Welcome everyone to Navigating Neuropsychology, a voyage into the depths of the brain and behavior. I'm John Bellone.

And I'm Ryan Van Patten. In today's episode, we chat with Dr. Geoff Tremont about interventions to improve quality of life for dementia caregivers. Geoff is an associate professor of psychiatry and human behavior at Brown University. He is also a Board Certified clinical neuropsychologist and the director of neuro Psychology at Rhode Island hospital and the Miriam hospital.
This topic is incredibly important for neuropsychologists and for the healthcare field in general. As we will discuss caregivers for people with dementia have a huge responsibility and they do so much for their loved ones and families and also for society more broadly, but they are human, so the burden of the caregiver role takes a toll on them. Personally, I find this topic to be very interesting scientifically but also tough emotionally. As we consider what it must be like to be in the shoes of a caregiver, and watch a loved one lose a part of who they are, as they progress into a state of further and further dependence. As neuropsychologists we should be skilled and knowledgeable when it comes to caregiver burden. But we should also express a genuine warmth and empathy for these people and help them in any way we can. Geoff does a great job of outlining ways for us to take these steps. With that in mind, here is Geoff Tremont. Okay, well, we're here with Dr. Geoff Tremont. Okay, well, we're here with Dr. Geoff Tremont. Geoff, thanks so much for coming on.

Yeah, definitely. So just to start off, why don't you tell us about your clinical and scientific work in geriatrics And specifically, in caregivers for people with dementia? What sparked your interest in this population?

Yeah I guess it's kind of an interesting story. When I first started out after I finished my fellowship and started working, we spent a lot of time thinking about feedback sessions with patients reviewing test results. I really felt that I saw some impact that we could have on family members in these sessions. And so I spent a lot of time kind of structuring those sessions, you know, developing written feedback and really trying to understand the impact of it and it led me to this idea of using our neuropsychological knowledge of brain and behavior relationships and clinical psychology and how we could use that with family members dealing with dementia. And so that led me to try to figure out what's out there in terms of interventions. And most of the interventions, really were, or have been led by non psychologists. So typically, it might be nurses, it might be social work, most of those areas is where they develop these interventions. And so, that got me excited about it. I ended up connecting with a psychiatrist who was working in a rehab setting and had developed this specific kinds of intervention working with families related to stroke patients and stroke caregivers. I saw an opportunity to then modify that intervention and apply it for dementia caregivers. And so that got me started in this area of working with caregivers, and then from there we did a lot, which I know we'll probably get into and talk about.
Ryan 04:09
Yeah, it's great whenever we expand above and beyond the assessment niche that we're in, we're great at assessment, right. But we can use, like you said, "our neuropsychological knowledge" to intervene with these folks as well. Before we move on, I think in psychology in general, it's always important and helpful to really precisely define the constructs we're talking about. So today, we're talking about caregiver burden. We want all of our listeners to be on the same page and know what we mean when we say that. So with the term caregiver, of course, we're talking about these people who provide assistance to folks with dementia. Geoff, how would you define "burden"? How would you operationalize it for us?

Geoff 04:55
Sure. Well burden is really a global term. Think of it as a construct that has multiple components. And a lot of times when we're talking about caregiver burden, we're really talking about perceived burden. And so you can distinguish perceived burden from objective burden. So objective burden would be the number of tasks you need to perform, how much time it takes to perform those tasks. And then perceived burden is the perception of the caregivers and their ability to cope with what they're faced, so this would be all the demands that are associated with being a caregiver. Does the caregiver feel like they have the resources to do it? And when their demands exceed kind of the resources or coping of the caregiver, then we would think of that as burden. What's interesting about that, because we're talking about perceived burden, then this suggests that burdens not perfectly related to dementia severity. But there's other factors in the caregiver that really drive a lot of the burden. So it could be somebody with a very early stage of dementia or cognitive impairment, but a caregiver who's feeling, perceiving, feeling overwhelmed thinking either about what they need to do or what anticipating the future, which could lead to feelings of burden,

Ryan 06:30
Right. And it sounds like you're arguing in this case that the perception of burden is really more important than what we might call an objective measure. You know, in working in medical settings, we often want to objectify and quantify something with a medical test or something like that. But in this case, you know, what really matters is what the person is subjectively feeling and perceiving above and beyond how much burden or stress an outsider might say is happening in a situation.

Geoff 07:06
Right. Yeah, I would agree with that.
So roughly speaking, how common is caregiver burden?

I think it's really common. I think that at some point in a family caregivers trajectory of care, they're going to encounter periods of caregiver burden. There's different ideas or different theories about how people experience burden or why people experience burden. And when they're caring do they adapt? or don't they adapt? Is there this idea of wear and tear? So just over time, Will people kind of wear down enough that they're going to kind of work themselves into feeling burdened? Or is this is there some type of adaptation that happens over time? I think that in general, the research supports this idea that people do adapt Over time that there is an adaptation, but there's ups and downs in the process of the caregiving trajectory that you'd want to think about in terms of different events that may happen along the way. So caregiver burden is very common. It's not everybody. And there are people who are very resilient, or who have good coping, who have good social support or other factors that we can talk about, that are kind of protective factors that prevent them from having extreme burden. But clearly it's a common thing and it really should be addressed with any caregiver or family member you encounter who's taking care of someone with dementia.

Right. In the adaptations you talked about, over time, someone getting used to these additional responsibilities they have and caring for someone with dementia, that I can imagine is made more difficult When the care recipient has a degenerative process, because it's not static so the challenges and the responsibilities change across time as the recipient declines, and moves from mild to moderate to severe dementia more is required from the caregiver. And so you have to adapt to new things.

Right, right and I think that the caregiver really would have to have a lot of support in place in order to adapt to these changes and to deal with the different events or different issues that pop up along the way of caregiving. So that's absolutely true.

