>> Welcome to Episode 3 of the Family Caregiving Matters podcast. Today, Dr. Judi Phillips and Dr. Sharon Hamill discussed dementia. What is it, how does it impact caregivers, especially our college-student caregivers, and treatments and resources that are available to help cope? We are delighted to be joined by our very own Cal State San Marcos graduate student, Sean Greiser, whose thesis focuses on this very topic. This podcast is being brought to you from California State University San Marcos. ^M00:00:37^M00:00:44Welcome to the Family Caregiving Matters podcast, a podcast dedicated to providing information and support to family caregivers with a special focus on college students and other young people who fill this very important role. >> We also share tips that are useful for caregivers of any age. And our goal is to promote the highest quality of life possible for caregivers in our community, and the loved ones they support. >> I'm Dr. Sharon Hamill, Developmental Psychologist.>> And I'm Dr. Judi Philips, Gerontologist, and we're both faculty members in the Psychology Department at CSUSM. We're excited to share this time together so we can provide support to you, our family caregivers. ^M00:01:36^M00:01:43Welcome to Episode 3, where our focus is on dementia caregiving. And by the way, do you know that today, Friday, February 19, is National Caregivers Day?>> Well, happy National Caregivers Day, Judi.>> So a huge thank you to our many caregivers of all ages, especially to our college-aged caregivers. >> Absolutely. They're doing a fantastic job. And welcome, Sean. We're so glad to have you here today. >> Thank you. I appreciate you guys having me on. >> Absolutely. I'm going to start out by giving a little bit of context because there are a lot of people out there that don't know what a significant issue, dementia and Alzheimer's are for our country. We estimate, and this data comes from the Alzheimer's Association, that more than 5 million Americans are living with Alzheimer's disease. And by 2050, we expect this number to go up to 14 million. When you think about all the people that are involved in taking care of those individuals, you're really thinking about more than 16 million Americans who are providing unpaid care to people with Alzheimer's or other dementias. It's estimated that they've provided an estimated 18.6 billion hours of care valued at $255 billion. This is a significant undertaking for families and friends in the US. Now, many of these caregivers include college student caregivers, like we were talking about in our last episode of this podcast. And it's important that we consider how is that experience different, perhaps, for these caregiving college students? So that's one of the many reasons we are just delighted to have Sean Greiser here with us today, both for his knowledge and the fact that he sees college student caregivers in the work that he's doing. So, Sean, again, welcome. And what we thought we would start out with is really understanding the concept of what is dementia? What are the major types? >> Okay. So, I'll just go through some of the-- I selected the four main types of dementia, most common forms. So, dementia now is actually categorized in the DSM-5 major neurocognitive disorder. But dementia is still kind of the key term that people throw out for an umbrella related disorders. But what most people think about with dementia really is is progressive memory loss that gets worse over time as the disease progresses. However, it can impact people in different domains or areas of their-- whether it's cognitive performance or behavioral. So a few of the main domains are language and memory, or excuse me, learning and memory, language executive functioning. So that's like things like planning. Also, complex attention. So, paying attention to things in our, you know, in our everyday lives, perception and motor functioning. So you can think of Parkinson's type diseases in that one, and also social cognition, which is how we think about ourselves with other people and interact with others. So, of course, the big one that most people know about is Alzheimer's disease. This is the most prevalent form of dementia. And this one is really, you know, marked by progressive memory loss and also emotional disturbances. So, this is really what we think about when we think of dementia in someone. Another very common form of dementia is vascular dementia, starts after someone has a stroke. This can occur in some of the statistics are anywhere from 15 to 30 percent of people will develop a form of dementia after having a stroke. Your risk for forming dementia after a stroke increased with age and other types of difficulties. So the vascular dementia is pretty difficult to nail down. A lot of tests have to be done after a stroke is done to determine whether it was caused by the stroke or whether you had dementia prior, and it's just exacerbated your symptoms are not. Some of the typical things that are seen are executive functioning loss. So, your ability to plan, things like that higher functions typically go down a little bit. We forget new information, or you might have difficulty in visual spatial complications, what they call it. So this could be forgetting familiar locations, forgetting how to drive to work, getting around your house, and things like that. The third one that I chose is frontal temporal dementia. This occurs in your frontal lobes and the temporal lobe. This is where things like personality or language. This one is pretty common actually, and typically occurs in younger