

# Daughterhood the Podcast

## Episode #49: African American Dementia Caregiver Daughters: The Important Need for Support with Dr Kalisha Bonds Johnson

Links for information mentioned during the podcast. **Show notes below the links.**

**Decide Research Lab** and to **REGISTER FOR CURRENT RESEARCH STUDY AND** Kalisha Bonds Johnson email address <https://www.nursing.emory.edu/pages/decide>

**Benjamin Rose Institute on Aging** <https://www.benrose.org/documents/20143/0/2016-Annual-Report.pdf/2d4bdfc1-c1b4-27c4-7246-a533b784df62?version=1.0&t=1556813761245>

**J Marion Sims:**

<https://www.npr.org/sections/thetwo-way/2018/04/17/603163394/-father-of-gynecology-who-experimented-on-slaves-no-longer-on-pedestal-in-nyc>

**Jasmine A Abrams** – Carrying the World With the Grace of a Lady and the Grit of a Warrior: Deepening Our Understanding of the “Strong Black Woman” Schema



abrams-et-al-StrongBlackWoman.pdf

**Jasmine A Abrams** – Underneath the Mask of the Strong Black Woman Schema: Disentangling Influences of Strength and Self-Silencing on Depressive Symptoms among U.S. Black Women



JAbramsUnderneath-1506255.pdf

**Cheryl Woods-Giscombe** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3072704/>

**The Body Keeps the Score** by Bessel Van Der Kolk, M.D. <https://www.amazon.com/Body-Keeps-Score-Healing-Trauma/dp/0143127748>

Running time - 41:38

**Rosanne** 00:01

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**Rosanne** 01:05

Hello, and welcome to Daughterhood the Podcast. I am your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system. Provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in Daughterhood. Dr. Kalisha Bonds Johnson is an assistant professor on the tenure track at Emory University's Nell Hodgson Woodruff School of Nursing in Atlanta, Georgia. She earned her BSN, MSN and PhD in nursing and specializes as a family psychiatric mental health nurse practitioner. In 2019, Dr. Bonds Johnson earned her PhD from Oregon Health and Science University, where her studies focused on how the caregiving experiences of African American dementia pairs, that is African American persons living with dementia, and their African American family caregivers were associated with their quality of life. In our conversation today, we discuss her past and current research regarding African American Dementia Caregivers and their care partners, the challenges of accessing needed services, the disparity in health care, and the important need for support. I hope you enjoy our conversation.

**Rosanne** 02:49

Alzheimer's and other dementias affect African Americans at higher rates than other ethnic groups. Yet African American older adults use fewer formal services. Your research looked at that through three sectors, formal services needed expectations of formal service providers, meaning the expectation that the primary doctor would be the initial contact and be able to provide guidance to services and formal service. What were the results of your research?

**Dr Kalisha Bonds Johnson** 03:16

It was interesting. So we took a lot of articles and to give everyone context formal services just basically mean healthcare services in the gerontological or older adult research. That's just one of the I guess, researchy terms we use formal services just means it's not informal. So it's not family, it's coming from a healthcare system typically. And so for the African Americans across these studies, I think it was 14 studies in the in the research that I did, the main sort of themes that came out with it, there is this formal

service need, as you mentioned, there are these expectations of these formal care or health care per providers. And then how much of this formal service is actually being used. And, um, caregivers want formal services, they want health care services, they want these things, which was kind of this maybe not controversy, but this concern in the literature was like, is it that African Americans don't want these services. And so that's why they're not thinking. But it did come out that they want them. They recognize that they need them. And sometimes, depending on the characteristics of the caregiver who is seeking the services, they tend to seek more or less. And then the expectation really did come out is that they wanted physicians to sort of be a part of the team and really have insight on their choices and what decisions they make. And we know that health care systems are set up like that, like you might get 15 minutes with my health care provider, right? So to say, Here are your choices, like whatever that decision is, here are the options. Now let's decide in this time what We want to do and again, you might have other family members that weren't able to attend the visit. And so you're wanting to pull this the whole team together. And that just isn't how healthcare is set up now. And then lastly, when we think about formal service use, like it did sort of depend on the health care giver. So those family caregivers that felt like, you know, they had a lot of caregiver man for you, they seem to feel pretty confident and not necessarily seeking services. And so this paper really is sort of where my work is going. Now, with this. I do we really don't know, what is driving the limited use of healthcare services for African American older adults and their family caregivers.

