuroleptics can be used safely in these patients.

These are probably the two fairly straightforward indications. The thing that's happening and this is just my subjective sense, is that dementia has been around for a long time and primary care physicians have been doing their best to try and manage these symptoms without any access to geriatric psychiatrists. But, until five-six years ago, the majority of patients with dementia were diagnosed by neurologists and so primary physicians would turn to neurologists and say "I have this patient with dementia who seems agitated, who has some psychosis, what can I use?"

Now, neurologists for many years used Seroquel as their medication of choice for people with Parkinson's disease who have psychotic symptoms, which is a common complication. So my guess is that that was the kind of trajectory, neurologists recommending Seroquel to primary physicians and the primary physicians getting a comfort level to where now Seroquel has become the kind of go-to medication for any kind of problem. It's sedating so it helps sleep. It's used for anxiety. It's used for psychosis. It just becomes like an automatic indication, which is a tragedy because it has many side effects and also a bloody expensive medication.

Then as I mentioned earlier, if we don't take care to understand the nature of the agitation, the cause of the agitation or the characteristics of the patient's symptoms, then we may end up using this hammer and just keep hammering away every symptom as if it were a nail and forget that there are other medications and definitely non-pharmacological interventions that can be used quite effectively.

Dr. Pederson: That's helpful. There are a lot of factors to think about and it's not as simple as there's an algorithm of when this person does this, this is the drug, when this person does this, this is the next step.

How do we select something that would be appropriate to relieve suffering, is there any guidance that you can provide the facilities?

Dr. Sairam: Settings like this kind of webinar and lectures is where there's a limitation because I can give generalities, but nothing sticks well as a case example. That's why my real energy and focus is working collaboratively with the primary physicians or nurse practitioners because it's a case-by-case example where they can see the thought process. Even though there's no algorithm, there is an art. There is a method to the practice. This is assuming that the care facility and others involved in the patient's care have done all the non-pharmacological interventions possible and then have reached the point where something is necessary.

One of the lower hanging fruits is insomnia. Sleep dysregulation is a very common problem in people with dementia and then very quickly, especially if there has been a change in their living situation, home to a care facility or home to hospital back home, this thing can get disrupted very quickly. If not attended to then the 'nightmare' - the day/night sleep reversal - becomes a very difficult problem to treat. Again, we don't have to reach for Seroquel for that.

My problem using Seroquel as a sleep aid is it's a very powerful sleep aid, it can be very sedating. It also has orthostatic effects, it can drop blood pressure. Someone who takes a dose of Seroquel at 10:00 o'clock at night and then has to get up to go to the bathroom at midnight, that's the peak for the low blood pressure and you're putting the patient at risk for falling. It's also very expensive, as I said. When we have medications that cost $4 a month, instead we prescribe a medication that costs hundreds of dollars a month. So you can use trazodone, you can use mirtazapine and then the sleep hygiene techniques of sound and light. The other sleep aid techniques that we can use should be tried first.

Some of the patients, especially if they have frontal lobe impairment, if they have frontal lobe strokes, they often present with mood dysregulation. They have wild mood swings. Not necessarily mania or depression, but they can be quite irritable. They can seem like they're flying off the handle. Instead of just getting angry they're getting verbally abusive or they can lash out unpredictably. A low dose Depakote is a really wonderful medication that has been used for many years very effectively in people with head trauma, brain tumors, anything where the frontal lobe damage is other than emotional dysregulation.

Then, finally, if we do decide that a neuroleptic is necessary not all of them are the same. They have very different personalities. They have very different receptor profiles and side effect profiles. In fact, you want to select the medications based on the side affects you want, to some extent. So if someone is sleeping okay or if I can get their sleep addressed with trazodone, which is a much milder, safer sleep aid, why would I go to Seroquel. I'd rather use Risperdal or Risperidone which has a more calming effect without being sedating.

Those are the examples I would give. There is a method to how we select, but it requires kind of ongoing education and familiarity. To me, it's no different from how I would select a blood pressure medication or a pain medication. They all do about similar things, but we just know that they have different personalities and know which one will work better in which situation.

Dr. Pederson: Another thing that's true about medications that we've talked about is trying to reduce doses or stop medications that aren't needed or maybe have even been started in appropriately.

You mentioned earlier in one of your comments that someone gets put on a medication and it just gets left there. People don't remember why it was started and now no one feels comfortable stopping it because they don't know what was going on. So we get into this loop and we need to be more vigilant about trying to reduce medications or get rid of things that aren't needed.

When you're looking at psychotropic medications, is there any rule of thumb that you use or any guidance that you could provide?

