

Podcast Interview Transcript

Dionne Coker-Appiah and Wendy Bennett

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 web site (www.press.jhu.edu/journals/progress_in_community_health_partnerships/multimedia.html). The following Beyond the Manuscript podcast is with Dionne Coker-Appiah, an assistant professor in the Department of Psychiatry at Georgetown University and coauthor of "Rural African-American Youth Speak Out About Community-Based HIV Prevention Interventions." Associate editor Wendy Bennett conducted the interview. The following is an edited transcript of the Beyond the Manuscript podcast.

Wendy Bennett: This was a qualitative study using focus groups to explore rural African American young people's perceptions to inform the development of community-based HIV prevention interventions. The study was conducted as part of a larger, on-going community-based participatory research (CBPR) project called Project GRACE. The study focused on HIV prevention in two rural North Carolina counties with high HIV rates among African Americans. The young people included in the focus groups shared their perspectives about how and when to access their peers with preventive messages and ways to design recruitment strategies to guide future intervention design.

Dionne Coker-Appiah: My name is Dr. Dionne Coker-Appiah. I am currently an assistant professor in the Department of Psychiatry in the School of Medicine at Georgetown University, and I actually started working with Project GRACE while a post doc at the University of North Carolina. I was involved primarily with analyzing the data related particularly to the youth focus groups. That is how I became involved in the project. I was then able to analyze this data and work collaboratively with our other co-authors on this manuscript, which focuses on intervention design.

Wendy Bennett: The project focused on exploring HIV prevention strategies among the young people in the community. Can you first place this project for us in the broader context of how it fits within Project GRACE?

Dionne Coker-Appiah: Project GRACE is a partnership that is made up of academic and community partners who are committed to reducing health disparities in rural communities in eastern North Carolina. This particular project is focused on reducing HIV/AIDS disparities among rural African Americans. The partnership identified this as the first issue to be explored and addressed. In the future, the partnership will explore other health disparity issues, but the first one was the HIV/AIDS issue, and that is the foundation for the manuscript.

Wendy Bennett: Prior to the focus groups, what was the role of young people from the community in Project GRACE?

- Dionne Coker-Appiah:* Initially, youth were not involved in the research process. However, through our work, we have been able to see how important it is to involve them in the process, and they have expressed a desire to be engaged in all phases of the research. After the focus groups were conducted, we began to reevaluate our governing structure, and have since added a youth advisory board as well as youth and young adult members to our steering committee. Through this process, which is also consistent with CBPR, we all continue to learn from one another. I believe that our research has been strengthened as a result.
- Wendy Bennett:* The focus groups were very interesting, and you reported on several themes that participants identified as important to consider when they were designing community-based HIV prevention interventions that would target young, rural African Americans. Talk a little bit about which themes you thought were most surprising or unanticipated and why.
- Dionne Coker-Appiah:* There were two basic themes of the four that really stood out for us, and one was related to our findings about potential collaborators in HIV prevention efforts. For example, we were very pleased to find a consistent theme across the participants that suggest that people living with HIV and AIDS would be powerful collaborators. Given the stigma that is often associated with HIV/AIDS and people living with HIV/AIDS, we were very excited to learn that youth really wanted to learn from those individuals. And they also believed in the efficacy of recruiting such collaborators because they were aware of the powerful impact that their personal stories could have on their sexual decision making.
- The other thing that really stood out for us was that youth really want to be able to discuss issues related to HIV/AIDS amongst themselves and with adults and caregivers. However, they indicated that they must have a safe, open, and facilitative space in which to do so. So they want this involvement on multiple levels, and they want to know that we care about them enough to address this problem and open that dialogue across generations. So those were two things that really stood out for us that we did not expect to find.
- Wendy Bennett:* What do you think you learned from the focus groups that were particularly unique to HIV prevention in this rural community?
- Dionne Coker-Appiah:* Our youth participants were not aware of specific statistics as they related to the prevalence of HIV in their communities and among their peers. Yet, on a more global and qualitative level, they were very much aware that HIV was a growing problem affecting many people in their communities.
- They knew that it was prevalent and that everyone—someone said, “From babies to the elderly”—regardless of their HIV status, could be affected by it in one way or another. We thought that was very powerful.
- Wendy Bennett:* Do you think that the feeling that HIV/AIDS affects everybody is unique to a rural community?
- Dionne Coker-Appiah:* I am not sure if it is necessarily unique to a rural community. I think it was unique to the communities that we were working with. It was interesting to hear these young people talk about how HIV impacts everybody. So they were not just thinking about, “Okay. If one person has HIV or AIDS, it is only impacting that person.” They were very aware that because it is a small community, because of the lack of resources, and because of the poverty, that even if one person has it, it has the propensity to impact everybody. I think that aspect of it is what made it unique for our particular communities.
- Wendy Bennett:* How do you think some of these results will influence the sustainability of an HIV prevention intervention that you would develop for this rural population?

