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Working With Caregivers of Dementia Patients

You are listening to ReachMD, the Channel for Medical Professionals. Welcome to the Clinician's Roundtable. I am Susan Dolan, your host and with me is Dr. Karen Hirschman, a Research Assistant Professor at the University of Pennsylvania School of Nursing in Philadelphia, Pennsylvania. Dr. Hirschman, welcome to the Clinician's Roundtable.

DR. KAREN HIRSCHMAN:

Wonderful to be here. Thank you so much for having me.

SUSAN DOLAN:

Define dementia.

DR. KAREN HIRSCHMAN:

Dementia. Well, dementia is not just memory loss but memory loss plus another cognitive area that has a deficit. So, cognition is mental activities knowing, thinking, learning, judging, and we can divide those areas into several components when we think about cognition and so someone has dementia they are going to have memory loss but they are also going to have a deficit in another area such as attention, essentially their ability to stay focused or on task, memory like I mentioned so long-term and short-term, language issues of speaking, comprehending others, and praxis making sense of what they see and what they do and then executive functioning, so planning and organizing, how they order their day and the things that are around them.

SUSAN DOLAN:

How many Americans have dementia?

DR. KAREN HIRSCHMAN:

Well, the most recent statistics in 2007 indicate that approximately 5 million people have Alzheimer's disease, which is just one form of dementia and the estimate is growing and they expect that by 2050 there should be between 11 and 16 million people with dementia. These are big figures. Okay, so these are figures that are total numbers of people estimated to have or will have Alzheimer's regardless

of whether they're diagnosed with it or not.

SUSAN DOLAN:

Describe the different types of dementia.

DR. KAREN HIRSCHMAN:

So, Alzheimer's disease is the most common form of dementia accounting for 50 to 70% of the cases. Vascular dementia is widely considered the second most common form of dementia. There is also something called mixed dementia, which is characterized by the presence of features of both Alzheimer's disease and vascular dementia. Parkinson's disease often has features of dementia. There is something called dementia with Lewy bodies which can cause a pattern of decline similar to Alzheimer's disease involving problems with memory, confusion, poor judgment. Frontal lobe or frontotemporal dementia is a disorder with cellular damage, which tends to concentrate on the front and side regions of the brain. There is one type of it that I should say that is called Pick's disease, which is characterized by something called Pick's bodies that they can view through abnormalities in the brain. Creutzfeldt-Jakob disease, normal pressure hydrocephalus, those are all other forms of dementia. So, dementia is essentially an overarch in category, so it's a catchall term for at least six months of progressive losses in brain function that interfere with a person's ability to do their usual every day tasks.

SUSAN DOLAN:

What are the symptoms and warning signs of dementia?

DR. KAREN HIRSCHMAN:

So, there are common warning signs and symptoms that we should be looking for when we are looking to see if there is a problem occurring and as we have talked about already the onset and decline happens over time, so it's not just memory loss but we are looking at other things, so recent memory loss that affects daily activities is one component but also you should be looking for difficulty performing familiar tasks. So, if your patient could not balance their checkbook when they were younger and can balance it now, they don't have dementia, they just can't balance their checkbook but if your patient was a bookkeeper and did this for a living and now the family is mentioning to you that the patient is having trouble paying bills, keeping track of money, then there is a problem that needs further assessment. Other areas that there can be deficits are difficulty with speaking or problems with language. If they seem to be presenting with impaired judgment or there is a report that they are disoriented to time or place, they misplace things, have disorganized thinking, changes in mood and behavior are also common and changes in personality, you know looking at this as a whole, so you want to talk with the family or talk with the patient to get a sense of what else is going on and do these things seem to be worsening over time.

SUSAN DOLAN:

How do you have that conversation with a patient who has symptoms of early onset dementia about their dementia?

DR. KAREN HIRSCHMAN:

So, there are some great resources. For example, the Alzheimer's Association puts out wonderful literature for physicians on how to have that conversation, how to sit down and what kind of language should be used. You know, when you share the diagnosis you obviously want to do it with your patient in a private quiet location, you want to ask them if they have a support person, so a family member, a spouse. It's important to talk to them about it in a very straightforward way and avoiding sort of the medical jargon but to communicate with them in a way that talk to them about, you know we think it might be Alzheimer's disease because of the following symptoms you are experiencing and giving specific examples, explaining to them what Alzheimer's is, that the cells in their brain are gradually starting to fail and that eventually the cells begin to die and this brain failure is the causing the symptoms they are experiencing. I think it's important to talk with the patient, talk with their family about not to be embarrassed or ashamed of their symptoms and that it's a physical illness just like any other chronic condition like heart disease or even arthritis.

