

Podcast: Unseen but essential: How caregiver policies impact healthcare with Mina Raj

Speakers: Kristen Chandler (host), Mina Raj (assistant professor of kinesiology and community health at Illinois)

Kristen Chandler

Hello everyone, and welcome to the Illinois Policy Unpacked podcast, where we inform the policy conversation in Illinois and beyond. I'm your host, Kristen Chandler.

Today we're joined by Mina Raj, assistant professor of health and kinesiology at the University of Illinois Urbana-Champaign, whose research spans kinesiology, community health, and nutrition science.

In 2016, the CARE Act was passed in Illinois, but according to Mina's latest study, we're missing key data to evaluate its success and ensure long-lasting impact. We'll further explore her work on caregiving, the impact of Illinois' CARE Act, and how policy can better support caregivers, who play a vital role in our healthcare system. Mina Raj, welcome to the podcast.

Mina Raj

Thanks for having me today. So, my background is in health administration and health policy, and specifically, I'm interested in supporting family caregivers of older adults as they navigate the health care system. So, my research looks at how can we meaningfully engage these family caregivers, who are often responsible for coordinating healthcare, managing medications, attending visits with their older relative. How do we make sure that they are well informed and well-equipped to support their older relative in the home?

The Care Act, which stands for the caregiver, advise, record, and enable act, is really hoping to meaningfully engage family caregivers in the hospital setting. We know that that is a very stressful time for caregivers, for their older relatives. They may leave and not really know what to do when they're back at home, and that's when we start seeing older adults returning to the hospital with maybe complications or just issues that arise because of errors that were made in the home once they've left.

If we can make sure that caregivers are well informed, educated, and even trained on specific skills before they leave the hospital, then we can reduce that incidence of having to return. So that's what the CARE Act tries to do, is identify caregivers and designate them in the medical chart so that upon discharge, those caregivers are given specific education on what to do when they get home to support their relative.

Kristen Chandler

Yeah, that's great. I remember when I was reading your study, you said that sometimes hospitalists are less familiar with patients and their situations, and so they'd be less likely to know they have a caregiver or to include them. So, this kind of alleviates that gap a little bit. Has there been an increase in the number of caregiver roles in the past decade or so?

Mina Raj

Absolutely. There was a study that came out pretty recently by Jennifer Wolfe and her colleagues in the journal of Health Affairs. They found that between 2011 and 2022, the number of family caregivers across the US increased from 18 million to 24 million, and that could still be an underestimate, because we know that family caregivers often don't self-identify as caregivers. They feel that they are just helping someone else. So, making sure that they are documented as caregivers is already kind of difficult to do. In Illinois itself, we have about 1.5 million people who are family caregivers, and again, probably a larger number than that, especially when you include long-distance caregivers, for example, so people who might be caregiving from another state, and they're not physically present. But they're still doing a lot of those caregiving tasks, whether it's calling doctors or helping their relative with grocery shopping or other tasks like that.

Kristen Chandler

Yeah, absolutely. Is there any way to include caregivers virtually? Is that a part of the CARE act at all?

Mina Raj

Not right now, but that's definitely something that our studies show could be really important. Some of our earlier studies in our lab looked at like family caregiver involvement in telehealth visits, for example. So, when caregivers accompany their older relative to an in-person visit, that's pretty natural. They're walking in the door. They're never asked to leave the room or anything like that. But when it's a telehealth visit, there's a little more opacity about how to include that caregiver. Sometimes, there are practitioners who might say to the older adult. "Oh, can you make sure you're in a private room and that there's no one in the room with you?" and so they might ask their caregiver to leave, but then their caregiver doesn't know what's going on.

The Care Act is really focused on the specific discharge point from the hospital, so when the patient is about to leave, that's when the caregiver is informed and educated. But it could be really helpful to expand that option to include telehealth for the same reason. So, there may be one caregiver who's transporting the older relative home after something like a surgery, but

maybe a different caregiver is actually the medical decision maker, and they need to also know what's going on.

Kristen Chandler

Great, thank you for highlighting an overview of the CARE Act and how it can be beneficial. As you mentioned earlier, family caregivers can help avoid institutional care and reduce medical costs by preventing things like medication errors and falls. What role can government policy play in supporting these unpaid caregivers while also helping to lower medical expenses?

Mina Raj

Sure. So, there have been multiple studies showing that when caregivers are well trained and educated on things like medication management, wound care, post-surgery rehabilitation, that this can actually reduce rehouse readmissions as well as hospitalizations and healthcare use among older adults. So, it can definitely reduce costs on both ends, as well as just general burden associated with having to receive more and more complex healthcare.

The example that I think can help really clarify this is medication management. In the case where an older adult – who we know is often prescribed multiple and like many different medications – they might go home and need help with managing all of those. So, meal timings, which medications you take in the morning, what needs to be eaten with food or a beverage versus what shouldn't be. If a caregiver isn't trained on that directly, their relative may be cognitively limited or have confusion or delirium when they're in the hospital. And so, you really want someone who understands how to manage all those different medications.

