

“Everyone should have the same opportunity to have good health and no one should suffer for reasons that are preventable.”

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Voices of Health Equity in Chicago
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CENTER FOR COMMUNITY HEALTH EQUITY



Center for Community Health Equity

The Center for Community Health Equity was founded by DePaul University and Rush University in 2015 with the goal of improving community health outcomes and contributing to the elimination of health inequities in Chicago.

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Voices of Health Equity in Chicago

Our *Voices of Health Equity* project collects the stories of people who have made health equity a central concern in their work. We are interviewing academics, clinicians, public health advocates, community organizers, and others to better understand how different disciplines and professions could work together to eliminate avoidable, unnecessary and unfair health disparities.

Monday, July 31, 2017
Interview by Amber Miller and Sarah Wozniak

Background: Lisa L. Barnes, PhD is Professor of Neurological Sciences and Behavioral Sciences at Rush University Medical Center, and a cognitive neuropsychologist in the Rush Alzheimer's Disease Center. Her research focus is on racial disparities in chronic diseases of aging, with a particular focus on Alzheimer's disease and cognitive decline. She is the Principal Investigator of three community-based cohort studies of older African Americans, and the Director of the Rush Center of Excellence on Disparities in HIV and Aging. Dr. Barnes is internationally recognized for her contributions to minority aging and minority health. She has published extensively on cognitive aging in older African Americans, and has received numerous awards for her work in minority communities.

Amber: Can you tell us about who you are and how you got to be who you are?

Lisa: I am a professor here at the Rush Alzheimer's Disease Center. I am a cognitive neuropsychologist by training, I actually do longitudinal epidemiology. I went to the University of Michigan to get my PhD in Biopsychology, and then I did a three year postdoc in cognitive neuroscience at the University of California, Davis. There I really focused on sort of smaller scale studies. I was studying stroke and other types of brain damage, but I quickly learned that I had an interest in health disparities work when I was working out there. As I started to get on the job market and looked for other opportunities, I started to read about Alzheimer's disease and how it was a huge disparity for older African-Americans. The evidence was just coming out at that time, so I started apply to for jobs and this job was open, so I applied, I interviewed, and I moved here.

Actually, I moved back here, I'm from here. So this was my first job. And so, my position is full research. Like I said, I'm a professor in two different departments here. But also I direct a Center of disparities on chronic diseases of ageing, with a particular focus on HIV. So I run three community-based studies, two focus on Alzheimer's disease, and one focuses on the intersection of HIV and ageing.

Sarah: Did you know you always wanted to go into this field?

Lisa: I always knew I wanted to study the brain. I was always interested in the brain from a very young age. I didn't know that I was going to end up doing Alzheimer's disease. I was very fascinated with memory. When I was in college and also in an internship, I had this really famous patient called "HM". He was a patient who had intractable epilepsy. At that time, there was no treatment so they did an experimental treatment where they removed his hippocampus, which is important for memory, on both sides. And what it did was it helped his epilepsy, but he was no longer able to make memories, new memories. It was profound memory loss- this was probably when he was in his twenties. So anyway, I had an internship at MIT, when I was in college, I was able to work with "HM" and just like study him for one summer. It was like "Oh my... this is a dream!" for someone who is interested in memory. So

that sort of put me on the path to wanting to understand memory and how the brain functions, how we form memories. So it kind of just led me to the field of brain damage with stroke patients during my postdoc, and then it landed me in Alzheimer's disease. Which obviously, you know, the characteristic symptom is memory loss. So I kind of came full circle, even though I didn't know I was going to end up in Alzheimer's. Since I started, I have sort of branched out. I am not just doing Alzheimer's, but any chronic disease of ageing that has a health disparity focus.

Amber: So who or what has influenced your career? Did you have any mentors that influenced your career in health equity?

