

Talking Through the Numbers – Episode 5

Caring for the Caregivers: Supporting the Informal Caregivers of Minnesota's Older Adults

Through interviews with researchers, community leaders, and service providers, Wilder Research Executive Director Paul Mattessich examines pressing issues facing our communities today to offer insight beyond the numbers.

This episode of Talking Through the Numbers is available online at <https://www.wilder.org/featured-media/informal-caregivers-older-adults>

Transcript

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Paul Mattessich: Welcome. Welcome to Talking Through the Numbers, a podcast produced by Wilder Research. Our goal: to provide insight on significant issues. We want to combine sound information with expert knowledge to enrich our understanding of things that affect our communities and our world.

Paul: I'm Paul Mattessich, executive director of Wilder Research. In this episode our topic is caregiving, specifically caregiving for an older person. Three experts have come to the studio for our conversation. Maureen Kenney is Director of Aging Services at the Amherst H Wilder Foundation, supporting informal caregivers of older adults through resource referral, education, support, and consultation in community and at the Wilder Community Center for Aging. Maureen has presented locally and nationally, helping build awareness of caregiving issues and supports available through community based programs. She holds a master of public affairs from the Humphrey School of Public Affairs at the University of Minnesota, and has worked in health care and the nonprofit sector for over 25 years.

Paul: Dorothea Harris leads the Volunteers of America, Minnesota Culturally Responsive Caregiver Support and Dementia Consultation, which was developed in response to the pressing need for culturally appropriate caregiver support and community education. She's developed and implemented new programs for African American, Hmong, and East African caregivers, and she has advocated for funding to support culturally specific caregiver support programs and expanding the number of diverse professionals. She

holds a master's in social work from Augsburg College and is a licensed independent clinical social worker.

Paul: Christin Lindberg is a research scientist at Wilder Research. Her work focuses on understanding the needs of older adults and caregivers to determine the best ways to provide support, including how to meet the needs of caregivers in cultural communities and the increasingly racially and ethnically diverse population of older adults in Minnesota. Chris has a master's degree in gerontology from Bethel University and is a certified professional gerontologist.

Paul: Welcome and thank you for sharing your time on this episode and on this very important topic. First of all, just to get started, and maybe this is for you, Chris, how do we define a caregiver? Who falls into that category?

Christin Lindberg: When we're talking about caregivers here, we're talking about the informal family members or friends who care for an older adult who needs some support in making their way through their day, taking care of the things that need to be taken care of.

Paul: So it is important to emphasize that today we're talking about informal caregiving.

Christin: Informal caregivers.

Paul: We're not talking about people who are paid and in organizations to provide care.

Christin: Yes.

Paul: Is there anything else that Maureen, Dorothea you'd add into the definition?

Dorothea Harris: Well, I like informal caregiver, of course. These are people working in the community and in their homes, but it's family members, loved ones.

Paul: How many people fall into the caregiver category, say in the state of Minnesota?

Chris: The 2013 figure is there are 585,000 caregivers.

Paul: More than half a million.

Chris: Mm-hmm. (Affirmative). Exactly.

Paul: Do we know for the United States, the country as a whole?

Chris: Yeah. It's about 40 million caregivers.

Paul: It would be in the category of informal caregiving.

Chris: Yes.

Paul: Do people themselves identify as caregivers or do they not think of themselves in that way? Would a caregiver know they're a caregiver? Maureen, do you have a thought on that?

Maureen: Yeah. That whole identity question, I think for the most part people don't identify as a caregiver. They identify as a spouse, as a son or daughter, a friend, a partner. I think it's key to normalize the conversation and maybe talk about it more as caregiving or caring as opposed to a label of a caregiver, content some people will never resonate with that

term caregiver. I think podcasts like this and dialogues in the community will help people understand that caregiving is a common thread through all of our lives. It's normal. It's been going on for hundreds and thousands of years, and it's really the crux of our communities that people care for one another. As people age we care for each other, so it gets tricky when we expect people to fit into a label, so I think it's more important to talk about caring.

Paul: Caring. Caregiving, caring. Dorothea, would you take that same point of view?

Dorothea: Yeah. I actually do. I think that our Western culture really wants to put people in a box and to make those labels, and especially people of color that have been through a lot of inappropriate labeling that they don't want a new label. That's why culture is so important, because we as professionals certainly want to serve people; however, we have to be able to, as Maureen said, communicate and normalize it and talk about it like it's something that people generally do in their homes regularly to care for one another, which they do.

