



PROFILES IN SCIENCE ENGAGEMENT WITH FAITH COMMUNITIES

Pamela PAYNE-FOSTER

Pamela Payne-Foster is a Professor at the University of Alabama School of Medicine in Tuscaloosa, focusing on primary care and rural health. We spoke with her about combating the HIV/AIDS stigma in rural African American churches, religion as relevant cultural context for medicine and research, and the importance of building trusting community relationships. All photos courtesy P. Payne-Foster.

People living with HIV and AIDS can feel very stigmatized by the church. How did you come to address this from a public health perspective?

I had done work on HIV/AIDS in grad school and med school when the epidemic was first hitting in the 80's and 90's. I had always worked in large cities, like New York City, Atlanta, DC, where advocacy around HIV/AIDS is very loud. When I moved to Alabama in 2004, I was at Tuskegee University's National Center for Bioethics in Research and Health Care. It was first time I was in the deep South and in rural settings. And the first thing I noticed when I got here was that, in terms of HIV/AIDS advocacy, it was absolutely silent. Nobody was talking about HIV. And when I looked at the literature, the epidemic was moving to the deep South and into rural areas, where before it had been in large cities of a million or more people.

There are a lot of myths and a lot of poor information out there about HIV, which is a major barrier. Even today, people are asking, "Is it transmitted by mosquitoes?" "Can I get it just standing next to somebody?" With the anti-retroviral drugs now, there's not as much fear, but still, in some communities, people have no knowledge of the progress we've made over the last 30 years. Because, where would they get that information? And that's when I saw the difference between some large cities, where they had these huge media campaigns and educational sessions, and the deep south, rural south, where there's none of that; it's an educational void.

So, I started taking a look at the numbers. I was in Macon County at the time, and in small counties, even one or two cases it makes a difference. And I was also hearing horror stories about how bad the stigma was, particularly from people living with HIV/AIDS. So I started doing research around the stigma with a collaborator in nursing. There was a little bit in the literature, but not a lot about the stigma being a cause of the epidemic increase in the South. We did one study where we asked people living with AIDS where they felt most stigmatized, and the answer was the church.

That hit me in the gut. It was horrible for people living with AIDS, but I also saw it as an opportunity because the additional message was that they felt spirituality and religion was very important for them living successfully with HIV. That was such a paradox. Here you had this stigma, which was negative, but also an opportunity for the church to address this quality of life issue for people living with HIV/AIDS.

That was my "A-ha!" moment. I applied for and was lucky to get a four-year MARI fellowship (Minority HIV/AIDS Research Initiative) from the CDC in 2011. MARI is focused on grooming minority researchers to be able to work in their communities, or to be more community-based and conduct HIV/AIDS research. So, I collaborated with CDC to develop an anti-HIV faith-based anti-stigma intervention. We called it project FAITHH, the Faith Based Anti-Stigma Intervention to Heal HIV/AIDS.

How did you design the FAITHH interventions?

When I was reviewing the literature on anti-stigma and faith-based interventions, there were not many in the U.S. that were

particularly focused on African American churches. There was one in Ghana, Africa. A Christian council of churches had a curriculum, and we borrowed heavily from them, but it had not been tested and evaluated rigorously. That was really my charge, to take that curriculum, add components to it, and make it more culturally competent for rural Alabama African American pastors.

It really was like a clinical trial. I had to recruit 12 pastors, and after I recruited them, I had to recruit 20 members from their churches to participate. We split up the 12 churches into three arms of four churches each. In one arm, we tested our intervention, which was like an HIV/AIDS 101 curriculum, but with more faith-based and anti-stigma messages. We compared it to another arm that received the regular AIDS 101 curriculum, and then the third arm was the control with no intervention.

The intervention was eight modules, and it involved going through exercises on the participants' education and knowledge about HIV. Our special curriculum also included them exploring their own ideas around stigma, how they might have been stigmatized in the past, how that made them feel. It helped to build empathy for those who are living with HIV, and then also to put a face on it.

We did a couple of pre- and post- stigma tests; one of them tests individual HIV stigma, and another one tests community stigma, or what they feel the community would say or do. We found that delivering that special curriculum as well as the AIDS 101 group increased HIV knowledge more than the control group and more importantly our curriculum decreased the HIV stigma more than our control group.

Why is it so important to work on the HIV/AIDS stigma specifically?

We are finding that although the epidemic is decreasing overall, there are pockets where it is not decreasing. CDC and NIH are saying the stigma is playing a role in that. If you don't really get at the stigma, you're not going to be able to eliminate the epidemic. That's the general context of why it's so important. The faith-based research is going to be particularly important to decreasing the community stigma so that we can get at the epidemic in a real, significant way.

Mostly, the response to the epidemic has been about addressing the low-hanging fruit, trying to get people to start and stay

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on the drugs and bring the viral loads down, and get rid of the epidemic that way. But the behaviors that people have and how they feel are also key factors, and I think religion and our research using faith-based partners is going to be equally important.

How did you connect with the pastors and churches?