Lisa: Well, I still have mentors. Initially, the person who got me on this path of understating health disparities and health equity issues, was a fellow named Carlos Mendes de Leon. He used to work here at Rush for many years. He was a professor here at the Healthy Aging Institute across the street. He left, probably about 2006, it has been more than 10 years- he went to Michigan. But when I first came here in '99, he was my direct mentor. I had my boss, but he was my direct mentor that I worked with on papers. [Our] paper on perceived discrimination shaped my thinking on social determinants and really trying to understand the social forces that shape disparities. So we worked together for several years before he left. You know, and so now I have other people I work with and who are ahead of me on the trajectory, but I would say that he was really influential on getting me on the path.

Amber: So going into your article, "[Perceived Discrimination and Mortality in a Population-Based Study of Older Adults](#)", what really caught my eye was in that first paragraph, "Discrimination is related to poor physical health, mental health...including breast cancer, psychological distress..." In what ways do you think discrimination is related to these poor health outcomes, especially with biological issues? Can we say stress?

Lisa: Exactly. I don't think that we have come that far that we have uncovered the underlying biologic mechanism. Stress is the number one consideration. Obviously because discrimination is an obvious stressor for minorities and other marginalized groups.

It's been hard to measure the biologic underpinnings of discrimination. So we have another paper where we have an indirect association where we looked at the relationship between discrimination and C-Reactive Protein, an inflammatory marker that you can measure in the blood. We have found that people who reported more discrimination had higher levels of this inflammatory marker. So that is, you know, and indication of some underlying inflammatory response related to these reports of discrimination. There are other things going on obviously, but that's one direction that we can look at. ...We can't really figure out "what is this? This bad feeling of being discriminated against, how is it getting under the skin?"

Sarah: Why do you think health equity is a concern in the work you do?

Lisa: Well, I think the very basic reason is because everyone should have the same opportunity to have good health and no one should suffer for reasons that are preventable. So I think, you know, at a very basic level, when you think about something like Alzheimer's disease where African-Americans are more at risk. A lot of the reasons could be social in nature, and those are modifiable things. It could be behavior, anything that we could actually modify to change the outcome, and if it's something that one group has less of than another group, then I think that it is a health equity issue that we can do something about. So especially when it comes to health, no one should have to suffer because of poor resources or lack of resources.

Sarah: I think the key word you said there was "modifiable". Especially when thinking of health quality and concern to equality, health equity is really about the unequal distribution.

Lisa: Exactly.

Amber: You said in your article, racism and discrimination exist on three broad levels, individual, institutional, and cultural. Can you explain a little bit more about what you mean by those levels? Or which one is the most profound?

Lisa: [Individual] is the easiest one to measure because you are dealing with the person and their perception. I think institutional is very difficult to measure, because it's in systems. So if you think about a big system like a hospital, you know, you might have racist-based systems within a hospital. Access to care issues, you know, who gets to see what specialist. It's hard to measure those things and change those things. In our research, we tend to focus on the individual because those are the things you can actually change or modify. For cultural, I'm sure I said something more along the lines of stereotyping. Having a cultural stereotype for some reason could be discrimination. I would say the one I come in most contact in is with and have most familiarity with is the individual level, just by the nature of it being measurable.

Amber: What was your goal in publishing this article?

Lisa: My goal was that when that came out in 2008, there have been a lot studies of perceived discrimination on these different clinical outcomes, but no one had really looked at whether it affects death, mortality, and risk of death. And so, we wanted to ask the question, "Can you take some basic simple measure, that's only 9 items, and see if it affects risk of death? And would it vary by race?" That was the issue we really wanted to see. The beauty of this particular measure is that it does not attribute the discrimination to anything. Not because of race, age, gender. It just asks, "How often do you have these things happen to you?" and we wanted to see first if there was a difference between Blacks and Whites, and then would it have a differential effect on risk of mortality. So that was our goal in doing that, we were actually surprised by the finding.

Amber: Yes, so were we.

Sarah: What was your first thought when you saw that? The relation of perceived discrimination and mortality risk was stronger among Whites than among Blacks? What was your first thought?