**Rosanne** 05:48

Okay. Well, and it's interesting, because we know that there's a disparity in health care. We do. We know that. I mean, from from thinking that pain tolerance is different to kidney functions are different. Yeah. So it's, there's there's a different level, that it's almost like, it's almost like viewing two separate medical fields.

**Dr Kalisha Bonds Johnson** 06:13

Well, it's convenient. Only when it's convenient.

**Dr Kalisha Bonds Johnson** 06:17

Yeah, we're two totally different species, almost at certain time. So like, you know, like, couldn't possibly feel like people, African Americans. And I'll probably go back and forth between those two. But as we were talking earlier, when I think about African American, I am speaking about individuals of African descent, who lived in the United States and also had enslaved ancestors were when I say black, I'm thinking about the whole black diaspora. So those are individuals who may have immigrated here, live somewhere else, often their identity shift when they come to America, because they are assumed to be African American. But there is sort of this different lived experience. And when you ask different scholars, they will probably give you different answers. But that's just my little two cents. But I said all that to say, you know, the idea that African American skin must be so much thicker than that has been in white scan, so they don't feel pain this time. But when you think about how different things in modern medicine were formalized, tested, you know, we think about Marion Sims in gynecology, he perfected different procedures on black enslaved women that he'd been used on non Hispanic white women. So the concept was, we weren't two different species, then when we think about Henrietta Lacks sales with cancer, we weren't too different. Totally, you know, I don't know, either two could be the same. So it's almost like the healthcare system that powers that be the policies and practices at

play, work to benefit the majority all the time. And for those of us who are not at the majority racial or ethnic group, we are used to benefit the majority, even if it's at our detriment. I'm sort of under the guise of well, they're different, they're slightly different. And no one has been able to scientifically so that were different, but because of those differences in lived experience, and how one is treated when they enter a health care system, I think that's where we get a lot of the difference that we see in the health disparities.

**Rosanne** 06:17

Yes. Okay.

**Rosanne** 08:31

Absolutely. And I think it would prevent someone from seeking that out as well. Yeah. Because if you if you know, you're going to be treated differently. It's not like you're gonna go running in there and be like, Hey, can you help me, you already know you're not going to be helped by? And that's a barrier in and of itself?

**Dr Kalisha Bonds Johnson** 08:49

I agree. I think it is for sure. And so that's why the work I'm doing really is sort of, lets go to these adult daughters who are caring for their parents who have some forgetfulness and see, are you seeking healthcare services? Are you aren't you? And if you're not, and why am I? And is there something that we can do? Be it the healthcare system or empowering these adult daughters to help them with navigating the system more effectively for parents? So I'm gonna tell you, I'm a nurse. I know the right lingo. I'm going to practitioner know how to talk the talk, but going into appointments to assist my grandmother who raised me from almost birth, I was two, when she's been I was placed in her custody after my mom passed away, recognizing that I know how to talk to her doctors. I know what to say, I know what questions to ask. I know what resources to mention. So I have a little bit of a leg up in navigating that for her is what sort of made me think, what about the families that don't have a nurse that don't have a Kalisha in their family? How are they navigating this because, you know, even as a clinician I'm like, spouses, you know, you pretty much get access, you can look at charts, you can add, you know, you get a lot of access to ones providers. If you're taking your child into an appointment, a lot of access as an adult daughter, or adult son or nephew or rhyme to navigate hair for an adult, parent or uncle. There's so many barriers

**Rosanne** 10:28

At every turn. And

**Dr Kalisha Bonds Johnson** 10:30

We don't make it easy for you.

**Rosanne** 10:31

No, no. And it's when you're caring for a child. It's like everybody wants to help. This is my child, this is a situation, what can we do? Oh, you've got this, this, this and this. But when it comes to caring for your parent, because they're older, it's like, well, no, we don't, Oh, they got old. It's not we can help in this, this and this, it's well, they're old. What do you expect? And that's horrible, horrible.

**Dr Kalisha Bonds Johnson 10:56**

As a society, it's like, you get old, you fall off the cliff, hope someone's there to catch you hope your family has money and time and resources, because we don't have much for you.

