

Podcast Interview Transcript

Adeline Nyamathi and Amanda Latimore

In each volume of *Progress in Community Health Partnerships: Research, Education, and Action*, PCHP editors select one article for our Beyond the Manuscript podcast interview with the authors. Beyond the Manuscript provides authors with the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. Beyond the Manuscript podcasts are available for download on the journal's website (http://www.press.jhu.edu/journals/progress_in_community_health_partnerships/multimedia.html). This Beyond the Manuscript podcast is with Adeline Nyamathi, a professor at the UCLA School of Nursing and coauthor of "Perceptions and Healthcare Needs of HIV-Positive Mothers in India." Associate editor Amanda Latimore conducted the interview. The following is an edited transcript of the Beyond the Manuscript podcast.

Amanda Latimore: This article describes a qualitative investigation of the barriers faced by 60 HIV-positive mothers in Chennai, India in seeking, accessing, and maintaining healthcare services as well as the general challenges the women experienced as mothers living with HIV. The focus group discussions revealed a number of issues such as stigmatizing behaviors of the healthcare providers as well as location, affordability, and timeliness of services. Suggestions were also offered by the participants on how to best deliver a future HIV intervention. Hello, Dr. Nyamathi. Thank you for joining us today.

Adeline Nyamathi: Good morning.

Amanda Latimore: So would you please introduce yourself and describe your role in the study?

Adeline Nyamathi: I am Adeline Nyamathi. I am a professor at the UCLA School of Nursing, Audrienne H. Moseley Endowed Chair, and also Associate Dean for Research and Academic Affairs. My role in the study was the principal investigator, and so I had a major role in writing the study along with our colleagues from India and very much involvement of the participants and leadership of major healthcare organizations in India as well.

Amanda Latimore: Please share with us the impetus for the investigation?

Adeline Nyamathi: The impetus is based on my long number of years of working in India. The issue about women living with HIV is a quite serious issue and while there has been some studies which highlighted issues of stigma, what I felt most important was to take this issue and just expand its focus in terms of understanding what were the experiences of the women in terms of seeking care, what were the issues that they had to deal with on a day-to-day basis. That was missing in the literature. What we have always known was about stigma. More importantly was to move this forward in terms of where we will – where we need to go in terms of an intervention project. So that was the impetus for why we wanted to do the study.

Amanda Latimore: Please describe the process of forming the community advisory board and how it – the CAB was involved in the development of the research question and selection of the study population?

Adeline Nyamathi:

The community advisory board was an integral part of our study because they were the group that informed us for quite a while. During my many trips to Chennai, which is in south India, we interacted with the individuals that became the CAB. These were the directors of the major maternity hospitals in the south. They were individuals who were in the STD clinic, certainly the women. NGO leadership was there. We have interacted with them for over a year to how we would put the study together and how we would approach the women.

When we actually then called for a more formal CAB, several of these people came together, even though we had a broader audience earlier, to meet in the Tuberculosis Research Center, which was the hub of this study. We came together at least, as I mentioned earlier, informally with leadership, but again, formally at least three times with these participants and the remaining 15 members to finalize how this grant was going to be put together on paper. We also met during the intervention and then at the end of the intervention to discuss the findings. Basically, the putting together of the CAB came from the larger group that we had been interacting with.

Amanda Latimore:

During the discussions with the CAB, how did the various community partners contribute in unique ways to the success of the project? Specifically, what kinds of perspectives or insights did you gain from their participation that you would not have otherwise had, and what do you think was the most substantial or essential impact?

Adeline Nyamathi:

What they helped us with was logistical issues, how to recruit, best timing, how do we enter sites., It was more of just procedural stuff that they helped us with. But the discussions were quite important and very illuminating in terms of the interaction among the members of the CAB because not only did we have the leadership of the hospitals and NGOs, but we also had women that were HIV positive within the group. What was quite interesting was that while the leaders of the maternity hospitals initially talked about how wonderful their services were and how there was no stigmatization at all, it was very clear from the women who actually attended the maternity hospitals, gave birth, etc... that their stories were quite different.

It was very eye-opening for the leaders because they got to understand that they may not always know what the day-to-day operations are within their institutions and they really vowed that they would make sure that education went on, that they would be able to intercede and make sure that the women were indeed provided proper care. The women were just amazing because they were forthright. They had no qualms about saying exactly what it was despite who was in the room.

Amanda Latimore:

Speaking of stigma, as you discussed in your manuscript, stigma from families and healthcare providers is a major barrier to accessing care for mothers living with HIV. Did stigma present any particular challenges during your investigation and if so how did you overcome these challenges?

Adeline Nyamathi:

The stigma issue came out more in terms of what the women were presenting to us. It's quite amazing that while the women will tell us about the stigma that they experience in their home and in their communities, they did not have an issue because of stigma to talk to us, so that was not a problem.. However, particularly in the rural areas, it is a major problem. We had women from the rural areas participating, but these women told us that they are so sick that they do need to speak out, get the care that they need despite what is going on in terms of stigma.

