Considering The Caregiver: Identifying And Addressing Dementia Caregiver Health

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- [Fawn] Our presenter today is Dr. Paul Arthur. He's an assistant professor and regional lead with St. Catherine University. He's been active in the field of occupational therapy for over 15 years initially as an Occupational Therapy Assistant and later as an occupational therapist. Paul's primary research interest, is in dementia symptom management and mediation of caregiver burden. He's been active in state and national service including roles on the state of Florida's OT Licensing Board, in volunteer capacities with the National Board for Certification, in Occupational Therapy and as a board director of the American Occupational Therapy Association. Welcome Dr. Arthur.

- [Paul] Hey, good afternoon and thank you Fon for the introduction. I'm thankful to be with you all today and too I'm pleased to have been a part of this incredible community occupational therapy, for almost my entire adult life. This afternoon I'm looking forward to discussing caregiver wellbeing for those taking care of people with dementia. This topic is reflective of what I've been doing and have been interested in for the past decade or so. It's also something I had a degree of uncertainty about as a practitioner. Today we're gonna discuss how prevalent dementia really is in the United States. What that means for our caregivers and why caregivers are so vital in our interventions in occupation-based solutions. Our learning objectives today are to identify the demographics of persons with dementia and their caregivers in the United States. To discuss the clinical application of measuring caregiver health as necessary in the provision of holistic care. And finally, to describe correlates of caregiver distress and identify some realistic management techniques that we can use in the clinic or elsewhere.

These are some of the key terms we're going to use today. Dementia, it's a progressive irreversible, neurodegenerative disorder. It's primarily caused by two abnormal structures within the cortex of the brain. The culminating disruption in death of nerve cells leads to memory failure, problems completing activities of daily living, personality changes and a myriad of behavioral symptoms. To receive a diagnosis of dementia you must have impairment affecting two or more areas of brain function. Caregivers, there are generally two broad categories. Formal which tend to be paid, your granny nanny services or aid services and informal or unpaid relative-based services. Those are generally your daughters, your spouses, your ex spouses, children and the like. Caregiver depression and burden are two factors that make up the most common outcomes, in caregiving research. They've been described as interrelated particularly in cases of dementia.

Oftentimes, when we talk about caregiver health or more specifically caregiver wellbeing, those are the two components that we're looking at. Constructively we tend to describe depressive symptoms as a condition of burden. That is, as one is increasingly burdened by their life or caregiving situation they begin to show signs of clinical depression and even major depression. We tend to commingle the terms dementia and Alzheimer's disease though it should be acknowledged that while Alzheimer's is certainly the most common form of dementia, it gets the most attention and for good reason as it consists of 60 to 80% of dementia cases. It's not the only form. You may have heard of vascular dementia, Lewy Body dementia, its associated with movement control and Parkinson's, mixed dementia, frontotemporal or other types of dementia. In it's brought broadest sense dementia is not slowing down. We can partially attribute that to our aging population.

There are currently around 5.8, million Americans living with dementia. One in three Americans will die with it. It's estimated there are nearly 27 million people, in the world with dementia. Like everything else, it seems to hit women the hardest, accounting for more than 60% of cases. To care for these nearly 6 million people with dementia there's a cadre of 16 million caregivers, most of them considered informal which again means they're not being paid for their efforts. Again, they're mostly women, generally eldest daughters and wives. We've mentioned women are most afflicted by the disease, though even still they're also more likely than their male or husband counterparts to take up the care of a loved one. National averages suggest caregivers, are caring for an average of 22 hours a week for people with dementia. And a study we completed in 2017 with 160 living caregivers of veterans with dementia, we found much higher numbers. Their caregivers reported spending about 17 hours a day, caring for their loved ones with around eight of those hours being in direct assistance, helping with ADLs and IADLs. Annual cost estimates are completed by the Alzheimer's Association, calculating the societal benefit of all this informal unpaid labor in 2018 and attributed to nearly $234 billion. The calculated lifetime cost of caring for someone with dementia is around $350,000. Schultz and colleagues have described, the informal caregiving experience as the provision of extraordinary care, exceeding the bounds of what is normal or usual in family relationships. This involves the significant investment of time, energy and finance but also the performance of tasks that are unpleasant, uncomfortable, stressful and exhausting. The wear on caregivers is not always sustainable.

