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Family Caregiving and Telehealth in the
Era of COVID-19
Tuesday, October 20, 2020
11:30 a.m. – 1:00 p.m. ET
Remote CART Captioning via Streamtext

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>> MURLEAN TUCKER: Welcome to family caregiving and telehealth in the era of COVID-19. This is sixth a multipart series of tele innovation in the era of COVID-19, lessons from the field.

I'm Murlean Tucker and I'm running this dialogue for health web forum with my colleague, Jeff Bornstein. Thank you to our partners for today's event, UC Davis Health, transatlantic research network, citrus, the Banatao Institute the international society for telemedicine and ehealth and the Gary and Mary west foundation.

And now I'd like to introduce Pauline de Lange Martinez, the moderator of this event. Pauline is a Ph.D. student in public health sciences at UC Davis where she is also a graduate research assistant for healthy aging in a digital world. Pauline, I'm going to hand the Mike over to you.

>> PAULINE: Thank you so much, Murlean, for the kind introduction. It's my pleasure to introduce you all to our webinar entitled family caregiving and telehealth in the era of COVID-19. Before we dive in today, I'd like to ask for your help as the audience to please complete a quick poll to help us learn about where you're coming from.

You should see the question pop up on your screen. Please take a moment and respond to the poll now.

The important demands on family care givers are bigger than over. They often sacrifice their own well-being in order to provide care for loved ones. The COVID-19 pandemic has exacerbated the challenges that caregivers commonly face including financial challenges, demands coordinating care, juggling child care and managing their own health.

Care recipients are among those most vulnerable to COVID-19 and care givers are facing shrinking support networks due to quarantine.

Intensified is a shortage of health care workers, as well as amplified rates of elder abuse and neglect.

Many care givers are struggling with being unable to visit family members who live in care facilities. The challenges seem insurmountable.

At the same time, the COVID-19 pandemic has driven unprecedented innovation and adoption of telehealth. Telehealth increases health care access and convenience. Resources and support for caregivers and loved ones can be made available from the safety of home and accessible by phone, tablet, or other mobile device.

Today, our panelists will highlight new telehealth resources made available in the face of the pandemic as well as set a vision for how care giver support will change in the future.

And now, it's my pleasure to introduce you to today's four speakers.

Grace Whiting is the president and CIO at the national alliance for care giving. Kathleen Kelly is the executive director of the Family Caregiver Alliance.

Alexandra Castillo-Weisgerber is the director of care and support for the Alzheimer's association, northern California and northern Nevada chapter.

And Dr. Janice bell is the associate dean for research, the Ph.D. program director, and a professor at the Betty Irene School of Nursing at the University of California.

Grace is a leader of care giving research and policy both nationally and internationally. We're so honored to have all of our speakers here and thank you for being here, Grace. And I'll pass the microphone over to you.

>> GRACE: Thank you so much for this opportunity to talk with all of you today about a topic that's near and dear to my heart and to be with such wonderful co-panelists who are also global and national leaders in the field.

So as we settle into the lunch hour, I want to provide some context for family caregiving and telehealth in the era of COVID-19.

If you're not familiar with us, the National Alliance for Caregiving is a Washington D.C. based non-profit organization, and we operate really as a coalition. Our mission is to build partnerships in research, advocacy and innovation to make life better for family caregivers. And we say family, we don't mean just people that you might be blood relation to or have in your family structure, but also your friends, neighbors, the families of choice where you might be taking care of someone even if there's no formal agreement or structure in place.

I want to start a little bit by looking at caregiving in the U.S. So one of the things we do at NAC is figure out what are the demographic trends driving the need for more support for care givers? Roughly every five years since 1999 we conducted a national research study with AARP called caregiving in the U.S. And this study has a representative data set, meaning that we can take the findings from the study and extrapolate it out to the population at large.

I want to touch on specifically a couple of points from this study that I think are relevant to today's discussion. But I'll note that one limitation of this data is that this study was fielded before COVID-19 really came on the scene.

So we fielded the survey instrument last year before so many of us were grappling with the pandemic. So keep that in mind as we talk about caregiving generally. And then we'll dive in and talk a little bit more about the COVID-19 specific impacts.

The first take away from the numbers is there are millions of Americans taking on caregiving responsibility. We know there are more people today than when we looked at this five years ago who are providing unpaid care to someone because of a health care need or functional limitation.