people, actually. So, anywhere from 40 to 65 is the most common onset for this one. But like I said before, it impacts your personality, people might become a little more inappropriate, socially, a little more impulsive, or you can go the opposite way to where you're more apathetic to your surroundings, to people interacting with you and things like that. Finally, one that a lot of people know about, because someone famous recently passed away with this dementia was Lewy bodies. So, if you think back, Robin Williams had this, and it was discovered after he passed away. So, this is the second most common form of dementia, and it's pretty similar to Alzheimer's disease and the types and characteristics in the brain. But this one is associated with damage in the areas of thinking, memory, and movement. So, this one, you'll see a lot of parkinsonism in there, sort of rigidity in movement, slower moving in movement, and things like that. And also, a little more extreme symptoms with hallucinations, so it can be either visual or auditory. But there's really a lot of things that Robin Williams was experiencing towards the end of his life that were hard for him to explain and for his family to explain. >> So, Sean, and in looking at this, I think for most of us, when we look at our loved ones, and we see maybe something where a grandparent or a parent starts to forget things, does that automatically mean they have Alzheimer's disease? >> No, actually. So, forgetfulness is a part of your natural progression through life. I mean, it's kind of an odd term, but development still occurs as you're aging. So it's part of the developmental process with people where you have natural forgetting, Alzheimer's and other forms of dementia are not a normal part of the aging process at all. So, whether someone-- it really has to do with how it impacts your life from your baseline to where you're at now. And so, it really impacts how you're functioning. >> And I know, Judi, when you're teaching your classes at Cal State and at MiraCosta, what kinds of things do you recommend if a student comes to you and says, "Hey, I'm seeing some memory difficulties with a family member. What should I do?" What are some of the things that you suggest?>> Well, I think the first thing I suggest is that they take their loved one to the doctor, okay, and to have them seen by their doctor to have a physician formally diagnose and run them through test, because sometimes we find that hearing loss, which is also a progression of aging, could be the reason for somebody not remembering things because if you don't hear it, you can't remember it. And therefore, doctors ^M00:10:00 can say, "No, we just need to have a hearing aid," but they are the ones who have the more in-depth knowledge. They need to go to a neurologist maybe for some more specific test. >> That's actually, when folks asked me about it, I often recommend that they see a neurologist because sometimes a family practitioner might mean well, but may not have the expertise that a neurologist would. But that family practitioner, and other physicians as well, can rule out things like drug interactions that sometimes you get behavior changes or memory losses and you think, "Oh my gosh, what does my family member have?" But it turns out that there's a drug interaction going on, they're taking a couple different meds. That's why it's really important that they have a physician evaluate their condition to make sure they know what it is they're dealing with. So Judi, Sean's just describe for us some of those different types of dementia. How does dementia caregiving impact caregivers?>> In 2018, the Center to Advance Palliative Care, and the Gary and Mary West Health Institute teamed up to conduct some focus groups and surveys of caregivers to find out what is the biggest caregiving challenges for dementia caregivers, okay? And they found that there were many different challenges, but four of the most prominent ones were dealing with the memory loss and impact of the disease on their loved one, handling the stress and the emotional toll on themselves that caregiving for someone, their loved one, with Alzheimer's disease would bring about, having patience with their loved one, and handling their loved one's mood swings and behavioral changes.>> So, those are the things that they're identifying as being the most challenging to deal with. What are some of the common emotional responses they're going to have to this? >> Well, there are many of them. Today, we'll just talk about four, okay? One is sadness. I mean, when you are dealing with the memory loss of a loved one, when you're dealing with their losing their memory of you, who you are, whether it's a granddaughter, a grandson, for our older caregivers, of a husband or wife, that can be very sad. All of the life that you've had before with them, they are gradually regressing back in time until they may look at you as their child or they may look at you as their brother or their sister. So, sadness is definitely something that is a emotion that is very common to caregivers of all ages, when they are caring for their loved ones with Alzheimer's. Also anxiety. What was identified by the survey is that Alzheimer's patients, and Sean, you know this, that they have mood swings and behavioral changes. They can be very calm one moment, and then they can just erupt and become very agitated, very aggressive the next moment. And so, that brings up a lot of anxiety. You know, what is going to happen in the next minute, what's going to happen in the next hour? So, this makes caregiving