We often see psychological changes, the primary focus of our discussion. Social isolation is too common. Having to forfeit relationships with friends and family that don't completely understand the situation. Financial challenges which we'll explore more shortly. Increased medical susceptibility, getting sick more often and for longer periods of time. Medical susceptibility can unfortunately lead to institutionalization for the person with dementia as well if that caregiver is unable to adequately care for them during their sickness. Caregivers when compared to persons of their same general characteristics who are not undertaking the same responsibilities are at a much higher risk for mortality or death which again, has negative impacts on the person with dementia as well. Imbalances in lifestyle and the progressive wear can also regrettably lead to instances of abuse or neglect which is particularly heartbreaking as the caregiver likely went into that situation without those intentions. It may also be that they entered the caregiver role unwillingly, in the first place. Around 40 to 70%, some authors have even said as high as 80% of caregivers, have clinically significant symptoms of depression. 25 to 50% of those meet criteria for major depression. As we've discussed, females tend to shoulder the most of the disease. It's been reported that over 70% report physical or emotional exhaustion. And female caregivers bearing the brunt of the disease we tend to see clinically signs of general fatigue, headaches, weight gain, sleep disruption and back pain, all for reasons you might imagine. This fourth of July weekend, I was staying with my teenage nephew and niece rattling off some facts and figures about the harms of premature alcohol use in adolescence. To which my niece retorted, correlation does not imply causation uncle Paul. Fundamentally, she's right. Correlation is most basically a statistical technique that tells us how strongly a pair of variables are literally related and how they change together.

For example, numbers of fast food visits and weight gain but that doesn't always work, does it? The high school soccer team that goes to the McDonald's twice a week. Well, their practice or physical output during the week, might be a lurking variable that's preventing that linear relationship between weight gain and McDonald's visits that we expect. I don't wanna get too far into the weeds here other than to say as sample size and reviewable data increases we begin, particularly clinically to rely on some of these historical correlates to inform our clinical judgments. A number of previous studies have highlighted age as a correlate of caregiver wellbeing. Interestingly, it may not be as directional or natural as you would think. Older caregivers tend to fare better than those who are young. Some of that may be due to some of the life pressures younger adults experience, climbing the business ladder, so to speak, keeping up with the Joneses. Some of those cultural pressures may not be as present for aging adults they're expected if you will to care for a loved one. It may also be that an oath has been taken, between the aging adults till death do as part for example. More ownership of the situation, perhaps less distractions for an aging adult.

For example, they don't have to contend with their own children along with a parent. We also find association with relationship type in caregiver wellbeing. Older adults caring for those, again who they've had a long-term intimate relationship with versus children, nephews and nieces that likely never even considered or intended to care for the aging adult. Spouses of care recipients tend to score more favorably on health skills than adult children and alternately related caregivers. Closely related to age and relationship type, the influence of gender on caregiver wellbeing with female caregivers tending to score more highly on depressive inventories, than their male counterparts. Ethnicity and race are also considered, in caregiver wellbeing.

In the most broadest terms and historically, Hispanics and African Americans tend to report lower depressive and burdened scores than Caucasians. There's also been some work done suggesting that terms of burden and depression are not as highly endorsed or accepted by some of those communities that may confound some of the ethnicity findings. We also want to consider level of formal education in the caregiver. Education has been predictive of depression and burden in previous studies and we've found this particularly so in caregivers with less than a high school education. Financial status naturally is considered. Particularly incomes that are less than $10,000 annually as conditions that may influence caregiver wellbeing. The function or level of assistance needed by the person with dementia is considered as a condition that could decrease wellbeing. In past studies the cut off has generally been, when someone needs assistance with two or more activities of daily living. There's been much writing on how the behavioral symptoms displayed by a person with dementia can influence caregiver wellbeing, suggesting that more outward symptoms may be most detrimental. The yelling, hitting, spitting when compared to subtle or inward symptoms like apathy or depression in one with dementia. Finally, caregiver leisure or time away from the situation can influence wellbeing as you might imagine, this can be extrapolated from reports of hours spent caregiving as well as in time caregivers have spent, performing leisure activities.

So I've painted a fairly bleak picture here, haven't I? You may be wondering how we go about formally measuring such correlates or how we can properly capture the sort of information. There are some good formal instruments out there to measure caregiver wellbeing as it's tied to depression and burden. The Center for Epidemiologic Studies Depression Scale or CES-D is quite popular. There's also a shortened 10-item version which is often used in research and sometimes in practice. As clinicians and researchers we tend to aim for brevity, particularly if instrument characteristics remain strong. The Zarit Burden Short Forms are also used regularly. It's a short one to two page form, can give you a pretty good baseline of caregiver compromise.