Paul: Sure. I know at the risk of putting people into a box a little more right now in the conversation, do caregivers, people who are doing caregiving have any particular characteristics? With half a million people I'm sure there's somebody representing every demographic in there, but are they mostly one gender or the other or certain ages or ... Anything that we know about that?

Chris: Well, it would lean definitely toward more female caregivers, and there are a lot of daughters who are doing the caregiving. But you're right that it is everybody. It doesn't distinguish much.

Paul: And Dorothea, you focused very specifically in your professional career on cultural differences. Are there particular cultural differences we should be thinking about right now?

Dorothea: Yeah. I would say that one thing in general that normalizes who we all are as human beings is caregiving can be a lot of work. You can see I'm working with a Hmong girl now and she never even heard the word caregiving, but she has a mother and a father and uncle and grandma. The house is just full of older adults, and I could see the stress on her and just the overwhelmingness of trying to work herself and do the caregiving, so we certainly want to be open and look for the traits and the behaviors of people that are caregiving.

Paul: It seems that we've seen an increase in the volume of caregiving of older adults over the past few decades. Why is this? What caused the change?

Christin: Well, it's complex, obviously, but there are an increasing number of older adults. People are living longer and they're living with chronic conditions, and there's a need for informal caregivers to take care of this growing population.

Paul: So Chris, you're saying the aging of the population, that demographic, the fact that we're living so much longer, that explains a lot of it.

Christin: A lot of it.

Paul: And that's happening in Minnesota and elsewhere.

Christin: Yes.

Paul: Why is this growth that we're seeing an issue? Why do we need to talk about it? Maureen, you were saying earlier it's important to have podcasts like this and other avenues for getting the word out, but just why is that?

Maureen: Well, as Chris said, the demographic shift, I think I've seen that starting in 2011. There's 10,000 people turning 65 every day, and that's going to continue for a number of years, and our formal system can't be the only source of support and resources and care for the family caregivers. We need to shift a reliance that a service provider is gonna be there for every family caregiver, because the numbers just don't support that. It's about integrating the capacity to care within our communities, within the health care system, within our neighborhoods, within home and community based services. In order to meet the needs that are here today and are coming, we need to be able to deliver services differently.

Paul: Sure, and maybe there's no answer to this, but you mentioned numbers. Do we have a sense for, among the older people who need care, what proportion are getting that care from a formal service provider, an institution, organization, whether for profit, nonprofit, whatever, versus those who are getting care from an informal care provider? Do we know anything about that?

Maureen: I don't know what the statistics would be. [Crosstalk 00:10:02].

Paul: That's okay.

Dorothea: I know in minorities and people of color I'm sure that the numbers do not reflect people of color as well as they do the mainstream, and again, because of culture, people of color are caring for their loved ones as part of what they do traditionally. The African American as well as other people of color predominantly here in Minnesota experience some of the largest racial and ethnic inequalities in the health care system, as well as incidents of chronic disease in the country. I was reading that from the Blue Cross Blue Shield 2018 The Cost of Health Inequities in Minnesota. We have not only elder adults but we have a lot of minorities that are dealing with comorbidities, various diseases that need care. There's just a lot of caregiving going on.

Paul: That of course is an answer to the question of why this growth in the caregiving is an issue for us; why we need to talk about it. Are there other angles on that of why you think this is an important issue? Dorothea or Chris, looks like-

Christin: Well, caregivers are really the backbone of the long term care system. The older adults are choosing to often remain in their homes as they get older, and that requires the support of somebody to be able to do that. It saves money, it's less expensive than going into a facility into assisted living or a skilled nursing facility. We have to be able to keep the caregivers doing what they're doing. As we've said, the stress and exhaustion experienced by caregivers is really well documented, and if we don't take care of the caregivers and support them, the backbone is going to collapse.

Paul: So we need to think about caring for the caregivers themselves.

Christin: Exactly.

Maureen: Paul, if I can add, I know years ago I saw some statistic that 92% of long term care is being done in our communities by family caregivers. I know right now on the Department of Human Services' website, they quote that the value of that informal caregiving, that family care, is close to \$8 billion, which is more than the State of Minnesota spends on Medicaid expenditures and long-term services and support. The state is recognizing that the value that these family caregivers are providing, it would bankrupt the state.

Paul: We couldn't do it.

[Maureen](#): We couldn't do it.

Christin: Yeah, and to add to that statistic too, I know that the estimate is that caregivers provide 544 million hours of care per year in Minnesota. That's in Minnesota.

Paul: That's a lot of full-time equivalents there.

Dorothea: It is. Exactly.

