

Jill Harrison:

Hi, this is Jill Harrison, Executive Director of the National Institute on Aging IMPACT Collaboratory at Brown University. Welcome to the IMPACT Collaboratory Grand Rounds Podcast. We're here to give you some extra time with our speakers and ask them the interesting questions that you want to hear most. If you haven't already, we hope you'll watch the full Grand Rounds webinar recording to learn more. All of the companion Grand Rounds content can be found at [impactcollaboratory.org](http://impactcollaboratory.org). Thanks for joining.

Jill Harrison:

Hello everyone. I'm Jill Harrison, one of the executive directors at the NIA IMPACT Collaboratory. I'm joined today by Drs. Richard Fortinsky, Leah Hanson, and Robert Penfold. Richard Fortinsky is a professor at the University of Connecticut School of Medicine, where he is a core faculty member at the Yukon Center on Aging and holds the Health Net, Inc. Endowed Chair in Geriatrics and Gerontology. Leah Hanson is a Senior Research Investigator and Senior Director of Research at HealthPartners Neuroscience Center, HealthPartners Institute, and Co-Director of Research at the HealthPartners Center for Memory & Aging. Robert Penfold is a health services researcher and health policy expert whose work focuses on developing and testing strategies to optimize behavioral healthcare delivery and patient outcomes. He's also a co-investigator in the Mental Health Research Network.

Jill Harrison:

Rick, Leah, Rob, thank you so much for joining me today. The NIA IMPACT Collaboratory hosts a monthly Grand Round series, each with a companion podcast. This past week, you presented a well-attended Grand Rounds about challenges conducting pragmatic trials of interventions for care partners of people living with dementia. Dr. Hanson, I wonder if we could start with you. I'd just like to ground ourselves first, before we dig into questions from our listeners. Can you please give us a high-level overview of what the challenges of conducting trials for care partners of people living with dementia are?

Dr. Leah Hanson:

Well, there are several challenges. One of the biggest challenges is identification of care partners of people living with dementia, and the second would be pragmatic outcomes. So finding the data related to caregivers isn't often routinely collected in the medical setting, and when it is, it's not placed in places that are easy to find. And so as we're designing our trials, we have to come up with strategies to find or collect the data related to the care partners versus the patient or the person living with dementia. And then similarly to enroll or recruit care partners into our studies, strategies for identification and consent.

Jill Harrison:

Great. Rick, Rob, anything you want to add in terms of big picture challenges?

Dr. Rick Fortinsky:

No, I think Leah captured it well. I believe all of us are operating in the outpatient care setting, and I believe that the issues in identifying care partners in other healthcare settings might be similar to what's experienced in the outpatient setting or there might be additional challenges, but I think Leah really did capture it well.

Dr. Rob Penfold:

The only thing I would add is that because of the legal and technical barriers to collecting care partner information in the electronic record—for example, that they are not members of the same health system as the person that they care for, including living in different states and being the durable power of attorney—it makes it quite difficult to not only find that information in the chart when it exists, but to collect that information from people whose authorization is required and may not be readily available to contact.

Jill Harrison:

Leah, let's dig into your project a bit deeper. Your project that you presented on is focused on an intervention of mindfulness-based stress reduction that is delivered virtually to caregivers. What are some of the potential technological barriers and planned strategies that your project team has to overcome them?

Dr. Leah Hanson:

Yeah. Thanks Jill for that question. We talked with stakeholders about this and there were some concerns that people living in the rural parts of our state, I'm in Minnesota, might not have internet or broadband access to be able to participate via the virtual, like a webinar, like a Zoom call, and/or may not be able to afford a computer and might have access only to a telephone. And so what we've done is we talked with the instructors of our mindfulness intervention and they were willing to offer participation via the phone. Without that virtual component we're able to email or mail course materials, but providing that phone alternative to the computer or iPhone experience was an important part of our design and something that we thought would be important to increase the range of people who would be able to participate.

Jill Harrison:

Wonderful. Rob, I'd like to transition to a question that we received from listeners about your project. You presented on information about how care partners were able to access the patient's portal. And there was a lot of interest in terms of how did care partners gain access to member secure messaging? How do you handle that proxy access when you're conducting trials of care partners for people living with dementia?