Dr. Sairam: There are two situations in which medication reduction should be considered. The one I alluded to earlier is that this is a progressively evolving illness, so we have to see the patient as being a different person today than they were six months ago. It doesn't mean that every six months they should be taken off the medication, but we should have some reminders. For me, it's usually the three month point that I start introducing the subject of cutting back the medication to see if the brain still needs it.

I have had patients where they needed a certain medication for years, like three-four years of the disease process, but it's not that they were started on say Risperdal one BID and they just remained there. Every three-four months I'll try to cut back the dose and then we'll watch and the family or the caregivers will tell me if the symptoms recur, in which case then the brain is telling me it still needs it.

The key thing is not that we automatically reduce the medication. It's more the reminder that the medication may no longer be necessary and so I think systems can put some measures in place for a reminder to be sent out to the physicians or to the care facilities. Maybe some kind of a marker that triggers this question so they can bring it to the attention of the providers. So that's one aspect.

The other one which I see probably equally often is polypharmacy, sequential polypharmacy, concomitant polypharmacy. I think with dementia, given how extensive this problem is, many folks in primary care settings, long-term care settings have had to come up with their own ways of figuring out what to do. So what I'm finding is that really well-meaning providers have some familiarity with medications, but not the kind of moderately deep level inside.

So a patient gets started on 25 milligrams of trazodone, it doesn't seem to help enough. Then they heard something about depression, so they added 10 milligrams of Celexa and 10 milligrams of Paxil. Then somebody mentions mood swings, so 250 milligrams of Depakote gets added. Then somebody says paranoia, all the aggressive behaviors, combative. Oh, we need a neuroleptic. Then you pick your choice, whether it's Seroquel or Zyprexa.

Finally, this patient is on really non-effective doses of multiple mediations, but there is a sense that you've been doing all this and nothing has worked so the patient needs to go to a geriatric psychiatry unit. This is where this is kind of polypharmacy that's really directed toward no particular end, but once they're in people are afraid to take them away and so then that creates nothing is being achieved, while a lot is being done.

So these are the two settings in which we have to have vigilance to see what we are doing and always look for goals and, of course, the famous statement of subtract before adding is very applicable in geriatrics.

Dr. Pederson: Sometimes as geriatricians we suffer actually from our rule of start low and go slow, which ends up putting people on drugs. Sometimes we have them on little bits that aren't effective, but they're still getting the side effects. So we have to remember if we're going to use something at least make sure that it's effective.

The other thing, too, that came to me as you were talking is just the whole concept of setting expectations with primary care, with families, with patients of "I'm giving you this medication for now, not forever" so that patients are ready to hear "it looks like it might be time that we start looking at changing that". Any thoughts on how we can maybe get better? We do it for antibiotics, we prescribe something for seven days, 10 days, yet a lot of other medications we prescribe and give people a year's worth of refills or something, so thoughts on that from your practice?

Dr. Sairam: I have less of a concern with families than with care facilities. Again, I don't want to put them down because they're working under tremendously difficult financial, logistical and regulatory circumstances. They have to insure the complete safety of a confused, unsteady, intrusive, wandering patient and at the same time prevent falls, use no medications and manage 10 patients with one and a half staff. So it's very difficult, but we also can't lean on medications which can potentially make things worse.

I haven't spoken much in care facilities, just on a few occasions, it's more about explaining to them the dangers of these medications. I find that the majority of the staff, once they understand that the medications could themselves be making their lives worse, as caregivers, by making the patients more ataxic, more confused, then they are more willing. This is where I transition to what are the goals for care, especially as the disease progresses.

Then the conversation is more with families about this is a terminal illness. There comes a time when despite our best efforts the person is going to pass away. For us, at that point the question is not what are we doing to your father, to your mother, but what are we doing for them. Meaning, at this stage if your father or mother could see themselves in this situation would they say just keep me comfortable and let me go, or would they say just keep doing these kinds of treatment interventions to keep me going when things are falling apart anyway.

In the mild to moderate state of the disease, my focus is on explaining to the family then the caregivers that administer the medications. As the disease progresses and in the later stages, I transition to the suffering, the concept of distressed suffering. I really walk away from medical terms and start talking about the more compassionate care-related terms, which then allows us to also find a more acceptable way to use strong, high doses of neuroleptics when appropriate.