So we estimate it's roughly 53 million Americans who are in that situation that's an increase to 21 percent, roughly one out of five Americans. And we also saw that when we look at these folks who were doing caregiving work that they're more likely to be caring for multiple people than when we last looked at this in 2015.

They're more likely to be caring longer on average to four and a half years with nearly a third of folks saying they're caring for folks five years or more. There's more caring in general to the point about that increase in caregiving.

One of the things that we ask about in this study is where is it that people get information? Who do they trust? And this is such an important conversation when we think about the national discussion around social media, about finding credible health information, for example.

One of the things that came out loud and clear is when caregivers tend to trust doctors and professionals and they tend to trust friends and family.

You can see on the list, further down are organizations like government agencies, online or social media, you know, non-profit organizations.

So it's really that high-touch impact with being with a front line physician that seems to have a place where caregivers feel safe to ask questions and they feel that they'll be getting the right answers.

One thing that surprised us is that the use of technology was not as high as we thought it's going to be. And most of the time, caregivers were using technology to manage finances or track records or to help them find some type of service out in the community.

So on this chart, for example, it talks about, you know, getting an assistive device or creating spreadsheets. But additional questions provided more insight into, for example, people might be looking for a home care worker and they're using the internet or online technology tools to do that.

It was only about half of care givers were using technology. And in the same way here, on the description of online solutions, you can see that people are looking for online solutions. But they're looking for technology that can help elevate activities of care that take up a lot of time or difficult on their own.

What I mean by that is if you look here, 26 percent of caregiver caregivers manage the prescription refills on an app or website. This is a process that without using technology, you would have to call the pharmacy, maybe walk down in person, wait around for your prescription. And so technology is replacing and making easier something that the caregiver would already be doing.

And let's talk a bit about COVID-19. And this question of disruptive innovation. When we think about silicon valley, we think about tech start-ups, some of the wonderful projects my colleagues have worked on, such as family caregivers alliance. That kind of work really questions the paradigm of how we think about caregiving.

And one of the things we've been looking at is what has COVID-19 changed? Has it actually changed the way we think about caregiving? Or is this kind of a moment in time and then we're going to reset, quote-unquote, back to normal?

So we started within our networks and with our stakeholders to develop what we're calling a caregiving framework. And the purpose of the framework is to describe the impact of COVID-19 on family caregivers to select evidence and tools and information particularly for people who are in the same household as someone that they care for and they can't range contagion or those who might be physically distant such as they're caring for someone in a facility or they live a far distance away, maybe across the country, from the person they're caring for.

Then we're going to take this information and aggregate it by activity area and use it to push influencers to act, whether that's people working directly with caregivers such as senior care centers, geriatric care managers, people innovating and developing services for caregivers, researchers who are studying what to do, or even policy makers.

So what I'm going to show you is a sneak peek of a framework currently in development. If you get excited, be excited but don't run out and share with everybody in the neighborhood because it's a conversation we're working on this fall and will continue to evolve with input from various stakeholders.

So the first part of the framework is really identifying what's the impact of caregiving on -- the impact of COVID-19 on the caregiving journey. And we bracketed this into care issues to all caregivers which you see in the blue.

Care might be specific to mental and behavioral health concerns.

For example, if someone has dementia, one of the things that has come up during COVID is challenges specifically related to the person's disorientation with the change in routine because of the pandemic or concerns that the person with dementia may not remember or recall that you have come to visit them and their memory loss they accelerate because they're lacking that social contact.

So that's a type of thing that we're sort of digging into when we look at this. I think the other thing that emerged from people much smarter than I am when we were workshoping this was several researchers and other colleagues said, you know what, a lot of these issues are pretty consistent, even without COVID.

So the other piece of this is we started to try to map some of those activities. I think what's missing from this is that piece, not just about technology -- you see access to

technology here in the green at the bottom with social and behavioral health considerations. But also just sort of broader access to the infrastructure you need to make technology work, whether that's internet access, whether that's financial security in your household. But you can see we started to map out here in the blue, these are the types of activities you do whether you're in the same household or not. And then if you're in the same household you're also helping with the physical high touch activities.

And we're hopeful that through the internet, through other technological tools, that we'll be able to aggregate some information that could make it easier for caregivers during this time.

So thank you so much and looking forward to this conversation. And I appreciate the opportunity to get us started talking about it.

>> PAULINE: Thank you so much for your presentation, Grace. And next we have Kathleen Kelly. Kathy will highlight the changing demographics of caregivers today and talk about the care alliance leadership. We're looking forward to your presentation, Kathy. Please go ahead.