SUSAN DOLAN:

If you are just joining us, you are listening to the Clinician's Roundtable on ReachMD, the Channel for Medical Professionals. I am Susan Dolan, your host and with me is Dr. Karen Hirschman, a Research Assistant Professor at the University of Pennsylvania School of Nursing in Philadelphia, Pennsylvania discussing dementia. Dr. Hirschman, what you advise regarding having a conversation with family members about the patient with symptoms of early onset dementia?

DR. KAREN HIRSCHMAN:

I think it's important that the patient gives permission for us that it's okay for you to talk with their family. I think it's important to share the same information about what Alzheimer's disease is or what form of dementia they may have. It's important to let them know that they're not alone, that there are lots of resources out there in terms of information that they can access to learn more about the disease and the progression, that they should start planning if it's early enough in the process and the patient can provide their feedback and participate in decisions about their care and about their future and there is a way to preserve their autonomy and to have that conversation with the family about planning for the future and what that means in terms of finances, living situation, and medical care.

SUSAN DOLAN:

What is your message of hope in that regard when people obviously are going to be very scared not knowing what the future holds?

DR. KAREN HIRSCHMAN:

Unfortunately, this is a disease that we cannot cure but working together with the family we can explain to them what is happening over time and that this is usually a very slow progression, that this is usually a fast progression for patients who are 65 and older who might be diagnosed with Alzheimer's disease. The importance of talking with your family having the patient and whoever they see as their decision-maker or their closest family members, people they would want with them in having this discussion, it allows them to start to begin that conversation about what they want and preserving their preferences, so allowing the patient to really convey how important it is for them to make it to a specific event with their family possibly or even looking forward about what they want and wouldn't want in terms of healthcare, so if they haven't put in advanced directive together to indicate what they would want medically if they became terminal and were unable to make decisions for themselves but also to designate someone to be that decision-maker for them and so that that person knows what the patient would or wouldn't want if they are then expected to make those decisions for them.

SUSAN DOLAN:

Tell us about the enhancing care coordination study.

DR. KAREN HIRSCHMAN:

So, currently we are testing a transitional care nursing intervention model, sometimes called the advanced practice nurse care model designed by Dr. Mary Naylor and her colleagues at the School of Nursing here at the University of Pennsylvania and this model has been tested in 3 NIH-funded randomized control trials with cognitively intact, chronically ill older adults and it consistently demonstrated improved quality and reductions in hospital readmissions and reductions in healthcare cost among intervention patients as compared to control patients receiving the standard of care and we are now extending that model to other high-risk populations and with our pilot funding from the Alzheimer's Association and now support from the National Institute of Aging and the Marian S. Ware Alzheimer's Program at the University of Pennsylvania. Our team is testing a range of interventions designed to enhance the care management of elders with cognitive impairment and their caregivers throughout the episode of an acute illness.

SUSAN DOLAN:

What have you discovered so far?

DR. KAREN HIRSCHMAN:

Well, one of the most interesting things is that we screen all elders 65 and older who meet our study criteria and we have screened over 2500 patients and approximately 50% of them have screened positive meaning they have got deficits in the area of orientation, recall, or executive functioning when they have been admitted. Only about 6% of those we have screened meaning who are eligible have a medical history of dementia in their record. So these are people who have anywhere from mild-to-severe impairment in multiple areas that we have discussed, so areas of cognition that had deficits in worsening memory but also issues of executive functioning which is how they plan and organize the world, problems with attention, staying focused on task, etc. and we were really surprised that we saw such a high percentage, research is reported slightly lower levels of dementia and cognitive impairment among the hospitalized elders. What is interesting about this study that we are also capturing deliriums of not just dementia but people who have dementia and delirium and these are the most common causes of cognitive impairment among hospitalized older adults and they are associated with higher mortality rates, increased morbidity, and higher healthcare cost.