Dorothea: And it's important for caregivers or professionals to really understand the value of how much caregivers need to have our support and for us to be there for them. They are so engulfed in being caregivers and doing what they're supposed to do, they don't even realize how much care, how much support that they actually need, so you almost have two patients or two clients. You have to be able to balance it out in order to be able to sustain keeping both of them together in a home.

Paul: What are the family dynamics involved in determining who will be a caregiver? How is that determined? Is it thought of as one person? Is it a shared responsibility? How does that interaction among family members usually occur?

Dorothea: Well, caring for an elder is a respectful and honoring ritual in many families. It's something that is a given. Not maybe or however it works out. It's a responsibility that's carried out by each family member. We see in cultures that might be the oldest son or it might be the daughter or a family member that's not actually a blood family but maybe a distant uncle or something. But it's always discussed. It's always something that the family system knows that this is the way we care for our loved ones, and as we're talking about elders, certainly everyone knows that they're going to get to the place where they're going to need to have some care, and because of this family ritual they know that it's going to be in place.

Paul: I don't know if the Bible has the term "aging in place" but we certainly have that term in our common vocabulary. What does that mean? When we talk about aging in place.

Maureen: I would say that I see it as having a choice. It's a choice in remaining living wherever you want to be, and that could be in the residence that you have lived in and raised your families, and living there with adaptations or services provided in that location. It's really where you call home and being able to have access to those supports that allow you to continue to live there. That can be in the actual structure of a home that's in the community. It's how you interact with whatever makes home home for you; getting to your faith community, getting out to see your friends, to interact with your neighbors. That's how I see it.

Paul: It's very holistic. It's the room you're in, the house you're in, the block you're on, the neighborhood, the system of supports and organizations you participate in, and so on.

Christin: Historically, people think of staying in your home or going to a nursing home, and that's sort of the counter to that. Everything Maureen said is exactly right, I think, but it also typically means not in a nursing home, more restrictive kind of setting.

Paul: Something you may all have some opinions on, if we just shift for a moment ... We've been talking of course about informal caregiving. But let's just think a little bit about the formal side. Are there services that we know are effective in supporting caregivers? You before Chris said it's important to care for the caregivers. What do all of you think about services that are effective in supporting caregivers that enable them to provide better care? Do those exist?

Christin: Yes.

Maureen: Yes. Absolutely.

Christin: They do.

Paul: Oh, yeah. Unanimity there. Dorothea, what would be an example?

Dorothea: Well, as I mentioned I'm just coming off of seven years of caring for my grandmother in our home, and prior to then she certainly was a very proud woman and wanted to go to assisted living. She did not want to bother me or the other family members, so we initially walked out to put her in assisted living, kind of a nursing home facility. It's a health care system, and you know what we're going through in our health care. There's just not enough workers, they're not paid enough, and her care just wasn't acceptable. We ended up having to bring her home.

Dorothea: The systems are out there. Of course, if you have a choice you'd rather be with family that's going to give you that kind of attention and love and support that you need. Institutions are doing what they can, but they're falling pretty short about now.

Paul: The institutions to care for older people; they have their strengths and limitations. What about you in that situation? Were there services that were effective in supporting you in the seven years of care you gave to your mother?

Dorothea: I did not see myself as a caregiver, even in my role as managing the caregiver department, and nor did I want to be a caregiver. I found it very respectful to be the granddaughter caring for my grandmother. I didn't really want the term either. That was my honor to be able to do that.

Paul: Maureen, any thoughts? What about services that are effective in supporting caregivers to enable them to provide better care?

Maureen: There's a whole menu of services that are available in our community from support groups, classes, evidence based programs. There's consultation, family meetings. What we have found at Wilder time and time and time again is we're hearing from those caring for older adults that connecting them with other caregivers is the most valuable resource we can do. Bringing people together, whether it be for a cup of coffee, for a more formalized support group, and listening. Having us listening as providers to the

caregivers, but having the caregivers being able to share with other caregivers, hear that they're not alone, hear that their situation is not as unique as they may think it is; I think the more we can convene people to come together so that they aren't isolated, they understand that the benefits, the joys, and the challenges of caregiving and that they will get through the particular frustration or challenge right now. We are trying to focus our energies on ways to build that convening of people, both as a destination but in the community, and how can we help others bring caregivers together.

Paul: That mutuality seems so important; that ability of caregivers to support one another, to maybe get information from one another, see how one another are doing, exchange ideas, and even just be there to listen if nothing else. Sounds important.

