OT's Mental Health Response to the COVID Pandemic: The Medically Complex Client with HIV

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- [Fawn] It is my pleasure to introduce Dr. Christine Helfrich. She is going to go over our virtual conference for the week. Take it away.

- [Christine] Thank you, Fawn. Welcome everybody. I'm very excited to have arranged this conference of speakers that are all going to be talking about different aspects of occupational therapy's mental health response to the COVID pandemic. Each day, we'll be having a little bit different topic with a little different population. Each of the speakers comes from a different area of practice and from a different area of the country. They will each be presenting their own unique perspectives, but I think everybody will be able to take something from each of the presentations and apply it to your own practice or your own setting. There's a lot of overlap in terms of themes, and I've learned a lot in helping people prepare.

I think that you will see their individual expertise with specific populations, but also some nice common themes that go across the different topics. So I think that these really will appeal to anybody. So hopefully, you'll be able to join most or all of the presentations this week. Today, we'll be having "OT's Mental Health Response to the COVID Pandemic: The Medically Complex Client." So today, speakers will be Danny Shin, Simone Gill, and myself. I'm an associate professor at the American International College in Springfield, Massachusetts, where I teach primarily in the doctoral program and teach research. My background is in mental health though. Danny Shin and Simone Gill are both from Boston University in Boston, Massachusetts. Danny is currently an occupational therapist.

.. He's not a practicing occupational therapist, but he's a PhD candidate in the Rehabilitation Sciences program at Boston University. His expertise is in neurorehabilitation and physical dysfunction, and his work focuses on examining how physical, psychosocial, and environmental factors impact fall risk in people living with chronic conditions. Simone Gill is his mentor, and she's an associate professor in the

Occupational Therapy Department at BU. she directs the Motor Development Lab, which examines how people's bodies and environmental demands influence walking and motor functioning across the lifespan. Her current research in her lab focuses on fall risk and how adults modify their walking patterns to cope with changes in their bodies before and after bariatric surgery. I have been working with the two of them on a project that Danny will be explaining in more detail, affiliated with Boston Medical Center, looking at the experience of falls.

These are just the disclosure slides. So the overview today is we'll go over the learning outcomes, then introduce the medically complex client, talk a little bit about the overview of the research context, describe the fall prevention intervention that this research was designed to develop, the impact of COVID-19 on the research and program development of the intervention and the lessons learned, and then we'll have a summary and time for Q&A. So the learning outcomes for today are that, after this course, participants will be able to, one, identify client factors, performance skills, and performance patterns in people living with HIV with an elevated fall risk. Two, to identify at least three characteristics that differ in people living with HIV who fell and who did not fall.

Three, to list an evidence-based fall risk assessment. Four, to recognize ways to pivot research participant recruitment and retention during COVID-19. And five, to identify a novel fall risk intervention for people living with HIV during COVID-19. So Danny will begin with introducing the medically complex client.

- [Danny] Thanks, Christine. So we'll be using people living with HIV as our model for the medically complex client. So HIV, or the human immunodeficiency virus, is a virus that attacks the body's immune system. As of 2019, it was estimated 1.2 million people in the United States had HIV. HIV works by attacking and destroying the infection-fighting CD4s and the loss of these CD4 cells makes it difficult for the body to

fight off further infections and also certain types of cancers. Without treatment, HIV can gradually destroy the immune system and advance to AIDS. Since the start of the AIDS epidemic in 1981, there's been a Herculean effort to help control this virus. By 1994, AIDS was a leading cause of death for Americans age 25 to 44.

One of the major breakthroughs was in 1995 with highly active antiretroviral therapy. This medicine works by controlling and suppressing the viral load. And if done properly and adhered to properly, can also make it undetectable to test. This causes less harm to the immune system and reduces the chance of passing HIV to partners. Unfortunately, some of the side effects associated with this lifesaving medicine are things, such as nausea, dizziness, fatigue, and pain that may lead to falls. Due to the effectiveness of highly active antiretroviral therapy, people living with HIV are reaching older and older ages. It's estimated that half of people living with HIV are 50 or older. As ages of people living with HIV increase, the risk for age-related complications increase as well.

Shifting HIV treatment focus from acute care to management of chronic conditions. Furthermore, people living with HIV demonstrate accelerated aging, which may lead to a higher risk for falls. So talking a little bit about the falls. Falls are an unexpected event in which an individual experiences a loss of balance and comes to rest on the floor. Falls are one of the most common causes of non-fatal injuries, and they lead to serious medical consequences, such as fractures and emergency room visitations to 2.8 million older adults. These consequences are not limited to only the medical burden associated with falls, but also a psychological toll. Older adults who have suffered a fall exhibit a fear of falling again. This results in less physical activity, decreased socialization, and this further exasperates any existing risk factors.

Due to this high incidence of falls in older adults, it's been extensively studied and also fall prevention interventions tend to focus on this population. But also people living

with HIV experience a high risk for falls. Up to 1/3 of middle-aged people living with HIV infections experience a fall each year. This rate of falls, up to 1/3, is similar to what the older population experiences. And following a fall, fractures are 40 to 60% more common people in people living with HIV than the normal population. Some established risk factors for falls are polypharmacy, which is the simultaneous use of five or more medications. This concept of polypharmacy affects people living with HIV, because it typically takes three or more medications to reach that viral suppression to keep the HIV in check.