Going back to your previous question, I forgot to mention there's one instance where we do end up using very large doses of multiple polypharmacy-like medications on most of the folks on our unit. A classic example would be a gentleman I had just a few weeks ago. He was in the sixth sphere of the disease, six feet two, very strong. His vision was already failing and it was very clear that he didn't have any depth perception. His family said he was a very private gentleman, very dignified, always careful about his personal dignity, demeanor and hygiene and he would never accept help from anyone, including his wife.

He was at the point where language is all gone, he kept his eyes closed most of the time and he would just hit out, just hit out, but once the nurses were done he was fine. Anytime they had to change his diaper, help him change his clothes, bathing, toileting, very aggressive, very combative, but that's when I changed my language. He's not combative, he's not aggressive. He is defending himself. He has no idea what's going on and suddenly strangers are coming and touching him in private places, talking, making statements that he's not able to understand, so he is responding from a very primitive level of self-defense.

So when I use things like this the caregivers understand that it's not a personal thing, that this man is not hitting me, he is defending himself. Then families also understand that we get it. We are not punishing your father for being combative, but to allow him to go through this kind of distress three times a day is also cruel. It's like saying I don't want to medicate him because it may cause side effects, but I'd rather him go through the torture two-three times a day of having to fight these predators and people doing things to him. So if I can use medications to ease the distress, make sure he's safe when the nurses care for him, even though we may need enough medications to have him somewhat sedated.

I've tried this now for five-six years with families and they all accept it, but the key question is the language we use. It's not a medical term, it's about caring, comfort, distressed suffering. That's my approach and for the most part it's worked. There are families that just cannot accept that this disease is a terminal disease. On a couple of occasions I've had to give the patient back to the care of the families, but nevertheless they end up back in the emergency room.

Dr. Pederson: I think that is just a helpful reminder. It's about what we're trying to do to help the person and how we make their life better, given where they are right at that moment. Before we get into the next topic, if anyone has a question on the phone?

Kelly O'Neill: We have a question.

Could you recommend a book, articles or resources for RNs and LPNs in nursing homes who want to become more knowledgeable about everything you've shared today so that they can have better conversations with physicians, psychiatrists and families?

I don't know if anything comes right to the top of your mind or if there's anything you'd like to share after this call that we can get out to the community, we can certainly do that, too.

Dr. Sairam: Here's a public confession. I started reading journals and experts when it came to management of behavioral symptoms in dementia a long time ago, the problem is that folks have to give evidence-based data. Before I came here when I was in Dallas my initial goal was to be an academic psychiatrist and I did design and start a couple of studies to study the effect of medications for behavioral symptoms.

The thing that struck me was, number one, the studies are all small. If you can get 20-25 patients in each group, that's a huge "n." The bigger problem is that if you have 20 patients in one group, the pathology is not the same. Even Alzheimer's disease probably describes at least two or three kinds of pathologies. The bigger challenge, as I mentioned earlier, is what is agitation?

There are so many factors that go into agitation, at least my personal belief, is that it's almost impossible to design any meaningful studies to compare interventions when it comes to treating behavioral symptoms or even psychiatric symptoms in dementia. The limitation of any kind of study that you may see in journals is that their quality is very poor and I really doubt that the control and the treatment arms have been sufficiently matched to be able to draw any meaningful conclusions.

This area, just like with chronic pain and I probably will be talking more about chronic pain as an analogy for the rest of the talk, is the art of medicine. The thing that we have to do is two. One is really become intimately familiar with the personalities of these medications on one hand, and on the other hand develop a level of sensitivity to the various situations that can cause a person to become in force agitated - and then you start matching the two.

Almost 90% of everything I talk about is what I learned post my Fellowship during those 10 years of running the geriatric psychiatry unit and then having similar discussions with other colleagues who are in the same boat. We all learn on the job, but with the kind of background understanding of this disease process, a level of humility to accept what I'm seeing in front of me is not what I think it is, that I need to probe a little further, and then a big part of a lot of the management is communication with families and the caregivers.

I stopped going to the geriatric conferences as well because you hear the same black box warning stuff. It still doesn't tell us how to use them. The speakers on the stage cannot talk like I'm doing now because they have to follow certain guidelines and restrictions. So it's on the job and with discussions with peers is where I would go.

Dr. Pederson: I think that's a good answer. Let's talk a little bit about the whole concept of end of life care issues in patients with dementia and what you see as the role of palliative care.

What are your thoughts here?

Dr. Sairam: The first thing I mentioned a few times. Everyone should understand that it's a terminal illness so it has two implications for me. One is that we should take the diagnosis of dementia very seriously and not throw it out just because we have a feeling that this person is 80 years old, looks confused, must be demented. That's not good because it's tantamount to telling someone you have cancer. We wouldn't say that until we were reasonably certain. In this day and age of electronic medical records, especially in a hospital setting, a very casual diagnosis of dementia can forever become an 80-year-old patient with dementia, even though the patient may have come in with delirium and may not have dementia.