You referenced a few different models of caregiver burden. Along those lines, I'm wondering about some other related and subjective psychological constructs like things we are used to dealing with in clinical psychology: depression, anxiety, psychosocial stress, poor overall quality of life. How do you see caregiver burden fitting in with these other symptoms?
Well, caregiver burden, as I said earlier is kind of this global construct. It's multidimensional. So you want to think about these other factors like depression, stress, anxiety, quality of life, all those things kind of fit under this overall rubric of burden. So I think of it as burden involves physical, emotional, social, financial, spiritual, so all of those things are tied. So there's definitely a relationship between burden, say and depression. It's not a perfect one to one relationship. One way that I've looked at it and we've looked at it in some of our research is to conceptualize burden as kind of the stressor and that people experiencing persisting high levels of burden are at risk for developing mental health issues. And so some of the papers we've done, we're able to show that if people are experiencing burden over say two time points over several months, then their risk for a clinical depression, or clinically significant depressive symptoms is related to that persisting burden, those who are able to have it at one time point, don't necessarily get to the point of having significant depression.

John 11:38

Yeah, must be really beneficial to be able to track change over time and get a couple of different readings on the burden measures. But before we switch to going further into the weeds, it might be helpful just to throw out some stats that are relevant here. So I have a few that all come from From the Alzheimer's Association [alz.org], so in the US over 16 million caregivers care for someone with dementia, providing over 18 billion hours of care annually, collectively, obviously, and the economic value of this overall effort was estimated to be about 232 billion dollars in 2017. That's billion with a B. And the majority of caregivers are women, and most of the caregivers are married to or in a long term relationship with the care recipient, but about one fourth of the caregivers, are adult children, typically daughters, and are part of a so called sandwich generation where not only are they providing care for their parents, but they might also be raising their own children and often work full time jobs in addition to other responsibilities. And so Jeff, I'm wondering if you've seen any differences between the experiences of An adult child caregiver compared to a spouse in terms of handling the responsibilities.

Geoff 13:06

Yeah, you know in our one big study that we'll probably talk about later we had about 40% adult children in that caregiving role. As you mentioned, this is really challenging, it can actually be more stressful in some ways for adult child caregivers for a couple reasons. One is this role reversal you know, so these adult children these are their parents and the parents have traditionally taken care of them obviously. And now this role is reversed, it's flipped, where they're having to provide care for them and it can be very uncomfortable, it might be care that's involving like toileting or dressing or things that are uncomfortable for the adult child. And also as you mentioned, this idea of they have their own life. And it can be very disruptive to families to marriages, and that type of thing. So typically what we see with some of the adult children is there is a quicker tendency
towards a placement, and maybe inappropriate placement for these kinds of caregivers because of this stress, and because of this kind of dividing their time, and those issues, so it can be challenging. Again like you said, mostly women who are in this role, so it's mostly daughters who are serving in this role.

John 14:35
Yeah. And another thing that's concerning to me is that as birth rates decline in developed nations, the pool of family caregivers is going to be continually dwindling and that's co-occurring with the baby boomer generation that's aging, it's going to lead to greater need for Caregiving and fewer caregivers to meet that need, and it's a bit scary. Looking forward here?

Geoff 15:02
Yeah, and I think what's interesting about that is this idea that the healthcare system overall is highly dependent on family caregivers. Many times and not even in dementia, if you think about across all health care systems. In hospitals and nursing homes in different places, they're highly dependent on needing these family members to provide care for people like when they're being discharged from the hospital and need assistance. So the whole system kind of needs family caregivers to operate. And if we didn't have those, I mean, the costs to the system or what other resources might be needed is really unknown at this point.

Ryan 15:44
Yeah, they're clearly incredibly important. Going off of something you said earlier, Jeff, about burden being tied to a person's perception of the overall stress. Maybe we don't have the data to answer this but I'm curious if we could take spouse caregivers, and children who are caregivers and think that they have the same amount of objective stress. Would it be the case that the children have higher burden - that they perceive more burden, controlling for objective stress, given what you described a few minutes ago about them being sandwich generation and having a lot of other responsibilities?

Geoff 16:27
Yeah, I think in general, that's true. I mean there's probably a lot of moderators to that. But in general, I think that's true that the adult children caregivers are going to report more perceived burden than spouses. Now that may be more also just a function of reporting as well, that the spouses are less likely to report it or maybe would rather deny some of those issues. So that may be part of it.
Right. We've alluded to the fact that clearly, caregiver burden has negative effects on the caregiver. But maybe can you quickly run through what are some of the negative physical and mental health effects of burden on the caregivers?

Sure. Well, we've already talked about some things. Mental health issues like depression, anxiety, people using more medications\psychotropic medications. These things have all been measured in caregivers, about one third would meet criteria for depression. There's suicidal ideation that happens in probably about one to six caregivers. A lot of family conflict, and this is a whole issue where having this stressor - being a caregiver or having someone with dementia in the family can create a lot of family conflict and stress. Something that we try to address in our intervention, this idea that everyone's not always on the same page, there's disagreement about what needs to be done. There's other issues related to maybe to finances and legal issues that can come up within a family that can create a lot of conflict. So in terms of mental health those are the main ones.

Right. There's also some evidence for earlier mortality, increased rates of dementia in caregivers. Right?

Right. Right. So there have been a few studies looking at this. One of the studies is that cache county study this is really the only study that's looked at, as far as I know, the caregivers own risk for dementia. And what they found is a six fold increase of dementia in those who are caring for individuals with dementia. There's also So, a 63% increase risk for mortality found among caregivers. In general it wasn't specific to dementia caregivers, but caregivers in general. And also after hospitalization of a individual with dementia. Spousal caregivers are shown to have an increased risk of death as well. So there's a lot of potential medical effects of being a caregiver. There's things like lower rates of perceived health we know that chronic stress affects the body negatively and and dementia caregiving, in fact has been used as the model for chronic stress. Those are perfect people if you want to study stress and how that affects the body. This is a perfect group because we know they have this kind of unrelenting stress, this problem that's progressing and these individuals are really experiencing a lot of stress. So along with it, then I think you see other medical and physical effects like poor sleep, obesity, lack of activity, being sedentary hypertension, inflammation related to stress and immunologic and hormonal factors as well.
Ryan  20:22
Right. Clearly there's global negative effects on the caregiver. And on the flip side, what moderators? Have we identified protective factors that may be characterological demographic features of caregivers that provide some resilience against these negative outcomes.