This leaves them vulnerable for additional polypharmacy when any additional medications are indicated. Multi-morbidity, which is the presence of two or more chronic conditions. In non-HIV infected people, multi-morbidity is associated with decreased functional status, quality of life, and disability. Also frailty, which is an inability for the body to reach homeostasis following an external stressor. This concept of frailty will be talked about in further detail, and one of the ways to conceptualize and capture this frailty is through the Fried Frailty Phenotype. And lastly, substance use, which is bound to be elevated in people living with HIV. And this is especially concerning because alcohol use has been shown to be associated with a decreased adherence to the highly active retroviral therapy, which may lead to increased virus and all the negative consequences associated with that.

So going back to talking about frailty. Frailty is the vulnerability to global health outcomes. It leads to reduced capacity to stressors and a loss of overall physiological function. So the ways that frailty is captured is using the Fried Frailty Phenotype, and this is captured using these five criteria. Using this phenotype, if you have three or more, you are labeled as frail. And if you have two or more, you are categorized as pre-frail. And slowness is conceptualized as the slowest 20% of the target population as defined at baseline, and it's based on walking 15 feet, and it's adjusted for gender and standing height. Weakness is similarly adjusted for by gender and by BMI, and it's

the lowest 20%. An unintentional weight loss of less than 10 pounds in the previous year would be categorized as unintentional weight loss.

And poor endurance and energy and low physical activity level is captured by using self-report. So with this elevated fall risk, and this identified risk factors for falls in people living with HIV, there is no known fall risk intervention in this population. To adjust this, I'll next talk about a recent study and a pilot intervention plan to use them as an example of how COVID-19 has affected the research in this population. This collaboration between the Boston Medical Center and the Boston University, Sargent College Department of Occupational Therapy, came about because of this need. Our lab, specifically the Motor Development Lab, was reached out by these collaborators who held expertise in studying people living with HIV with substance use to help assist with investigating fall risk and developing a fall prevention intervention.

This is a conceptual model for their ongoing cohort study that's been going on for the past five years, and it's being conducted by our collaborators. They are interested in studying the relationship between alcohol use and falls, and to see if frailty and functional impairment mediates this relationship, and the similarity with polypharmacy on illicit drug use. Our lab was brought in to pilot test the feasibility of this falls prevention intervention, tailored to address the identified risk factors in this population. And Christine will be talking a little bit about one of the first components we used to develop this intervention, which was the qualitative piece.

- [Christine] Thank you, Danny. So I was invited to participate in this research because of my background in qualitative research and my background with many aspects of this population. I have worked a lot with people who are homeless, which is a factor for many of the people in this study, is either current homelessness or past homelessness, as well as substance abuse. So we took a two-pronged approach, as Danny mentioned, a qualitative and a quantitative approach to collecting data about the need

for a fall intervention and what would be most attractive and useful to the people who were participating in the intervention. I began by doing five individual qualitative interviews before the pandemic occurred. So those interviews were actually held in person.

I interviewed five different people who ranged from their late 20s to their 60s. The majority of the people in the study, currently, that Danny described, tend to be in their 40s to 60s. It's a cohort study. So people have been in there for a while. And I did wanna interview a few people though that were younger to try to get that perspective as well. Because in addition to recruiting from the current study, the investigators are also recruiting new people. And because the life expectancy is shorter than normal because of all their co-morbidities, we wanted to make sure that we would have people that would be staying in. So the five people that I interviewed represented a wide range of living situations and a wide range of abilities, in terms of their motor ability level.

I interviewed people who, one woman who was using a scooter who could get up and transfer herself in a very sort of dangerous way, as well as people who used walkers and canes and who also were able to walk independently. So we had the whole spectrum of people. They also had a variety of living situations. We had people who were living alone, people who were living with a roommate, people who were living in housing. That was rather precarious. We did have one man who was homeless. They also had various levels of drug and alcohol activity at that time. In the previous study, everyone had been required to be an active drug or alcohol user. But this time, many of them are in recovery, but there was nobody who was completely sober or clean entirely.

So the interviews lasted from 40 minutes to an hour and a half. There was one that was 40 minutes because that was as long I could get him to talk. The rest went the full hour

and a half with me really needing to stop them, because they enjoyed having this opportunity to talk and to describe what was going on with themselves. The interviews focused on asking them about their experience of their falls to begin with, how recently they had fallen, and then to describe their last several falls to me in detail. And this was one of the most illuminating pieces of information because, in the quantitative data that the research assistants collected in order to identify these individuals, they ask every six months how recently people have fallen and how many times they have fallen.

And the data that I got from the narrative interviews was very different than what they were reporting on the structured interview forms that the RAs were asking them. I think that had to do with, one, my role as a researcher, and two, my outside role as a researcher, as not part of the regular team, but also the way that I asked the questions. It wasn't a simple how many times have you fallen? It was tell me about that time? And then sometimes they would remember the other times and talk about that in more detail. So it kind of illuminated the value of collecting data from a qualitative perspective and how you get different types of information.