>> KATHLEEN: Thanks. Thank you. I'm pleased to have the opportunity to present today about the care experience that we've had in California, sort of the ground level experience. It's been quite a wild year.

For those of you that don't know about Family Caregiver Alliance we've been around for 40 years. We work in the area of direct services to families, research and policy. So the intersect of those three. And we've been integral to the development of the resource development system which I'll share a little bit about today.

I'm going to give you a snapshot of the caregiver profile in the services. And Murlean, I'm having a problem with the slides. Can you advance my slides, please?

>> MURLEAN TUCKER: Sure, just one moment.

>> KATHLEEN: Thank you. Snapshot of the services, what has been the response we've seen in COVID? And I wanted to take some time talking about a new initiative in telehealth and the conversion of offering digital service delivery to family caregivers across the caregiver centers in the state. Can you advance the slide? Thank you.

So changing caregiver profile, you know, some of this is in Grace's presentation, too, but bringing it down to California, we have 5.5 million caregivers in the state.

Most caregivers are under the age of 65. I think we need to keep that in mind that perspective. Especially when we enter a relationship, talking about use of technologies. We have a very diverse population in the state of California. Most of our caregivers are in the work force. And most of them due to age and work kinds of responsibilities, have increased use of technology in daily transactions. So this has become a more normalized event. Next slide, please.

Now, talking about what we see in terms of our client characteristics. This is not a stock photo. This is a picture of my neighbor who for seven years struggled with dementia and a host of other kinds of chronic care conditions. And she recently passed away last month from the combination of all those factors.

And that's actually my dog, Ollie, who became her support animal during her journey. And they struck up quite a friendship, as you can see.

So the characteristics we see in our population, people that we are working with closely, and especially those we do full assessment and care plan with. The caregivers are in their 50's. The help seeking caregivers that are reaching out for help are largely female and always have been. If you look at the two kinship relationships that are the most -- represent the majority of individuals that we work with, they're adult children and spouses sort of evenly divided. We have a very diverse group of ethnically diverse group of caregivers and persons with disabilities in our population. Again, most of them are employed.

We work with largely middle income, but we don't have income restrictions. So we're looking with very low income, high income, but mostly in the middle who are not eligible for services. We deal with a complex care component of people coming in seeking help at the time when they are doing a great majority of the activities of daily living and instrumental activities to daily living along with multiple medical care tasks.

They're in high distress in terms of their emotional wellness, and 70 percent of our population has dementia. Next slide, please.

In terms of COVID-19, it has -- we've sort of mapped this process out internally in our organization about what was happening at the beginning as opposed to what we call sort of the more maintenance kinds of activity. But overall, it's just increased the complexity of providing care in the home for all of the reasons that Grace alluded to.

But including the issues around, there wasn't PPE available in the very beginning, the bricks and mortar services like day care programs, even home care, they don't exist in California. They're closed still in the state. And home care is a little bit more frequent of a value. But the need for information about larger scope of needs for families is also one of the components that we really don't talk about too much. But it really makes a difference if you're working with families, if there's information coalitions available to be able to relay that information to what's available in the community.

It's accelerated the need for remote service delivery. We see this in telehealth consults, moving from 170,000 a week to 70 billion almost overnight. And we have multiple folks that are younger -- married with children in the work force and that sandwich generation has all of the issues that they're facing while managing the care of an individual who has, you know -- does not have the outside kinds of activities that they normally would have participated in.

And we're also caring, you know -- these individuals are caring for an older adult with cognitive and physical impairments. Next slide, please.

So, excuse me, by way of little bit of background, we're on the journey to provide digital service delivery. It started for us at FCA with a development of CareNav in 2015 when we started to bring together, you know, experts from around the country to talk about the state of the art in assessment. And then we moved on from there with partnering with our technical partner, Quality Process, to build back out a client record system. But a client record system with a difference. So it would be interactive. It would be able to be largely self-administered in certain components.

And we went down that road and started to build out in 2017, we had our first pragmatic trial of expansion with the LA caregiver resource center located at USC.

And in 2018, we proposed statewide expansion. And combined with other kinds of advocacy efforts going on, focusing on family caregivers, we received a three-year \$30 million augmentation that started in fiscal year 2019 -- excuse me, 2019 to 20 that expanded the components, the technical components, and technology components along with a standard evaluation being done by university of California Davis, school of nursing and the state wide marketing plan.

