Jill Harrison, PhD:

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. Thanks for joining.

Vince Mor, PhD:

Good afternoon, Dr. Thomas. It's a pleasure to have you for our podcast related to the IMPACT Grand Rounds, and I'm delighted to have this opportunity to have a person-to-person conversation about your study related to the impact of hot versus frozen Meals on Wheels for older persons with cognitive impairment. Quickly summarize for those who haven't listened to the entire recording of the Grand Rounds, what was your study about and what were the results?

Kali Thomas, PhD:

Sure. Thanks for having me here for this podcast today. So we conducted a pilot pragmatic clinical trial in which we were interested in understanding the differences in the effect of home-delivered meals, specifically two types of home delivered meals. One, which is the traditional daily delivered model in which a paid or volunteer driver brings a lunchtime meal to a home-bound older adult's home. They may socialize and visit with the client. They report any concerns that they have about the client back to the program. It's meals plus socialization and an informal wellness check, this traditional model. Compared to a model that has emerged in recent years that's lower cost, in which meals are frozen and mailed to participants' homes.

So we wanted to understand for people living with dementia, how these two different kinds of meals related to time to nursing home placement. We enrolled 243 individuals who were on waiting lists at Meals on Wheels programs across the country. We worked with programs in Florida and Texas, so at three programs, and those folks who were on waiting lists who had self-identified as having a diagnosis or a medical professional had told them they suffered, or they were living with cognitive impairment, memory loss, or dementia, we randomized them to receive one of these two different kinds of meals. We took the data from the programs that they had collected on individuals, including their social security numbers and some PII, like date of birth and zip code and gender, and we linked those data with the Medicare enrollment data. With the Medicare number, we could link those to the nursing home minimum data set to identify the time to nursing home placement.

This was a pilot study, so we weren't powered to determine a significant effect, but we did observe that at six months, 7% of participants who received the traditional daily delivered meal, and I'm going to put an asterisks by that because of COVID, it didn't end up being daily, and we can talk more about that. But 7% of those who received daily delivered meals were admitted to a nursing home within six months, compared to 13% who received frozen meals. So this was about a 6% difference between groups. That was not statistically significant. But in their presentation we had this nice figure that definitely showed a trend over time in terms of time to nursing home admission.

When we adjusted for age, sex, race, and living arrangement, we had a log hazard ratio of negative 0.68, suggesting that individuals receiving daily delivered meals had almost to 50% decreased instantaneous likelihood of going to a nursing home, compared to the group receiving frozen meals. And again, it wasn't statistically significant, but it does suggest that there's something there that we'd want to continue to follow up on to understand.

Vince Mor, PhD:

Great. Thank you very much. That's actually a great synopsis. And so a lot of people will say, "Well, how do you know whether people liked it, whether it was good for them," et cetera. My recollection was that you also did a qualitative sub-study. Describe how you went about doing that, and did you ask people consent? Because up until then you hadn't really gotten any consent.

Kali Thomas, PhD:

Yeah. So I'd love to talk about this aspect of our study. We learned a lot through this process. To start off, yes, you were correct. We had a waiver of consent for enrollment into the study because, as I talked about in the Grand Rounds presentation, our study met the five criteria to qualify for a waiver of consent. For folks interested, we have a protocol paper that details all of the rationale that we used.

You're right though. From the secondary administrative data, we couldn't really get a good insight into mechanisms and experiences. So we had qualitative sub-study in which approximately a month after folks began receiving meals, we invited a random sample of participants to participate in telephone interviews with the research team. In those interviews, we asked questions about their interactions with the drivers, about their experiences receiving these boxes or these daily deliveries, how they may have prepared the meals, their experience eating the meals, their satisfaction. So we got some really good in-depth qualitative data around participants' experiences.

Part of the whole exercise, in addition to understanding mechanisms of impact, if you will, or what was underneath the hood, we also wanted to see, can we recruit people living with dementia to participate in interviews? Can we assess their capacity to give consent? And, in addition to all the research questions we asked, the qualitative, in-depth, semi-structured interview guide, we also administered the modified telephone interview for cognitive status, the TICS-m, because we wanted to understand how experiences may have varied across different levels of cognitive impairment.

What we found actually with the TICS-m was that over half met the threshold for having indicated dementia. So yeah, we learned that we could recruit folks, we could administer, we could ask these questions, and we could administer the TICS-m among a sample living with dementia.

Vince Mor, PhD:

So how did you train your staff to figure out whether somebody had the capacity to give consent to participate in this phone interview?