Lisa: I am not publishing this. [laughs]

That was my first thought. It is so funny now because I have a colleague and she calls it the "Barnes Effect" because it's so crazy. You know that perceived discrimination is higher among minorities, so what's going on here?

Amber: Exactly. You had said [in the article] although Blacks experience more instance of perceived discrimination, it may have more effects on older White individuals.

Lisa: I don't remember what I said in the discussion, but this kind of finding has come up again. So it wasn't like it was just some weird artifact, it's come up again. The only thing I can think is that, there are two things I can sort of think about. One, is that you know, by the time you get to old age, especially for minorities, they are still here. They haven't died from heart attack, stroke, all the things that generally take people out, they are still here, so they are really resilient and hardy. And so, you know, maybe these kinds of things don't affect them as much. They can have some extra coping skills. Things that sort of help them, sort of buffer the effects of this negative experience.

The other possibility is that Whites are not used to having to experience discrimination. So maybe, that experience is just really detrimental to their health. Both of those are happening, maybe one, it's really hard to tease that out, but we were very surprised, and the fact that it has been replicated a few times, it makes me know that there is something there. Then maybe, more about the hardiness argument, because really, it says that African-Americans have a lower life-expectancy. By the time you reach [the age] 65 and you're still able to be in a research study, you're different. You survived a lot, and so you're just really resilient. I think that's probably driving a little bit more.

So I think the main message in the paper, the reason we went forwards with it is because we wanted to say treating people badly is bad for you regardless of race. It's just not good.

Amber: I know, I was really surprised. Those are two good points you brought up about it potentially being that Blacks have developed coping strategies and adaptation skills. Also, you mentioned the period of time that you were interviewing these people, especially White individuals, you were looking more at older age and them being discriminated against. So it could just that particular time, which is why although they are experiencing fewer instances [of perceived discrimination] it is effecting them more because they've never had to cope before?

Lisa: Exactly.

And I'm not sure if I've mentioned this in that paper, is that I think another part of this is that older Blacks tend to under report experiences of discrimination that has been shown in numerous studies. You would think that it would be really high, but actually college students report more discrimination than older people.

The only thing I can think of is that they are either comparing their life to what it used to be, you know, it is much better now than what it used to be because things have changed. These people would have been coming of age in the 20's and 30's during segregation and Jim Crow and all of that. If you compare, then obviously it's a lot better.

Or it's just as you get older, you just become more emotionally stable and you just sort of select out the positive things in life and decrease the negative things. But I'm telling you, there are so many studies that have shown older Blacks do not report high levels of discrimination, and you know that they've gone through it. I'm not sure what's going on there exactly...

Sarah: So what would you say was the biggest impact of this article?

Lisa: So at first it just made a little splash. There wasn't a big impact. I think the "Barnes Effect" has something to do with that.

I think over time people have taken notice, and I know people have talked about it and have cited it in other papers. I think it still sort of adds to the literature. But still, I haven't seen any other paper that's looked at mortality. I haven't done an exhaustive search, I'm not sure, but I think we were one of the first to talk about mortality and discrimination. Most people were looking at mental health.

Amber: So what do you think are some of the biggest obstacles when dealing with community health in Chicago?

Lisa: So remember I study a small section of the population, older adults. And I study a disease that has a lot of stigma in the minority communities, so I think for me a big obstacle, there are two. One, is dealing with the stigma of a brain disease and trying to get people to understand that, this is common and something that people go through and we need to educate ourselves so we can do things to sort of prevent it.

I think the other thing is probably most people who study health equity have issues with this, is just recruiting people into studies, because you know, of the past abuse with minority communities. People don't want to feel like a guinea pig. Research just doesn't have a high regard in minority communities just because of what has happened in the past. So I think that's a huge obstacle and that requires me to spend a lot of time in the community. A lot of face-time with people explaining the purpose of the study, explaining what we will do with the results, and giving back, making sure they understand what their contribution is in helping with and it's an integral part of what we're learning. I think if everyone was like, "I'll be in research,

I'll do it!", then that obstacle won't be there, but that's a huge obstacle. Just the stigma and getting people interested and involved in the research.