especially difficult. And then there's stress. No matter what is the physical or the mental disability of your loved one, stress is a part of being a caregiver. We also have found that life satisfaction is much lower for caregivers than non-caregivers. And many times, it is lower for women caregivers than men caregivers. So, these are just some of the issues that may have an emotional toll on our caregivers who have loved ones with dementia or Alzheimer's. But there are also impacts on caregivers' physical health. And these will be topics of podcast in the coming weeks. >> Judi and I have spent a lot of time working with caregivers on campus. And we recognize that people have some real deep interests in diving into more detail about the emotional impact the physical impact. And so, we have committed to making sure that future podcasts, give us more opportunity to do that. So, we will be coming back to that in the coming weeks. Sean, coming back to these disorders, what kinds of treatments are available, and is it curable? >> Unfortunately, at this time, there is no cure for any of the forms of dementia that we talked about. But that doesn't mean that there are things that you can do to help calm the issues that we were just discussing. You know, there's always, I like to say there's kind of two types of treatments available. So, we have medications and can be referred to as alternative treatments. So, medications, there's always, you know, there's always a risk and things like that, but there is some good evidence that they're useful. So, there's things that are termed as anti-dementia type medication. So, these were originally developed for like Alzheimer's disease, because we knew the exact mechanisms in the brain that were being destroyed. So, these things will help to kind of calm that slow that process down and hopefully slow down the process of memory loss and behavioral changes and things like that. So, you know, those have been shown to be a little bit helpful. There's also different types of medications that have that weren't, typically, that weren't actually developed for Alzheimer's disease or other forms of dementia. So, one example would be antipsychotic medications, so used to treat those behavioral and emotional symptoms that are displayed in people with dementia diagnosis, whatever the form might be. Those aren't necessarily always the best thing to do to use, but they do show some help and, you know, relieving the stress that people with dementia might feel, and especially with helping the caregiver to be able to provide better care to them, if they're in a state where it's, you know, easier to do so. And then I'll get on to the second topic, which was alternative treatments. So, these are things that aren't necessarily medical in, you know, like a medical treatment per se, but do show some good promise as well. So, a lot of these are really sensory treatments, I'll call them. So, things like massage, or music, or aroma therapy, these have shown to be really helpful to people that have dementia that are experiencing stress. So, you can do things like giving them massages at certain times of the day where you know that they might be a little more agitated or anxious during the day, and seeking to kind of cut that off right when it starts, things like that. One would be music. So, these are, you know, you might play certain music that you've enjoyed in the past. You know, that definitely helps people like me or people without dementia, a lot. You can do things like that, or also aroma therapy, as well, where you put sense in like a diffuser. It's been shown to help people with dementia and without as well, too. So, there's a lot of things you can do. And I think one of the best things, one of the best goals that you can have when you're using these alternative treatments, would really be trying to keep them in the home with you as long as you can. Living in the home with familiar people, it just leads to better outcomes long term, and you still get to have your loved one at home with you, which I think is really, really important for the family dynamic. >> That's a great point. And for those people out there who would be considering doing these kinds of things, Judi, where can people get information and support? >> I think the two most prominent organizations are the Alzheimer's Association. They actually have a 24/7 helpline, and that number is 800-272-3900. And then there is the Alzheimer's San Diego Organization. And they are also offer many types of support. Both the, what we might call the national organization and the Alzheimer's San Diego Organization have support groups, and they also are open for educational types of seminars, probably now virtual, you know, but they're probably still going on, so that you can become more educated about the different stages of Alzheimer's. If your loved one is in stage one, knowing what comes next can also be important, right, so that you can be prepared. And so, we will put those phone numbers and the URLs to their online presence on the website. >> Terrific. ^M00:20:00>> And then I also had a student tell me just recently that Facebook has a private site for caregivers. And I think you have to, how should I say it, apply, you know, put in some information as to why you're interested in it, and then you are allowed on, you're accepted. Now, I haven't found one that is specifically a Facebook page for college-age caregivers. But there may be one out there that I just didn't see. >> Sean, I know you did some research as part of your thesis, you were looking at Facebook pages?