I asked them about the cause of their fall, how they perceived caused their fall. We expected to hear a lot more about being intoxicated and about drug and alcohol use. It was very interesting. They differentiated falls that were caused from intoxication versus falls that were caused by tripping, or low energy, or the other things I'll be talking about in a few minutes. But what was most striking was that the falls that were related to intoxication were really seen as just par for the course, something that they weren't really gonna do much about. It would be like, "Well, yeah, I was high and I passed out, and when I went to stand up, I just collapsed and I fell.

" And they didn't see that as the same kind of falls when they trip, or when they would fall because they were dizzy in trying to get out of bed from change in blood pressure or something like that. They just sort of took it for granted that when they were

intoxicated, they would be falling. And the injuries that they described related to those falls were similar. There was a woman that had one of the most unusual injuries. It was because she was intoxicated, and she sat on a box, and she fell through the box, 'cause it didn't hold her weight. And she was stabbed in the arm by a screwdriver that was in the box. It was a box of tools.

And she was stabbed through the arm and went to the emergency room and just brushed it off completely. And again, that's the kind of data that doesn't show up in the quantitative data that the research team is collecting about their falls, about people's experiences of falls or how many times they're falling. 'Cause they're just not even mentioning those kinds of things. In addition to the causes, I also asked a lot about their strategies to prevent falls or what they do when they fall. So how do they get help? Do they go to the hospital? Do they ask for help? Do their doctors know? Do they talk to their doctors? Out of the five people that I interviewed, there was only one that had regular conversations with their doctor about their falls.

Another person that I interviewed had fallen twice, very severe falls with head injuries, and he had a number of other serious medical conditions. And he didn't go to the hospital or even call a doctor for two days, because he lived in an apartment that was subsidized, and he had not had hot water for six months. So he had the people planning to come to fix his water, and he was not about to risk missing that appointment just to go to the hospital for a head injury. So he was of great concern, in terms of the severity and the implications of falls. So their insight and resources, in terms of being able to deal with what happens when they get injured, was very interesting as well.

In addition to the individual interviews, I also conducted four focus groups. And those focus groups were done with... The first two were done with a variety of people to try to get different perspectives about, again, a little bit about their experience with the falls,

but really more about what kind of an intervention they would be interested in participating in and what it would take for them to participate in that intervention. So we were interested in finding out from them, the interviews were conducted after the pandemic started... I'm sorry, the individual interviews were pre-pandemic; the focus groups were after the pandemic. So the focus groups were all conducted virtually via Zoom but without cameras, so they only called in.

And that was, in part, due to the research team's concern that people wouldn't have the technology available to be able to call in to Zoom and to be on camera. So that was a big question I had for them. One was what was their interest in participating in the intervention? What would it take for them to participate? They wanted incentives of some sort, pizza, gift cards, transportation, that sort of thing. They all agreed that they could attend on a regular basis. And I suspected that they would be interested based on the individual interviews and people looking forward to this contact with medical professionals. Because these individuals are very isolated so having contact with their treatment team is something that they look forward to.

The focus groups that occurred after the pandemic really highlighted this, in how isolated they were and how much they wanted contact. They talked about being willing to be able to be on Zoom, but I had to really change the language. They didn't understand when I said, "Can you participate virtually?" I had to explain, "Can you FaceTime on your phone? Do you have video on your phone?" They didn't have the normal expected language that we would typically say, like, "Can you call into a Zoom call?" To them, they said, "No," but here they were on a Zoom call. So it took that, going back to their language and understanding it in their terms of what they would understand and then asking them specific questions to help them figure out if they had a phone that would allow them to do that.

It turned out that they all could. There were some concerns about being on camera. Confidentiality was one of them. It was very interesting to me that they didn't all know that everyone in the study was HIV positive. And they talked about it in code until they realized that. They didn't want that disclosed to anybody. They were very concerned that in a focus group or in a group on falls, that their HIV history would be revealed. They weren't concerned about their drug use, in the least, even if it was illegal. It was their HIV history that they didn't want revealed. But they really did want the interaction. They were willing to come in and meet in person if transportation could be provided, despite the risks of the pandemic.

And these were conducted back in June and July of 2020, when things were really, a lot more was unknown, and things were really shut down. And the other interesting thing that came out in the qualitative groups was how they talked about the experience of falling and how they interpreted that. And I'm gonna talk now about some of the findings. So we did categorize the findings into these four categories. But I wanted to just finish up on my thought about one of the interesting things that came out, was that in one of the focus groups, I think it was the second one, I was talking to them about falling and saying, "When's the last time you fell? And how many times have you fallen?

" And they all thought I was talking about falling off the wagon, falling off their sobriety. And this went on for probably 10 or 15 minutes, and I kept trying to redirect it. And other people were chiming in, I thought first it was just one person that didn't get it, but then other people were chiming in and doing the same thing. And we realized that I had to really explicitly say physical fall to make sure that we were all on the same page. But they were so used to talking about their drug use that talking about falls was sort of like an extra topic to them. When I analyzed all of the individual interview and focus group findings, we were able to categorize them under four categories.