Geoff  20:45
One thing I should say is that and we should definitely emphasize this is that I'm making it sound like caregiving is horrible and no one should ever want to be a caregiver. And you should avoid trying to be a caregiver. The important thing to say is that there are positive aspects of caregiving. People get a lot out of being a caregiver, and feeling like you're helping this person, here's a person that you love who's cared for you or who's been there for you and now you can help them. That's a really important factor, feeling needed and useful, feeling good about what you're doing, appreciating life, being able to stand back and look at what you're doing and appreciate life and what you've been through and that you can provide this help. I think helping people recognize positive aspects of providing care can be really helpful. But the things that are going to help people other than that are things like social support, having family members who are on board with you and understanding what you're going through as a caregiver. And helping and providing both emotional and that pragmatic physical help. So in terms of personality factors individuals who have this kind of resiliency, who are very much task focused in their coping, these individuals are going to do better in terms of burden and have some kind of protection against that.

John  22:30
I'm glad you talked about the positive side of caregiving. I mean, clearly we need more caregivers than we have right now. So we need to convince people that it's good, especially if my future children are hearing this, they have to take care of me [laughs]

Geoff  22:45
Right! Absolutely. Yeah, there's some other interesting thing that might be worth just briefly talking about is this idea. There's this healthy caregiver hypothesis. So kind of goes in the face of what we've been talking about. Basically following women who have risk for orthopedic injury, and they're kind of following them, and they ask this question about "are you a caregiver?", "Are you currently providing care for someone on an ongoing basis who has a chronic illness?" In the sample and they follow people over time and look at and measure a few different things. And so what's been interesting is when they've studied these caregivers versus non caregivers in this normal epidemiologic study, what they find is kind of the opposite of what's found in some of these others studies that have been talking about it that is lower mortality, greater physical functioning, physical strength, and
better cognitive functioning. So it's kind of like in that scenario, the fittest people, the healthiest people are the ones who are choosing to be caregivers or who are ending up in this caregiving role. So it's kind of an interesting idea of A different way of looking at at caregiving.

Ryan 24:04
So from what you just said, Jeff, when I'm taking is that caregiving probably for the vast majority of people, although there are positive aspects to it, and we definitely want to emphasize those to see the good in it and what can have value. By and large overall, it is a stressful and difficult event or series of events sort of thing for someone to take on. But in this orthopedic study you just described, there's a selection bias. It sounds like where people who are caregiving are those who are already healthier than those who are not caregiving.

Geoff 24:44
Right, right and just how that all ties into this picture of caregiving is not entirely clear. We were targeting in some of the studies we're doing we're actually going after people who are stressed so we're not just Going after the general pool.

John 25:02
Yeah. And also we talked about the perception. That perception is so important and if these people are perceiving that it's more of a choice for them, then they're caring for their, let's say elderly parent as a choice. They don't have to. It's sounds like that might also be protective.

Geoff 25:19
Absolutely, yeah. And we end up with a lot of reluctant caregivers in our studies. People who get stuck in that role for a variety of reasons. Then you get this idea of kind of role captivity, you're stuck in this role, and you can't get out of it and kind of this got put on you and you didn't really ask to be the caregiver.

John 25:43
Yeah, I could see how that would be a lot more stressful. But in terms of the difference between caring for someone with dementia versus someone with just a significant physical ailment, like a spinal cord injury, let's say or blindness, I was wondering if you might be able to speak to this. Why is it particularly burdensome to care for someone with dementia compared to carry with someone with just a general physical ailment?
Yeah, and we've touched on some of these things before, you know, this unrelenting and progressive course of dementia, that's affecting activities of daily living and affecting the person and who they are their personality, their behavior is significant. In dementia it's obviously very common to have behavioral disturbance, neuro psychiatric symptoms, I think this contributes to it. And we see behavior problems right up there as a big predictor of burden stress, depression, placement, nursing home placement, that type of thing. And then back to what we talked about earlier, too, I think in terms of the perceived burden and this idea of the unknown course of the disorder that there's there's a lot unknown, there's a lot of anticipation about what's going to happen. Is this person going to not know me? Are they going to lash out? Is there going to be some type of aggression or violence, that type of thing and not knowing when they would need to make certain types of changes, adjustments, supervision, those issues. I think that's driving most of it.

Okay. And maybe similar question but difference between someone caring for someone with dementia versus TBI, stroke, other non neurodegenerative issue? It sounds like it would be a similar answer where it's let's say a traumatic brain injury. Typically not a progressive illness where you have an acute event and maybe that is similar to a physical ailments. Do you think?

Yeah, I mean you think about what those caregivers need who are dealing with stroke, TBI, especially, you know, initially what people need is a lot of education. Education is going to go a long way in helping them understand what's happening with this individual. And it's a time limited, sort of recovery process. So people are going to be a little more hopeful. I think where stroke and maybe TBI and dementia caregiving may overlap is really in the longer term and dealing with what happens okay, what happens when someone's like a year or two years out from their stroke or TBI, and now they have these set of impairments or behaviors that they've acquired as a result of this injury. And now these have to be managed and dealt with by the caregiver and that's where probably there's a lot more overlap and there's probably similar types of burden and other issues that caregivers and Family members encounter.

I'm also thinking maybe one other big difference is that, which might be actually more stressful initially for someone, caregiving for someone who just had a traumatic brain injury or stroke, is that it's a very acute change. So they go from not being a caregiver to 100% being a caregiver overnight versus maybe the individual with dementia, who's
caring for someone with dementia, who has a more slow accumulated set of responsibilities,

Geoff 29:32
right. Yeah, absolutely.

Ryan 29:34
So we know that there are a lot of community based resources for people with dementia and their caregivers. Fortunately, I'm thinking about the Alzheimer's Association and other similar groups. But from what I've read, the literature suggests that unfortunately, caregivers often don't take advantage of these. Give us a sense as to why not, like what are some of the barriers that get in the way of caregivers Reaching out to these community resources.

Geoff 30:03
Yeah, it's an interesting question and something that we've tried to address in some of our research and I always think about it when meeting with families and patients and trying to, you know, encourage or at least offer these resources to people. I think that some of the research shows that a lot of the caregivers don't really think they need them. They lack knowledge, really, about what the services might offer, what kind of benefit they could get from it. There's an overall sense with caregivers that they should be okay, that they should be able to manage this. Like, if it's a spouse, I married this person, I promised I would take care of them and I would be with them and you know, regardless of what happens and so people don't really see themselves as having You know, a problem necessarily themselves, they see the patient, obviously the care recipient is having a problem, but they tend to focus everything on that care recipient and don't see that they themselves may have an issue. So I think that's part of it. Sometimes the care recipients also get in the way, and they say they are opposed to it, maybe because of their own lack of insight into their problems. They're like "you don't need to go to this group", or "I don't want you to leave" or that kind of thing. So I think that can also be a barrier. But I think it's important to communicate...it's important to recognize this of our caregivers, and try to provide this information/education about what resources are available.

