

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. 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 Dr. Karen Lyons. Dr. Lyons is a professor and gerontologist at the William F. Connell School of Nursing at Boston College in Chestnut Hill, Massachusetts. Her program of research has focused on how the family care dyad experiences and navigates illness. She's well known for her work on the Theory of Dyadic Illness Management, which is currently used across disciplines to study dyads in cancer, stroke, heart failure, and dementia. Dr. Lyons, thank you so much for joining me today.

Dr. Karen Lyons:

I'm very happy to be here. Jill.

Jill Harrison:

The NIA Collaboratory hosts a monthly Grand Round series, each with a companion podcast. This past week, you presented a well-attended Grand Rounds about dyadic designs, their foundation on theory and analytic methods in the context of embedded pragmatic clinical trials for Alzheimer's disease and related dementias. Can you please explain dyadic research, in a nutshell, to our listeners?

Dr. Karen Lyons:

Oh, that's a great question. I think dyadic research, really, is the simultaneous focus on two people in a relationship. And so, most often it is that family care dyad that we're focused on. That would be the person who is experiencing the illness and also their family member or care partner who is providing care to them. There are lots of other types of dyadic relationships that are studied, but it really is a simultaneous focus on both of them and the interactions between them. And that's what distinguishes it from, let's say, individual research where we are really focused on an individual and their outcomes.

Jill Harrison:

Thank you. It struck me during your talk, just how challenging dyadic research can be. For example, at the beginning of your Grand Rounds talk, you described the phenomena of a person living with dementia and their care partner as being in the same boat, but weathering different storms, so to speak. And it's the challenge of dyadic research to go beyond simply collecting data from the two people about their respective storm, and to capture that relational interdependence, interpersonal context that the dyad is experiencing.

Jill Harrison:

I wonder if you could comment on that and share, what are some of the key hallmarks that differentiate more tokenistic or lip-service approach to dyadic research versus rigorous, sound dyadic research? In other words, how do we know it when we see it?

Dr. Karen Lyons:

Yeah. And I think it is confusing, and I think especially to people who maybe are new to the area. Because I think that the confusion comes from sometimes, including two people in a study. And I think many people have called that dyadic research or have talked about it as dyadic research, when it really isn't. I think it's more than just including two people. And I think part of this is because the vast majority of research that's done in all contexts is individual level. It's how we're all predominantly trained. It's how most research is conducted. So, including two people in your study is complicated anyway, right? To recruit two people rather than just an individual. But that's not really dyadic research. Dyadic researchers would really talk about those things that you just mentioned. We have to be focusing on the interdependence between the two people or how they're influencing each other or the transactions between them or the patterns between them. Are they both experiencing good outcomes or poor outcomes?

Dr. Karen Lyons:

And so, in terms of just including two people and maybe even collecting data from both of them, many times people are still focused on outcomes around one member of that dyad; for instance, the person living with dementia or the care partner's outcomes. And so, it really takes another kind of movement, even though it's more complicated, to get to dyadic research, which is really truly focused on something relational between those two people.

Dr. Karen Lyons:

That doesn't have to mean you're studying relationship quality, but there's something about why you have two people in this study in terms of looking at their outcomes simultaneously or the patterns between them and that interaction between them that is of importance to you.

Jill Harrison:

For researchers that are looking to build their competencies in designing dementia trials with a focus on dyadic research, what types of training resources would you recommend?

Dr. Karen Lyons:

Oh, that's such a great question. And I think that the thing is, we've come so far in dyadic research in the last 20 years, and we have great methods and statistical approaches for dealing with dyadic data. And I think you'll find many webinars available. They're not as, let's say, widespread as maybe they could be. I think there's certainly ways to understand and get exposed to the actual statistical approaches. There is a free webinar by Kenny, who really was one of the instrumental people in designing and coming up with the Actor-Partner Interdependence Model. Niall Bolger and J.P. Laurenceau often give dyadic workshops, especially through UMass Amherst Centers for Family Research. But I think what is equally important, and I talked about this during the presentation, is we can't just focus on the methods and statistics, because it's always easy to reach out and find somebody who can do that. You might not have it in your institution, but you might be able to reach out to a statistician or methodologist or somebody at another institution.