Dr. Rob Penfold:

It is certainly the letter of the law for a care partner to request and receive proxy access to the chart to be able to talk with the patient's care team. And that happens about 5% of the time. Most of the time, the care partner logs in using the patient's credentials and accesses their secure messaging that way. This is of course not supposed to be the way it goes, and it's not technically legal and not technically allowed, but that's the way it happens most of the time. In light of that, we pretty much turned a blind eye towards that sort of regular utilization of the IT platform. The other consideration we had was if we contacted a care partner to participate in the trial and they didn't have access to the portal or were not users, that the barrier to them doing this very clunky process where they had to fill out a paper form, submit it to the health system, the health system has to approve it, and then they finally get proxy access, that that would be a significant impediment to us recruiting them into the trial. So we decided not to do that.

Dr. Rob Penfold:

Part of our inclusion criteria that I didn't talk about is that we required the care partners to have had to, for us to have evidence that the portal had been used on behalf of the patient in the last six months. And considering that the patient had diagnosis of Alzheimer's disease or related dementia, the presumption was that it was the care partner using the platform rather than the patient. So that's how we did it. That seems to be how it's done in normal practice. But like I said, maybe not according to the letter of the law.

Jill Harrison:

Wonderful, thank you so much. One other area of interest, which will certainly vary by trial or specific project was this issue of identifying care partners. What general design tips or advice would you give investigators who are wrestling with this design issue?

Dr. Rob Penfold:

Our general approach was to use automated data extracted from the medical record and or claims to identify first, the patient's Alzheimer's disease or related dementia, and then use the emergency contacts inside the medical record to identify the appropriate care partner. And that seems to be working extremely well for us. Emergency contact information is missing less than 1% of the time. And our experience in reaching out to enroll care partners has been that the vast majority of people who are listed as the primary emergency contact are in fact, the people who are providing care on a regular basis. That does not preclude us doing some subsequent screening for the person. So for example, we administer a telephone-based screen to the caregiver to make sure that they themselves are not diagnosed with dementia, or at least we have a screener in that regard. So that's been our strategy and it's proven to be quite effective actually.

Dr. Rick Fortinsky:

This is Rick. We are just getting underway going into the field. And so what we're about to do, and we're going to wait until after Thanksgiving to begin contacting caregivers. What we're doing in our study is we really want to simulate, as much as possible, the situation where the outpatient clinics where we are working will routinely offer care partners dementia educational programs. So we've designed our study in that fashion. The clinicians who work in—we have a geriatrics outpatient center, and we also have a dementia care specific outpatient center—all of those clinicians have a vested interest in reaching out to care partners to offer educational programming. That's really what motivated our study. So after the electronic health record search for the emergency contact of the patients with dementia, as Rob just mentioned, we are having the lists reviewed by each provider to verify that indeed, that list of patients and the care provider or the person listed in the chart is indeed the right care partner to contact. So we're actually having our providers screen those lists because in the situation where there's no longer a research project going on, the providers really want to be able to initiate the invitations through their office setting for care partners to join a particular dementia educational program.

Dr. Rick Fortinsky:

So far, what we have found with the first few providers who have looked at their lists is a very high hit rate, the same way that Rob has mentioned, in that the person listed in the, either emergency contact or other person to contact, or else there is sometimes evidence of an individual in the patient's chart who has been accompanying that patient to visits all along, that that turns out to be the care partner who the provider really does believe is the right person to contact to invite them to participate in the dementia education program.

Jill Harrison:

Wonderful. Leah, anything you'd like to add in terms of advice for investigators that are grappling with the issue of how to identify care partners?

Dr. Leah Hanson:

Yeah. I think it's important to recognize that dementia is underdiagnosed in the medical records. And so, in fact, we're going to be missing quite a few care partners of people living with dementia because of that. In addition, there's people that have a diagnosis in their electronic health record that may not know it's there, or may not remember it's there. And so I know our IRB wants us to be sensitive when we're sending out mailings and contacting people, exactly what we're saying to them about what we know about their condition. And so I think the strategies of partnering with the physicians and going through lists and confirming are really important. The study I'll begin recruiting for hopefully in the spring kind of uses a hybrid approach of both recruiting as part of the medical care visit at three sites of specialty memory care and targeted mailed invitations as well.

Dr. Rob Penfold:

Leah just said something super interesting, which is that dementia is underdiagnosed. And that is certainly the case that we've experienced at Kaiser Washington as well. And we actually considered recruiting folks who had evidence of memory problems or organization or other kinds of symptoms that might be consistent with a diagnosis of Alzheimer's disease and related dementia in their primary care notes, structured diagnosis of mild cognitive impairment.