John 31:49
And Geoff some some of the caregivers that I've worked with have also expressed being so overwhelmed by the responsibilities, especially managing doctor's appointments, for example, that They said that even adding a support group would increase their burden. You know, it wouldn't be beneficial to them, at least they've expressed this to me. And I know we're gonna talk about your your phone based interventions in a bit that could potentially alleviate some of this, but I'm curious how you suggest responding to that kind
of sentiment if there aren't any other options?

**Geoff** 32:21

Yeah, you know, I think that's a common response. It's something we've encountered a lot. And, you know, I think what it's back to what I said earlier about this idea that everything is focused on the care recipient, the person with dementia. And so it's a lot of times I think it helps to reframe it and to talk about how in the long run, it's important for the caregivers to take care of themselves to be the best caregiver for the care recipient, that they have to think about their own health. And oftentimes I'll compare that to When you have a child. If you have a child and you're caring for the child, if it's all focused 100% on the child and you don't take any time for yourself, or if you're married, for the couple, taking time for that marriage, that relationship and it's everything is zeroing in on the child, those situations, you know that being able to be a good parent actually suffers. And so it's I think a lot of it is a is a reframe, of going through that with them. And also identifying other sources of support. I mean, a support group is great. I think that my experience with support groups is that a lot of people don't relate to those kinds of groups, they don't really want to be a part of support groups. So maybe there's other things that can help people to cope, in addition to support groups. So another strategy is identifying alternatives is taking time for themselves to do you know, some exercise or something they really Enjoy away from those responsibilities as a caregiver.

**John** 34:05

Yeah, I love that. The analogy that I usually use with patients is that imagine, when you're on a plane, and the first thing they tell you is if the oxygen drops, the mask is going to come down, make sure you put your mask on before you put the mask on your children because if you're passed out, you're not helping them. So that usually helps clarify things for them.

**Geoff** 34:29

Yeah, that's a good way of presenting it.

**John** 34:31

So when caregivers can't care for people with dementia any longer it's, it's just too burdensome, they get overwhelmed. Often the next step is to place them, the care recipient, in an assisted living facility, an ALF (assisted living facility) or a SNF (skilled nursing facility) with with ALF being a lower level of care in the SNF being a higher level of care. So I'm wondering where's the line between having an In Home caregiver, and placing someone in a facility, what's the threshold for recommending that higher level of care?
Yeah, it's an interesting question. I think that everyone has different ideas about when placement might be necessary. And every family probably has different ideas or different "what is it that I would need to place this person in care", or where do they draw the line. I think that some family members are just totally resistant to the idea of placement and no matter what, they're not going to place and they're going to seek more in home care, whereas others may be willing to consider it based on certain issues like it could be behavioral issues. It could be like a wandering it could be even something like incontinence where it just gets to be so challenging to care for the person or related to Need for constant supervision and the caregiver not being able to provide that level of supervision or the level of physical care like transfers or showering, bathing, that can drive placement. So I think that the idea of Is there a certain kind of point where someone would need placement or where most people would say you should be placed. It doesn't really exist because every family kind of has these different ideas about what they want to provide for their loved one. And if they've had these conversations in the past with the care recipient, and I remember this from my own family of my mom saying like never put never put me in a nursing home, no matter what. And that puts you in a really challenging position. You know if you end up being a caregiver, where if you have to do this Then there's lots of feelings of guilt and this isn't really what the person wants. And that creates a whole nother set of maybe burdens, stress, and guilt that you that you experience when placing.

Yeah, and I think it might be culturally dependent, too. I know from from an Italian background, it's looked down upon to place and so I can also see an extra barrier for some families with this kind of cultural ties.

Right. Absolutely. You know, and there are some intermediate options. You know, some people do, like adult daycare, I think is a great option for people and they can provide a lot of respite for caregivers I mean, there's an expense to it for many people, but in general, the adult daycare, they can do a lot of ADLs you know, they can shower people, they could do the bathing, they could do other kinds of grooming and things that the caregiver then would have to do and also provide this just time For the caregivers to go do some of their activities, even if it's a couple days a week on this kind of respite, either an adult daycare or even like a respite where care recipients would go stay in a say like an assisted living or nursing home just for a weekend or for a week so that the caregiver can
go away or have some other time that can be very helpful for people.

Ryan 38:24
Yeah, that's a great idea. Do people find the term adult daycare to be pejorative? Or Not really?

Geoff 38:33
Yeah, you know, I guess a lot of times the care recipients are actually getting adult daycare probably don't. I don't think that their cognitive functioning is to the point where they necessarily react to it, right. I think if it's brought up when people are more cognitively intact or sometimes with caregivers, they might have a reaction to that.

Ryan 38:56
Yeah, make sense. Still, though, it sounds like definitely a great idea. The more gradations we can add in so that it's not a sort of a sharp change in cut off where the person goes from being completely at home and taken care of by a caregiver to you know, moving into a SNF right away. You know, that's a very sharp distinction and will probably cause a lot of upheaval and it's a lot of adjustment for the care recipient as well, which can sure be difficult for both the caregiver knowing that their loved one is now in this new scary situation with people they don't know. And obviously hard for the recipient themselves.

Geoff 39:39
Yeah, absolutely.

Ryan 39:41
Stepping back now, bigger picture. placement in an ALf or SNF incurs a very high cost in terms of healthcare resources. So we all know that the baby boomers are aging and our infrastructure just really can't support a large number of new patient into these facilities. So there's you've talked about this a bit earlier, Geoff, there's a great incentive to keep people in their homes for as long as possible. Of course, we want to give them good care. But we have to balance. There's just only so much space and only so many resources to care for people in these institutions. And as I referenced, there is evidence that nursing home placement doesn't actually reduce caregivers distress because they experience emotional stress and worry about their loved one who they have been caring for but it's
now out of their hands to some extent. So my question is, does the empirical literature suggests that interventions for reducing caregiver burden are capable of delaying placement in ALF and SNF?