Amber: Just being hesitant because they are not really understanding what it is you're doing with the work.

Lisa: Exactly.

Not just with older people, I think it's across the board in minority communities. There's a lack of trust in research and researchers.

Amber: How have things changed? Do you think things are getting better from when you started recruiting [for research] until now?

Lisa: I think there has been a lot more education, a lot more effort in the community, like community-based participatory research where we're not actually studying people, but working with people and there is a clear partnership. I think that that's changed, it has not always been like that and I think that has helped. This partnership has helped solidify their research questions, it's helped to get buy-in from the community, and I can see that people are actually enjoying being a part of something that is bigger than themselves, because we put the effort in to explain it and work together as partners.

So I think there has been a definite improvement. I don't know if it's across the board for all areas of research, but I can definitely say for aging research, which they are a hard nut to crack because they have had the most experience with the abuse. It's been much better working with the older communities, they are much more open and receptive to what we have to say.

Amber: Do you target any specific communities?

Lisa: You know, I don't really. But what ends up happening is that my studies do tend to be concentrated on the southside of Chicago, and I'm not sure why that is. It may be because we have a community engagement team, a lot of them have networks on the south side, so you go to your networks first. So that may be the case. We do have people on the west side, all the way north, like Northwestern and that area. Maybe like 70% of our participants live on the south side because we target churches, and so the big mega churches tend to be on the south side because Chicago is so segregated and because it's a study of African-American, you have to go to where they are. So I guess it's not targeting on purpose, but it is sort of targeting based on geography.

Sarah: So when thinking of community health equity in the future, are you optimistic with how things may be going?

Lisa: I like to think of myself as an optimist, in general. [But] my kids don't believe that. They think I'm the most pessimistic person ever [laughter].

But I do think we are going to go in the right direction, and the main reason is because we are getting more people involved. I think the more narrators you have, your narrative just becomes richer. And so, I think we are doing a really good job in attracting young people. People are interested in healthy equity and issues about social determinants. We're getting them from all areas, not just Public Health anymore. I think that's really going to help us move forward really quickly in the field. Just fresh new talent. So I'm optimistic about that aspect and I hope you share my optimism because you represent the future as well.

Sarah: I feel like you have to be. Like you said, there is so many health equity issues. There are so many different fields now coming together. It is more than just public health, sociologists, researchers, with community-based participatory research, I am optimistic.

Amber: You have to have the social workers, physicians, and researchers and a broad base of professionals come together, because it's hard to accomplish [goals] without everyone.

Lisa: Right. You have to have this broad lens.

I think that's why the Alzheimer's Disease Center here is so unique, because we are multidisciplinary. When I go out to other places, I can really see how we differ. We work with neuropsychologists, neurologists, psychiatrists, nurses, social workers, statisticians. We have people looking at the same problem but from different angles. You're looking at the whole elephant and not just the tail. I think that's important for health equity because it's just a multifactorial phenomenon and you're not going to be able to solve it from looking at one direction.

Sarah: Do you have any advice for students who may be read this and may be tackling health equity issues?

Lisa: I think for health equity research, it's important to have a passion about it. I mean, you can't approach it from an intellectual standpoint. So I think if you're a student coming into it, if you have an idea don't be afraid to explore, but get into the community, you know? And get to know the real issues. What are people worried about? What are they thinking about? What's affecting their health at the most basic level from their point of view? That is going to form your research question, and that is what we are trying to do here. I don't just sit in my ivory tower, like, "Let me think, what is wrong with the world?" [laughter]

So, bringing your own fresh perspective to the research, don't be afraid to do that if you're a student. But then also, going to where the people are, meeting them where they are and just finding out, what's the issue? I'm interested in this, what do you think? And getting their opinions as well.