So we were on our way looking at a digital service delivery. And it's a good thing, too. It really came in handy.

So we were tasked with the expansion and implementation activities and there were three components. One was to pay attention to organizational change and internal operations because many did not have the capabilities to, you know, continue -- to really take this on. Individual practice and skill building. And then of course, to look at the technologies that not only CareNav but other digital communication technologies in order to have a well-rounded program. Next slide, please.

So we started off with six months of planning and then six months of really intense implementation activities and we kicked it off with three months prior to COVID. And I pulled out this slide because it was the touchstone and really actually the mantra for the entire implementation activities and even as we move into year 2 with converting in many of our functions to a digital platform, and that is be brave enough to suck at something new.

And this is because we knew that this is going to be new tear territory for just about everybody and we're all in a learning process so we'll make lots of mistakes. But we're also going to learn quite a bit about how to do this digital service delivery process. Next slide.

So in terms of the organizational change, there's many, many infrastructure issues we don't really talk about. But there's infrastructures issues, IT issues, security, and the certification. If you want to deliver HIPAA compliant services, you really need to pay attention to those. So we had a lot of work around individual organizations, even changing their website because they all have an entry portal -- if people can get to CareNav through the individual CRC websites and they can start the process of intake online.

We also knew we had to build individual practice in terms of building skill sets for digital delivery as well as clinical skills, assessment and new assessment process and the kinds of things we're asking at this point as opposed to earlier times.

And then we had to obviously have the train on the use of technology and those were the technical components and the use cases for all of them. Next slide, please.

Now, I'm going to talk a little bit about CareNav. Sorry I can't go through a more robust presentation on it, but essentially CareNav is a HIPAA compliant interactive client record system. It houses client data and has interactive functions for use by the caregiver. It's similar to a social care electronic health care record. If you want to look at it that way.

So we knew that the CareNav formed the basis because it collected the information that we needed but it also provided information to the family member as well. And it was their place to go for services.

So within CareNav, we have a uniform assessment, and we have reassessment capabilities. We also do a rolling client satisfaction questionnaire as well. But that's one part.

We also do tracking and report for contracts but it enables us also to figure out what percentage is used by what client. All of that tracking reporting is with the individual and aggregate results for within CareNav.

It has a client dashboard which I'll show you in just a minute with tailored content, service authorization, information, and care plan. And so people can go there for a variety of functions, which I'll show you in a minute.

And then secure communications within the envelope of having the CareNav dashboard available. Next slide.

So this is the dashboard. I'll just kind of go through it briefly. You are coming into a password protected level of client record. There is going from left to right an inbox that contains messages, much like you would message your physicians. These are all secured messages. We all know that email is not secure. So you can securely message your family consultant or your social worker for any other kind of information. It can contain caregiver action plan that is done after assessment with the family consultant and putting out -- directing the clients of action steps that the caregiver needs to take in consultation. This is a plan that's done together and focuses on the kinds of things that a caregiver wants to work on. It also has other kinds of information that might be applicable to the step.

Looking at the right top, it gives the contact information for the caregiver support team within the organization. And then dropping down, there's a whole database of consumer content coded to the individual questions that the caregiver answers along the intake and assessment process. So it's tailored to their responses. So they're there, available for the caregiver to read. We can see whether they've read that. The length of time on an individual document are all information that we're gathering from this.

There's also other kinds of documents that are germane to services that we provide so they can track if they have respite vouchers and those kinds of things.

Functions that we're working on this year is to have a summary of key measures for the caregiver on the assessment information so they can take that away with them and use it as if you had a record of all your test at a health care facility.

Integration, better integration of classes and training that they can take and scheduling for appointments and some of the better integration of the content database that we have.

So with that, I'm going to flip to the last slide, which is content information, if you want to reach us. Thank you.

>> PAULINE: Thank you so much, Kathy. Those were really great experiences that you shared with all of us. Next, we have Alexandra Castillo-Weisgerber. Alexandra will highlight some of the challenges caregivers face during the pandemic. And she'll share some of the resources that the Alzheimer's association offers to address those challenges. Alexandra, please go ahead.

>> ALEXANDRA: Thank you so much, Pauline. Thank you for having me today. I'm going to talk a little bit this morning about how the Alzheimer's association has moved to the virtual format during the pandemic.