Adeline Nyamathi: It is almost a paradox. Yes, they do have stigma. They talk about it. They may not take their medications regularly because, for example, a guest may be in their home and they don't want to show that they have to take these special medications, but at the same time, what I find is that they are becoming stronger in terms of being vocal about the issues they are experiencing, and for some of them, not all, they are overcoming their issues with stigma so that they can receive the care that they need to keep strong and take care of their children and their husbands.

Amanda Latimore: Your interview tool, based on the comprehensive health-seeking and coping paradigm, included questions about barriers to caring for children and parenting while ill. Among women that have HIV, what are the unique challenges of being a mother?

Adeline Nyamathi: Many of them had husbands, and in India many of the women, not all, who are infected are infected because their husbands transmit their virus to them. So, as a result, oftentimes the husbands are sick while the woman is beginning to get sick, they have not quite gotten the symptoms of AIDS. So, the challenges that these women have is while she needs desperately to take care of herself and keep strong both emotionally and physically, she has to deal with all the issues in her own home setting.

She has to deal with the fact that oftentimes she has in-laws that are very stigmatizing to her and sometimes to the husband as well. There's often blame brought on the women, that they must have caused it somehow and in addition, oftentimes in India the first time the woman knows that she is HIV infected is when she is pregnant and delivers her child. Now things are beginning to change because women are being tested, but that is traditionally how women first learn they are infected..

So here you have a woman who has to deal with issues of being HIV infected, having a child who may or may not be HIV infected, often having a husband who is already symptomatic and having health issues that the woman needs to deal with as well, and then on top of that, having a family who may also be very stigmatizing. We have talked about where plates and utensils are not shared. They are misinformed and eventually what does not come out in the paper is when the husband dies then the woman is in a much worse situation, particularly if she is living with her in-laws. So those are the challenges that these women have to deal with.

Amanda Latimore: In working with the women that participated in your study, what lessons have you learned from working with them and the Chennai community and what advice would you give an investigator interested in working with this population or working in Chennai?

Adeline Nyamathi: I think that community-based participatory research and what the journal stands for is so critical to making decisions on the appropriate interventions. We need to hear the voice of the women. We need to understand from them what works and what does not work and part of this pilot study, which was – this qualitative part was to get the information from the women themselves in terms of how they would like the intervention to be formed, how it should be delivered, what the components are, whether men should be included or not. So, we received from the women, which represent the community, what the intervention should look like and our intention is to now design a research study where we will actually provide the intervention in a randomized, controlled fashion. It was the women who actually provided us the important details about what the intervention should look like, so cultural sensitivity is quite important when we do this kind of work with vulnerable populations who experience health disparities.

Amanda Latimore:

Could you talk a little bit more about the intervention?

Adeline Nyamathi:

The intervention is going to include many of the aspects that the women talked about. Certainly, they wanted more information about HIV. They wanted to know more details about how it is transmitted. They may know some of the basic facts, but there are lots of misperceptions about whether it can be transmitted by insects or whether you can get it from sharing plates. They are quite interested that the family members, particularly those who are stigmatizing them, be educated. We envision education not only for the affected population but also with physicians, nurses, even the attendants who take care of the women to make sure that everyone is educated in terms of how HIV is transmitted. We found that to be quite important.

We also learned that if you have a malnourished woman who we are encouraging to take her medication, that is not going to work, so what they wanted was to be provided nutritional supplements. Included in the grant would be how we can have low cost but high nutritious supplements that could be provided to the women. You know, they actually are getting some nutrients already from the government, but they mentioned how the packages are very large. It has the AIDS symbol on it which people recognize and if they have an issue with disclosure it would be a problem. So it is providing nutrients that are in proper proportions and education.

It is how to involve the people around them who are maybe stigmatizing, to educate them. They do want the husbands to be included with education. Some wanted them included and some did not, so the answer would be to include them in some breakout sessions. But the other women wanted the sessions to be women only, so we will honor that as well. Another important issue was life skills. These women, especially after the husband dies, they need to support themselves and their family, particularly if their in-laws throw them out of the house, which happens on occasions as well.

Providing information on life skills, what kinds of small employment opportunities they may have like basket weaving and things like that. These women also wanted legal information and advice and so that would be part of it as well, so that is sort of in a nutshell what the intervention we would need to test would include. It would be very comprehensive and certainly the whole issue of mental health, social services, physical or, you know, health of the body itself are all aspects that are going to be quite important, overcoming barriers to getting to see the doctor, all of those things. For some, pharmacy was an issue, not being able to get their medications in a timely manner. Those are all things that we would need to include in a comprehensive program.

Amanda Latimore:

I think this is a perfect example of how information from an investigation which highlights the needs of the community is actually being utilized to improve the health of that community, so I definitely applaud what you have done and what you are going to do. Do you have any final thoughts that you would like to share before we close?

Adeline Nyamathi:

I just want to acknowledge the importance of community-based work because there are so many studies in different areas, not necessarily this area, that are generally crafted within the ivory towers and lots of studies do not show results. I think that one of the most important things that we need to do as researchers is to make sure that we do not only listen to but implement what the community is telling us in terms of the interventions that would work best for them.