- Dionne Coker-Appiah:* First and foremost, because we used a CBPR approach to guide our entire research process, we definitely believe that our findings truly represent the voices, concerns, and preferences of the community. And as you all are aware, CBPR processes inform the development of culturally appropriate and sustainable interventions, and we believe that the manner in which we designed our intervention will promote and support ongoing sustainability.
- Wendy Bennett:* More specifically, what have you been doing after the focus group? Have you used the results to inform the development of an intervention that will target these young people in the rural North Carolina counties where Project GRACE is?
- Dionne Coker-Appiah:* We are very excited to share that we have used our findings to inform the development of TORO, which stands for Teach One, Reach One. TORO is a community- and family-based lay health advisor HIV prevention intervention that trains caregivers and their pre- and early adolescent youth between ages of 10 and 14 to be educators. The intervention uses ambassadors and allies to deliver these messages to youth and caregiver dyads in the community. As such, youth are educating youth, and adults are educating adults. But what we really want to highlight here is that not only are youth talking to youth and adults talking to adults, there is also an interactive component that enables and promotes intergenerational communication, which we believe is a critical component of HIV/AIDS prevention.
- As we mentioned in the manuscript, youth really want to talk. They really want to talk about HIV/AIDS. They really want to talk about how to prevent it, and they do not want to talk to each other about it all the time. They want to talk to adults who may be wiser and may be able to guide them in a different direction. So we thought that it was important for TORO to have youth talk to each other, have adults talk to each other, and then bring everyone together to begin this process of intergenerational communication. And that is where we are with our intervention to date.
- Wendy Bennett:* Is that an intervention that you will be studying as part of the CBPR process, or is this more of a programmatic change within the community?
- Dionne Coker-Appiah:* Yes, it is definitely an intervention that we will be studying as a part of the process. We have currently completed the pilot phase, and we are in the second intervention phase. So we are working on our second wave as far as the intervention is concerned. We have not analyzed any of the data yet. But that data will be coming out, and we will be sharing it as soon as we have it available. But yes, it is being tested, and we are very excited about how everything has come along since the focus groups.
- Wendy Bennett:* What do you think are the broader policy implications of this study in terms of HIV prevention for African-American rural young people?
- Dionne Coker-Appiah:* One of the things that is quite interesting, and I am glad you asked that question, is that we believe that our findings may inform future school policy changes with regard to sexual health education. For a number of years there has been an abstinence only until marriage policy in North Carolina. Fortunately, actually on June 30 of this year, House Bill 88, which was the Healthy Youth Act, was signed into law. This law allows schools to continue to teach abstinence-based sexual education, but they are now following it up with additional comprehensive information about contraception and disease prevention, which is something that had not been done in the past.

Dionne Coker-Appiah: For advocates of comprehensive sexual education programs, this legislation can be viewed as a move in the right direction. What we hope is that our research will continue to shed light on the fact that African-American youth and adults residing in rural communities are disproportionately affected by the HIV/AIDS epidemic, and thus need to be more comprehensively educated about the issue. What we believe is that if the work that we and others are doing in these communities can be coupled with similar efforts within the school system, we will have a greater chance of thoroughly educating our youth and eradicating the HIV epidemic—not only in these communities, but in communities across the United States. We are very excited that that legislation is moving, and we are hoping to be able to use our work to continue to move it in the right direction.

Wendy Bennett: Have you been able to partner with educators and school board leaders in terms of making some of the changes that you recommend?

Dionne Coker-Appiah: Not as much as we would like, just because of the barriers associated with trying to get into the school system and trying to introduce some of this work, particularly around sexual health education. So, it has been somewhat of a challenge. We are hoping that with the new legislation those lines of communication will be opened even further, and we can begin to have dialogue about what we are finding in our research.

Wendy Bennett: Also, I imagine they will be very interested in the results of this study as well as the intervention that came out of it. I really want to thank you for participating in this. Do you have any other comments or thoughts that we did not cover in enough detail?

Dionne Coker-Appiah: I would like to end by highlighting some take-home points that we all would like to leave the audience with. The first one is that when we are doing this type of research, it is really important to understand the efficacy of using CBPR to guide the entire research process. Number two, we really believe in the importance of integrating youth perspectives in the research, especially research that focuses on youth. And number three, we really want to highlight the fact that we need to begin to draw on the collaborative strength of using youth and adult dyads in lay health advisor-based interventions.

Because bringing youth and adults together is a very powerful combination and we know from our research that these kids want to talk to adults. They really do, but they are often afraid to do it or they are uncomfortable. They do not know what to say. So if we can begin to open up those lines of communication, I think we will make tremendous headway in HIV/AIDS prevention and prevention in other areas of health disparities.