Just going to begin by pointing out that most likely dementia does not increase the risk for COVID-19. Just like it doesn't increase the risk for the flu. But we know that dementia related behaviors, increased age and common health conditions that often accompany dementia may increase the risk. As we heard earlier from Grace, people with Alzheimer's disease may forget to wash their hands or take other recommended precautions to prevent illness. I facilitate a group in health partners for early stages of the disease. My husband and I love to go on walks but every time my husband sees the neighbor he wants to go up and shake their hand. So it can increase that risk of getting COVID.

So as I mentioned, we have transitioned our programs to -- from in-person to virtual platforms either by webinar or by phone. These programs are live and free. And on this slide, you can see some of the educational opportunities that we offer to our caregivers and the general public, so whether it's the ten warning signs, communication strategies, we have a new presentation out called COVID-19 and caregiving. And we know that with the absence of the adult day centers and the decrease of in-home care providers that our caregivers are managing a lot more of the daily care duties. So it's important that they have the information and the education and resources needed to provide that care.

So in addition to education, we have our caregiver support groups which are meeting live on Zoom or over the phone. We have our early stage programs. So these are for individuals who are living with an early stage diagnosis of Alzheimer's or another cognitive impairment and the education and support groups are really geared for this specific audience. We have a peer to peer program, which is more of an individualized program, so somebody living with an early staged diagnosis can connect individually with another individual living with a diagnosis of Alzheimer's. And then our social engagement programs we used to do in-person museum tours and now they're being conducted virtually and still engaging constituents. They'll usually have other families members who can join as well. That's a great social interaction.

And we have the multi education and support programs, offering many programs in Spanish, Chinese, Vietnamese and more.

Some of the innovations that I wanted to discuss during COVID-19. So while we know that, you know, that having programs virtually is different than the in-person, we've really seen an opportunity to reach more people. Those who are in rural communities, those who aren't driving anymore. Those who are living in the early stages and couldn't get to a support group or to an education class, we're able to reach more people. So an example of that is our international Spanish symposium, this is an annual program we post in-person in the greater bay area and reached around 300 constituents. We transitioned the program to a virtual program because of COVID and invited people around the globe resulting in more than 900 attendees from other countries, including, Puerto Rico, Columbia, just to name a few. So able to reach more people.

Another program that we've been able to expand upon is our Alzheimer's association international conference. It's the world's largest gather of researchers around the world focusing on Alzheimer's and other dementias. We held it virtually because of COVID. And in prior years, the average attendance was about 5,000. This year, hosting it virtually, we had

over 33,000 participants from around the globe. And in fact, ironically, last year in 2019 at AIC, there were several studies surrounding telehealth and it was shown that interactive technologies offer opportunities in the short term to really reduce the burden of hospitalizations and in-person care while simultaneously supporting services and education materials.

The next project that I wanted to discuss is a project echo, and echo stands for extension for community health outcomes using videoconferencing technology to improve access to special care in local communities. So multidisciplinary teams and care practices come together in regularly collaborative interactive learning sessions to share information and learn from each other via case based discussions and brief didactic presentations. During the six month biweekly program, the caregivers gain specialty to consultation to deliver care to patients in their own communities.

And finally, briefly wanted to mention the US pointer study, which is the Alzheimer's association US study to protect brain health through lifestyle information to reduce risk, the US pointer as abbreviated. It's a trial to evaluate whether lifestyle interventions that target risk factors can protect cognitive older adults at risk of cognitive decline. Conducted with a large group of Americans in many states.

Pointer entered a pause phase in the early days of COVID-19. However in mid-July the trial was restarted and they're actively recruiting participants again. For any information on these programs that I just noted, please feel free to visit the website at [alz.org](https://www.alz.org) on the slide.

We have a 24 hour help line that's available. This is something that we've always offered at the Alzheimer's association. It's a free service. Available around the clock. No matter if it's Christmas eve, 2:00 in the morning. If you have a question, if your loved one is having -- if you're not sure how to handle it, looking for a resource, you'll reach a clinician who will help provide that consultation and give information and support. Again, we have bilingual staff and translation services available.

We have a very robust website. This is an example of one of our topic sheets. So whether you're caring for a loved one at home or if they're in a community setting, we have some really good tips for caregivers and those living with a diagnosis for professionals alike. So we encourage you to visit our website.

If you're looking for a specific program or care at home or medical services, we have our community resource finder that just has a plethora of information and can get you connected to the resources around.