Geoff 40:48
Yeah, there's definitely some big studies that have shown that you can prevent or delay placement. You know, the big studies have been done in dementia caregiving are the NYU studies done by Mary S. Mittelman. Their studies are kind of unique in that they have this huge memory center that they're working in. And the type of intervention that they provide it's like, you can get as much telephone counseling as you want. It's family therapy sessions. There's the home visits, there's a lot that they offer as part of this program. But in their studies, they were able to show that they could delay placement for people pretty significantly. And they've also shown in these intensive caregiver interventions, where they're working with people in the center, who have access to all these resources, they can also reduce depression over a very extended period. So even bringing it all the way out to bereavement. So they can follow people all the way to the point where the care recipient dies, and they can show that the people who had this intervention had a smoother bereavement and had less complicated grief. So pretty incredible. But I think it's also may not be something that's available foreveryone.

Ryan 42:08
Right. I wonder what the cost benefit of an institution like that is that they have at NYU in terms of finances. So it's obviously really expensive to set up something like that and provide all of that care, but then you're delaying placement, which saves money in the back end. I wonder if we could be able to show enough cost savings in a model like that, to get funding to create more such institutions and more places?

Geoff 42:36
Yeah, you know, it's a good question. You would need like a health economist to sit down and really analyze that. I think that when you're in the healthcare business, and like when I'm dealing with hospital administrators, they don't tend to think big picture like that. They're not thinking about the bigger picture of costs. When setting up a program, they want to know like, are these people going to be covered? The people who are providing these services? Can we bill for it? Are we going to be able to cover the costs of that?
Ryan 43:09
Right. It's unfortunate.

Geoff 43:12
Yeah, yeah.

Ryan 43:13
I want to follow up on something we've sort of skirted around earlier, which is the idea of a caregiver themselves experiencing cognitive impairment. So we said that being a caregiver puts a person at higher risk for dementia. And obviously, this would be very problematic if a caregiver themselves is starting to experience cognitive impairment, we would have a blind leading the blind sort of situation. Geoff clinically in your work, have you seen this and if so, how do you handle it?

Geoff 43:47
Yeah we have encountered that. I mean, obviously in a situation where you have a spousal caregiver and they're both older adults. One person may have dementia. It's not unheard of that the other person could have some type of cognitive impairment. And we know that it's not uncommon, particularly in Alzheimer's disease for people to have lack of insight. And so like you're saying it's blind leading the blind, it's kind of like to people who have no insight into their cognitive limitations. When I have encountered I typically try to get another family member involved. And you know, asking the caregiver is there is there an adult child? Is there someone who we could talk to, I also express my concern, usually to the referring physician about the impairment like I suspect, impairment in the spouse or whoever it might be. And that's something that should be looked into. So I might say that to the referring physician. One of my neurology colleagues will actually go ahead and give a mini mental to the caregiver. I haven't gone as far as that. And I think there's questions about that considering that the caregiver is not my patient. But if you conceptualize this as this whole situation of someone having dementia managing dementia, that the caregiver is an important piece of that process, or the system that's caring for this person, you could maybe make an argument that it would be appropriate to at least, you know, maybe ask a few questions of the caregiver about their own cognitive functioning.

John 45:39
So why don't we maybe talk about some specific interventions that have been studied, there are several different types of interventions specifically aimed at caregivers. One type that you've written a lot about is multi component intervention, which seems to be pretty effective and can reduce depression and burden in the caregiver and even delay
institutionalization of the care recipient, like you've mentioned, can you tell us what multi components, psychosocial intervention looks like for dementia caregivers?

Geoff 46:13
Sure. the intervention that we were talking about before this NYU intervention is a good example of a multi component intervention and that would involve things like educating people about, about dementia, educating people about caregiving and the kind of effects of caregiving, the negatives, the positives, support, so providing supportive approaches, it could be like peer support, support groups, social media, things like that some type of support, they can incorporate that family therapy, trying to address the what we talked about before family conflict and kind of getting people on the same page counseling, having home visits where you can actually look at what's happening in the home, help people set up the home. So that it's kind of dementia friendly to make it easier for caregiving. And then things like also opportunities for respite. So these interventions basically have all these different pieces. They're just like throwing everything at the caregiver. And the studies that have been done, whether it be the NYU study or the reach studies, which are these multi site studies that have been done and in pretty large samples. They have positive effects, you know, but they the positive effects are relatively modest. I mean, yeah, you can delay nursing home placement when you throw everything at the person, but in general, the the effects are still relatively modest, and I think we have a longer way to go. And, and I do believe that this idea of multi component is important that we really need to pretend not, there's not just going to be one, you know, magic pill or magic treatment for caregivers. And they're going to really need lots of these pieces that we're talking about. And lots of things even that are not necessarily formal treatment, but other strategies to help them to cope and manage, manage what they're facing.

Ryan 48:23
Right and multi component interventions, although, as you mentioned, they work. They're often pretty impractical for caregivers, right? So caregivers inherently have a high number of responsibilities in caring for their loved one. So they spent a lot of time in the home with that person. The idea of having them come in repeatedly to this intervention to drive somewhere. Often, the clinic is more than a stone's throw away from their house. So it's asking a lot of them. Ideally, we would make our interventions as user friendly and practical as possible to reaches as many different people as possible. So we can get higher attendance and larger effects. So with this in mind, Geoff, you were the PI of an NIH grant testing the FITT-C. The family intervention, telephone tracking for caregivers. Can you tell us a little bit about the background? The theory, the thought process behind developing this protocol?