**Rosanne 11:06**

No, no, i Nobody can, you know, to think of the cost and how much it cost, it's nearly impossible to save for it. And the amount of money that it cost per month is more than people have paid for their mortgages in their houses all their lives.

**Dr Kalisha Bonds Johnson 11:21**

Yes.

**Rosanne 11:21**

And then everybody thinks, Well, you just run out of money and you go on Medicaid, which is you get what you get, you don't get upset, because, you know, this is what we have, this is all we can offer you. And by the time you get to that point, it's too late to bring anything else in. You know, like I said, I love you all of your researches is riveting to me and what you found with, especially with dementia, caregiving, and you know, dementia, caregiving is a different meat grinder. It's a different, it's just it's different. But there's so many different levels of it from the change in the relationship between the two of you to the changes in your care partner. What you found, which was interesting was, the more the relationship between the people, and when you involve your care partner in the decision making, it seemed to help. Can you talk to me about that a little bit?

**Dr Kalisha Bonds Johnson 12:17**

Yeah, so I was really interested. And just focusing on this sample that I was given from Dr. Carol Willard out of the Benjamin Rose Institute of these African American dyads is a word I use a lot in my work, which just means to and here I'm using it to people, so it's the person living with dementia, and then their care partner or family member who was assisting in that care. And so I was really curious to see what was happening in these relationships, like, did it matter was the quality of life affected? And so I definitely want it to look at, like sort of the idea of does it matter if you're cared for by a spouse? Or are you cared for by and a non spouse is I think I broke it up because I didn't have enough to tease out in the daughters and sons in that that way. But daughters, sons nieces, grandchildren were like non spouse and yet spouses. And then I was also curious in what we call daily decision making. So it was things like what time I'm gonna go to bed, or what clothes I'm gonna wear, what maybe what I'm going to eat for breakfast. So it was involving that older adult in the decision making, and that comes from our own lived experience. So my grandmother started taking care of me in her 50s When I was two, he's now almost 90, she probably will not be thrilled when I say that so 90 next year. And I can't make her do anything about it would be so disrespectful to force her to do anything she didn't want to do. So I was really interested in this idea of how involved in one state even when there's forgetfulness, even when there's cognitive decline, even when there's dementia, and then also what that relationship quality might look like. And so as you alluded to the adult dog sign, that's where I go now the non spousal caregivers, again, predominantly adult daughters, but a few other relationships mix in had worse quality of life, and the person they were caring for when compared to this spousal caregiving pairs or dyads,

which is not what we typically see in the literature when we look at the non Hispanic white. For them, it's typically that the spouse is we're having a hard harder time and they equate that to longer hours caring for the person and being there more consistently, but for these non spouses, they were having a really hard time and also when the person living with dementia did and feel like they had a say or a voice in that decision making that sort of daily decision making. They also had worst quality of life. And then when the caregiver reported more dyadic strain some more issues in that relationship with the personnel caring for they also had worse quality of life. And so this is interesting, I might be onto something here. And so I started looking more intentionally at caregivers, because you know, there's lots of research about, you know, African American black caregivers, non Hispanic, white or Caucasian caregivers, and Asian caregivers and Hispanic caregivers, but there wasn't a lot of like drilling down to see what it's gonna look like, what's the makeup, and when you start looking at African Americans, they're predominantly adult daughters, middle aged adult daughters. So you're not done with your career, you're often still caring for someone other than your parent. Financially, you're not in the same place, as when you think about these non Hispanic white caregivers who are typically spouses who are probably often at retirement age, or really close to retiring. And so just the financial trajectory will be different. The life goals plan, the day to day happenings, all of that's going to be different. But we really haven't taken the time and research to tease that out. We just kind of compare caregivers across the board and say, well, these are doing better than they are and and then one thing that comes up consistently is African Americans seem to have a lot of positive caregiving experiences. What it's really hard to say, this sucks mom and dad. Yeah, it's a lot easier when it's your spouse to be like, you know, this really sucks. And I don't want to do this anymore. I can tell my husband all those things. Right? I'm not gonna tell my grandmother that.

**Rosanne** 16:52

No, no, of course

**Dr Kalisha Bonds Johnson** 16:53

Even if it's true.

**Rosanne** 16:54

I don't think she take kindly to that.