To recruit 12 pastors, I first had to recruit some ministers to work with me. I contracted (paid) ministerial liaisons from four different African American denominations, and they helped me to recruit the pastors and also deliver the interventions to the participants. I had done research before with just pastors, which was not as difficult; they do still somewhat stigmatize HIV/AIDS, but there are more and more pastors who are willing to talk about it. This study was a little different because I not only had to involve the pastors, but also their congregational members. They had to get permission from either their deacons or their elders, so it involved the whole church. It took about a year and a half to recruit those 12 pastors and conduct the interventions which indicates it takes time to build that trust and relationships with the religious community with me as a researcher.

How did the church members respond to FAITHH?

In the follow-up afterward¹, some of the church members said they were very negative at the time of intervention; they focused on how the person got the HIV, or is this person homosexual, those kind of things. But during that follow-up, they said that the study had opened their eyes a little bit; it shifted them more toward loving the person and embracing them into the faith community. So, there was growth for some of them around those issues.

Also, in the churches we worked with, there was usually somebody who participated in the study who was living with HIV. The congregation may not have known, but the pastors usually did. And those people were very appreciative to have something like this in their home church, so that was also positive.

Where am I now is trying to get more and more church leaders to adopt and do the curriculum; I’m in the dissemination phase.

What have you learned about doing this kind of work?

I know a sociologist working in HIV who doesn’t understand why I work in the Black church. Her reasoning is that the epidemic disproportionately involved Black gay men; the church isn’t low-hanging fruit, so why do research there? But, she doesn’t understand the significance of the church to the Black community.

Here in the deep South, in the rural areas, religion is very important. The first question people ask you when they meet you is, “Where do you live, and what church do you go to?” So it’s crucial for scientists to understand how important religion is in people’s lives. And specifically for African Americans, scientists have to understand the historical significance of the church, particularly in the context of slavery and oppression and how the church not only serves as a spiritual center but also a political and human rights place for their everyday lives. I don’t want people to ignore that.

Considering a person’s faith is important in medicine now because if we don’t take a spiritual history of the person, we could miss something important. If we don’t understand them from a religious context, we might not give them the best care, or it might be a barrier to care or us connecting with the patient.

Specifically for researchers, they’ve got to understand different religions, the cultural context, and the cultural implications for research. Particularly if researchers want to work in this kind of setting. Pastors will ask, “Where do you go to church?” In order to partner with faith-based leaders, we have to understand what their faith is and how to connect with that culture. So, even though you can’t screen the project team based on faith, it would be good to know whether they have ever worked with other faith groups or community engagement—work that requires time and patience and relationship building.

Any tips for a researcher interested in doing similar work? Any special considerations?

In order to do this research, there have to be personal relationships. In academia, we’re on a five-, six-, or 10-year swing for tenure and promotion which are important for our

academic survival, so we often don't have time to develop relationships. It really does take a long time so one really has to juggle other work that might balance off community-based work; the additional pressure is that if you don't set it up right, everything else is going to crumble, and it is really an art and a science.

The groups that I was trying to recruit from helped me with both recruiting others and with performing the interventions. The pastors that I did recruit, I had known for several years and had developed ongoing relationships with them, but I could not have recruited pastors without other pastors helping me. That's just the way it is.

The strength of the relationships you build is very important. Two people working on the project with me were not Christian, which could have derailed the project, but because of my strong relationships with the pastors, we were able to continue our work. Building that trust is time-consuming, but critically important, especially because of the history of the Tuskegee syphilis experiment in this area. It is still a very sensitive topic which still engenders great distrust of communities of color with researchers.

I also made sure that the pastors really were valued as a part of the research team. I'm from a community-based participatory research (CBPR) background, which values acknowledging all contributions. So we made sure that the pastors were included in the authorship presentations; their names were on the posters, and they also got an opportunity to go to the national conferences.

Working with the churches there and working with community partners, I've also had to continuously be aware of my humility, because sometimes I'm wrong. There were

times I thought I knew what I was doing, but they let me know quickly, "No, that's not right." And my ego has to be strong enough to take that.

Additionally, we were on the road a lot, which is a consideration for those that have families at home. I had to do this research on the weekends, Saturdays and Sundays, which is not a typical work academic schedule.

Did anything surprise you in the course of this project?

Two things were very surprising. One, the level of HIV knowledge is pretty poor—not only for the community, but we did a side study with people living with HIV, and their knowledge was poor as well. There were simple things they didn't know, like what the acronyms HIV and AIDS stood for. And they didn't really understand HIV and AIDS themselves either. If we want to make sure their care continues, it's a challenge if they don't understand why they have to take medicine every day even when they feel fine.

The other surprise was with more visible advocacy. One of the modules was about advocacy, working on behalf of people living with HIV. I think they were fine with, "Okay, let's give our members some education; maybe we could do testing for our members and the community." But getting them to lobby on behalf of people living with HIV, or start up a ministry group, or a support group in the church, they really struggled with those. We wanted the churches to go to that next level, but it was harder for them to grasp; the churches just aren't there yet. But I think it's important for church leaders to be at the forefront of advocating for community members, so I would like the next phase of my research move into this area, trying to help them develop those advocacy skills. ~

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Pamela Payne-Foster with members of Project FAITHH.

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