The nice things about these two instruments is that their norm referenced, meaning the numbers really can tell you something, about the potential clinical implications of the score. For example, for the CES-D, scores of 10 or greater are predictive of significant depressive symptoms. Likewise for the Zarit scores of 17 or higher indicate unhealthy levels of burden. You can also look more formally at behaviors. This can be done, excuse me one of the most challenging aspects of caregiving and dementia. We've also done some preliminary work suggesting that caring for people with four or more behavioral symptoms seems to be the clinical tipping point to influence caregiver health. These scales, the Agitated Behavior and Dementia Scale or the Neuralpsychiatric Inventory can serve as checklist to identify such behaviors. For example, agitation, aggression, hallucinations, delusions and wandering. Not only can they help you identify the behaviors but they can help you understand how often they're occurring and how seriously it's impacting the caregiver. Those of us working in clinical settings, while I think we appreciate the utility of formalized assessments to learn more about our clients, we understand we can't always or perhaps more strongly can rarely spend that much time delving into formal questionnaires or assessments during our evaluations or interventions.

Here are some things we can do. We can inquire about the caregivers level of formal education. I know what some of you are thinking, how can I slip that into the conversation, without really upsetting someone? These likely won't be questions that we're asking at our first meeting. This is generally how I broach the subject. I want to learn more about you to see how I might be able to help you in this situation. We appreciate that for most caregivers and persons with dementia, the best place you and your loved one can be is here at home. Lemme try to learn more about you so we can make this journey as smooth as possible for you. This can be similar to asking someone about their financial situation. Initially, that sounds really intrusive but so too is asking about dementia symptoms. Is your loved one voiding in inappropriate places, exposing themselves to others, do they have inappropriate relationships? Those questions too are intrusive.

Some preliminary work I've done in this area, does show some promise in asking the simple questions. How difficult is it for you to pay for the very basics? I'm not asking your income, I'm not asking how much your car payment is but isolating this question alone and analysis of a data set of 160 persons with dementia and their caregivers, controlling for some of the covariates we discussed today we found that for each unit change in financial status, we could expect one and a half points higher, on the Zarit Short Form, one of the skills we discussed earlier. The strength of association was stronger, only in behavioral symptom counting which was just slightly higher. Again, some will see financial questions as intrusive but to ask a single question with a simple four points scale to identify caregivers susceptibility to health risk, there could be some utility there. Now if they say not at all, we might need to inquire further, look at some other things but it obviously doesn't mean they're not at risk. But perhaps that's one of those covariates that doesn't apply in their case. We can also ask him about the level of assistance needed. This is likely built into your documentation system already so you may be able to point, click and count. Recall the covariate of assistance with two or more activities of daily living. This is likely present with many of the people you see with dementia but can also be used to cue you to start asking questions, for example, to the caregiver, how are things going for you? Are you getting enough sleep? Do you have any support mechanisms in place? Counting behavioral symptoms can also be useful. In our work on cut offs as mentioned if we are seeing four or more behavioral symptoms regularly, we should also start asking the caregiver about how things are going for them.

Finally, caregiver health or quality of life. This can be a rabbit hole oftentimes in dementia research, these will be fairly basic questions that we're asking. For example a four point scale. How is your health? Poor to excellent. How has your health been in the past three years? It's worse, it's the same, it's better. Does your health keep you from doing what you wanna do? Not at all, a little, quite a bit. How does your health compare to peers? Is it worse, the same or better? Now, let's talk some about how we might intervene with distressed caregivers. Probably we'll consider psychosocial interventions, environmental interventions and then some community based services like respite care and Adult Day Services. But let's start with psychosocial interventions. These interventions may target the caregiver or both the caregiver and the person with dementia. They might include education on the disease, what to do now, what to expect, how to plan for the future. These interventions have, although a bit simple, have been quite successful, they tend to need to be introduced in a digestible way and in a continuous way with follow up.

