



ADA Live!

Episode 81: Improving the Lives of Older Adults

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Host: Mary Beth Harrison - Southeast ADA Center

Dr. Walter Boot: Hi, I'm Wally Boot.

Dr. Sara Czaja: Hi, I'm Sara Czaja.

Dr. Neil Charness: And I'm Neil Charness, and you're listening to ADA Live.

4 Wheel City: (rapping)

Beth Miller Harrison: Good afternoon. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University and the ADA National Network, welcome to episode 80 of ADA Live.

Hello everyone. I am Beth Harrison, Director of Knowledge Translation with the Southeast ADA Center. Listeners, you may submit your questions about the ADA at anytime at ADALive.org. Welcome and thank you for being our guest today, Dr. Walter Boot, Dr. Sara Czaja, And Dr. Neil Charness.

As you know, the month of May celebrates older Americans and recognizes the contributions and key role that older adults play in the vitality of our neighborhoods, families and lives. One aspect of aging that can certainly impact quality of life is cognitive

impairment. According to the Centers for Disease Control, more than 16 million people in the United States are living with cognitive impairment and age is the greatest risk factor for cognitive impairment. We do want to distinguish between the cognitive impairment acquired as we age versus an intellectual disability that is developmental in nature.

Sara, in general, what does the term cognitive impairment mean in the context of our conversation today?

Dr. Sara Czaja: Our work is on cognitive impairment that occurs in later life and I think one very important distinction is between what happens normatively with aging, normal age-related changes in cognition such as declines in things like our processing speed, our working memory from actual cognitive impairments.

Cognitive impairments can take on many faces and can be broadly defined as when a person has difficulty remembering things, learning new things, making decisions, concentrating and these difficulties impact their day-to-day activities. Some cognitive impairments are mild. We often hear the term mild cognitive impairment, and some are much more advanced and make tasks even more challenging. Here we can think about different types of dementia or cognitive impairment due to a traumatic brain injury or stroke. These are more severe cases of cognitive impairment.

It's also important to note that sometimes when one experiences what seems to be a cognitive impairment for a person of a certain age, it might be due to other things such as lack of sleep, anxiety, stress or medications. It's important that anytime you think you are experiencing a cognitive impairment to make sure to talk to your physician so that you can get to the root of the cause.

Beth Miller Harrison: Thank you. Thank you, Sarah. It sounds like impact on quality of life is a big component. Neil, who exactly is considered an older adult? Just as an aside, today, I'm hosting because I was considered the oldest adult in the room to do the hosting today. So who is considered an older adult?

Dr. Neil Charness: Beth, that's an excellent question, and I think if you were to ask 10 gerontologists, you'd probably get 10 different answers. So let me try a couple of levels,

but let's start with the legal one first. So legally constrained definition might look at, for instance, the Age Discrimination in employment Act. And note that you can file a claim once you reach the age of 40. Pension age is another very common one that people use. For instance, in the United States, ages 62, 65 and 70 are the ages for different levels of pension entitlement. There are a host of other areas, biological, psychological, social, all of which provide different definitions.

The other thing we're keeping in mind too is that the definition is really dependent on the era you are discussing. For instance, if we look at life expectancy at birth and then pick the midway point, that might be a good way to go. But think about 1900. Life expectancy at birth in the United States was about 47 years. Halfway, you're old at 25. Today, life expectancy is a little more like 81 for women, 76 for men, about 79 years overall. So if you think of that Age Discrimination in Employment Act, definition of 40, then halfway from 79 is about right.

However, the one I'm more partial to is the maximum longevity. Think of John Calvin, who was a French woman who died at the age of a little over 122 years. Let's take that and say about 120 orbits around the star we call the sun, that's the maximum longevity. And that would make 60, which is conveniently what we chose for ENHANCE as our definition of older adult.

But let's keep in mind a popular one, subjective age. That's what happens when you ask people, "Who do you consider old?" And typically, almost irrespective of the age they happen to be at, it's someone who's about 10 years older than you are. If you think back to the saying in the Vietnam War of college students ... I was a graduate student back then ... "Don't trust anyone over 30," which is about 10 years older than we were at the time.