SUSAN DOLAN:

And how often you are seeing that?

DR. KAREN HIRSCHMAN:

Well, the combined group having both, we are in the process of trying to tease that out of the data but we are seeing approximately 20% of the sample having delirium in addition to other cognitive impairments. We also are finding that a percentage of them improve once they go home the area that was affected, so they don't have dementia but they have some form of mild impairment that may or may not become dementia over time, but at the time they were hospitalized they had some form of impairment, so we are seeing over time some people who are resolving their level of impairment.

SUSAN DOLAN:

How are you obtaining the data?

DR. KAREN HIRSCHMAN:

We are screening all of these patients within the first 24 to 48 hours of their admission to the hospital within reason, so there are some people who are coming right out of the OR and that is not appropriate, so the general timeframe is 24 to 48 hours, we screen them and we enroll a dyad, so we are not just enrolling patients we enroll them and their caregiver and that is, you know, increasingly important since patients who have cognitive impairment aren't always the best historians about their care and about what they are capable of doing, so we interview both the patient and the family member at baseline upon enrollment in the study and then we also do assessments and interviews with the patient and the family member who enrolls in the study at 2 weeks, 6 weeks, 12 weeks, 24 weeks, and 52 weeks postdischarge from the initial hospitalization.

SUSAN DOLAN:

What do you hope to find?

DR. KAREN HIRSCHMAN:

What we are hoping to find is that we are going to decrease caregiver burden, improve functioning for the patient, reduce cost, so re-hospitalizations and decrease the cost in caring for these patients.

SUSAN DOLAN:

Does the study include caregivers?

DR. KAREN HIRSCHMAN:

Yes. In this population with people with cognitive impairments, the patient isn't always the best informant. They aren't always the best at giving you an accurate assessment of their capabilities, what they are able to do on a daily basis, so we have included the caregiver or a family member identified by the patient as somebody involved in their day-to-day care as part of the enrolled subjects, so we enrolled them as a dyad and they have to be a dyad in order to enroll in the study, so we are providing support to both the patient and the family members through this intervention study. Often these family caregivers are less to deal with the complex needs of these elders with cognitive impairment following a hospital discharge, and study findings suggest that their lack of knowledge and skills contribute to the poor patient outcomes that have been reported and increase caregiver burden and depression among this population of caregivers. So, we are interested in looking at whether or not our current nursing intervention is going to change some of those outcomes.

SUSAN DOLAN:

How do you believe the results of this study will impact medical professional?

DR. KAREN HIRSCHMAN:

I think that we are most interested in trying to find new ways to provide care for this population that are going to dovetail nicely with the changing healthcare environment, so that we have got nurses providing care to these dyads, the patients and their family members as they are discharged from an acute event, working closely with the patient's physicians and other providers to help keep them out of the hospital and assess medication conflicts that may be there, so they are doing medication reconciliation. So, we are looking at this intervention that we have used, this transitional care nursing intervention, this model of care to try and change the system and ideally if it could be reimbursed, obviously what we are providing is a free service and we are looking for buy-in of this model in other ways and I think that if we can continue to show that it has decreased re-hospitalizations and improved outcomes for these population, both the patients and their families that the buy-in is there.

SUSAN DOLAN:

What's your best advice as to how healthcare professionals can be better prepared to care for dementia patients in the future?

DR. KAREN HIRSCHMAN:

I think being very aware of what the warning signs and symptoms are, listening to both the patient as they currently do but also to family members that may be raising some concern, approximately 50% of people 85 and older will develop Alzheimer's disease, that the greatest risk factor is advancing age, so as our population ages this is going to be something to look for and 50% of your patients 85 and older will have some form of dementia. I think it's about being aware and cognizant of what is there. I think also what is important is remembering that our society has a stigma associated with the diagnosis of dementia and so when talking with families about this and being very well aware of it I think that in the future we need to continue to strive towards decreasing that stigmatization.

Thanks to Dr. Karen Hirschman for discussing dementia. I am Susan Dolan. You have been listening to the Clinician's Roundtable on ReachMD, the Channel for Medical Professionals. Please visit our website at reachmd.com, which features our entire library of on-demand podcasts or call us toll-free with your comments and suggestions at (888-639-6157). Thank you for listening.