For example, just giving a caregiver a copy of the well known 36 hour day text might not be helpful. Rather working through the book with them or tailoring it to their needs or situation at the present time. When I introduced the 36 hour day in the clinic, I highlight chapters for them to read or consider. Caregivers tend to appreciate that, most of the time they don't have enough time to read the whole thing. Group therapy and support groups can also be beneficial. The Alzheimer's Association and other entities tend to host these services. Increasingly, they're available online in synchronous and asynchronous formats but can also be helpful to promote in a physical location. A reason for that is it provides a more intimate experience and perhaps even some respite for those experiencing, the caregiving situation. Increasingly, you can locate such groups via zip code online which is convenient for caregivers but you shouldn't assume that they know that stuff's out there and available to them, you may need to direct them.

A study I was fortunate to be a part of included the provision of tailored activities to engage persons with dementia in something meaningful. This has been found to be beneficial three pillars of avoiding new learning but identifying prior interest and designing related interesting, occupation-based activities. This might start with an activity inventory done either in person, excuse me, with the person with dementia or their caregiver. Identifying some past interest for example, sorting a hook free tackle box for someone who likes to fish, an exercise bike for someone who used to like to exercise. This can safely engage and meaningfully occupy someone with dementia's time and suitably give the caregiver some time on their own to focus on their own needs. In our studies with caregivers and veterans employing this approach, caregivers who are assigned tailored activities gain nearly one hour of additional time for themselves per day. That's significant, that time can be used to take a shower, cook a meal or take a break. Environmental interventions may also improve, caregiver health by improving navigation and accessibility for a safer, easier environment for their loved one. Environmental design has been associated with agitation, aggression, depression, social withdrawal, and psychotic symptoms. Oftentimes a simple targeted intervention with consideration of environmental design can address many caregiver concerns. We don't want to make too many changes here too quickly. We also want to avoid making drastic changes to home layout and design as this too can cause issues for someone with dementia and thereby make life more difficult for the caregiver. Environmental interventions don't have to be expensive, particularly in today's technological age. Provision of adaptive equipment, a potty chair near the bed to reduce wandering, bells on doors to perhaps decrease caregiver anxiety, monitoring systems, watches, bracelets to alert of location and condition.

Now we'll discuss a few more community-based services, you might want to consider. Respite care is a frequently, advertised service in many communities. Its most generally getting some rest, time away from the person with dementia. Usually seen in two forms, informal, other family members or friends are coming into sit with, entertain or engage the person with dementia. There are also more formal services, like Granny Nannies is a popular one down here that offer respite services. The Department of Veterans Affairs has a number of programs that offers veterans with dementia to be admitted in the hospital for short periods of time. Or perhaps their caregivers attend funerals, have medical procedures or that sort of thing. One unfortunate or unintended consequence we see, when these sorts of programs are utilized is the likelihood of some distress to the person with dementia. Being in an unfamiliar, perhaps more restrictive environment. So it's certainly okay to encourage caregivers to see what's available to them.

Also be aware of some of the issues that can arise from such programs. Most of these programs have short term, dose response relationships. That is they work pretty well while they're in place. I'm getting away as caregiver, I'm getting some rest that's improve my health but then long term once the dose is removed person with dementia is back in my home, the health problems tend to resurface pretty quickly. Adult Day Services. Again, you've likely heard of these oftentimes, community based services. My experience with persons with dementia is that they either love them or hate them. They can be a great way to develop community for both the person with dementia and their caregiver. They can also be expensive, oftentimes but not all times they're out of pocket. Unlike their respite counterparts, the positive effect for the caregiver tends to last only while the service is in order. The general design of adult services is that it's more lasting though. Increasingly where I am in Florida, we see short-term availability.

For example, come for programming on Tuesday and Thursday. That gives the caregivers some plan time for self to take care of their other needs. They're certainly worth looking into for your clients.

Now while we've just described a number of support services the availability and use of these services can be dependent, on a number of factors. At this time, Caregiver Support Services vary widely by region as does the financial support that's available. In the United States rural areas often have the least, community resources for support and economically disadvantaged regions tend to provide less financial aid to persons seeking. Satisfaction is an important variable of care as it's been positively paired with care utilization, compliance and results. Naturally, if consumers aren't pleased with the level of care they receive, they're less likely to continue participating and have less favorable results. A number of correlates have been associated with user satisfaction of support programs, including caregiver relationship, diagnosis, price of care, region and the length of time receiving care. Affordability of support services can be of concern for many caregivers. This is particularly true in the Latino or non-white Hispanic communities. Despite similarly demanding caregiver situations and caregiver strain, minority populations tend to use formal support services much less, than their Caucasian counterparts.