Motor function, which related to their balance, losing their balance when they bent over or tried to stand up, there was a number of that as I mentioned. But there was also balanced-related issues to sitting up and getting out of bed. There were a number of people that would fall over and lose their balance when they were trying to get dressed or trying to get out of their bed. Their use of assistive devices. And this came up with both their grip strength and their ability to use assistive devices, which was... Danny's gonna talk more about grip strength. But it was fascinating to me from the very beginning that that was such a big factor in looking at why people fall.

This is not my area of practice. And I realized when they talked about assisted devices, in fact, how important grip strength is. That they would reach for a grab bar in the shower and not be able to hold themselves and fall. Reminders to both exercise, they would forget, or just forget to eat, forget to get nutrition, forget to plan ahead. So the need for reminders related to the intervention came up. The last one was strategies for adapting equipment. And of course, as an OT, this was of particular interest. Adapting the environment was a particular interest. We talked about things like putting all of their things in lower cupboards or at a height where they didn't have to reach up too high in their kitchen.

But we also talked a lot about obstacles that were in the way in their homes, both the typical things that we would think about, like scatter rugs and stuff like that. But the other things that came up were the conditions that individuals were living in. So things like their room being full of cardboard boxes and how to navigate around those. Another one was about being able to go to other places. So the woman who used the scooter really does quite well in her home, but she has friends that she likes to go visit. And when she goes to visit them, she can't really, she doesn't have an adapted environment. So if she has to go to use the restroom, while she's in someone's house, there's a good chance she's gonna fall, because she doesn't have her grab bars.

So the whole idea of constantly being aware of strategies for adapting the environment came up. So at this point, I'm gonna stop talking about the qualitative findings. They'll come up more in terms of how the intervention was developed. And I'm gonna turn it back over to Danny to talk about some of the quantitative results.

- [Danny] Thanks, Christine. So for the quantitative analysis, I was brought on to help look at their aims from their initial grant and analyzing to see if there's a relationship between any of the risk factors that they were interested in, like alcohol use and falls, and substance use and falls, and also stuff that I was personally interested in, which was more looking at the functional or physical activity piece. And so I went about and looked at their existing data from their baseline data collection. First, I looked at it as a whole sample, and then I divided it up into people who fell and people that did not fall and see if there's any significant differences in many other assessments that they did to hopefully find an area that would be best to intervene for our intervention.

So what I did was, from their baseline, I ran a cross-sectional study. There were 248 participants total that I analyzed, and the mean age was 52 years old. And if you think back to when I was talking about my background, middle-age participants, or middle-aged people, living with HIV have a similar fall rate as older adults. So this sample size was actually perfect to analyze people living with HIV and falls. These people were recruited from a primary care clinic, which was hospital-based, and a community-based health center serving the homeless population in downtown Boston. And the inclusion criteria was a documentation of HIV, a past year of, excuse me, substance dependence, the ability to speak English, 18 and older, and willing to provide contact information, as you keep in mind that this was a cohort study.

So being able to provide contact information was very key for follow-up. As for the experimental procedure, when participants came into the study, they were first interviewed and many assessments were conducted. I'll just highlight a few of them.

So for demographics, they were asked about their education level, their marital status, their level of support, or social support that they may have. To gather information regarding falls, the AIDS Clinical Trials Group Fall History Questionnaire was used. And it asks questions, such as have you had a fall in the last six months? Following this fall, did you seek medical attention? Did these falls lead to a fracture? And to capture alcohol use, a validated a 14-day timeline follow back was used.

And for looking at fear of falling, the Modified Falls Efficacy Scale was used. And this scale provides examples of a variety of ADL tasks, and that's how confident you are that you can do the following without falling, such as walking into your shower or cooking some simple ADL task. And depression was captured using the Center of Epidemiologic Studies Depression Scale. And many of these things feed right into the frailty phenotype, so everything was kind of embedded to address that mediator that was part of the conceptual model. As for physical tests, the physical tests that were administered was the Short Physical Performance Battery. It's a group of tests that combines the results of gait speed, chair stand, and balanced tests.

And it's been used as a predictive tool for possible disability and to aid in monitoring mobility. And so, for static balance tests, there was a side-by-side, semi-tandem and tandem stand, and single-leg stance. And for dynamic balance, there was a chair stand and repeated chair stand test, and the four-meter walk test. And lastly, they measured grip strength using a handheld dynamometer. And I believe that's it for the physical tests. And as for the quantitative findings, this is just the overall sample. There was 14.5% experienced homelessness in the past six months, and this was defined as at least one night out on the streets or without shelter, and the age was 52. And over 3/4 of them were unemployed.