And then our Alzheimer's navigator is a free online tool that helps guide caregivers to answers by creating a personalized action plan and linking you to infer maze, support, and local resources. And the great thing about this tool is that any family can join. So everybody can be on the same page and get a good idea of how we provide the best care for our loved ones.

And with that, I'm going to move over to a video, a testimonial from the one of our caregivers who's been attending our support groups amongst the pandemic. Go ahead, **Murlean.**

[Video]:

>> About the group, I was a teacher for 30 something years. I knew about classrooms and I taught -- teaching at the college. And one of the things that made a good classroom was a safe environment, a sense of place that develops into a sense of self, and that's what I found with the Alzheimer's group is that they gave you a sense of space and sense of self. And what happens is you have your biological family. And then you have your family of choice. And these people here, I don't know about the others, but they're my family of choice. And because you know you can talk to each other and share things and not be judged. And that's the safeness of it.

[End of video].

>> With that, Pauline, I'll turn it back over to you. Thank you so much.

>> PAULINE: Thank you, you gave such a great overview of resources. Next is Janice bell. She will discuss barriers to telehealth including the digital divide and multicultural care giving. Thank you for being with us today, Janice and I'll pass it over to you.

>> JANICE: Thank you so much, Pauline. My colleagues have done a great job of discussing key issues related to caregiving and telehealth in the era of the pandemic. To wrap up the panel and quick off our Q&A session I'm going to summarize trends in caregiving, some challenges that the pandemic has created.

So as Kathy mentioned in her presentation, we're seeing shifts in the age of caregivers, and this means more older adults in spousal caregiver roles, adult children caring for older parents. Young adults caring for their aging parents and their own children. The pandemic has only amplified the challenges that these caregivers face.

As the US is becoming more diverse, caregivers are becoming more diverse, and this brings a diversity of cultural and spiritual differences that can impact the caregiving experiences. This includes dementia, cancer and even frailty and the supports and resources that caregivers need vary with the condition of their care recipient.

Relatedly, care in the home has become increasingly complex with nearly half of caregivers performing medical or nursing tasks in the home that were previously done in inpatient settings.

Another trend that's relevant to telehealth is our increasing reliance on technology. And Kathy has mentioned, too, that we're sending billions of texts, millions of tweets, billions of status updates every single day. This means that people are generally familiar with the technology and they're willing and able to engage in telehealth. Now, looking at the challenges associated with the pandemic, which again, some of my co-presenters have described, their new health concerns for caregivers, and this means concerns about keeping the care recipient safe. What do you do if the recipient gets COVID? What do you do if you get COVID and who steps in to do the care? They're seeking medical care, bringing in paid help or making institutional placements because of potential for exposure. There are cancelled appointments, earlier discharge come means that they're being discharged quicker and sicker. Caregivers are facing limitations in their social support and increasing social isolation. So fewer of their members of their social network are available to help for a variety of reasons associated with the pandemic.

And then as Kathy mentioned, there are also restrictions or closure of some of the resources that caregivers relied on and this includes things like adult day care, includes gyms and restaurants that give them a break or help cope in other ways.

There's financial strain because of loss of employment. And through all this, caregivers are adapting to new technology challenges and some are hampered by the digital world. And this referred to not having technology, having problems with digital literacy or having unreliable or inadequate internet coverage. We can all relate to this issue in our telework.

So looking at this digital divide, these problems are compounded for many caregivers and many of these are older adults and you can see older adults lag in social network site use and technology adoption generally.

This has implications for both social support during the pandemic as well as for the potential to engage in televisits with the care recipients.

Importantly, broad band use falls off for older adults typically around age 75. And many family care givers have low or fixed income, which is another factor that affects technology adoption and digital literacy. So even as the pandemic has magnified the potential of telemedicine to expand access to care, it has highlighted some dissipaters that exist in the system. Broad band access is one issue, but so is digital literacy and sometimes even insurance coverage or remote monitoring devices.

So you can see here a graph on the left that shows UC Davis health system televisits which increased by over 4,000 percent during just the month of March this year. But this option was disproportionately adopted pie younger patients and in preliminary data we saw older adults who were missing follow-up appointments. So we clearly has have ought of work to do. We have new opportunities to offer support in virtual visits and meetings and for many caregivers this can mean all the difference in them being able to participate.

And then finally, I think we have opportunities to help caregivers coordinate care through access to digital platforms.