But to kind of summarize, there are a lot of difficulties in setting a very specific cutoff, and so I prefer to talk about aging adults, which is anyone listening to this broadcast, likely after they've reached typical reproductive age. That is their teens.

Beth Miller Harrison: All right, great. Thank you, Neil. You really touched on a lot of different aspects of aging and the different definitions that I honestly hadn't considered, and I guess really as you said, aging adults is pretty much all of us.

Dr. Neil Charness: I think so.

Beth Miller Harrison: On that timeline somewhere. Let's turn a little bit to what does cognitive impairment actually look like in older adults. I know Sara, you've shared with us what it is and Neil, you shared with us who is considered an older adult. But Sara, could you talk a little bit about what cognitive impairment might look like in an older adult?

Dr. Sara Czaja: Yes, and I'd like to preface this by saying cognitive impairment can take on many forms, and the way it manifests itself varies across individuals. Certainly, there are common symptoms of cognitive impairment, but there is also individual variability. If we think about mild forms of cognitive impairment, this may involve things like forgetting names of people who are very familiar, forgetting appointments, forgetting medication regimens, bill-paying times.

Now, we all do this occasionally if we're under stress or haven't slept or for some other reason. However, if this becomes a pattern, then we typically think that this is a mild form of cognitive impairment. People with these types of impairments can many times compensate for the impairments through environmental support aids or memory aids, and there are also, as you know, more severe forms of impairment such as dementia, a form of which is Alzheimer's disease. Here, people progress through stages of the disease from mild dementia where the cognitive impairments become more pronounced than in mild cognitive impairment, moderate where we also start to see behavioral problems, and then more severe stages where people forget even ... they fail to recognize people completely, even though it may be a spouse of 50 years, are unable to do basic activities of daily living.

The other thing to realize about cognitive impairment is it's not only affecting one's cognition, it's also affecting one's ability to socialize. Many times people with cognitive impairments, even mild cognitive impairments, become socially isolated because they're

embarrassed or they withdraw from social situations. They feel they can't contribute to conversations like they once did. It can also have economic consequences if people are no longer able to be employed, and emotional. Sometimes cognitive impairment is associated with depression and anxiety when one recognizes that in fact they are experiencing changes in cognition.

All of these factors ultimately impact on a person's ability to live independently and their quality of life, and importantly, the quality of life of their family members as well, because as we know, when we think about things like dementia, especially Alzheimer's disease, most people with Alzheimer's disease are cared for by an informal caregiver, such as a spouse or a daughter, some other relative, and in fact, this impairment is not only placing a burden on the person with dementia, but also on the person who's providing care and support.

Beth Miller Harrison: Yeah. The social and emotional aspects of the cognitive impairment are very important and certainly impact quality of life. I know that you and your colleagues have been awarded some notable grants for the study of cognitive impairment in older adults. One of these from the National Institute on Aging focuses on early detection of cognitive impairment in older adults. Dr. Boot, could you tell us why early detection of cognitive impairment is so important and how this new grant will help?

Dr. Walter Boot: Sure. I think the NIA-funded study you mentioned is the Adherence Promotion with Person-Centered Technology Project, or APPT, A-P-P-T. The goal of the APPT study is to design artificial intelligence-based reminder systems to encourage people to regularly engage in home-based cognitive assessment.

Dr. Walter Boot: Early detection of cognitive impairment is important for a number of reasons. First, although we're still exploring what can best be done to slow cognitive decline, early intervention is key in order to quickly determine the cause of this change and intervene as soon as possible. And as Dr. Czaja mentioned, sometimes changes in cognition have their roots in sleep or stress or it could be something more serious, so it's important to know when these changes have occurred and to do something about them if possible. If potential for serious decline could be detected well in advance, this would

allow the individual and their family to better plan for the future to make decisions before the capacity of the individual who is experiencing cognitive impairment is affected.

Finally, this would be a major advance in developing clinical trials to combat age-related cognitive impairment and dementia. If we could way in advance detect signs of impending decline, we could design clinical trials that only include people at risk. This would make the clinical trial far more efficient.