Dr. Rob Penfold:

But for exactly the reason that Leah mentioned, that we might reach out to someone and they might not know that these things are being documented in the chart. Even though we have open notes and people could have reviewed the documentation, we were extremely reluctant to reach out to folks and say, "Hey, would you like to participate in this trial for folks with dementia?" and them having a negative reaction. So there is this really interesting advancement that could be made to use machine learning or some other kind of predictive analytics to better identify people who have not had a formal diagnosis reach out perhaps to their primary care doc and say, "Hey, we noticed this documentation. Do you think this person is a candidate?" in order to get that caregiver training sooner in the process. So that's something we're thinking about.

Jill Harrison:

Great point. Thank you so much for adding that. My last question for the three of you, and Rick I'd like to kick it to you first please, is for researchers that are looking to build their competencies in terms of overcoming some of the design and methodological challenges of conducting embedded pragmatic trials for care partners, what types of training resources would you recommend? Where should they start?

Dr. Rick Fortinsky:

Well, I do believe that the IMPACT Collaboratory is starting to develop what are called [value proposition tips](#). I believe that researchers have to be able to identify healthcare systems that are interested in partnering to conduct pragmatic trials with care partners of patients. And that is sometimes easier said than done, especially among researchers who have made a career out of studying care partners of people with dementia. The value propositions notion really is trying to understand from the point of view of a healthcare system partner for research, what do they view as benefits of offering education or

support to care partners of their patients living with dementia. And so really before starting to even design a study that might involve trying to embed a care partner intervention in a healthcare system, investigators really do have to devote the effort to spending time with champions, trying to find champions within the healthcare systems, and the settings within those healthcare systems, such as outpatient settings, to really make sure that the justification for the healthcare system to invest resources, and that really means time and effort on the part of their staff, as much as it might mean actual money. How they're really going to benefit those healthcare systems by offering interventions geared toward the care partners of people living with dementia.

Dr. Rick Fortinsky:

And oftentimes that value proposition has to do with if care partners are not well equipped to manage the symptoms that develop as dementia progresses, then patient care in the home setting is going to suffer. And even though clinicians in the healthcare systems might be providing the best possible care during the course of those relatively brief office visits that occur, say, every three or six months, if in between those visits, the care partner is not really well equipped to manage symptoms of dementia at home, then care is going to suffer and there will be adverse outcomes for those patients. So to me, that's really honestly the most important tip as far as getting started for new investigators who really want to be able to make an impact in a healthcare system, by going the route of trying to improve the capacity of care partners to help manage patients living with dementia.

Jill Harrison:

Wonderful. Rob, anything that you'd like to add in terms of where investigators should start, if they want to build competencies, if they're looking for training?

Dr. Rob Penfold:

Rick covered nicely some of the resources that are available from the Collaboratory, especially. I think, especially for the traditional university based researchers who are not participants in the healthcare services research network, as folks who work in institutes that are embedded within health systems, we really have a tremendous competitive advantage vis-à-vis our relationship with the health system to meet with clinicians and system stakeholders to design interventions that are consistent with the kinds of roles and responsibilities that the clinicians would have, and that fit with the workflow and general culture of care within each of these different places. So for junior folks in that setting, they have a sort of deep bench of mentors that can help them in that regard. And I guess I would say that for folks in a more traditional university setting, try to get hooked up with somebody in the HCSRN to help them with mentorship that way.

Jill Harrison:

Great point. Thank you. And Leah Hanson, HealthPartners. We're going to let you have the last word. Any final remarks from you?

Dr. Leah Hanson:

Yeah. For training, I just want to say to people who are getting into this field is that the community of scientists or researchers in the field of care partner research, caregiving research, are very welcoming, and I think we learn a lot from each other. And so I wouldn't hesitate to reach out and build a network and get advice from people who have been where you're trying to go. And then finally, in my experience, the IRB manager has been able to help kind of shepherd and guide me and give me advice

to how I am able to get approval for my research and move it forward. So I'll end with those last two pearls.

Jill Harrison:

Wonderful. Thank you so much. Leah Hanson, Rick Fortinsky, Rob Penfold, it's been my pleasure to speak with you today. Thank you so much for all you do for IMPACT as well as improving dementia care. Greatly appreciate your time. Thank you so much. Thank you for listening to today's IMPACT Collaboratory Grand Rounds Podcast. Please be on the lookout for our next Grand Rounds and podcast next month.