Geoff 49:29
Yeah. So, like what you said, we looked at what was out there in terms of caregiver
interventions, and we're really worried about the cost, the personnel, the amount, the number of personnel the amount of time needed to kind of implement these and also keeping in mind that caregivers are reluctant to use resources, to engage, and showing up for for their own kind of health treatment and appointments. So as a result we were looking for some type of intervention where we can help the caregivers. And as I said, in the very beginning, I was working with a psychiatrist who is who had some intervention he had developed for stroke caregivers. And it was partly done over the telephone. It was done initially like in a rehab setting. And then once the patient went home, they did some follow up phone calls. And there was some structure to it. And it was based on a couple different theories that I'll talk about. And we basically took that intervention and modified it to be a completely telephone based approach. So there was no face to face, it was all done over the telephone. So the underlying theory then just to highlight that of this intervention is based on the mostly on the transactional stress and coping theory, which is Lazarus and Folkman. And this theory addresses this idea of appraisal and how, again, going back to this idea of like, what is burden? What is stress? that when there are certain demands of a situation we do this appraisal of is this a threat? Is this something that is a problem? And in most cases with dementia, people would say yes, they will react this as a threat, this is something that I really need to deal with. And then there's a secondary appraisal, which is, Do I have the resources, the skills to cope with this? Am I going to be able to handle this? And if that's the case, if people say, Yeah, you know what I can, I can do this I can, I can do it, I can deal with it, then we think of that as kind of positive stress that people we all have when we're busy and we're working. We've got a lot going on. We're like, okay, I can manage this. There is stress but I'm managing it and I'm okay. Versus feeling like these problems exceed their resources and then we're talking about negative stress. And so in this model, the idea is to address that issue of the secondary appraisal, and helping people to view the situation and to give them skills and help them with coping to increase their ability to experience more positive kind of stress than negative stress. So that's one aspect of the model. The other piece that is a little more complicated in terms of understanding how it would work with dementia caregivers when we're working just with one caregiver, and that is the McMaster model of family therapy. So this initial intervention that was developed for stroke caregivers had this component of this model of family therapy, the McMaster model, which is really like a mental status of the family. And so the idea is that the family has all these different components to it. Family functioning has different components like roles and communication and problem solving and that there's a pattern to how the family functions. And when an event happens, a stressful event happens an emergency, a crisis happens, people go to their patterns of family functioning, and they behave in ways that they've always behaved, in terms of what their role is, and all these different pieces. And so what we want to do is understand more about how that family functions. So we can help people in adapting and in changing aspects of how the family functions. So we incorporated that into this intervention in working with one caregiver, as opposed to working with the family. Obviously, it'd be ideal to be able to have the adult children and have other people who may be involved engaged in the intervention, but just Practically it wasn't feasible.
Right. What you just laid out, the theory, the underlying rationale for how you conceptualize caregiver burden and then building the FITT-C off of it is really helpful. Can we now move forward? And can you talk a little bit about the randomized clinical trial of the FITT-C? see the big picture takeaways, the results and conclusions?

Sure. So what we did is we once we developed this intervention, we had some focus groups. We did a kind of an open trial and got some feedback about it. I met with professionals who dealt with caregivers to adapt and modify this intervention, and we did some preliminary testing of it. We finally came to a point where we were ready to do a study- a randomized trial. The hardest issue is always the kind of the control group and what's going to be the comparison group. A lot of the past studies looking at caregiver interventions would use a waitlist, would use like an education group, minimal contact kind of education group or check in group or something like that. We really wanted to test this model and say does the content of this model really work? Is it something more than just nonspecific factors that you think about for psychotherapy, and so we ended up developing a comparison group that we called a telephone support, which was really kind of a non directive supportive condition. And, that was over the telephone just like our intervention, it was the same number of sessions about the same amount of time. And it was not directive, it was more about "Tell me about what's going on with with caregiving", "how are things going with you", it's encouraging people and providing support. And so that was the comparison. So we randomized people to either The FITT-C program which is very structured, or this other group of social support, and it was done over six months, and it was 16 telephone contacts over the six months, that started out more frequent and then over time they decreased in frequency. And what we found at the end of treatment, so after the six months, we found that our FITT-C program actually had reduced depressive symptoms in the caregivers compared to this support program and also reduced their reactions to the care recipients, depressive behaviors and other behavioral problems. We didn't see any change in burden, which we could talk about. And then in a secondary analysis, just to round this out, we looked at community resources and hospital based health care. And we found that the people who got the FITT-C had increased use of community resources. So these would be like, good things like going to a support group, contacting the Alzheimer's Association using like Meals on Wheels or those kinds of things, and reduced hospital stays and emergency room visits for the caregivers, not for the care recipient, but for the caregivers. We were able to publish papers, two papers on that one with the overall study findings and then more recently, the healthcare utilization findings.

That's great. Clearly the the FITT-C worked in a lot of ways and I do really like your use of the active control group. There's a big difference between that and simply a waitlist where we can't really tease apart whether differences across the groups are simply due to
contact or something specific about the intervention. So that was really helpful. you referenced the one surprising nonsignificant finding that burden did not decrease. Can you speak to your thoughts on on why that happened?

**Geoff** 58:12

Yeah, I mean, I think that if you look at the past studies and other research, it's kind of hit or miss with burden. Some studies show an effect, some studies don't show an effect. And I think I'm not entirely clear why we didn't see that we had an earlier pilot that we did, where our intervention was 12 months instead of six months. And in the 12 months pilot, we did see some effect unburden. So I'm wondering whether it's more about kind of time intensity, like really bringing people through a lot of different situations and, working with them and helping them. I think it speaks to this idea of just a one time intervention is probably not going to be the answer. That we need ongoing. Support for these people and ongoing interventions and other things that we can work with them through their caregiving trajectory all the way through to the, you know, bereavement process.

**John** 59:14

So unfortunately as in many areas of psychology, you know, most of our work in this area has been in white people with quite a lack of any ethnic diversity in most studies, I think your FITT-C one was predominantly white. Is that correct?

**Geoff** 59:31

Yes, yes.

**John** 59:32

So, you know, it's obviously not a good thing, because ethnic and cultural background could potentially moderate the relationship between caregiver interventions and outcomes. So I was wondering if you could tell us just very briefly about studies that did recruit ethnically diverse samples and what the overall findings were?

**Geoff** 59:51

So that's been a big struggle for us really based on our location, in terms of trying to recruit a diverse sample. We've struggled with that with a lot of different studies in this area. But yeah, the one study I talked about I mentioned it earlier the REACH studies. So the REACH2 study was a multi site approach where they a priori basically had said that they want to collect three different groups. They recruited White, Black, Hispanic/Latino, and they had multi sites, I don't remember how many sites it may have been seven or eight sites. And they had bilingual staff, so they could include people who were Spanish speaking. And they really thought about this in advance to look at this multi component
intervention that we mentioned before, and the effect in these different populations. And basically, the findings were that all the groups benefited, regardless of you know which ethnic group they were in. In general, the Latino group showed the most benefit, where the African American, the Black group, showed the least benefit, and the White group was kind of in the middle.