So that's one aspect, but the flipside is once this diagnosis is established is really for the family and everyone to understand that this is a terminal illness and there comes a stage when we really have to look at what we are doing <u>for</u> the person, as opposed to what are we doing <u>to</u> the patient. That's where palliative care comes in so handy because it can really help us pull away from the medical model of symptom, diagnosis, patient and treatment, as opposed to person, distress and care.

The question that was posed to me earlier about how can we educate ourselves, these are the ways I have educated myself and the folks that I work with is we get on-the- job examples of how do I transition from treating this as a patient to treating this as a person. The other thing that I often use, especially in families where really there's a lot of resistance to the use of psychotropic medications, especially a resentment that dad was never crazy, he should never be in psychiatry unit, he doesn't belong here, so there's a lot of anger that's often directed at the professionals, the nurses, I really spend some time.

It takes a lot of time and effort to really confront the families that their anger is at the disease. They can direct it at the professionals, but at some point they still will have to come to terms that their loved one has a terminal illness. So until we help them through that process, there'll still be this kind of head butting with us, with the nurses. This part of the terminal disease needs to be with the families, but also kind of internalizing and helping them begin the grieving process and then letting go. Allowing for whatever needs to be done requires letting go.

The other thing I explain to families is to look at the later stages of dementia as if it were childhood. A child learns to hold things, swallow bigger objects, then walk and then manage bowels and then manage bladder and often most of this follows fairly predictably. They lose bladder control, then bowel control, then gate and balance and then swallowing big objects and eventually swallowing itself. So when I explain this all to families it helps them understand and accept the kind of later stages.

One of the battles that I encounter is with regards to walking. There comes this awful confluence of the dementia progressing to the point where ataxia is setting in just because the coordination is affected. Those patients who come to my attention and who need psychotropic medications, many of which are partly ataxia, it's easy for the families to blame the medications and the doctors for causing their father not to be able to walk. That also requires some effort to help them understand that yes, the medications could be doing this, but it's also the disease process.

The reason why I really encourage the involvement of palliative care is those folks have a way of explaining things that I don't have and it also gives me another support. So the combination of a geriatrician, hopefully a geriatric psychiatric provider, a palliative care provider and spiritual care, if the families have that connection, is a really good combination to help them through the kind of terminal phases of this illness.

Finally, as I mentioned, there are some patients where I have to use large doses of medications. There is no other way to care for the patient safely and also insure the safety of the caregivers. There again my approach is if someone has late stage cancer and has severe pain we would never deprive them of strong narcotic pain medications, even if the medications make them sedated, confused, doped up or even hasten their death by causing respiratory suppression.

So it's the same analogy here. It's a terminal illness, but instead of physical pain they have a lot of emotional distress and a lot of emotional pain. They're having to defend themselves when they wake up, when they go to bed, when someone is feeding them, when someone is changing their diaper. It's just not fair to someone in kind of lost, childlike helpless state to be in this frightened, anxious state.

If we've tried everything else and nothing else has worked, it is appropriate to ease their distress by using strong medications. We're not treating any symptom. We're not treating any psychiatric problem. We are relieving them of their distress. Again, if this message is reinforced by folks from palliative care and the team in general, then it's received with a little less distress from the family side.

Dr. Pederson: I think that's helpful.

Any other thoughts we didn't cover today that you want to catch in these last couple of minutes?

Dr. Sairam: Only if you want to leave people even more depressed than they already must be. If you want to, you can look at the slope of the graph that depicts the need for geriatric psychiatry or just the incidents of dementia and associated neurobehavioral problems. By the way, with dementia we should also now include all kinds of vascular pathologies, poorly-controlled diabetes, poorly-controlled hypertension. The slope has about a 70-75 degree angle and then the growth of geriatric psychiatric providers has a slope of about 5 to 10 degrees.

The only thing I can say is opportunities like this and then the message getting disseminated. So it has to be one geriatric psychiatrist working with a team of 15 to 20 primary care providers, nurse practitioners and kind of reinforcing this message and then, as I say, involving palliative care and virtual care to see at least the later stages of this disease not as an illness, but as the natural end of life. That we've seen so many other illnesses, too, and not just make it a medical management issue.

Dr. Pederson: Thank you so much, this has been really helpful.

Dr. Sairam: I appreciate the opportunity to participate today, thank you.