And 35.5% experienced heavy drinking in the past 14 days. And all this, this demographic information taken together, it kind of talks about what Christine said, how

their living environment was very unstable and they're precariously housed. And they had a lot of barriers to accessibility for healthcare and for any other support. And it highlighted that the basic needs need to be addressed in the fall intervention prevention as well. Okay, and then now this data is now split up between people who fell and did not fall. There were actually 34% of the cohort who fell in the past six months, with 65% experiencing a repeat fall within that six months. So that rate of 1/3 of people that fell was similar to older adults, and it's similar to what previous literature shows us about people living with HIV and what their fall rate is.

And then, when we divided them up by people who fell and people that did not fall, there was a significant difference in alcohol use in the past 30 days with people who fell, having more days of alcohol use. As for the Short Physical Performance Battery, people who did not fall scored much higher, and there was a significant difference between people who fell and did not fall. But interestingly, if you look at these results, both people who fell and did not fall, that have HIV, they both scored under a 10, which is indicative of a lower extremity disability, or mobility limitation. 14.5% experienced homelessness in the past months And this was actually significantly different between people who fell and people that did not fall.

And some other findings that are significant in people who fell were the level of sedative use, which is consistent with fall prevention literature, that sedatives and tranquilizers are highly associated with falls. Self-report with fatigue. Feelings of lightheadedness. I thought this was an interesting result, because sometimes this is a side effect of their medication. Concerns with losing balance. Self-reported depression and falls efficacy. So taking these results together and viewing them from an OT lens, it helps inform the intervention themselves. So the client factors, which are specific capacities and characteristics, or beliefs, that reside within the person and influence their performance in occupations, the demographics at the interview, and the

qualitative focus groups informed that many of these participants had stigma due to their HIV status.

And they also, looking at the quantitative piece, we can see that they have frailty and they have decreased mobility, which might limit their interactions with their environment and also increase the likelihood for falls. And their performance skills, which are goal-directed actions that are observable as small units of engagement in daily life occupations. In our intervention, we hope that if we use home exercise to develop strength and coordination and endurance to help mitigate fall risk, these aspects of exercise will be motivated by having goal setting, which I'll talk about a little bit later in the presentation. And lastly, the performance patterns, which are habits, routines, roles, and rituals, the social habits, and anxiety, and social support that was found in the quantitative and qualitative piece shows that we must take a pretty expansive role when we're adjusting fall risk.

And so we can't just look strictly at physical limitations, but look at the person with a holistic view. So all these areas are used and considered as areas that we can intervene in our intervention. Some other considerations that we used to design our study and our intervention was a paper published in the New England Journal of Medicine by Bashin and colleagues this year. Their limitations informed the intervention, and I'll talk about them throughout as I talk about the intervention itself. But one of the primary ones was that, in their intervention, the recommendations that was made were unable to be followed by some participants, because they had barriers due to travel, co-payments and insurance coverage. So this is especially pertinent in our population that we're working with, because we found that they are under-resourced and that they are dealing with homelessness and food insecurity.

So this was definitely a limitation that we hope to address in our intervention. And lastly, the MOS-HIV. This is a cognitive function questionnaire specifically for the HIV

population. And through my quantitative analysis, we found that the sample as a whole found a difficulty with reasoning and problem solving and trouble with attention. And like Christine mentioned, sometimes they need reminders, because they might even skip a meal or they might just have food insecurity. Okay, so jumping into our intervention. This is a screening tool that we use to test eligibility. What is presented in this slide is a standardized fall risk algorithm from the CDC. So you can use either the validated 12 question tool, which is called Stay Independent, which I will talk in further detail on the next slide, or these three clinical questions that were part of the algorithm.

So the three questions were: feels unsteady when standing or walking, worries about falling, or has fallen in the past year? And if a participant that you're screening says "Yes" to any of these three questions, they are categorized as high-risk for falls. This is the 12 question tool, the Stay Independent. And to score this, if a participant says "Yes" to any of these questions, they're gonna be receiving a score of either a one or two. And if they answered, "No," then there'll be a score of zero. And after the conclusion of all these questions, you would add up the score. And if the score is over a four, the person will be labeled as fall risk. So how our intervention was designed is we'd first ask those three clinical questions.

So feels unsteady when standing or walking, worries about falls and fallen in the past year. And if they say "Yes," they would be eligible for our study. And if not, we would use this 12 question tool again. Because although those three clinical questions are incorporated in this 12 question tool, some questions are not. And there might be some people that have not fallen yet, and they might not necessarily be worried about falling. But they might say "Yes" to some of the other questions. So I think it's helpful to identify people that might be at risk for falls that haven't fallen yet. And that might be one of the best ways that we can intervene. And this is one of the first areas that was affected by COVID-19 as we were designing this study.

And recruitment and initial screening prior to the pandemic, as mentioned in my quantitative analysis, participants were recruited from primary care clinics and community health centers, serving the homeless. And with many of those places running at lower capacity, or a temporary shutdown, or people living with HIV maybe not wanting to engage in research during this pandemic, we had to kind of narrow our focus down instead of just having a broad recruitment setting. But we narrowed it down. So we used our existing participants from past studies and from our cohort, and we ran analysis to see if they answered yes to any of those three clinical questions by proxy from any of the assessments. And we identified a pretty solid sample from using that method.