John 1:01:08
One other question that popped up for me is that do the caregiver interventions differ based on the neurodegenerative etiology of the care recipient’s cognitive impairments. So is it more effective for people who are caring with those who have Alzheimer's disease versus Parkinson's? I don't know if that's been parsed out in the literature or

Geoff 1:01:30
it really hasn't been addressed. But in general, if we think about the conditions that have the most behavioral neuro psychiatric disturbance, those are going to be the ones where people are going to struggle the most and probably may need the most help. So you think about things like frontotemporal dementia, Lewy body dementia, those are maybe much more difficult and challenging to deal with and help those caregivers. In general, that's what I would say, each case is going to be unique. The behavior problems is a huge issue. So neuropsychiatric symptoms, and behavioral disturbance. Those are oftentimes the big issues that need to be addressed and helping caregivers problem solve that. Helping them reframe some of that understanding more about like, this is the disease. This is not the person who's lashing out against you. And working with caregivers to reframe that can be very helpful.

Ryan 1:01:30
Right. I can imagine there are idiosyncratic differences in caregivers themselves and how equipped they might be to handle memory, ie ad or motor like Parkinson’s symptoms in the care recipient. But overall, broadly speaking, it definitely is intuitive and makes sense that the neuropsychiatric/the behavioral symptoms overall are the most problematic. For the caregivers. So to step back, we’ve talked about multi component interventions and their pros and cons, and then your line of work and these telephone interventions where the latter is cheaper, more practical, more attainable for a lot of caregivers who can't maybe reach or make it to all of the multi component intervention in person sessions. So have there been any studies that compare telephone based interventions to multi component? if we stacked them up side by side, if they haven't been compared in a single study, can we look at effect sizes and say, is one more effective than the other in terms of the outcomes of interest like burden and depression on the caregiver?
Yeah, so there haven't really been head to head studies of the telephone versus face to face, or multi component interventions. In our study, we were able to look at the effect sizes and how those effect sizes compared to other multi component studies. And they were pretty much in line with those. And so we felt confident just to conclude in our papers that our intervention had a comparable effect sizes, as a multi component intervention. But as I said earlier, these the effect sizes are still relatively modest effect sizes, and I think there's other things we need to do going forward.

I believe you're currently working on a new grant for portable FITT-C dissemination, is that right?

That's right. Yeah.

That's really interesting. Can you just quickly tell us a bit about that?

Sure. Yeah, we just actually just put that grant in. I've been thinking about ways of trying to disseminate or implement this intervention and this is a big issue. Because there are lots of dementia, caregiver interventions that are out there that have found efficacy. But typically it's like 3%, very few of these have actually been translated or even studied in an implementation study. And so what people are getting out there in the community is probably not what's most effective. So we're trying to figure out ways to implement and study this type of intervention. And so what we've done is I partnered with a biomedical engineer, and we're going to try to take our FITT-C program from the telephone and pull that into some type of mobile application. And we've already kind of developed a framework for that, and we've just put in NIH grant, R21 to try to, to do some development on this project.

Yeah, that's awesome. So I want to I want to switch gears just a little bit and talk about clinical practice for a second. So when when you're clinically evaluating an older adult and diagnose him or her with dementia, how do you think about the caregivers wellbeing? and what have you want to be the most effective way to write reports and recommendations for caregivers in these situations?
As we've mentioned earlier, I think of the caregiver as part of the clinical picture for the patient with dementia and so understanding who is the primary caregivers important, what is their role? and that really needs to be addressed, assessing the the caregiver we try with all our patients who come in with a caregiver or coming with a family member, we will typically administer something like the Zerit burden interview, which can be a way of assessing burden. But also, you know, you get that informally, I think by including the caregiver in the interview process, you can get a feel for their stress level. And then I always mentioned in my reports, we always talk about Alzheimer's Association, getting educated. We mention that and we kind of say "the family should consider this". A lot of times we're addressing issues of trying to get the family on the same page. So it's important for the family members to be informed and educated about what's going on with the person and involved in the care.

And when do you involve other clinical professionals like social work, for example, and are there other professionals that might help with with this issue?

Yeah, I think if you have availability of social work, that can be really helpful, especially when there are family issues we talked about earlier, this idea of family functioning. So when there's family dysfunction. When there's financial or legal issues, social work can be really helpful to get involved. I think therapists and counselors can also be helpful for people. I know we have some in our community who specialize or have experience working with caregivers. And so I think they can also be, a really good resource.

I also just wanted to talk for a moment about elder abuse because whenever you have vulnerable populations, it's always important to think about their safety and well being. Especially since for cognitively impaired older adults who are being taken care of by a caregiver abuse is actually more likely as caregiver burden increases. And so, Geoff, I wonder if you can just talk about your clinical experiences with suspected elder abuse in this setting and how you might have dealt with it if you have had to deal with it.

Yeah, well, it hasn't come up too much in my practice, I think that's mostly because I see people early stages like most neuropsychologist were doing MCI, mild dementia, it doesn't come up, I think these situations tend to be more so as people become more impaired. What has come up for me, are issues like exploitation, financial exploitation by families
and friends. And I think that in those situations, obviously it's important to alert professionals like for in our state, it's elderly affairs need to be alerted referring physicians, you know, getting them involved, I think is really important. But you know, like, when you think about elder abuse, there's different types of abuse, like physical, emotional, verbal types of abuse. So some of those things like physical abuse the signs are visible, the emotional and verbal, I think is more difficult to detect and careful questioning about what the care is like what's happening, you can often get at that. One thing that I think is interesting to mention here is oftentimes caregivers, it's more about a lack of understanding, and a lack of education about dementia that can lead to problems. So some of this obviously, is intentional and people have bad intent and they want to get money or they have some problem with with the care recipient or something. But a lot of this is also kind of unintentional, where people are just not educated about what dementia does. And people people tend to create problems as a result. So one quick example is a patient I had whose daughter was just extremely upset because the mother couldn't remember that her husband had died which is upsetting to the daughter and the daughter would constantly yell at the mother about how you should know that, you know, he's dead. And she would bring him to the grave site. And every time she went to the grave site, she relive the death. And it created a huge problem. And it was really based on a misunderstanding, but it was it was very kind of abusive to the care recipient, she was really so stressed because of the way that the daughter was behaving. And so with some education, it could really help that situation.