**Dr Kalisha Bonds Johnson** 16:56

What? Sorry had a moment. Let me get myself together. Where if my husband said what you heard me, do I need to repeat it, you know? It's just a different dynamic.

**Rosanne** 17:07

Right, right. Well, and it's an, you know, in the African American community with knowing that we're not going to be helped, like, we're, we're it. So we, you know

**Dr Kalisha Bonds Johnson** 17:19

We're all we got

**Rosanne** 17:20

We're all we got. So you tighten the reins, and you're caring. So it's harder, I would think, and I believe your research backs this up to reach out for that help. Because what do you do? And then even if you do reach out for that help, Are you betraying for lack of a better word?

**Dr Kalisha Bonds Johnson** 17:38

Yeah

**Rosanne** 17:38

That system that you're in?

**Dr Kalisha Bonds Johnson** 17:41

Yeah.

**Rosanne** 17:42

And how, how does? You know? How does that shake out?

**Dr Kalisha Bonds Johnson** 17:45

I'm still figuring out how it shakes out. But you're right. As you were talking to made me think about one of the daughters I interviewed for my current study. He has placed her mother in an assisted living, and it's a swanky assisted living. I mean, I think she is paying. I mean, if I had to guess, probably 10,000 a month

**Dr Kalisha Bonds Johnson** 18:05

Easily. Beside, you know, a little more generous. Yeah, rent, mortgages, other regions of the United States, but still, like, I mean, easily, she's probably paying that. And her mom's friends have told her, you know, basically, they're not happy with her. And I can't believe you did that to your mom. You know, you're supposed to be taking care of her. And she said, if I take care of her, that's what she told me when she said anything to her mom, friends. She just kind of accepted it. And she said, if I take care of my mom, and I can't work, and I can't work, then there's other things I can't do. I think our mom financially has some really nice resources set up. So most of her mom, I think the majority, if not all of her mom's retirement are in different resources. It's covering all of her mom's things, but she's like, what about me? How would I live? Like, how would we survive? I wouldn't be able to get Mom any extra things, you know. And so he said, If you could take one thing for the African American community, can you fix that? I don't know. Like, right. Right. Like, how can we change a community's view of this? It's not a nursing home, but people think, you know, all long term care facilities are assignment. They're not there are differences amongst them.

**Rosanne** 18:05

Easily.

**Rosanne** 19:28

But in their, in their view, that's what they see. They see. Well, she's not with you. Therefore

**Dr Kalisha Bonds Johnson** 19:33

She's not with you, you failed her. Yes, you are not a good daughter. And that pressure. That societal pressure because that's across the board. I know. I've talked to all races and not all but several races and ethnicities. And across the board society wise women are expected to be the caregivers

**Rosanne** 19:54

Right.

**Dr Kalisha Bonds Johnson** 19:54

But then if you add in discrimination and racism and sort of this other thing, where my own race. My own people, my own community are looking at me negatively because I don't think you'll have that as much. I don't think there's that sort of extra in the same way,

**Rosanne** 20:11

Not in the same way. I believe you're absolutely right. Not in the same way we don't.

**Dr Kalisha Bonds Johnson** 20:14

And so you think about all that pressure to hold it all together? Yeah. Which is why when we look at the health outcomes of African American caregivers, they're not better than non Hispanic white caregivers. We might have more positive aspects of caregiving, right. But financially, we're struggling, more our health is deteriorating more, there are just things. You know, the body keeps score, I think is the that book.

**Rosanne** 20:41

Yes It is.

**Dr Kalisha Bonds Johnson** 20:43

And it does, you know, and so I've been really interested in this idea of the strong black woman and the Superwoman scheme, and there's been several authors, I think, I don't want to misquote I think Jasmine Abrm Abrams is one and then Cheryl Woods-Giscombe scaleway is another one, who have really been sort of taking this idea of as a black woman. And I'll probably go between, you know, because the researcher is supposed to say, they but the black woman in me is like us, so who knows what pronouns are gonna come out at any given time. But you know, really, this, this idea of, I need to do more, I gotta hold it all together. The family is riding on me to do this. And so I have to be strong for everybody else. I'm not putting my mask on before I'm securing someone else's man. And so are there ways that we can unlearn that? Is there a way that that can be unlearned?

