

# What Experienced HIV-Infected Lay Peer Educators Working in Midwestern U.S. HIV Medical Care Settings Think About Their Role and Contributions to Patient Care

Maithe Enriquez, PhD, APRN,<sup>1</sup> Rose Farnan, BSN, ACRN,<sup>2</sup> and Sally Neville, MSN, RN<sup>3</sup>

## Abstract

This qualitative study examined the role of experienced HIV-infected lay individuals who work in HIV medical care settings as educators. Participants in this study had been in the role an average of 4 years, and referred to their work as “peering,” a newly coined verb in the vein of nursing. An overarching theme was that the title “peer educator” captured neither the scope of their work, nor the skill set they contribute to patient care. Peers brought unique contributions to the HIV care team that were vital to encouraging patients to stay engaged in care. Peers felt undervalued and expressed the wish to be “professionalized.” Results from this study suggest that peers show promise as behavior change agents who can model healthful behaviors, particularly for newly diagnosed patients or those struggling with engagement in HIV care and adherence to treatment. However, peers need and want more formal training in behavior change science, and peer-led services must become more uniform and readily available to patients across HIV care settings. Research is needed to document the positive impact that peers can have on HIV-related health outcomes and to increased knowledge about the attributes of successful peers.

## Introduction

WIDESPREAD EFFORTS TO IDENTIFY INDIVIDUALS with HIV infection, link them to care, and suppress viral load by treating with antiretroviral therapy are much less effective than they could be, due to the widely prevalent problems of lack of engagement in medical care and non-adherence to HIV treatment.<sup>1,2</sup> In the United States, a range of providers (specialists, generalists, physicians, nurses, physician assistants) deliver HIV treatment services with variability in health systems, practices and resources. Such variability can complicate the integration of uniform adherence interventions into HIV medical practice settings nationally.<sup>3</sup> Many HIV medical settings need novel adherence programs that do not depend on the ability of providers to deliver adherence interventions.<sup>4</sup> The current treater/provider-patient model, particularly in less-resourced settings, relies on busy health care workers to provide desperately needed HIV treatment adherence interventions to patients.<sup>5</sup> However, providers have limited time during each encounter, and spend almost one-half of it in activities outside of face-to-face contact with patients, such as

documentation.<sup>6,7</sup> Moreover, despite providers’ motivation, expertise, and empathy, fundamental differences in thought processes and background create challenges in understanding patients’ real barriers to adherence; conversely, such factors can prevent patients from connecting (i.e., forming a trusting relationship) with the health care providers in their medical care setting.<sup>8,9</sup>

Researchers and clinicians working with other chronic diseases (e.g., cancer, asthma, diabetes) have developed successful peer-led programs and behavior change interventions to enhance health outcomes.<sup>10–12</sup> However in the HIV arena, most peer-led intervention programs have dealt with prevention and increasing HIV testing uptake. Peers have exhibited the ability to act successfully as change agents in HIV prevention endeavors.<sup>13</sup> A handful of research studies that examined peer-led HIV treatment adherence interventions have shown promising results. In two recent studies, peers were capable and effective in delivering complex behavioral HIV medication interventions.<sup>14,15</sup> Peers effectively engaged populations in treatment adherence that traditionally have been labeled as difficult-to-reach, such as street-entrenched

<sup>1</sup>Sinclair School of Nursing, University of Missouri, Columbia, Missouri.

<sup>2</sup>Truman Medical Center, Kansas City, Missouri.

<sup>3</sup>Kansas City Care Clinic, Kansas City, Missouri.

substance abusers.<sup>16,17</sup> A randomized controlled trial of a peer support intervention targeting treatment adherence and depression had null findings, but concluded that the study results indicated the need for comprehensive and intensive interventions to address non-adherence.<sup>18</sup> Currently, peers serve as educators in some HIV medical care settings nationwide, and anecdotal reports acknowledge that peers often focus on enhancing treatment adherence. However, published literature that describes peers' roles, activities and perceptions about how peers' impact the health outcomes of patients in the HIV medical care setting is quite limited. One qualitative descriptive study reported that HIV-infected peers bring support to HIV-infected individuals in care and treatment.<sup>19</sup> The majority (78%) of the peers ( $n=23$ ) in this study were working in clinical settings. The investigators used a social support framework of informational, emotional, instrumental, and affiliational support to categorize 37 reported activities of the peer educators who participated in their study.<sup>19</sup> The HIV/AIDS Bureau has called for "research efforts that document the positive impact of peer programs on HIV care and treatment."<sup>20</sup> This study was undertaken to contribute further to the scientific knowledge about peers in the HIV medical care setting.

