

AsthmaCommunityNetwork.org Podcast Series

Episode Transcript

Episode 3 - The Caregiver Perspective on the Value of Community Health Workers

Narrator: Welcome to “Asthma Community Network – Conversations for Advancing Action” –a podcast series from AsthmaCommunityNetwork.org - an online Network designed for people committed to improving asthma outcomes in their community. This podcast series is designed to share best practices for reducing the impact of asthma through delivery of comprehensive, community-based care, especially in underserved communities. In these podcasts you’ll learn about strategies for managing effective program delivery systems, addressing environmental triggers, and leveraging community assets through partnerships.

Today, we’ll discuss the importance of community health workers from the perspective of a family.

Wilvia Bito: At the beginning, like all the other moms that I had met, I wouldn’t let my child do anything. As soon as my child was sick, it was like, we all sick, we all got to sit down and do nothing. We have to keep track of what’s going on. But nowadays I feel so confident that we just follow the procedure. So I feel very confident telling them, and I feel well prepared, and I feel very grateful that, to know there is something that you can do without running to the hospital.

Narrator: That confident woman is Wilvia Bito, a mother of two. She lives in New York City, in the Washington Heights and Inwood neighborhoods in Manhattan. Many programs designed to close the gap in asthma disparities recognize that it is critical to educate the caregivers and families. Wilvia faced the challenge familiar to many parents of children who are diagnosed with asthma. Initially, Wilvia Bito was not confident at all of her ability to help her children manage their asthma.

Wilvia Bito: Well the first year was very difficult. I didn’t know every time my child got sick, for me it was hard to manage, to understand what was going on, as a parent, first parent. My husband knew a little bit because he went through that with his parents. But me as a mother, I just got panicked and I just got nervous, and I couldn’t manage so my husband was the one taking care of the children, taking them to the hospital, and doing all the running around.

Narrator: Wilvia and her husband turned to the Washington Heights-Inwood Network for Asthma Program. WIN for Asthma, as it is known, is based in New York Presbyterian Hospital. It was developed to bridge the gap between the care the hospital can provide and the additional help families need at home to effectively manage their child’s asthma. Helping families provide patient care at home often requires overcoming disparities in asthma management. Cultural issues often play a key role. One in three families in the Washington Heights/Inwood neighborhoods live below the poverty level and more than half of the residents are foreign-born. To overcome these and other challenges, WIN for Asthma created a partnership with New York Presbyterian Hospital. According to Patricia Peretz, WIN for Asthma’s program director, the partnership provides comprehensive, integrated care at the community level.

Patricia Peretz: The community health workers who we hired are actually from this community, speak the language, and their goal is to provide culturally appropriate services to the community in a way that resonates with the population. Um, what I think is particularly unique about our program is that the community health workers are actually based in community-based organizations, yet they maintain a strong presence in our hospital where they conduct daily rounds meeting with families of children admitted to the hospital with a diagnosis of asthma.

Narrator: When Wilvia Bito contacted WIN for Asthma, they arranged for a home visit to determine the environmental exposures that might serve as asthma triggers for Wilvia’s children.

Wilvia Bito: The first time we made the program, we filled out some paperwork and after paperwork they just tell us, we are gonna have a visitor in the house which I found very interesting because the doctor already knew my children were diagnosed, but the doctor would not come to home and see what do we need at home, or what we don’t need at home, that is gonna affect the children with the asthma. So the health care provider came [um] to my house, which I found very surprising, and said, ‘Wow, these people had time for me, dedicated time for my children too.’ So I opened my door and that’s when everything started there.

Narrator: Thanks to training received at New York Presbyterian, a community health worker from WIN for Asthma was ready to conduct a home environmental assessment at Wilvia’s home. One of those workers is Yamilca Alardo who says it’s amazing to have the chance to communicate with families at a level of comfort they can’t always find with a doctor. A community health worker can assess and address physical and psycho-social factors that may impact a family’s ability to address asthma.

Yamilca Alardo: For me, it’s like, I can say it’s my passion because when I met the family first, I, they are with fear. They’re scared I think. And they don’t want to talk to you or express themselves with you. But I think that’s the challenge – to speak with them and to build let’s say a bridge or a trust in between, you know, me and the family.

Narrator: Once a community health worker has developed that trusting relationship with the family, they can begin to work together to address barriers to effective care and find possible asthma triggers in the home. And in many cases, those triggers are found in common household items and practices that a family member would never identify on their own.

Wilvia Bito: Like I had a lot of books which was not good for the children ‘cause it was collecting dust. And, we had, there was construction outside the building and I had all my doors, windows open and that was actually not good neither. All the dust was coming inside. I was cleaning every day, but that’s a dust that you don’t see coming in and that was affecting my children. We had a lot of stuffed animal giveaways, children. People usually give away those stuffed animals that we love so much but I didn’t know that it was collecting dust too, and that was affecting my children.

Narrator: Another key component of the home visit is to educate families on the effective use of medicine to manage their child’s asthma.

Wilvia Bito: Also they asked me that, you know, ‘What kind of medicine are you using?’ I said, ‘Do I need to know that?’ You know, it’s very important that you know which one are your medicine name, which nowadays I learn the name and the milligrams, and the time, and the schedule. So it was very interesting how they teach me, help me, and guide me how to survive in this, with the asthma.

Narrator: Finally, to effectively connect the bridge between asthma management in the home and clinical care, WIN for Asthma’s community health worker encouraged Wilvia to set goals in coordination with the hospital for managing her children’s asthma.

Wilvia Bito: So my health care provider, she told me to have a good relationship with the doctor; find out what the child needs, what kind of medication, always learn the names, and always ask the doctor to give me an asthma plan, which was very helpful too.

Narrator: WIN for Asthma exemplifies one of the key strategies of the Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma Disparities. That is, to enhance capacity to deliver integrated, comprehensive asthma care to children in communities with racial and ethnic asthma disparities.

Since 2006, WIN for Asthma has served more than 400 families in its yearlong care coordination program. And among the program graduates, there has been a more than 50 percent decrease in emergency room visits and hospitalizations. Nearly 100% of the program graduates state that they feel in control of their child’s asthma. Wilvia Bito is one of them.

Wilvia Bito: This summer was very interesting because my child has been playing baseball for two years and people thought I was crazy. ‘How are you going to let your child play, you know your child has asthma, what about if something happened.’ Something happen, I’m ready, I’m prepared. I have medicine with me if he needed it, otherwise we have doctors that I can communicate...I can call my doctor anytime; they’re ready for me, you know. So I don’t have that fear with me. I’m ready.

Narrator: For additional resources on the role of community health workers in asthma management and to hear other podcasts in this series, visit asthmacommunitynetwork.org/podcasts.

And for more information on asthma management, go to AsthmaCommunityNetwork.org – an online Network for people committed to improving asthma outcomes in their community.