So, when that patient goes home, if caregiver isn't trained, then they're more likely to be readmitted because of two medications interacting with each other. For example, government can play a really important role in investing in state community and healthcare organizational programs to make sure that these caregivers are trained at the federal level. For example, there is a recent change to the Medicare Physician Fee Schedule, which enables a certain set of clinicians to bill for training caregivers on things like speech or language pathology or physical therapy, for example. And so, continuing to invest in those types of caregiver training programs can be really helpful. That program is specifically for the outpatient setting. Making sure that government policies that train caregivers for a wider scope of health conditions and needs in the community as well as in the hospital, can be really helpful.

Kristen Chandler

Yeah, that's really great to hear. It improves communication between physicians the caregivers and the patients. Anecdotally, if, even if my dogs have something wrong, they're sent home with four different medications, me with a clear mind still thinks that's a lot to manage for my

own dog, let alone somebody who has just come out of the hospital may not be have the clearest mental state having to handle all of that. So that's really great that they're trying to bridge that communication gap. You mentioned earlier that there has been a significant increase in caregivers from, I think you said 2011 to 2022. Do you forecast that there's going to be an increase in the upcoming decade as well?

Mina Raj

Definitely. Our population of older adults is growing rapidly, and so the number of family caregivers is definitely expected to increase. On top of that, we have younger older adults who are getting more complex chronic conditions earlier in life, and so they will need more complex care, more advanced support from family caregivers. And then when we add Covid to the mix and the effects of long Covid and issues that kind of stemmed and began during Covid, we saw more caregivers that had to take on roles in response. Abilities that they weren't previously taking on. So, with that, we also have started to see more young caregivers. So, this includes young adults, adolescents and even children who are helping parents, grandparents, other relatives manage healthcare tasks.

Kristen Chandler

Yeah. So it does. It's not one-size-fit-all. Caregivers and patients could look like any age range. You touched on this a little bit earlier, but caregivers are often left out of telehealth and hospital visits, especially when they don't have a relationship with the care team. What changes could help better integrate caregivers into the health system?

Mina Raj

Sure. So definitely training, as I've mentioned previously, with the CARE Act and the caregiver training services. I think from the clinical perspective and the organizational perspective, we also have to reconsider what the healthcare team looks like. There have been several initiatives to think about family members as Partners in Care, rather than visitors. And that really, that really began during Covid, when we were seeing that when family members aren't present in the room, what a difference that can make to a patient. And so we need to think about how to train clinicians and staff in the healthcare system on how to meaningfully engage with caregivers – when to include them, when to distinguish between different types of caregivers and their different roles. For clinicians, some of our studies have shown that they can actually learn a lot from caregivers who can provide additional information that patients might not provide.

So, states kind of opt in to implementing the CARE Act, and this means that organizations so hospitals will add a question about designating this caregiver to their medical chart. But what we found is that many clinicians don't know why that question is there, and so they may not

consistently fill it out or really have that conversation with the patient about, who is the caregiver, what? What is their role in your life? And so, the actual implementation is unclear in Illinois in terms of other similar policies. Some concerns I've heard about the Caregiver Training Services policy that I mentioned earlier through Medicare are, is it really fair to bill for hours training a caregiver, and will caregivers opt into that? Will they use the service if they know that they're being charged for it? And how much do caregivers have to pay for that type of service in the end?

Kristen Chandler

Yeah, absolutely. Thanks for highlighting that. In your report, you outline five policy priorities to strengthen the CARE Act. Could you please walk us through those recommendations?

Mina Raj

Sure. I'm just going to move my pages here. The first priority area that we highlighted was to actually consistently, and in a standardized way, identify and designate caregivers. So, this is really the first step that typically should happen upon admission to the hospital, where the patient is asked, "is there a caregiver?" and what is their name, and that caregiver is then educated at discharge. If we're not doing that first task of designating caregivers, then the rest of the structure and process doesn't work, so we need to systematically make sure that we're doing that and that clinicians are aware of why this is important. So that would be more at the organizational level. So, making sure that this policy is prioritized in the clinical workflow.

The second area that I highlighted was to expand telehealth options. So, I mentioned earlier this example of long distance caregivers who might not be able to drive or fly at a moment's notice to help discharge their patient from the hospital, but they might be coordinating other people to do that work when the patient goes home, so making sure that we have options for them to virtually be involved in discharge training, and that becomes kind of a train-the-trainer model, so they might then go back and train other caregivers, or neighbors, for example, to help with tasks in the home.

The third area is to think about Medicaid waiver programs and investments. Those make sure that caregivers, once they go home, still have an option. So, once you leave the hospital instead of going back, because, you know, if some education or training was missed, how can we use community-based programs that can help caregivers by answering questions that they might have once they go home.