**Rosanne** 21:42

And do you think there is? Have you found that yet? Or is it? Is it so and you know, listen, it takes a long time, right? Anything, any kind of systemic change in anything takes a long time? But do you think that there's a foothold for you a foothold to get in to be like we can change this? Or is it so totally ingrained? That? It's just, it's just there?

**Dr Kalisha Bonds Johnson** 22:09



I don't. I don't know yet. I don't have enough research to know, I'm hopeful. I mean, I think, you know, the one thing about when you do what we consider intervention work, there's a place where you want to intervene or something you want to change, some things you can't change, can't change your age can't change your race or ethnicity. Gender is kind of fluid now. So some might say you could change that. But things like having too strong of a superwoman schema or strong black woman. I mean, I would hope that that might be something we could mold or change, or at least recognize, this is why I do what I do. Is there a way to rethink that or, you know, maybe it's, I just don't have the right language. So someone would teach me the right language, then I feel more confident in these hospital settings in these visits. And I'd be able to get my needs met. Because the other thing is, you do have to have the right language like healthcare professionals are tall, a certain lexicon got a certain way to do things. And if you can just tap into the right words at the right time. Yep, not related. I had a family member who reached out or put something on Facebook, and I said, Call me. We were talking, I said, this is what you need to tell them. I've talked to a colleague, as I'm psych, this was diabetes and heart stuff, I do mind their sleep, appetite, you know, psychosis. I can help you with those. Hey, these other things, told and scam and cards. I'm like, say I like wrote it out. Like I texted it to him. This is what you say exactly to the paramedics. And when the paramedics got there, they said, Well, technically, she doesn't seem as bad as you said she was, but because you said what you said, we're gonna take her to the hospital anyway. So really, there is this known language that I think we could teach people say this, instead of that, ask it this way instead of that way, not that I don't. I don't think we're trying to be secretive, I think, does that common language?

**Rosanne 24:17**

Well, I think it's because there's so much that goes on. And when somebody when somebody starting, you know, you're going through the whole story from 1995. And it's like, no, no, you've got to hit the high points. And that it's like the magic words, you need to know the magic words because that's what they're listening for. And once they hear it, then it kicks them into the next step. Oh, okay. Then we can do exactly, exactly what the what the problem is, when you're caregiving. You're, you're so focused, and usually there's something going on, you don't usually just go in like, Oh, hi, we're just here. Say hi. Like, you're going in for a reason. And you're our De, you're already upset, you're already stressed out, you're probably sleep deprived, you probably haven't eaten all day. And, you know, like, all of these things are on you. And then you have to be strong for that person and keep it together for the doctor, because then they're gonna be like, Oh, I can't talk to her.

**Dr Kalisha Bonds Johnson 25:20**

Right. And that little performative. You also have to perform a little bit, yes, yes, you know, cuz you can come across as neglectful no black woman can't come across as too angry, because that's a whole thing.

**Rosanne 25:31**

That's a whole different yes

**Dr Kalisha Bonds Johnson 25:33**

You know, so there's these things, you kind of have to show up a certain way. And if we had a cheat sheet, right, to give these African American daughters, they know how to navigate the healthcare

system for their parent. Course, let's give them a cheat code. So that's what my research is trying to do trying to figure out the cheat code. So right now.

**Rosanne** 25:57

I love that.

**Dr Kalisha Bonds Johnson** 25:59

It just came to me see you just created a space for creativity. Thank you so much.

**Rosanne** 26:03

You're welcome. Happy to help.