At the same time, as we move forward with these opportunities, we need to make sure that we advocate to improve access to technology for all, and at the same time, improve support for televisits through coaching and other such interventions, marly for older adults and those with low income. We also need to ensure that the interventions that we develop are tailored to the heterogeneity of caregiver experiences, with age, culture, the kinds of tasks that caregivers are being asked to undertake, the care recipient's condition, and other unique circumstances to the caregiving experience.

I think we can further support family caregivers by making our digital supports available during expanded and flexible hours that can meet the multiple competing demands of the caregiving role. With that, I'll turn it back over to Pauline.

>> PAULINE: Thanks so much, Janice. That was a great way to wrap up our presentation. And really appreciated all of your thoughts. So now, I'd like to transition to questions for our panelists. Feel free as the audience to write your questions in the Q&A panel and we'll try to get to as many questions as we can today.

The first question I have today is for you, Grace. I loved your visual of caregiver needs and responsibilities. Where do we need innovation in telehealth?

>> GRACE: Thanks so much for that question. I think there's a couple of places in telehealth where innovation would be very useful. One is on the policy side. One of the things we're seeing during COVID is relaxing of the regulations and that -- in telehealth that I think is holding us back. For example, saying that you have to be licensed in the state of the person that you're working with over telehealth. And a lot of that, we've sort of begun to play with out of necessity, different rules because of the pandemic. So I think part of this is really just thinking about what if those rules were unnecessary and we remove barriers and expand telehealth.

The other thing I think is really understanding what the activities of care are. And I keep coming back to the great work that Kathy has done with atlas of care in mapping what it is that care activities are in real time and understanding that the complexities of caregiving is not one person and another. You're usually coordinating between multiple people. Your technology has to really make life easier for caregivers. It has to replace something that they're already doing and the user interface and the use phase has to be simple as what they're doing without the technology.

So asking people to learn a whole brand-new system, essentially if that system's not tied in with the health care provider, you know, hasn't shown to have a lot of success. I'm thinking of the veteran's iPad program here. How is this tech improving or making life easier in the way that Uber has made transportation easier and Facetime and Skype and Zoom has made communication easier? I think understanding the roles and activities is really important.

>> PAULINE: Great point. I definitely agree with you. And I think there's been so much innovation out there in terms of different resources and support, but they're not all talking to each other. So caregivers can be overwhelmed with the number of apps and resources out there. It's hard to find a one size fits all. And I think some of the resources that we heard about from Kathy and Alexandra can help to start to meet that need.

So Kathy, my next question is for you. What trends have you seen for rural caregivers, especially those who might not have access to telehealth strategies due to connectivity issues? Any strategies that you know currently exists for rural caregivers?

>> KATHLEEN: Yeah, rural caregivers, this is one of the issues that we need to solve for people who really live outside the cities or suburban areas where connectivity is more accessible. And we've talked a bit about this, but I think this pandemic really brought into focus that especially on health care and even social services that we need to pay attention and do the advocacy work that Grace alluded to to make connectivity a health care utility because it will be in the future.

In the meantime, there's a variety of things we've tried over the years. We've repurposed adult learning centers that are in the smaller towns and smaller opportunities to deliver, you know, programs at a congregate site, like the adult health or even some of the rural health clinics. We've taken excess capacity and utilized it for the kinds of programs we're all talking about, the technical consultations, the kinds of information, educational or skill building programs that we offer to family caregivers.

Past that -- and I think this is one of the things that the VA has found with many of their veterans as well -- is that we use the telephone and convert some of the materials and classes we do in sort of a hybrid fashion and use telephones to do that work with rural caregivers overall.

>> PAULINE: Thanks so much. Here's another question. I'll pass this one to Janice. Can you touch on any tools that a primary caregiver can use to engage and provide extra resources to caregivers?

>> JANICE: Well, we were thinking about trying to implement health coaching for virtual visits for older adults. So certainly, I think that sometimes, we expect that people can just show up and use the technology but may not be able to get the most out of those visits for a variety of reasons.

Also for telemonitoring, I think that -- I'm thinking about my own dad who's got some monitoring devices that he's supposed to be using and he really doesn't understand what he's doing with those. So I think sometimes, providers are sending people off with devices and assuming that they can make it work. So if we can maybe take some of the strategies from health coaching, we might be able to support some of that.

>> PAULINE: Good points. Next question is for Alexandra. Have you seen the adoption or administration of cognitive tools and assessments conducted by primary care physicians or geriatricians via telehealth? What are the benefits and challenges of this? And how is data shared and tracked?