>> Yeah. So yeah, a lot of these pages are moderated or set to private and have moderators. Really the, you know, the easiest way would be to go search the pages on Facebook, and you can always see the list of the moderators if they have them on there. And they're usually very nice in response to people. And you can just send them a message asking if he can join. Sometimes they limit it to people who care for a family member with a certain diagnosis, so that it's more relevant or specific to you. But that's not always the case. You know, a lot of the same resources that they provide or go for all forms of dementia and things like that. >> This is wonderful. And Sean, I know that you've also been thinking quite deeply about supports that are available and how families are dealing with dementia caregiving during this COVID-19 pandemic.>> Yeah. So, I've actually begun a study on dementia caregivers, specifically caring for family members, about how caregiving has been impacted or changed during the COVID-19 pandemic. So, really, we want to hear about how things are going right now, if there's been changes, how those changes have gone, and how that's impacted you and your family. So, this is anywhere from a 25 to about 45-minute survey. It typically doesn't take people nearly that long. You can always come back and take breaks if you want to. But it's completely online. We'll share the link at the end of this podcast. Participants are also entered into a drawing for a $25 gift card that will be sent out after all the data is collected and will send it out to the winners of that drawing.>> And who is eligible to participate? >> Yeah, just like most studies, in order to participate, you have to be over the age of 18. In the caregiving for a family member with a diagnosis of dementia, and it can be any form of dementia, though, it doesn't have to be just the ones that I talked about earlier on in the podcast, it can be any form of cognitive impairment. >> Sean, does the caregiver has to be the primary caregiver, the one that's most involved in the care?>> So, no, they actually don't have to be. One of the qualifications, I guess, or that we like to have is someone who does at least one form of direct care for the person with dementia. So, this can include, but is not limited to providing medications, feed your loved one, take them to the doctor's visit. So, something direct form of care, but they don't have to be the primary or the decision-making caregiver. So, it's someone who, you know, deciding about estates and things like that. They don't have to be that. >> Okay. And if one of our listeners wants to participate, what is the URL, and we will post it as well, but what is the URL for the study?>> Yeah. So, the URL for the studies, this will take you directly to the survey, is www.bit.ly/COVID\_support. And that will take you directly to the survey. All those letters are lowercase too.>> Great. Thank you so much, Sean. Judi, as we're talking about resources, one very important resource that we've been discussing, before we started this podcast, the three of us were talking about it, and that is, where do you go to get your loved one vaccinated with the COVID-19 vaccination? >> You can go to any of the county sites, or you can go to some of the pharmacies that are at CVS, Vons, Ralph's, or Albertsons. Now, you have to be 65 or older, normally, to be qualified now, but some new information has come about that now, informal caregivers are now eligible for the COVID vaccine. And these informal caregivers, we would call family caregivers, I have not seen any age-related to designate who has an informer caregiver or not. But there is a specific process that you have to go through. What you have to do is you have to get a doctor's note, a doctor's letter. And this doctor has to be the doctor who is taking care of the person who we would call the care recipient, the one who is your loved one, whether it is your grandmother, your mother, your father, et cetera. So, the doctor has to write a letter that is very individualized. It can't be Xerox, it can't be reproduced, it has to be a very individual letter, which identifies the informal caregiver as the person who was taking care of a patient underneath their care. And in the letter, it has to use the words informal caregiver. You cannot say family caregiver. The doctor has to say informal caregiver. And when you then sign up at one of the county COVID vaccination sites, this is the letter that you need to bring to show them. You can sign up online or you could also go to 211, and they are open 24/7, to help those who have no computers, or those who have difficulty getting on computers and using computers, to schedule their COVID vaccine appointments. >> And 211 is the 1, your area code, and 211. So, we have some folks that might be in Riverside County or Orange County. So, 1, area code, 211 to get that kind of information. Judi, Sean, this has been wonderful. This has been such great information for our community to know about dementia, how it affects us, where we can go to get some help, and future podcasts will continue to address specific issues that come up when we're talking about being a family caregiver, whether it's for loved ones with dementia or other health difficulties. For now, I just want to say thank you so much to both of you for spending this time with us. And next time, we will be turning our attention to a more in-depth discussion of emotional outcomes from caregiving, and also the very important, how to build support systems to help you cope.^E00:28:10