Additionally, immigrant populations often find eligibility and service criteria confusing and intimidating which can prevent the delivery of service. All things you should keep in mind when recommending. How to find out what might be available in your treatment areas. Consider Area Agencies on Aging. This is an agency designated by your state to address the needs of aging persons in your regional or local areas. The Alzheimer's Association has a great network. It's very powerful nationally but can also be useful to you locally. Consider county-based or local senior centers. They're very accessible. Websites or materials might not always be as accessible but you can only stop by to develop your own understanding of the services available in your area, into the clients you serve. State Departments of Elder Affairs, are another fertile area for information and services. That will of course vary by state but generally it can be a good place to get started. Use your colleagues and home health care. I regularly consult with our social worker who knows some of these rural areas quite well and can direct me to the proper responsive person who might be the gatekeeper to the service that we've discussed today. Consider your State Practice Associations. There may likely be aging interest groups who you can get connected with and develop a community of stakeholders who are working with the same types of access issues in practice. Ultimately, we need to empower our caregivers to start asking what's available to them. With belt tightening and financial changes, most organizations aren't readily advertising or looking for people to join their programs and service department. Caregivers need to be empowered to ask what's available for them and have an advocate in us if their search, is not always fruitful.

Let's move on to a case study where we will seek to apply some of what we've discussed today. This is Albert, he's an aging adult with dementia. Albert and his daughter moved to North Florida after their community was severely impacted by Hurricane Katrina. Albert's daughter in her mid 40s, is the only surviving family member and assures primary responsibility for his care. In the moderate stage of dementia Albert has have been difficult to manage. His daughter reports throwing, biting, refusing to shower and wandering in the evenings. His daughter was a successful restaurant manager, in Louisiana but has since had to scale back to weekend bar management to care for him. She doesn't feel she can leave him alone at this point. Let's consider the following questions based on this case. Take a few moments to review the following questions and come up with some answers. So first, let's look at what do known correlates tell us about her health? Someone mentioned she's Caucasian. That's right, so as a known correlate, she may be more susceptible to depression or some sort of compromise. She's female, that's good. She's caring for someone, her father rather than her spouse that's good as well. We don't know much about her finances but that's a good thought. Potential financial implications. She went from a full time job to a part time job. We also see that she's the primary caregiver. That's important, we might want to know, I guess we'll move on shortly but we might want to know, based on her being the primary caregiver, if she has any support services there. That's good, someone added that. Priorities in screening. We have a fairly short amount of time as a clinician to get the information, what would be our priorities? What would we wanna find out about? Sure, perhaps a simple inventory on the caregiver's health. Anything else? Right, it might be valuable to either counter behavioral symptoms or find out more. It does look like from the case you already did have, more than three, actually more than four behavioral symptoms so that would be a good one. Someone mentioned her understanding of the disease. That's excellent, that's really, really important. Environmental assessment, that's excellent and one of the reasons I think it's particularly, important is because she has moved, right? They moved from Louisiana there to North Florida so they're likely in a new environment. Particularly makes me wonder about his wandering, while it is common for folks with dementia that could have something to do with it being in this new environment. We may want to know time for self, is that the only time she gets time for herself, is when she's working her night shift at the bar?

And again, you mentioned finances already that's a good one. Interventions, what potential interventions, might best meet their needs based on what we've heard? Someone mentioned stress management, that's good. We can do things like deep breathing, any sort of reflective activities, anything else? We talked about environmental assessment earlier but also modification. Being a new residence is there anything that's influencing the behaviors? Structure for the environment and routines, that's good. Perhaps assistive technology for tracking, lessen worry about getting out, getting in trouble. Any sources of support, she works at night that makes it a bit harder for her to use something like an adult day service or a sitter service. Someone talked about advocacy for respite care, that's good. Guided education regarding the disease, that's good. So that's kinda like the 36 hour day or similar education to go through and kinda planned, this week we're gonna talk about behaviors, next week we're gonna talk about environment, that's good. Anything else?