>> ALEXANDRA: Great. Thank you for the question. So as far as the adoption of specific tools, the Alzheimer's association does have an amazing app and website where we encourage our primary care physicians and those who are diagnosing individuals that really kind of walks through the diagnostic and management of it. And then as far as the second part of the question, which was how the data was shared and tracked in the COVID world, so while we don't see it on our end, we're definitely hearing that there's a trend that folks are utilizing to share it.

>> PAULINE: Here's a quick question for Kathy. Is CareNav available in other languages?

>> KATHLEEN: Currently, it isn't available in other languages. We are looking to translate it first into Spanish. But we had to start out with English first [chuckling]. But we are aware of that. So we're working on it.

>> PAULINE: Great. Yeah, there's definitely a need for many, many different languages, especially here on the west coast.

>> KATHLEEN: Uh-huh.

>> PAULINE: Time is flying and there's lots and lots of great questions coming in. We could have used another hour for questions here. But before we reach the end of our time, I wanted to take a few moments and go around and ask each of you to share a one-minute overall takeaway from today's discussion. What new lessons have you learned? So we'll start with you, Grace.

>> GRACE: Well, one thing I feel like I've learned is just the importance of these types of national conversations. You know, we're having this conversation because of COVID and because we're really looking at technology. But it felt like for a long time, we were sort of waiting to jump start, you know, technology, whether it was meaningful use and putting people on medical records or new pilot programs. And I think now, people are convinced tech is necessary. So one of the things I'm really taking away from this is taking the lessons that are

out there and helping to amplify it and get the word out and say let's fought make this just a moment of time we forget about it, but the things we know work, let's build up the infrastructure to make sure they continue to work after we weather the pandemic.

>> PAULINE: Great point, yeah. And COVID-19's definitely accelerated this. And we hope that it will continue. Kathy, how about you?

>> KATHLEEN: Well, we've worked in the area of technology particularly in information dissemination and service delivery for many years. But what I can say about, you know, flipping over to delivering services as an option and choice for families, we're really at the bottom of the curve right now. COVID certainly accelerated this trend in terms of utilizing technologies for all sorts of different processes that people who maybe ordered groceries online are now orders groceries online. Never talked to their doctor on a telehealth visit are now talking to their doctor in a telehealth visit and so on. But the delivery structure and the way we deliver that information or support, we're at the learning curve phase of this on a much broader scale and a much more wholesale scale so to speak.

I think what we'll find in the next five years is a lot of experimentation and understanding about what is the appropriate way or the best way, the most effective way to deliver these services. And we're really at the bottom of the learning curve. There hasn't been a lot of research done, certainly not a lot of research on a system-wide basis to understand what it means to deploy this on a broad scale population sample. And I think we're moving in that direction right now.

>> PAULINE: Great. Alexandra, any quick takeaways?

>> ALEXANDRA: Similar to what Grace and Kathleen mentioned. I think we really have an opportunity here to reach more people and to really provide those services to individuals and families who haven't been able to receive those. The couple I was talking about are actually an integral area and haven't been able to attend an early stage support group in their area because there wasn't one. Now there's this opportunity. I hope when you go back to in-person, you will still have them. So the hybrid model of doing the online type of program and over the phone, if the individual doesn't have the internet connection, really being able to meet our clients where they're at and providing the services. So thanks again for having us.

>> PAULINE: And Janice?

>> JANICE: I think that now, more than ever, it's time for us to get really serious about making caregivers part of the health care team. So many ordinary challenges that caregivers face day-to-day has been amplified by the pandemic and I see so much potential in technology for us to address many of the challenges that they face. I think we need to put our heads together to make thoughtfully tailored solutions that really can adapt to the variety of experiences that caregivers -- their challenges.

>> PAULINE: That's such a wonderful discussion today. Thank you so much to each of our speakers for sharing their experience and expertise on this webinar.

I want to thank our sponsors, the Gary and Mary west foundation, the transatlantic telehealth research network, international society for telemedicine and e health, citrus, UC Davis health. This wouldn't have been possible without your gracious contribution. Our next webinar will be taking place on Tuesday, November 10th on the theme of telerehabilitation.

We have experts lined up that you wouldn't want to miss. This has been recorded and archived on the D4H website. Thank you for joining us today. It's been a pleasure to moderate this webinar. I wish you all a good day, afternoon, or evening. Thank you so much.

[End of event].