**Dr Kalisha Bonds Johnson** 26:05

So yes, I'm actively recruiting right now, probably for the next year, depending on how quickly I can get dyads these payers into the study across the United States. So I am looking for African American adult daughters who are assisting a parent, it can be up parent in law can be a fictive kin parent, but assisting a parent who has some forgetfulness. I have a pre screening survey that the adult daughter typically is the one that goes online and completes really quickly takes about five to 10 minutes from that information. Someone on my research team contacts you either by email or phone to say whether or not you're eligible. And if you're eligible, then I interview you and your parents, I know makes people nervous when I say the parents, you want to interview my Yes, I do. Because I had hand crafted about 20 minutes survey 20 minute visit us surveys that I think your parents can complete. If we get to a survey they can't complete five we skip it to get to a question they don't know. They don't understand, skip it. So the idea that during that visit, is the adult daughter present with the parent, I discovered it works well that way there are 10 questions where the parent gets to answer questions about their relationship. So I let the daughter know in case the daughter wants to leave the room so the parent can have the privacy to discuss that without feeling watched a judge. And then after that 20 minute visit, unless the parents really talkative and sometimes it's been an hour and a half visit because again, how often do these older adults get someone that's like, I just want to hear from you. Write tell me and it's a liker scale stuff. So agree, disagree Yes, no, true false. And then after that, I email the interviewer to the questions longer about 40 minutes for the adult daughter to fill out. And usually we do it over zoom, they fill it out and then zooms by so I'm there in case the daughter has questions, I usually block about two and a half hours because technology is great when it works. But when it doesn't work, not so much, not so much. Or if your parents really talkative, I don't want to blow up your schedule, and you're like, blocked off an hour and took an hour with your mom, right? So it's a one time thing, they get \$25 Both of them for their time as a gift card. And then I'm hoping to collect that information from about 70 pairs and about a third of the way there. And then with that information, we're gonna crank out the numbers, review the transcripts, do a little bit of work, analyze that data, figure out what's what standing through with areas that we might be able to intervene on working with what I'm calling some key informants. So some people who have skin in the game and I've been doing this for a while, as well as the community advisory board that's associated with that. So it's not just Kalisha coming up with these ideas. It's a collective co creation of a program, think think it's gonna be a program some sort of a deliverable to give to people for them to test it. And then the last year, so of the grant, is this finding another set of payers that didn't participate in the first part to try out what we come up with to see if it's gonna work.

**Rosanne** 29:13

Oh, that's great. And then that will be kind of like a roadmap then.

**Dr Kalisha Bonds Johnson** 29:18

Yeah, the cheat sheet I hope the roadmap, yeah, something that they can use to help them with navigating systems. And part of the reason I'm really interested in going across regions is that I know there'll be differences, but wouldn't it be nice to find some collective similarities?

**Rosanne** 29:33

That'd be great.

**Dr Kalisha Bonds Johnson** 29:34

Yeah, so that's it. And then of course the writer really big great to pilot it across the US and multiple spots.

**Rosanne** 29:41

That's fantastic. Such important work.

**Dr Kalisha Bonds Johnson** 29:44

Thank you.

**Rosanne** 29:44

It really is.

**Dr Kalisha Bonds Johnson** 29:47

You know, I love what I do. I truly love what I do. I get really excited helping people. I was on the call previously asked me not to share this with you before we get on it. What do you do for fun? Hmmm My work is fun, but that sounds really nerdy.

**Rosanne** 30:06

It doesn't sound nerdy, it sounds like you need Well, you know, we all need an outlet, right? But if it's fun, then that's part of it.

**Dr Kalisha Bonds Johnson** 30:15

I do really enjoy meeting people hearing people's stories. Like, just I really do love people. And so it's nice to just feel like I've helped a little bit but I'm gonna have to figure out something to do. I'm gonna have some self care things like nails, hair, facials, massages

**Rosanne** 30:33

Right?

**Dr Kalisha Bonds Johnson** 30:33

But hobbies?

**Rosanne** 30:34

Well, well, and I'm sure when you when you're talking to people, because there's, there's such joy. And I don't want to sound corny, forgive me, but

**Dr Kalisha Bonds Johnson** 30:44

Oh it's okay I already said my work is my hobby. It's fine.

**Rosanne** 30:48

Okay, well, when you're talking to somebody who's older, and you you see that connection that you make with them, because they don't have that opportunity.

**Dr Kalisha Bonds Johnson** 30:58

Yes.

**Rosanne** 30:59

And it's just, it's like, they're just talking to you and and just to sit there and be in their presence and make that eye contact with them. And listen to them. It's

**Dr Kalisha Bonds Johnson** 31:09

So powerful.