Okay, we'll kinda move forward and we can talk question and answer too. So this afternoon we've identified demographics of persons with dementia and their caregivers within the United States. We discussed the clinical application of measuring caregiver health as its necessary in the provision of holistic care. Finally, we've described correlates of caregiver distress and identified realistic management techniques. We appreciate that continued increases, in the aging population, necessitate a broad public understanding of Caregiver Support Services. with aging adults receiving the fast amount or majority of assistance from informal caregivers, their needs can't be overlooked in the general plan of care. Considering and measuring caregiver health is important and doesn't need to be time or labor intensive. While a number of caregiver interventions, psychosocial, environmental, respite and day services have been implemented and tested, it's our responsibility to do all that we can to maximize the productive and healthy lives of our patients and their caregivers. This can include referral to resources and being an advocate for those who may not always have the loudest voice. I wonder if anybody has any questions about what we've gone over today. I find these references here at the end of the presentation to be particularly valuable for you to review not just because I was the author of some of them because they do have a nice bit of information where you can review.

Here we have Alzheimer's disease facts and figures and that's reported every year. So if you're ever looking at older information in 2016, 17 be sure to make sure you're looking at the latest information. I recently wrote an article on, "Informal Caregiving for Persons with Chronic Conditions" that you can also look at or review. I mentioned our findings about counting the numbers of symptoms and how they relate to caregiver distress. That's another article there, the third article, "Relationship Between the

Number of Behavioral Symptoms in Dementia". Secondly, there's a good article on the Zarit Short Form, if you're interested in learning more about that. The study we did in 2017 for 160 veterans with dementia, you can review that as well in the Gitlin article, I believe it's the fifth one down. "Screening for Depression in Older Adults" and that's this 10-item CES-D. You can look at it there and learn more about that. Then ultimately, the very last article, is a systematic review so it can give you a good idea of some of the best interventions and hopefully that we covered partially today for, caregiver outcomes in dementia.

So I'll open it back up. I've been rambling so I'ma open it back up for questions, if you have any. Looks like maybe we have the Alzheimer's Association site that we can pull up. So here is the Alzheimer's Association website. This can be really valuable to refer your caregivers to and I would suggest if you only have a fairly minimal amount of time, this is where you wanna send them because there's this, just right at the very beginning there's a Help and Support. Then there's also the 24/7 helpline, this can connect you with researchers, it can connect you with other caregivers. Increasingly with technology persons with dementia can use some of this as well. So for example, the I Have Alzheimer's and that's gonna give them some education. What to expect, what to plan for. A lot of the caregivers and patients with dementia that I see, that's the piece that's missing for them, they haven't thought ahead. They haven't made those plans for the future. You all likely see that in your clinics and in your homes, even with environmental modifications. Well, how are you gonna get up those stairs and sleep in that bed 10 years from now? But with Alzheimer's, it can oftentimes run more quickly, sometimes within seven years being the distance of disease. So what are you going to do when you can't make these decisions for yourself? Have you already set up your powers of attorney? Have you just really planned ahead for the future?

So here's a number of things, since we're talking about caregiving today, let's start there. So Daily Care, Stages and Behaviors, Care Options. Again, we talked about planning, that's something that's often missed. And the Alzheimer's Association works really hard and again its a really powerful organization, a place for you to look. So for example, Daily Care. Daily Care Plans, Food and Eating, we talked about bathing with our case, the individual that didn't like to bath or take a shower. Here's a place for them to learn more about that. Behaviors during bathing. I had a client not too long ago that was very conservative and didn't want people seeing his private parts and that sort of thing and just would adamantly refuse to get in the shower. So I can give them advice and they may take that, hopefully, they'll take it at its word but if they also want some more resources, you can direct them to someplace like this where we can talk about behaviors during bathing. Back here, some other things we see. Let's actually look at community, since we talked some about that. Help and Support, Community. So Online Community, local chapters. Here's a way for them to type in as I mentioned earlier, their zip code. It's actually not my exact zip code but you can type in the zip code and find out what's available for you. I mentioned Alzheimer's Association being natural, excuse me, national as well as local so that's another way for you to find those resources for them.

Back to caregiving, Stages and Behaviors. This often has to do with the planning process, perhaps they can't afford or you can't afford the 36 hour day type programming, you can direct them to the Alzheimer's Association, it can be a really positive, really good place to get that information. We mentioned wandering early in our case, earlier in our case, six in 10 with dementia wander. This can make them feel like they are part of the community, right? I'm not alone, everybody is doing it, for lack of a better term so those are things to look at. I'll go ahead and come, let's see back to the classroom and see if you've all come up with any questions yet. Looks like at this point, we may have a poll. So here we're wondering what issues do you see with caregivers in your practice? Fatigue, certainly. Lack of resources, good. Sleeplessness, many of the things we covered, loss of income, lack of help on the caregiver, good. Appetite was a good, burnout and guilt, irritability. And so that's good.