Dr. Karen Lyons:

The most important thing, when you're starting to really venture into this new field for you, is to really get yourself into the literature of dyadic research, the concepts that are used, and the theories that are used. Because you won't find a lot of guidance in individual research on how to move towards

conceptualizing a dyadic relationship and what you should even be studying in terms of how those two people influence each other. And especially when you're starting to design interventions. So, the methods are very important, but you'll find those; they're out there. And there's lots of places, but I'm happy to share some resources for people to find some of those workshops and free webinars. But I think the most important thing is really getting into the literature. It's a very specific type of research and not something that you can just rely on individual research to guide you in.

Jill Harrison:

You mentioned some of the interpersonal context. I'd like to get to some of the questions from our Grand Round attendees, and one was around that topic. One of our Grand Rounds listeners wanted to ask the question: can you please provide other examples of interpersonal level variables?

Dr. Karen Lyons:

Yeah. I do get this question quite a bit. And I will say that connected to this too, is sometimes people ask, "Well, what are dyadic outcomes? And are there any? And where are the measures? And should we be developing them?" I think there are two things that are related to this. One is that the outcomes are at the level of the dyad. That can be looked at in two different ways. One could be that you're literally just looking at quality of life, but you're looking at quality of life for two people at the same time and how it co-varies. And that's also considered dyadic research. The other is, you're really looking at an outcome that is capturing the interpersonal context, and that could be anything from relationship strain, or it could be about a mutuality, reciprocity. Pretty much anything that involves two people can be looked at, in terms of an outcome. Communication.

Dr. Karen Lyons:

But most of the time in dyadic research, those are not the outcomes. The outcomes are usually connected to health. But what's important is including the interpersonal concepts and measures in the study to explain those dyadic outcomes of health. I would say, if you looked at the dyadic research world, the vast majority of those interpersonal variables and measures relate to the relationship, the quality of the relationship. The amount of relationship strain between the person living with dementia and their care partner. How much communication is happening between them? Is there a lot of concealment? Care partners tend to downplay and not talk about their own needs because they feel guilty about doing that, so that's something that impacts communication. I talked a little bit in the presentation about symptom incongruence and whether people are on the same page. Do they see something different? Are they appraising something differently?

Dr. Karen Lyons:

Other examples would be collaboration and support. Those tend to be some of the biggest ones. Shared activities is another. Do they go for walks together? Do they do fun things together? Anything that's trying to pick up the interactions between them that would explain whether or not they have positive interactions, negative interactions, their interactions are more verbal or nonverbal. And again, that's going to depend greatly on the dyads that you're focused on and what's possible in terms of data collection. And it's also going to depend greatly on what the outcomes are, or if you're in intervention, what you're trying to change. So sometimes, I've even looked at things like dyadic self-efficacy, which can really impact whether or not they're engaging in symptom management behavior. How confident are people in that dyad? Do you have a dyad where a care partner has very little confidence and somebody with an illness has a lot of confidence, or vice versa? And do you have a dyad where they are

on the same page around care values and preferences, or a dyad where they barely communicate with one another and actually have very poor relationship quality between one another?

Dr. Karen Lyons:

The interpersonal variables tend not to be outcomes unless you're doing a lot of marital research. They tend more, in the type of work that we're talking about here, to be the magic of helping you to understand the dyadic health outcomes.

Jill Harrison:

Thank you. I have two more questions from our listeners. The first is: one of the challenges for designing a dyadic study is the lack of measures reflecting perspectives from persons living with severe dementia. Studies rely on caregiver report for this group. What is your suggestion or thought for those who are interested in this subgroup, especially for a grant proposal? Collecting both self-report and proxy report may be more suitable for people living with dementia in its middle stages. Do you have any thoughts?

Dr. Karen Lyons:

I do. And I think that is the challenge, right? And obviously, there are many different areas of research where there are great challenges collecting data from people. And so, I think I would say a few things. One is, whether or not dyadic research is the appropriate research to do in those situations. The other-- because I think I said this in the presentation: even though I am a dyadic researcher, all of my research is not dyadic. There are times when the answer to the question is not a dyadic answer, especially if we can't get data from two people. So I would say that, again, I think it's important to step back and say that it might be individual level research with an individual outcome, but I'm going to include whatever I can from this other person in the relationship. And I think that is completely okay, and it's very needed and a very worthy, valuable line of inquiry.