**Rosanne** 31:10

Yeah

**Dr Kalisha Bonds Johnson** 31:10

It's beautiful. I love it. And I have had every daughter that I have done this with has said, Wow, thank you. Several of them have said I didn't expect my parent to participate that much. I didn't expect them to share that much. I didn't realize they felt this way. So it was really I think a nice thing more than research often takes so much. I remember one of my mentors saying we share research takes we don't give, we take, oh, I don't want to be a taker. No. So it's nice to know that yeah, I'm taking some information, compensate you slightly for your time. But hopefully, I'm creating this beautiful memory that they have with their parent. Even if it is just what, you know, a little bit of time, a little bit of time, hopefully, hopefully, it's a powerful, beautiful moment for them because it is for me.

**Rosanne** 32:01

That's beautiful. Well, and it's it's also hard to because with dementia, I think we all fall into that bin of well, you know, they're just sitting here. And it's it's not true.

**Dr Kalisha Bonds Johnson** 32:13

It's not

**Rosanne** 32:14

And you get to see that

**Dr Kalisha Bonds Johnson 32:15**

I do!

**Rosanne 32:17**

They come, you know, and that's that's all it takes with dementia. And it's hard, because there's so much that's lost. But there's so much that's left. And

**Dr Kalisha Bonds Johnson 32:26**

Oh go ahead I agree I sorry, I talk over people it's my family of origin, I tried to get better,

**Rosanne 32:32**

You're fine don't worry about it I'm Italian. I'm used to all of it don't worry about it.

**Dr Kalisha Bonds Johnson 32:34**

Have three conversation going on at once talking in and out of them. But no, I don't know if I mentioned that I'm a clinician. So one day a week, I'm still engaging with diet with dyads. And so I'm at the Integrated Memory Care is at Emory. It's an entirely Dementia Friendly primary care practice. So we expect you to call me we expect him to come in with a family member.

**Rosanne 32:36**

Wow.

**Dr Kalisha Bonds Johnson 32:36**

If they don't come in with someone, we're like, wait a minute, what's happened, we've obviously the messaging was wrong. And so it is so nice to talk with the clients and their families and to just meet with them and mingle with them and hug them and love on them. But they'll let you know, sometimes it's not a good day. And they're like, I'm all ready to go. Yes, yes. And then they stand up. And I'm like, this other time, you know, it just really is nice. And at the clinic, I see all you know, races and ethnicities that come through the door, there's, it just really is I truly enjoy what I do. And I don't know if I would have had it not been raised by my grandmother, and grew up in this neighborhood of older adults and really developed this affinity for older adults and really wanting to be everyone the way I want somebody to see my grandmother.

**Rosanne 33:50**

Right. That's beautiful. And that's what and I'm sure your patients feel that.

**Dr Kalisha Bonds Johnson 33:57**

I hope so you know I got about a couple that have cussed me out every now and then but it's fine. I deserve it sometimes.

**Rosanne 34:03**

Well, I'm wondering what happens when a caregiver when you can see that a caregiver is struggling.

**Dr Kalisha Bonds Johnson** 34:10

Yeah.

**Rosanne** 34:10

What what do you do in that situation? Because, you know, a lot of times caregivers, they can't bill for us. They don't know what to do with us. And what do you do with that situation?

**Dr Kalisha Bonds Johnson** 34:20

You know, that made me think of two things. The first is I use the visit for the caregivers to usually I talk, I'm always going to talk to the person living with dementia. That will depend on their disease progression, how long that conversation is, is it a couple minutes, are they interjecting throughout the whole entire visit? And my visits ranged from about 30 minutes to an hour depending on what's going on, which is really nice. Again, as a site provider, I get to do a lot of talking. And so I sometimes take that visit to reaffirm them to let them know that they are doing all that they need to do we have an amazing social worker and nurses and nurse practitioners that work on the team. And so often they'll schedule time with our social worker whose name is Jenny, or the nurses we have to Elizabeth, really easy. Um, so they'll schedule time with them if they needed to depend on if it's medical, if they're needing resources. And so it's more social worker, they're wanting to do some support groups that our social worker does, it really is a neat place to work and a nice practice. So that's the one thing I do. The other thing is, I really wish there was a way that we could bill for both people. You know, yes, a caregiver comes in with their person. And we have a way to see both of them. Yes. Because caregivers do not have time to then make a separate appointment. That leaves the person they're caring for, who knows where adult day, you know,

**Rosanne** 35:54

Or not

**Dr Kalisha Bonds Johnson** 35:55

With a friend or not tries to, you know, they don't have that extra time to schedule appointments for themselves. And then we wonder why their self care. So terrible. That's why, right, because we really haven't evolved in a way to say, you know, what, I'm gonna while you're in the here, visiting with mom, daughter's gonna be sitting over here, and then we'll put the two of you together, you know, like, there really needs to be a new model that looks at a way to do that. Yeah, not my area of expertise. But somebody listen to the podcast and figure that out. I wouldn't take credit, just do it.