So due to the pandemic, we had to think of some alternative ways to recruit. Some of the measures for the intervention include a pre and a post-test, and these are both completed virtually and in-person. The first one is the Canadian Occupational Performance Measure. And this is a client-centered outcome measure which will help provide the basis for setting intervention goals. One of the limitations that was identified by one of the papers when we were developing this intervention was that sometimes if exercises are not tailored to the participant, or if exercises and home exercises were recommended from a community health center or some established programs, then what happens is that participants might be less likely to adhere.

But if we use this Canadian Occupational Therapy Measure, this will allow us to know what motivates our client, and this will allow customization of the intervention itself. And we were gonna gather similar information similar to what the cohort study looked over. So history of falls, falls efficacy. But in addition to that, we know that vision is a major component to fall risk. And so we will be gathering vision, and we'll also be gathering additional data regarding resources, like the food insecurity piece that was highlighted in the qualitative analysis that Christine did. And for the motor function, this will be kept consistent, where we do the Short Physical Performance Battery and

capture grip strength using the handheld dynamometer, because those two things go right directly into the Fried Frailty Phenotype that I talked about a little bit earlier.

And so for the pre-intervention assessments, this will be done virtually and also in-person. So anything that can be done virtually, such as the COPM, or questions regarding resources, or a current medication use, substance use, that will be done virtually. And for things that need to be done in person, such as the Short Physical Performance Battery and grip strength, that will be done in person. So the intervention itself is entirely virtual. And what I mean is the home exercise piece. And also we have 10 video and phone group sessions and weekly phone check-ins with an occupational therapist to provide problem solving and support. The home exercises will be done three times a week for 10 weeks, and these exercises will be taught in person during the pre-intervention assessment.

And participants will be provided video clips as reminders as we know that memory might be disrupted in this population, and this was something that was highlighted as something that should be emphasized by the focus groups, so a series of reminders. And that kind of goes right back into what we'll be doing with the phone check-ins. The phone check-ins will be formed to help address any questions regarding the exercises and any challenges related to falls during the previous week. And from the qualitative piece, we found that having the ability to have group sessions and having a sense of, I guess, a sense of, I wouldn't say purpose, but they really love the piece where you can meet as a community and talk amongst each other.

This was something that happened during the focus groups. Everyone got really close, and especially during the pandemic. That social piece is something that's missing. So we included it during our intervention where we'll have a weekly group session, and we'll be discussing challenges related to falls. And we'll encourage participants that they can turn off their cameras if they would like to, if that makes them feel more

comfortable. Because during the qualitative piece, we found that some participants, they were doing their focus group during maybe their work break, or maybe they weren't surrounded by, maybe their environment wasn't something they wanted to broadcast necessarily out to the world. So we found from that piece that we should encourage participants, you can turn off your cameras and definitely still get that social piece you can get from a group.

To summarize, our interventions will address motor function, strength, and endurance using the exercises, and they will be tailored to each participants level of fitness. Assistive devices, which were indicated as area of need in the qualitative analysis. And then we'll be looking at reminders and the need for reminders will be addressed with these weekly phone calls and strategies for adapting the environment. This will be implemented during the weekly phone calls to help adapt each participants environment to mitigate any fall risk. So simple things, such as removing the typical things like throw rugs, or try to make lighting as best as possible and other kinds of suggestions in that manner. And lastly, the post-intervention assessments will remain the as the pre-intervention assessment.

Okay, so now I'll turn over the mic now to Simone, and she'll talk a little bit about lessons learned and any takeaway points.

- [Simone] Thank you, Danny. There were some lessons that we learned from our studies with these participants, and some of them had to do with the special population that we were working with and others had to do with pivoting due to the COVID-19 climate that we're in right now. One area includes recruitment. We, and other studies, have certainly recruited by hanging flyers in particular areas, perhaps places where participants receive medical care and those can be effective. But especially with this population, passive recruitment is not as advantageous. Having someone who can, if possible, physically go and meet with groups of participants who might be interested

in taking part in studies would be wonderful. As Danny said, we have access to a cohort of participants who are in another study who then could participate in ours.

And a part of that advantage includes being able to create a relationship with participants, particularly when they're part of a vulnerable population, to create a relationship and trust with that client. And that not only helps them to participate or, hopefully, decide to participate in your studies, but also gives them the level of comfort to really be able to feel comfortable enough to ask questions and make sure that they are treated in the way that they should be when they're engaging in studies with us. Another aspect of altering our recruitment a bit for this population includes the importance, not only of interactions, but the environment in which you are talking to participants, doing things like making sure that you're not in a distracting environment or that you're in a space that makes the participant feel comfortable enough to share details, which might be very personal, can be very important for vulnerable populations.

I talked a little bit about recruitment materials and that flyers, which are more a passive form of recruitment, might not be as advantageous. You also, even if you do have flyers, may want to create materials that are tailored specifically to the population, which involves information that's really, that they care about, that that's critical to them in terms of the importance of participating in your study. We always compensate participants who take part in studies. But for this population in particular, there are barriers to access that might really influence their ability to participate. So making sure to provide compensation for transportation, for parking, and so on, if they're able to come in person, is quite important. And last, in terms of recruitment, I wanna bring up, again, the debriefing process.