So starting with loss of income, particularly in the veteran community that I've worked with, you wanna be sure, there aren't any options available for the caregiver to receive some sort of financial benefit based on that care. It's changed a bit with the federal government in the past couple years. When I first started working with veterans with dementia, they didn't allow. So if I had dementia, for example because I was a Iraq war veteran, my wife could get care to care for me, could get support to care with for me, however, for example, someone in the Vietnam era, if they had dementia, that care wasn't set up because of some of the Vet statutes that were in place. So you do want to see just what's available for them, particularly if they're veterans. I know everybody is not but this aging population, it's good to look at. Loss of appetites, yeah, that's important because associated with fatigue as well. Limited caregiver participation, that can be common as well. Just not wanting to deal with it, putting them in front of the TV. Just have to watch for isolation, you have to watch for neglect of course and those circumstances. Irritability, I can't imagine how irritable I would be if I were the only caregiver, for my kids so it's certainly understandable but how can we work with that, translate that to more positive behaviors? Emotionally drained. Certainly, just trying to find, I think for those folks a lot of times getting them with the community that can at least understand what they're going through. We mentioned in the presentation folks that just, yeah, just increasingly isolated and how can we get them involved? How can we associate them with some other groups?

See what else do we have. Physical injury, right? The back pain as we mentioned from providing physical assistance, during transfers and mobility and that's OTs bread and butter, right? To teach those interventions but making sure they understand before it's too late 'cause a lot of times as you all know with the back pain and that sort of thing. And then ultimately how do you get paid for all this? Depending on your setting the ICD 10 codes for caregiver, training, most of them start with FOF or Foxtrot, Oscar Foxtrot that's how we generally bill for caregiver training. There are a lot of codes but you of course wanna work with your office and your payers to identify the right ones for the right situation but I think our field is particularly well suited to care for these caregivers. Anything else? Were there any questions? Any further questions? Yeah, how about that? What treatments today do you think you might use, in your own practice treatment ideas?

So some of the resources, I wanted to include resources, I know as occupational therapists we wanna take care of most of it right ourselves but it's important to know what else is out there. As I mentioned in home health using my social worker, not my social worker, my colleague that's a social worker to help me identify what is available, especially in some of these rural communities. And oftentimes, it's just finding that gatekeeper, right? Determining who really doesn't answer their phone and work 40 hours a week so that's good. Here are some questions, as a OT in home health how would I include goals for caregiver health? I think generally you want to talk about. See, that's a great question. Generally when I'll write them I wanna talk about, caregiver knowledge, less than health so we're putting it 'cause likely your patient, really in any environment is going to be their person with dementia. But caregiver training, how can we make life easier for this caregiver? Unfortunately, there was another question, do you see an increase in primary care physicians, referring OT in the early stages of dementia? No, I don't see that in my practice really at all and it's quite common in early stages of dementia not to take it seriously. That's not so much an indictment of the healthcare system but really people with dementia in general. I think I can get through this, I just have minor memory problems. Often it's not caught until it's later. That's one of the primary complaints, we have in dementia intervention is boy, I wish I would have had you five years earlier but it's too late now to implement some of these strategies. So I think it's something we can do a better job at but no, I don't think it's identified as early typically until it's really a problem.

So the mid to late, mild to late stages of dementia. Yeah, and more training of caregivers. I think that's the most valuable. The most valuable piece is equipping them with knowledge, letting them know that there's stuff out there. With the technological age we're doing so much better than we were doing 20 years ago. There's so much more information free and readily available and just letting them know what the future holds. Not to be morbid, but just to help them figure it out and do what we can for them. Anything else? Well, I think that's all, thanks so much for putting up with me and listening to something I'm really passionate about. I hope you all do take some time to review the resources and think about what you can do for the caregiver as you enter these dementia dyad type environments, I'll turn it over to you Fon.

- [Fon] Thank you Dr. Arthur for a great talk. I appreciate you sharing all those resources and I appreciate everyone's time today. Hope everyone has a great rest of the day. You join us again on Continued and occupationaltherapy.com. Bye everyone.