Maureen: It is, and I think of one example recently where I was in a conversation with a caregiver who was so isolated and she just needed to come and share her story, and yet she was in a very crowded world. She was living in a multigenerational household. She had a full-time job. She was very involved in her church community and with her neighborhood, going to the gym. But she still felt so alone 'cause she felt like nobody understood the challenges. So I think it's so important to recognize even when people appear to be surrounded by others, they still may be really feeling isolated about this role that they are currently in and not knowing how to process all of that.

Dorothea: I totally agree with you, Maureen. I remember recently going to a church and doing a little talk, and I asked ... I'm not looking for caregivers. I'm looking for those that have a family member or elder, someone that they're providing some kind of care and making sure they're safe and being taken care of. I believe all the hands raised in the church. That's what we're trying to come away from is a term, but something that needs to have support and some kind of gathering that you're talking about. We certainly have support groups and caregiver breakfasts, and things are starting to be very well attended, as long as we don't label them. We have to just be careful and make 'em feel like, "You're all one and you're all dealing with these same issues in your home."

Paul: Right. Again, those bonds, the mutuality, the similarity. What about the overall network of services when you think about "the system"?

Dorothea: People are telling us what they need. We have a menu of services; however we have to be good listeners and be able to have a cultural sensitivity to what works for other populations, and I think that that is going to move us along just a bit further where, for example, there are families that like to have in-services, people come into their homes, PCAs, those to help 'em out. Well, a lot of people are not open to having people come into their homes. You might have to find out what works a little better for them in order to keep them in their home, but to work it in a way that is acceptable to them.

Paul: It's gonna be important for us to continually learn from people themselves and continually improve what we're doing so we can be more effective. That's a good transition into change; taking action. Assume you could change things. What is one thing that you would do as an expert on this topic to address the caregiving issues that we have discussed? Anybody have an idea? Where would you ... Just one. I'm sure you have a lot of ideas, but what's one thing you would change? One thing you would do to address the caregiving issues we've discussed? Maureen?

Maureen: I'm gonna answer this question both as an expert, as you say, in aging services, but also as an expert as a family caregiver, and I really think we have a lot of space to improve in how the family members, those that have been identified as providing direct care, are involved as the care team in our health care system. I think all too often family caregivers are given directions, given recommendations, and not involved in those decisions. As much as we say we are moving in that direction, there is so much room to improve in that; because I truly believe that the health and safety and quality of care of an older adult is really dependent on the care that's being done in the home in addition to the formalized medical system we have. How can we integrate this better and really recognize the role that the family caregiver is offering?

Paul: Dorothea, how about you? What's one thing you would do?

Dorothea: I think that predominantly many families of color are very familiar and comfortable with caring for their loved ones, and I think that we have to provide an opportunity and a trusted space again to bring families back together to talk about this with the new generation coming in and maybe seeing it a little bit more differently. We are very capable of planning and working this out. We just need to come back to the family, come back to the village, and talk about what's the best way to do this, because we really like to keep families, communities, culture together. We have to learn to work with the mainstream system in helping us to do what we know we are capable of doing.

Paul: Sure. Chris, how about you?

Christin: Well, I think we keep looking for the magic key that's gonna unlock this and have caregivers accepting all the help that's out there that's been provided for them, and I think what we really need to do is just back up; we need to listen to the caregivers, respond to what caregivers are saying, we need to customize the services for each individual situation, and we need to be family centered. We need to be supportive of the families, as Dorothea said, and the communities. We want to lift people up to be able to do the work, and I think as Maureen said too, in the medical system we have to look at the family unit. We have to be supporting everybody who's involved.

Maureen: If I can add, 'cause I think there is a lot of talk about family caregiving, and we need to define family as also the community that a person chooses to be in that relationship with; because there's been a movement lately, I'm really talking about solo seniors and people who don't necessarily have a spouse or children. When we talk about family caregiving, it can be a broader definition, maybe it's friends and neighbors leaning in in that space, so as not to alienate those that maybe don't have that traditional family that we so often talk about.

Paul: Maureen, what about policymakers? They have a lot on their mind, they don't always have a lot of time. What's the message? If you were sitting in the governor's office, and of course we're nonpartisan; we're bipartisan. But if you were sitting with the governor right now or if you were addressing a committee and the legislature, what's the primary message that you would want to give them regarding how they should address caregiving issues?

Maureen: I would encourage them, because they know who their constituents are, and we have a large older adult population and we also have a large caregiving population ... I would

really encourage them to look at every public policy proposal, bill, legislative action that comes before them, to look at it through the lens of "How would this impact an older adult in our communities?"

Paul: A caregiving lens, an older adult caregiving lens is what you recommend.