John 1:11:28
Yeah, I've seen that firsthand to. I have to constantly remind my grandpa who's caring for my grandma, that is normal that she repeats the same question. she'll ask someone if they've had a cup of tea already, you know, five times within the span of a minute. And you know, he's not verbally abusive, thankfully. But I have to remind him as he gets frustrated that it's normal part of the process.

Geoff 1:11:51
Yeah, I think that's a much more common scenario than abuse, although obviously abuse does exist and exploitation those are serious issues.

John 1:12:01
I'm wondering about those people who don't have a caregiver in their lives, older adults who have neurodegenerative diseases who are declining cognitively and they don't have the money for good health care. Do you run into this situation in your clinical practice?
How might we help these kinds of people?

**Geoff** 1:12:20
Yeah, you know, I do encounter these people. I don't think it's an uncommon situation. We often see these people in the hospital because of self neglect. They're living alone, they don't really have contact with anyone, they're isolated. And they end up in the hospital because someone is worried about them or they fall or there's some issue like that. So I think it's a relatively common situation. And it's challenging on, what do you do for them? There are a lot of community programs obviously dependent on where you are, but there are a lot of community programs like for in our state Elderly Affairs has programs to help people like community action programs. They also have this program here, I don't know how available it is in other places, which is a program for keeping people out of institutions, keeping them in their home, who are at low income levels. And they provide all kinds of services for them and then we talked a little bit about Adult Day centers, which could be helpful. I know that some of the adult day centers here have some capacity to see people who don't have an ability to pay so they can see them at a lower rate. Also, we talked a little bit about involving elderly affairs, getting state agencies involved I think are really important for these kinds of individuals. But its a major problem because as we talked about before, the health care system our whole model of caring for older people is dependent on family caregivers, and the system would collapse if we didn't have family caregivers.

**Ryan** 1:14:04
All right. Well, this has been great, Geoff. Thanks for this overview. We've gotten to a lot of details as well. I wanted to ask you one sort of broad big picture question about your career that I think could be really helpful for some of our listeners.

**Geoff** 1:14:20
Sure.

**Ryan** 1:14:21
So you are both a Board Certified clinical neuropsychologist, and you've had several large NIH grants, which we've talked about the FITT-C grant. So for trainees up and coming who are interested in both clinical work and research, obviously juggling these multiple roles is no easy task. It's a lot of work. A lot of training on both the clinical side and the and the
research side. Can you give us a little bit of advice in terms of how to juggle these these different things, how to be successful both in a busy clinic and doing solid science.

Geoff 1:15:00
Yeah, I always joke with everybody that I'm 80% clinical and 80% research [laughs]. And one of the things early on that I thought was important for me was to not say no to things. And which ends up being you're busy, you're doing a lot. I mean, I think this in this type of job, you're going to be busy. But that was kind of like my thought process. In the beginning, I'm going to say, "I'm not going to say no to things I'm going to, if people want me to be part of our project, even if maybe I'm not going to get something, it's not obvious that I'm going to get something out of it. I want to be part of the project. I'm going to do it I'm going to say yes, I'm going to help this person with their stats, I'm going to help this person with whatever" and that got me hooked into a lot of research. The other thing in terms of juggling between clinical research is really like blocking time. And in the beginning that was blocking time on the weekend unfortunately, but that's what it was. But I felt like if I could get a block of time, I could be very, very productive. On say, like a Sunday morning, I would come into my office, and I would just focus on one project. And really, you know, get into it as opposed to trying to do little pieces during my day, which I still do to some degree but especially when you're trying to get a big project or grant put together, having those blocks of time are really helpful. Other things to think about are always thinking about opportunities for like preliminary data, pilot data. So small grants, particularly like internal grants, many institutions will have small grants, so go after some money from the institution to get some pilot data to then help you do a bigger grant. And don't be afraid to ask your administration of your hospital of your program or Whatever it might be for support for some block time. So I've gone to my hospital in the past and said, you know, can you buy me a laptop computer? Can you buy me some RA, some research assistant time, those kinds of things. And so that's mainly how I've done it is trying to block off times. And once you get some funding then it can buy out a little bit of time and protect some of your time so you can do these tasks.

Ryan 1:17:32
That's great advice. Yeah. Much appreciated for us and our listeners, I'm sure. So this is the point where most interviews would end but we would like to ask you a couple Bonus questions sort of along the same lines of your opinions about the field and giving us and our listeners some advice. So the first question that we like to ask all of our listeners is, if you can improve one thing about the field of neuropsychology, what would it be?
Geoff 1:17:59
Well what I would say going back to the very beginning when I was talking about feedback and neuropsychological feedback, and I'd like to see us spend more time looking at outcomes of our evaluations, impact of our recommendations, and thinking about how we evolved going forward, from assessment to intervention to bringing about change for people and measuring that change. I feel like we have a big impact on people, our neuropsych evals have that impact, but we don't really measure it. We don't really know what things we do in terms of maybe what we recommend or how we present findings, how that impacts people and how it impacts their care. I'd like to see us really focus on that and help us evolve, especially in this kind of changing landscape of healthcare where we have to we have to prove our are worth and show our effectiveness.

John 1:19:04
Yeah, that was very similar to what Christine Trask had shared with us several episodes back. And I completely agree. I think that's so, so important for us. The second question is, what's one bit of advice you would give to trainees that would really make a difference?

Geoff 1:19:22
Yeah, you know, I think that something that people don't think about too much is learning about finances, business, budgets, contracts, like learning about that kind of those issues. I never really thought that I would need to know that. And I encountered this kind of stuff all the time, whether it would be like a NIH grant budget, or dealing with contracts with the hospital or even just dealing with my own contract, working for the hospital and and those types of things. So I think learning about finances, business, that's actually something that would be nice to Incorporate and think about as you're going through training before you're out on your own.

John 1:20:07
Yeah, absolutely. I think grad schools should have have courses devoted to that exact topic.

Ryan 1:20:15
All right. Well, this has been great. Geoff. We really appreciate your time. Thanks for coming on the podcast.
Geoff 1:20:20
Yeah. Well, thanks for having me. It's been a lot of fun.

Ryan 1:20:23
That does it for our conversation with Geoff. If you found today's episode interesting and engaging, feel free to share your thoughts and our questions on our website at nav neuro.com/10. And join us next time as we continue to navigate the brain and behavior

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