Kali Thomas, PhD:

One of our co-investigators, Dr. Michelle Hilgeman, she's a geriatric psychologist and does a lot of great research and clinical work with veterans living with dementia, she led a two-hour training session for our qualitative research team. And this session covered everything on how to assess capacity, common responses that people living with dementia might give, or responses that might indicate cognitive impairment or not understanding, but sort of accommodations in a way that hide that, if you will. I learned a ton from her presentation.

So in addition to sussing out or getting a sense for whether or not people are truly understanding the purpose of the interviews and what participation means, she also trained our research team on how to administer the TICS-m. The training included teaching our interviewers how to assess, over the phone, whether or not participants could make a clear choice and show understanding and show reasoning and rational reasons. And this was verified and checked through this four-item consent checklist that we had approved by our IRB.

In addition to that initial training, our interviewers met frequently with Dr. Hilgeman, just sharing experiences or, "This is what happened during this interview. How can I do this differently next time?" And so it was this ongoing learning opportunity for our interviewers.

Vince Mor, PhD:

So for the researchers who might be listening to this who do work in the area of dementia, it is often the case that you call up and you're trying to find and have a conversation with somebody with cognitive impairment, and a caregiver or a spouse or somebody gets on the phone and tries to be the intercession between you. How did that work out and how did you instruct your interviewers to deal with that?

Kali Thomas, PhD:

Because that did occur, we had a prompt. If this happens, this is what you can say. And I think the script had something like, "We are interested in hearing the perspectives of," insert name here. "We'd also be interested in talking to you about your experiences, but right now we want to hear from," insert name here, or something to that effect. Because we did have, another part of this qualitative sub-study... This was a big pilot, huh? Another part was that we also were recruiting caregivers to do interviews with us. So we gave them an option to share their voices, recognizing that many of them were acting as gatekeepers, if you will. But by saying, "We want to hear from you too," we thought that might be an approach to let them say their piece, if you will.

What we actually found was getting ahold of caregivers is really hard, and the caregivers we were able to recruit are exactly who you're talking about. Those the answered the phone who said, "Well, I can talk to you," or didn't maybe want us to talk to their loved ones.

Vince Mor, PhD:

Yeah, it's very difficult doing that. In the studies I've done, it's very difficult. So let's switch gears for a second. So you did all of this work with three Meals on Wheels programs. Tell us a little bit about how you started working with Meals on Wheels and how you developed that relationship. Because these are stakeholders, you had to ask them for lots of stuff, including the complexity of getting people on waiting lists. How did you do that?

Kali Thomas, PhD:

Yeah, we did ask them for lots of stuff and we're trying to be really, really thoughtful about those asks. I talked about this briefly in the Grand Rounds presentation, but this relationship started, golly, a decade ago, which makes me feel older than I actually feel. But I was contacted by the new CEO of Meals on Wheels at the time. She'd just seen a research study, asked to talk to me. I think you supported this decision, maybe even financially, for me to fly down and meet with her in person. And she shared with me what she saw when she walked on the job and what her goals were for the organization and how she really thought evidence would be the way to move the needle forward and help these programs establish themselves as key players in the delivery of long-term services and supports.

And I really just listened. And then we cooked up a research project together that was the first of, I think, maybe eight or nine different funded projects as partners. I think the one thing that's really been key to this relationship is always listening. So as researchers, we can always come up with questions we think are really cool or use novel methods or new data or what have you. And that's really fun and exciting, but I think it's even more impactful when those ideas are generated from listening to community partners. So we've had lots of conversations over the last several years, and as the programs

are evolving and the Senior Nutrition Network is evolving, so that we can continue to produce evidence that informs discussions I think it's all around relationship building.

What was really fortunate in this circumstance was this is was with a national membership organization. So when we had research proposals like this pilot, we worked with them in identifying their members who might be really interested in participating. They do an annual, I guess it's biannual membership network survey where they ask programs, "Would you be interested in participating in studies?" So that's how we identify these real innovators and folks who keep raising their hands to participate in this work. That was a long-winded way of saying relationships matter a lot, listening matters a lot, and especially for those of us who are doing pragmatic research, relationships are key.

Vince Mor, PhD:

In the field. So thank you very much. That's just perfect. It's a great note to end on. For the researchers out there, the young researchers particularly, it is actually all about relationships and investing in those relationships and the real community, and to listen to your partners and try to work with them to solve problems that they have, as opposed to you imposing your ideas on what they are able to do. It's a very, very classic example, Dr. Thomas, and I really appreciate your being on, and for having given a brilliant Grand Rounds last week. Thank you very much.

Kali Thomas, PhD:

Thank you, Dr. Mor.

Jill Harrison, PhD:

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.