Maureen: And "How does this impact the family caregiver?" That can be anywhere from bonding bills and transportation-

Paul: Yeah. Everything.

Maureen: To how we're funding long-term care, and if we're reducing that, how are we then boosting community based supports funding? There needs to be a balance. If they could just look at things through that lens, I think we would see some movement in being a more caregiver friendly community, caregiver supporting community.

Paul: Caregiving lens for all policies. Dorothea, how 'bout you? You're sitting there with the Gov. What would you say?

Dorothea: You know what, I totally agree. I would just make sure that health equity is really inclusive. Long term care is inevitable. If we can be more proactive know that it's rushing down the pipeline, I would really, really, really agree that we have to look at it from a long term care perspective, 'cause it's a lens that is going to be able to catch people as they come through this pipeline.

Paul: Sure, integrating it into our approach to long-term care. Chris, as a researcher or another persona or whatever, what would your-

Christin: I think we need to look at the bottom line is the relationship, and I think relationships take time and we just have to be patient. We need to build that in. It isn't always gonna be about saving money; that that has to be a piece of it is just being patient. But also on the financial side I think that there are some things that we could do, and I think sometimes policymakers want to have that kind of fix. I think that we can be providing financial assistance with tax credits for caregivers. I think that we can be expanding consumer driven models that would allow caregivers and families to receive funds and decide how best to use them within their own, unique situations.

Paul: What about advice for just a typical person? Typical person out there in the community. They don't have a lot of time necessarily to spend on this issue, but maybe they want to be helpful. What could the typical person in Minnesota or the U.S. do to address the issues we've been discussing? Dorothea, an idea?

Dorothea: Yeah, well, I would say start talking about it, even if you don't have the blood relative. In many families we're not blood, we're just community and that's just kinda how we roll. As Maureen mentioned about the study about the solo seniors, I think that everyone has some kind of network or someone, so start voicing what it is-

Paul: Get the word out.

Dorothea: That you would like to have your quality of life be as you age, and start putting some of those things in place. I even thought about Medicare. Maybe that should be a question. It's inevitable. Nobody's gonna leave this earth without caring for someone or being

cared for, so let's take it up a couple of notches and open up space to be able to talk about this a little more.

Paul: Chris?

Christin: Oh, I absolutely agree.

Paul: You ditto.

Christin: Yeah, big ditto. What Dorothea said.

Paul: Maureen?

Maureen: I agree as well and in that conversation, if you know there are people caring for a spouse or parents, anyone in their lives, asking them "How's it going," and then stop and listen. Don't give the list of "Well, you should do this," and "You should do that," and "What I did." So often, people want to be helpful and they want to tell you how they did it, and I really think you gotta give that space when you're checking in with someone that you know is caregiving, to check in and really listen. We need to do more listening.

Paul: Good. So Dorothea, Maureen, as we close, question for you. If people want more information about what we've been discussing today, if they want more information about caregiving, where might they look for that?

Dorothea: Well, we have a culturally responsive caregiver support and dementia service hotline, and it's in four different languages. I would welcome our listening audience to give us a call.

Paul: We'll post a link on our website too, so we'll get that information out for sure.

Dorothea: All righty. Our number is (952) 945-4034, and again, it's in four different languages so just pick up the phone and just call and someone will respond to you.

Paul: Maureen? Other ideas?

Maureen: Well, there's our Wilder website. Wilder.org. On our website we used to list an exhaustive list of resources, and we're now focusing more on stories about family caregiving and in different opportunities, and really looking to the local resources like the Senior Linkage Line and minnesotahelp.info for that repository of a list of resources. I really would just recommend that families, individuals connect with their local resources to know what's available locally. I've heard from a lot of caregivers that there's so many resources out there that it gets overwhelming, but the national ones that I tend to go to are the National Alliance for Caregiving, the Family Caregiver Alliance, AARP, and most recently I've been really excited about the work that Next Avenue is doing. Doing some stories, some interviews, and giving some tips in a very modern, relevant way. So there's a number of resources and we can post them on the website.

Paul: Great. Thank you. So thanks again to our three guests: Maureen Kenney from Aging Services at the Amherst H Wilder Foundation, Dorothea Harris from the Volunteers of American, Minnesota Culturally Responsive Caregiver Support and Dementia Consultation, and Christin Lindberg from Wilder Research. Please visit our website,

www.wilderresearch.org for more information on this topic. And if you have suggestions for a future podcast, please let us know.

Paul: I'm Paul Mattessich from Wilder Research, and I look forward to Talking Through the Numbers with you on other topics.

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