**Rosanne** 36:28

That's brilliant. That would be wonderful. And how many African American daughters do you see that say, I really don't know how much longer I can do this. But I'm gonna keep doing it. Because I don't, I can't do anything else. I can't place my mother, I can't place my father. How many do you come up.

**Dr Kalisha Bonds Johnson** 36:45

Pretty much all of them.

**Rosanne** 36:46

Yeah, that's what I was wondering what what do you say to them,

**Dr Kalisha Bonds Johnson** 36:49

We try to get a strategy, I will say some, so it depends on their son or daughters who don't have siblings, and maybe their parent, their other parent has passed away. So that's the hardest situation because there really isn't a lot of an outlet, right? Hopefully, they're in a sorority, or they have charged members or somebody where they can get loved on and feel supported. Other times, it's a parent and a daughter, or daughters. And so it's like, I'm doing that, as long as my mom is okay with us doing it, or my dad is okay, with us caring for, I'm gonna stick this out, I'm going to do it. Because this is what they want for their spouse. Sometimes it's a group of siblings. And so then it's who is parents fam with, like, how do we shuffle them? Across the siblings? How do we try to do we consider placement, but usually placement into a long term care facility is the absolute last thing people want to do. And so you cannot lead with that, as a provider or a staff member or someone working with this. If you lead with that you shut you shut that family down. Because that's not where they want to start. That's the end of the conversation and a conversation they'd much rather not have most of the time, but it's one that again, dependent on finances and in situations and how many people can be a part of that. The caregiving team that isn't going that way.

**Rosanne** 38:20

Well, how can people find your study or get involved with your study?

**Dr Kalisha Bonds Johnson** 38:25

Ah, I'm gonna send you fliers.

**Rosanne** 38:27

I will put them I will put them with my show notes. Is there any is there a website or anything or?

**Dr Kalisha Bonds Johnson** 38:32

Yeah, no, I am working on a website. Okay, You can Google Kalisha Bonds Johnson. I don't think there's that many of us, Kalisha Bonds Johnson at Emory, Kalisha Bonds Johnson, PhD. That's how I find a lot of people I'm looking for I'm like, Oh, so and so so and so and put PhD behind it and then it usually populates pretty quickly. So you can email me, which is a Kbonds@emory.edu. So first initial of my first name, technically my maiden name, it's Bonds at Emory.Edu. I'm working on a website. I do, say The Decide Research Lab so it'll be some hopefully it'll have Decide in that in that website, somewhere. Um, but yeah, so I'm around I'm on socials,

**Rosanne** 39:20

If you could share, I don't know if you could give one piece of advice. What would it be?

**Dr Kalisha Bonds Johnson** 39:26

That you are the consumer. If COVID taught us nothing else. When consumers don't go to hospitals, they suffer financially. So health care needs people. We need you and you are the consumer, so if you are not getting your needs met. If your providers do not hear you, they are not listening. Find somebody else if at all possible, because you need to feel heard. You need to feel seen. You need to feel like you

can ask for whatever it is you need. You may not be able to get it again, we already discussed, you can't always get what you want. But you should always have the freedom to be able to ask it and feel like you're asking it and what I call a brave space. Safe spaces we say we create them. I'm not sure we do. Brave spaces are where you feel brave enough to ask what you want to say what you want, and it be okay. So if you are not in a situation where you're in a brave space with your healthcare providers, you might be with the wrong provider.

**Rosanne** 40:27

A big thank you to Dr. Kalisha Bonds Johnson for being my guest today. For more information about her research, or to enroll in her research study, email her at [Kbonds@emory.edu](mailto:Kbonds@emory.edu). I hope you enjoyed our podcast today. Head over to [Daughterhood.org](http://Daughterhood.org) and click on the podcast section for Show Notes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood the podcast. Feel free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song mamas eyes from her album Lessons in Love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughter hood.