The fourth priority area is to really consider young caregivers. When children, for example, or adolescents, accompany an older relative or older adult to the hospital, we might not think of them as a caregiver, and so we might miss that opportunity to train them. One of the studies

that my team conducted a few years ago with young adult and child caregivers found that one of their main priorities and needs was for training and education related to health care, and many talked about how this lack of training was related to their mental health. When they go home and they're in charge of coordinating care or managing medications, and they don't know how to do that, it can be very distressing, and the resources for young caregivers is very limited right now. So, making sure that we're including them in that policy, and really calling them out there.

Kristen Chandler

That would be great, because it's healthcare policies, or insurance policies can be really unwieldy, right? Like the difference between coinsurance and a copay and how to get prior authorization is complicated for someone to do for themselves, let alone someone who is not as familiar with a with a policy. So, yeah, something like that would be extremely beneficial.

Mina Raj

Yes, and it's, it's complicated for adults. So imagining, you know, a 16-year-old trying to navigate health insurance for their grandparent is, is really, is really complicated. And then on top of that, how to change a bandage for a significant wound is, you know, just even, even more challenging.

And then the fifth priority area that I highlighted was something we talked about with integrating community health workers, direct care workers, and thinking about how we can invest in their workforce development and professional training so that they can actually help the healthcare system and healthcare organizations. One concern when it comes to CARE Act and implementation of more programs and processes in healthcare is that clinicians and staff are already burnt out. They already have so many documentation requirements and so many patients that they're managing and different responsibilities within that environment and so adding another thing to the list can be a barrier to change. So, thinking about how we can include direct care workers or community health workers in a hospital setting, for example, so that they could train caregivers, or maybe having family caregivers that train other caregivers could be another policy investment and priority so that we're effectively using those resources, and we're not overwhelming the healthcare system either.

Kristen Chandler

Okay, great. Thanks for clarifying that. Another barrier you mentioned in your analysis is lack of data around the CARE Act, which can be harmful in implementation and evaluation for the program success. Could you tell us a little bit more about how data might be helpful for that, and what types of data would be helpful to analyze the program?

Mina Raj

Sure. This is something I think about a lot, because there is a lot of opportunity when it comes to implementing and developing policy. Sometimes, we end up in a chicken-and-egg situation, where we don't have the data to inform a policy, but we don't have a policy to help us get that data. So in terms of the CARE Act, most fundamentally collecting information on which organizations are actually implementing and practicing the CARE Act would be helpful. Which organizations have included that question in their medical record, which organizations are consistently documenting and designating caregivers, and what are some of the facilitators and barriers to actually implementing and documenting that information.

Also understanding clinician and staff awareness of the policy would be helpful data to gather so that we can figure out how the policy might need to be modified or enhanced to make sure that it's not another task, and that it's actually helpful in being included in the workflow. Additional types of data that are really important are designating caregivers and educating them on discharge, and having information about patient health outcomes and caregiver outcomes would be really important to have. That is really what drives policy change. In the end, we want to see that quality of care is improving. We want to see that costs are being reduced. We want to see better outcomes in patients. So, if we could actually track patients over time, once they leave a hospital, was a caregiver designated? Was that caregiver actually educated during discharge, and then what happened to the patient a week after, a year after and how are they doing, including caregiver outcomes, could also help us have a more comprehensive understanding of what we call "spillover effects."

When we think about policies to help a patient, especially in this scenario, it can also help a caregiver. For example, one that comes to mind is diet modifications. So, a caregiver might be helping an older adult with diabetes, and that's why they went to the hospital. And if the caregiver is trained on discharge about how to modify their diet to help them better manage their diabetes, the caregiver might also learn some information that could help them manage their own diabetes. And so, with one one intervention, you've actually helped two people, and that caregiver might have children or a partner or friends with diabetes, and they might then share that information, and then that network of people who have benefited from just 20-minute intervention is just growing. So those are some of the data points that would be helpful to understand how the policy is working as is, and then how we can actually improve it if needed.

Kristen Chandler

Yeah, absolutely, that's really helpful to share with the public and with legislators and other people involved with the CARE Act. I know that healthcare data is notoriously difficult to get a hold of, but it sounds like it could be really beneficial in looking at the program success and how

it could expand, including some of the suggestions you had. Great. Thank you for sharing that. Mina, where can listeners learn more about your work?

Mina Raj

I lead the Aging, Caregiving, and Technology lab within the Department of Health and Kinesiology at the University of Illinois Urbana-Champaign. We have a lab website, if listeners want to visit that.

Kristen Chandler

We hope you found today's conversation on the CARE Act insightful. A big thank-you to our guest, Mina Raj, assistant professor of health and kinesiology at the University of Illinois Urbana-Champaign, for highlighting the importance of legislating access and support for caregivers, especially as the number of caregivers in the United States is on the rise. Stay tuned for more discussions that inform the policy conversation in Illinois and beyond. Until next time, thanks for listening.