With all studies, we debrief to let participants know what they took part in, why the study is important, how it relates to them and the population that they're a part of. But

again, if you create a relationship with them, they feel comfortable enough to really ask questions that they might have during that debriefing period. In light of COVID-19, I mentioned that we pivoted, and Danny talked about the intervention, which we originally intended to be in person and pivoted to create a hybrid format so that participants could take part in person for some of the assessments that we're conducting, but also participate virtually. So the advantage of participating virtually is that there are platforms, like this one that we're using, that really helps to increase the access to some participants who might not be able to make it in for the sessions to take part in your study.

And that might be due to things that I mentioned before about barriers to access because of transportation, but it might also have to do with time. With an intervention specifically, interventions take quite a bit of time. Participants may have to go several days a week to a particular site. But with a virtual format, they can take part and not necessarily have to physically go visit a site. The other piece that's advantageous, in terms of a virtual format, is that, in COVID-19, it facilitated this ability for us to also include a group portion. And participants talked about how important it was for them to have support from other people who are a part of their population, who really understood what they were going through.

So we really saw the richness that shifting to a virtual format created, because we were able to still offer that for participants. In terms of home exercise, having a virtual format means that you're not necessarily going to include equipment that's traditional for physical activity interventions. So clients in other studies might be asked to go to a setting that has special equipment that you might find in a gym. That's not something that, obviously, we're doing during COVID-19, but it's advantageous because more people can do home exercises without the use of important, very complicated equipment, expensive equipment, which again, increases access to that kind of physical activity for clients who might not have the equipment or have access to those

kinds of materials, and then hopefully, leads to their ability to continue to do that after the intervention.

So if you have clients who come in and use your specialized equipment for eight weeks and then go off afterwards, but have no access to that kind of equipment, it might be challenging for them to generalize that to their everyday lives. But if you include home exercises that they can conduct in their own homes, then that kind of opens the possibility for them to continue to do that long-term and opens the possibility to actually including functional movements that are a part of their everyday environments, which hopefully, would actually lead to decreasing fall risk. We did a hybrid format, as I mentioned, also with our assessments, because some of them could be conducted over the phone, even if not over a virtual platform.

So that is another advantage. Also, lastly, I'll say that, in terms of confidentiality, that people who are parts of vulnerable populations might not necessarily want to be seen visually on a video chat but can still participate by turning their cameras off and talking to the group. So we also saw that as a very huge advantage for this population so that there were multiple ways in which they could participate and hopefully still benefit from the intervention. Thank you. We'll now take any questions that you might have.

- I can also talk a little bit more about some of the findings that we weren't sure if I would have time to talk about from the focus group that were specifically related to the pandemic and participating in the intervention. As you've heard multiple times in this presentation, people were very excited to be part of a group and have that interaction with other people. And we saw this pre-pandemic with the interviews that I did, which is typical to see in a narrative interview, but it was really most striking in the focus groups. Because in the focus groups, we had a really hard time getting people to stop talking. The RAs were very concerned that how was I possibly gonna do a virtual focus group with people just on the phone?

And it's much harder on the phone than it would be in Zoom, which, it was being like being on the phone, because they couldn't see each other. We could see their little squares and see them lighting up and know who was talking. But the people that were participating couldn't see who else was talking. So there was more talking over each other and that sort of thing, because they all wanted to participate. I did not have to do any teeth pulling to get people to participate and they didn't wanna end. And the more that they went on, they would get off-topic. Somebody would talk about needing adaptive equipment, like needing a medical bed, and someone else would say, "Oh, I have one.

I know where you can get one." And they wanted to start exchanging phone numbers and exchanging emails. When at the beginning, they didn't even want their name shown. They put names on that really couldn't be seen. So they also talked about the desire to get out of their homes during the pandemic, both to get away from their children, to get away from the other people in their house and feeling trapped. Because again, the mobility impairments made it more difficult. For those people who were homeless, there were some that were living in shelters, some that were living in long-term shelters, and some that were going kind of couch surfing. And they were able to participate in the focus groups just fine.

And I think there will be no problem with them participating in the intervention itself. They did some other unique kinds of things, like I found that they were usually sitting outside for the focus groups or for the interviews. Again, I couldn't see this, which was a downside for me, but it would come up during the interview, because we'd hear cars honking, or sirens, or something like that, or people walking by and talking to them, because they were sitting out in the park doing this on their phone. There was another gentleman that was participating, and he got interrupted several times, and we really

couldn't figure out what was going on with him. And he then, finally, disclosed that he was at work.

He worked in a warehouse, and he was taking his lunch break to do this and was sitting out at the employee picnic table to participate. So I was very concerned one day when it was pouring rain here and really bad weather, and I didn't think people would show up for the focus group because it's harder to sit outside, obviously, on your phone in the rain, but they all found a place to do it. That man that day with the picnic table, that day was raining, and he was sitting under kind of a metal overhang. So we could hear that in the background, but they found a way to participate. And my experience in working with people with homelessness is that their sense of resourcefulness is just really amazing.