Of all these benefits, it depends on the idea of people regularly engaging in home-based cognitive assessment, but as we know, people's engagement in long-term health-related behaviors is often poor. Adherence is often poor for lots of things like diet, exercise, nutrition. The APPT study is intended to develop smart technologies to support adherence at home-based cognitive assessment because we believe detecting cognitive decline as early as possible has many of these benefits.

Beth Miller Harrison: I think that the idea of the home-based cognitive assessment is an interesting one. We're going to take a little break, and I do want to thank you, Walter, Sarah and Neil. ADA-listening audience, if you have any questions about this topic or any of our other ADA Live topics, you could submit your questions to. 1-404-541-9001 or through our website, www.ada.org. Let's pause for a word about our featured project, the ENHANCE Center.

Voice Over: ENHANCE, short for Enhancing Neurocognitive Health, Abilities, Networks and Community Engagement, is a center funded by the National Institute on Disability, Independent Living and Rehabilitation Research. This center will focus on older adults living with cognitive impairment, including mild cognitive impairment and traumatic brain injury. The objectives of the ENHANCE center are to understand the challenges older adults with cognitive impairment encounter with living activities, how these vary according to the type of cognitive impairment and needed areas of and preferences for support. Also, to identify, develop and evaluate potential technology solutions, to disseminate these findings to multiple stakeholders and to advance new knowledge in the aging, cognitive disability and technology space. To learn more about the ENHANCE Center, visit their website at ENHANCE-RERC.org.

Beth Miller Harrison: Dr. Boot, Dr. Czaja And Dr. Charness, the newly funded center through NIDILRR that we just heard a little bit about in our commercial is a very exciting opportunity, and one that is going to hopefully bring a lot of recognition to this field of study. Could you talk a little bit more about the ENHANCE Center and what your hopes are for it?

Dr. Sara Czaja: ENHANCE, it's important to recognize, is a multi-site center and it involves Florida State University, Weill Cornell Medicine and the University of Illinois at Champaign-Urbana. Our team has actually been together for some time as we also have been working for 20 years in the CREATE Center. CREATE is funded by NIA and it focuses on older adults and their interface with technology.

As noted, the goals of ENHANCE are really to focus on how can technology support people with cognitive impairments. Our target populations, as stated, are those with mild cognitive impairment, cognitive impairment due to stroke, or cognitive impairment due to traumatic brain injury. We believe in a design thinking, user-centered design approach. So we feel that in order to design technology supports that are efficacious for these populations, we really need to understand, what kind of challenges are they encountering with their living activities? How do these challenges vary across these three sub-populations? What are some of their preferences for support? And then when we have this information, we can identify, develop and evaluate potential technology solutions. Okay, I'll turn it over to my colleagues now.

Dr. Walter Boot: Okay. So yeah, this is Wally. Within the ENHANCE Center, there are four main projects. Some focus on exploration and discovery. Some are determining proof of concept and proof of product of novel technology solutions to help older adults living with cognitive impairment continue to engage with their community and also live independently.

One of the large studies is a study looking at 270 participants over time, and these are individuals with cognitive impairment, and also their caregivers. And this will be a longitudinal needs assessment study that will gain insight into the everyday challenges older adults with cognitive impairment experience, how these challenges vary over time,

technology solutions that they currently use to meet these challenges, but also where these technology solutions fall short so we can build better technology solutions for the problems that people are having.

As Dr. Cjaza mentioned, it's always an integrative process where we involve users in the design of the projects in terms of needs assessment and then once we have prototypes developed, we have people come in, we have them interact with the prototype and then we redesign so that we make sure that our product is useful and usable.

Dr. Neil Charness: Another of our projects are designing and evaluating technology to support social connectivity and resource access. As Sara has mentioned earlier, one of the major challenges facing people, particularly older adults with cognitive impairment, is the risk of social isolation.

Another of our [inaudible 00:19:56] is on technology-based mobility solutions, because many people report difficulties with being able to find their way around their communities to go shopping or to visit their doctor's offices and so on. Another focuses on designing better perspective reminder systems to support memory. As Sara had mentioned as well, memory problems are very common and we're trying to find ways to mitigate those particular problems.

And another exciting aspect of all these projects is the idea that if we can apply artificial intelligence and machine learning, we can have systems that are adaptive, that can change based on the abilities of the individual, and particularly sensitive to the changes that might be needed as those abilities change over time.