Dr. Karen Lyons:

I think if you have proxy data from people who can't self-report... And again, I think we really need to be very open to, at what point can we not have somebody self-report? I certainly think there's some research where we can clearly go into moderate stages of dementia. And for some people I've even been in studies where we have gone into severe stages of dementia, depending on the concept. But I completely acknowledge there are end-of-life situations and other instances where we are just not going to be able to get self-report data. And in those cases, my preference and my biases would say that we should not be substituting proxy data for self-report data, because we have too much evidence that it's not the same thing. So, what I would suggest in that circumstance is acknowledging that in the grant proposal. I don't think reviewers are unreasonable about this.

Dr. Karen Lyons:

If it's not possible to get self-report data, bring in the proxy data. But don't call it "proxy;" call it what it is, which is somebody else's best guess or appraisal of what that person is feeling. Because I think there's too much wrapped up in what's influencing that appraisal that makes it very unreliable as a substitution for that person. And I think we still learn a lot about why that family member or care partner sees or appraises the phenomenon in that way and tries to give their best voice, but clearly influenced by other things that drive that appraisal. And we've seen that. A care partner's care strain and depression and their own health status influences their appraisal of a person with illness.

Dr. Karen Lyons:

I think I would be candid and open. I think what really gets people into trouble is if they don't include a voice that is possible to include. And this person is bringing up something where it may be incredibly challenging to do it. But I think, as a reviewer, when I review, I certainly, I think, have trouble when somebody is not including someone in early to moderate stages of dementia, when that is possible.

Jill Harrison:

Thank you so much. The final question today is: what do you think that healthcare systems might do better to understand how members of the dyad influence each other's health or wellbeing?

Dr. Karen Lyons:

Yeah, that's a great question. I think the healthcare system is large, a culture unto its own. And I think it differs around the country and by country. I think where it can start is with clinicians. And that's where I see great potential and optimism and movement. I think, first of all, we need to have the research and evidence that suggests that we are not getting the full picture when we include only one voice here. And I think many people know that, but we're not studying it enough to have the body of evidence needed to drive changes in a healthcare system. I think that's one thing. I have worked with great clinicians over my entire career, both nurses and physicians and social workers, and I think many of them try their hardest to bring in both voices into the clinical setting.

Dr. Karen Lyons:

It's not always valued by that healthcare system or reimbursed by that healthcare system. And I think it often puts clinicians in very difficult situations of how to bridge gaps between two people who may be seeing things differently, and then, how do you move them towards shared decision-making or goal-setting? I do see that NIH is starting to really value that and is bringing up things like triadic research, which is probably a whole other topic here, but I think what I see, in terms of changing a healthcare system, is that we need the body of evidence to say that we are not getting the full picture, and we can't optimize the outcomes of both of these people.

Dr. Karen Lyons:

And I think that's a really important thing to keep in mind here. We have two people, and actually, in many, many cases, we have more than these two people, being impacted by one illness. And I remember that from support groups with caregivers of dementia persons, a very long time ago as a doctoral student. No illness should impact more than one person, right? But it does. I think we have caregivers and care partners and family members who are being impacted by this experience just as much as that person who has the illness or the dementia. And so, a way to be able to move forward in conceptualizing that dyad as a unit of care and being able to start really changing the healthcare system to value that, to focus on it, to train people in how to do that, to give them the time, reimburse the time, to focus on the needs of both; I think that's the change we really need. I just don't think it's going to be possible one clinician at a time. I think we need clinicians and many other interdisciplinary researchers and professionals working together to create a body of evidence, particularly informed by theory, that will really show us that the system is not working for dyads and families. It's too much focused on the individual.

Jill Harrison:

Thank you so much for that. I love ending on a high note about the aspirations for dementia care and improvement of healthcare systems. Thank you so much, Dr. Karen Lyons, for joining us today. On behalf of myself and other leaders at the IMPACT Collaboratory, I want to thank you so much for your time.

Dr. Karen Lyons:

Thank you so much, Jill. It was a pleasure to be here.

Jill Harrison:

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.