- Thanks for saying that Chris and adding that. It's really valuable and also answers a question that a participant had, which was, it was mentioned that one of the participants was homeless. Was he fully able to participate? And I think that really addresses really well that question. Chris, there's another question here that is related to the focus group. And someone is asking what was the size of the focus group and did the size vary?

- The focus groups were between three and five participants. They were pretty consistently around four. So with a minimum of three and a maximum of five. We kept them smaller than we would have done if we had been in person. We did recruit more; we recruited up to seven to eight, knowing that we would probably get about half of that. So they were pretty consistent.

- Thanks, we have some other wonderful questions here. Someone's asking, when do you expect to release the results from the intervention and where will we be able to find them? We are hoping to conduct the intervention this winter and spring, which we will

be able to do, since we've pivoted to a format that can be done during COVID-19, and we'd be happy to share those results once we have written that up. Someone says, where was this study conducted? We're located in Boston, Massachusetts, so that's where we conducted the study. Another person asks, "Sorry if I missed this, but after the intervention, did the fall rate go down? Did substance abuse patterns change?" That's a great question, because we know that our collaborators have told us that in the cohort that include the participants that we've been examining, that their substance abuse patterns do change over time and have decreased over their time in that study.

We are looking at their fall rate, and we don't yet know whether their fall rate has decreased. So that's a part of what we'll be examining. One question is what was the outcome of the participation in the 10-week exercise program? Was there reported decrease in falls? Thank you for that question. Again, that's something that we are going to be examining and hope to get back to you on very soon. The next question is do the reported cognitive issues stem from medication, environmental factors, comorbidities, or a combination? Danny, would you like to take that question?

- Sure, I would say we don't... I think it would be an interaction of all those things. I don't think we will be able to definitively say it's one thing over another. But maybe one of them would maybe exasperate it. But I would say it's an interaction between all those factors listed.

- Thank you, Danny. There's another question here. What were they most wanting to talk about? Personal needs or general issues? Chris, if you wouldn't mind taking that one.

- Sure, so it was a combination. They talked about their personal needs. But what was really striking was how common those were across the group. I see another couple of questions here that are related to the focus group, so I'll just answer those real quick

too. The study did not provide internet access for the focus group piece. But that's something that we've looked at doing for the actual intervention if there's anybody who does need internet access or does need to use an iPad or something like that. There are some resources that I think we'll be able to provide for people. And the version of Zoom that we used was a more protected version, because this was research and we were going through the Institutional Review Board.

We had to be very careful about any identifications. So we did, which was another reason that we didn't record the video part of it. We only recorded the audio part, and we had that transcribed by a service that signed a disclosure agreement. And the clients that participated in the focus groups also signed a confidentiality agreement as part of their consent form, as you would do in any research study with a focus group to not share any details. So I think I'll turn it back over to you, Simone.

- [Simone] Thank you, Chris. Another question is how would your client disclose their experiences with other treating professionals? Do they sign disclosures to share information? How did they improve their environment to do modifications to the environment? Did you allow any other family members to share in the groups? So the participants in the groups were just the clients themselves. There weren't other family members to share in the groups, and they were free to address anything that they felt was important to them during that time. So that could include information about other treating professionals. But because that information is confidential, we wouldn't talk about specifically who those individuals were, but rather, with Chris' qualitative expertise, be able to then gather information about themes that emerge from the conversation.

The age group, I'm just answering a question, age group was, if I'm not mistaken, 45 to 70. Is that right, Danny?

- [Danny] Yes, yeah that's pretty much correct. The average was 53, for at least the cohort anyways. But for the focus groups, I wouldn't know their ages.

- [Fawn] Thank you. And another question. Yes, the participants were only from the community. There weren't any that we recruited from nursing homes or assisted living. And we're hoping to be able to get back to, as I said, about what follow-through might have been like for adapting to the environment. The study will be ongoing, and we hope to tell you about the results. There's a question here: when someone is homeless, maybe staying in a shelter, are they provided cell phones, access to computers? Nice that they can adapt and continue with participants.

- No, they weren't specifically provided with cell phones and internet access. They all had cell phones actually on their own. And again, this is one of the myths about people being homeless is that they don't have cell phones. That's actually one of the things that they really typically do have and is there one main means of communication with other people. And I just wanna say that some of the people, in case there's any confusion, some of the people in the focus groups were in like an... One of them was living in an assisted living building, and one of them was in a homeless shelter. So we did have a variety of people. We didn't specifically recruit for those.

Those were just people who were participating in this study. But it looks like we are about out of time. So I'm gonna turn it back over to Simone to wrap things up.

- Yes, we thank you so much for giving us an opportunity to talk to you about our study. We look forward to being in touch about our results after we conduct everything and wrap up with the participants. So thank you again to all of the participants and thank you to ot.com for this opportunity.

- I just wanted to take a final moment here to thank you so much for day one of our virtual conference. I hope everyone enjoyed today's talk, and you can join us again tomorrow. Thanks to all the presenters today. Thank you very much.