And finally, of course, dissemination, training are really important components of our center. As we learn important information about how to design technology for older adults living with cognitive impairment, then these dissemination and training activities we hope are going to be able to get this information out to relevant stakeholders, including the business community, so that our findings can have broad impacts on the design of these products.

Beth Miller Harrison: Thank you. Thank you so much, Wally. It sounds like the project is going to cover a lot of different aspects, and I know you talked about some of the challenges that people with cognitive impairment encounter in daily life living activities, such as mobility issues and issues with memory and those kinds of things. Do you expect to find some common challenges in older adults with cognitive impairment when it comes to daily living activities?

Dr. Walter Boot: Yes, I think we will find some common challenges of course, because cognitive impairment affects cognitive abilities, which are common among our three sub-populations, right? Everyone engages in reasoning and decision-making, memory, so yes, there will be some common challenges for daily living activities, but we do also expect some variability, which is why it's important to look across the three subgroups. Also, people's preferences may vary, potential solutions for these challenges and what kinds of solutions they're currently using. So as my colleague said, it's always very important to try and understand user groups and how they vary before developing solutions to meet challenges.

Beth Miller Harrison: When we talk about the challenges, and I know Dr. Boot and you all have alluded to the technologies that you hope you're going to be able to discover ways to help people meet the challenges of cognitive impairment, could you use some examples of a challenge that cognitive impairment might pose and a technology that might address that challenge?

Dr. Walter Boot: This is Wally. Maybe I could take a crack at this one. I mean, a simple example would be someone having difficulty remembering appointments or having difficulty kind of remembering birthdays or things like that. A simple example would be an electronic calendaring system, for example, electronic scheduling system. And I mean, this sounds like a simple solution, but if you've ever tried to train someone to use, for example, Google's Calendar, it's not always intuitive. It's not always easy to use. So I think part of what we're trying to do is take technological solutions that are out there currently that could help people kind of be better organized and have better prospective

memory and adapting that so that it kind of meets the abilities and needs of the populations that we're focusing on in the center.

Beth Miller Harrison: Thank you, Wally. Thank you for that, and I think that the technologies, I think you alluded to it earlier about social isolation and how technology can help mitigate some of that. As we close today, are there any resources you would steer our listeners to or any advice to our listeners who may think that they or a loved one has a cognitive impairment?

Dr. Sara Czaja: I think one thing for sure is if they do think they have a cognitive impairment, the first thing to do is to discuss it with their primary care doctor. Having that discussion is a good starting point, and of course as Wally stressed, it's very important to get the proper assessment so that one receives the correct diagnosis.

Beth Miller Harrison: Thank you for joining us for ADA live. Our three guests for this episode of ADA Live have been Dr. Walter Boot, professor, Department of Psychology, and a faculty affiliate of the Institute for Successful Longevity, Dr. Neil Charness, professor of psychology and director of the Institute for Successful Longevity, and Dr. Sara Czaja, professor of gerontology at Weill Cornell Medicine.

For questions and comments on this podcast, submit any time online at ADALive.org. A list of resources related to today's topic will be posted on ADALive.org with the archive of this podcast. You can access all ADA Live episodes on our website at ADALive.org. Every episode is archived with streamed audio, accessible transcripts and resources. Listen to the SoundCloud ADA Live channel at SoundCloud.com/ADALive. Download ADA Live on your mobile device podcast icon by searching for ADA Live.

Listening audience, celebrate, learn and share the ADA anniversary year round and the 30th ADA anniversary on July 26th, 2020. Check out the ADA anniversary toolkit from the Southeast ADA Center and the ADA National Network. Get logos, social media posts, monthly themes, and other resources to keep the celebration going. Visit www.adaanniversary.org.

If you have any questions about the Americans with Disabilities Act, you can submit your questions anytime online at ADALive.org or contact your regional ADA Center at 1-800-949-4232. Remember, all calls are free and confidential.

ADA Live is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda with Beth Harrison, Mary Mortar, Emily Ruber, Marsha Shwanky, and Barry Whaley. Our music is from Four Wheel City, The Movement for Improvement. See you next episode.

4 Wheel City: (rapping)

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