## Methods

To better understand the role of peers in the HIV medical care setting, their unique contributions to patient care, and peers' perceptions about their impact on HIV-related health outcomes, we used the methodology of narrative description.<sup>21</sup> Narrative description is useful as a research methodology in practice disciplines.<sup>22</sup> The examination of the personal stories of our population of interest (i.e., peers living with HIV who had experience working in HIV medical care settings) represented a quality method for examining peers' perceptions about how their presence impacts the people they serve (i.e., HIV-infected individuals).<sup>23</sup>

## Sample

The inclusion criteria for study participation were: age 18 years and older, diagnosis of HIV infection, work as a peer educator in an HIV medical care setting for at least 1 year, and the ability to speak English or Spanish. Information about the study was distributed via a letter of invitation to individuals who had completed the People to People Peer Education Program ([http://peer.hdwg.org/pet\\_sites/peopletopeople](http://peer.hdwg.org/pet_sites/peopletopeople)), which is part of a national study that is a collaborative effort among the American Red Cross, Kansas City Free Health Clinic, and Midwest AIDS Training and Education Center-Missouri. Some of the peer educators who participated in the study asked if they could give copies of the letter of invitation to other peer educators with whom they were acquainted. Hence, snowball sampling was another recruitment method utilized in this study.

## Procedures

The Institutional Review Boards of the University of Missouri-Kansas City and the Privacy Board of Truman Medical Center approved the study. The letter of invitation directed interested peer educators to call the investigator on a private cell phone number. The investigator gave potential partici-

pants detailed information about the study by phone and reviewed the inclusion criteria. If the person qualified for the study and wanted to participate, then a mutually agreed upon date/time to conduct the interview was set. Interviews occurred by phone or in person at a location of the participant's choice (e.g., investigator's office, private room of public library, private area in a restaurant). Written informed consent was obtained in advance of the phone interviews (i.e., the consent form was mailed to the participant in a plain envelope and was returned to the investigator in a stamped/addressed envelope) or at the beginning of the interview, for those conducted in person. Each participant received a copy of the consent form to keep for his/her records. All participants were informed that they could stop the interview at any time and that if any information had been shared with which the participant was not comfortable, it would not be used in the research. All participants stated that they felt comfortable with the information that had been shared. Interviews lasted between 90 and 120 min, and each participant received a \$50 gift card for his/her time participating in the study and to assist with transportation costs.

## Data collection

All interviews were conducted in English or Spanish by the same bilingual investigator. One interview was conducted in Spanish, as this was the participant's preferred language; all others were conducted in English. Before the interview began, there was a series of demographic queries (i.e., gender, ethnicity, years of education, age, number of years living with HIV, number of years working as a peer educator, service as a volunteer or a paid peer educator). An interview guide with primary questions was used to conduct the interview (Table 1). Each interview commenced by asking the participant to share his/her story about becoming a peer educator and concluded by asking 'is there anything else you would like to share?'

## Data analysis

The interviews conducted in English were transcribed verbatim. The interview conducted in Spanish was transcribed verbatim, translated into English, and then back-translated for translation accuracy. To further enhance accuracy, the transcripts were read while listening to the audio-tapes. Emotion and other characteristics, such as voice inflection, were then added to the transcriptions. Content analysis<sup>24</sup> was used to identify categories and themes in the data. Two investigators, one who conducted the interviews

TABLE 1. GUIDING QUESTIONS FOR INDIVIDUAL INTERVIEWS

1. Tell me your story—how did you get to be a peer educator?
2. Tell me about the type of training you received to prepare you to be a peer educator?
3. What do you like best about being a peer educator?
4. What keeps you motivated to do this type of work?
5. What are the unique contributions that peers bring to the HIV medical care setting?
6. What are your thoughts about how to improve peer-led programs in HIV medical care settings?
7. Is there anything else you'd like to share?

and one who did not have any contact with participants, conducted the data analysis. Categories and themes were discussed to reach 100% agreement in the coding. To enhance trustworthiness of the analysis, one peer educator who participated in the study was asked to review an overall description of the findings. Suggestions from the peer educator's review were then incorporated into the final analysis.

## Results

Fifteen adults from three Midwestern cities (Chicago, Kansas City, and Springfield, MO) willingly gave detailed accounts of their experiences working as HIV peer educators. Participants (Table 2) were a diverse group of nine men and six women who had lived with HIV an average of 16 years and had worked in HIV medical care settings as peer educators an average of 4 years. Most participants in this study were in a paid position and were over the age of 40; there was an average of 13 years of education. All participants gave virtually the same reason for having become a peer educator: they wanted to "be there" for others. As stated by one participant: "the diagnosis (of HIV) was so traumatizing, I didn't want anyone else to go through that and feel alone". Two of the participants had the experience of having a peer in their own medical care setting and believed that "having that role model" contributed to their desire to become a peer educator.

Three themes and one subtheme emerged from the data, with the overarching theme that the title 'peer educator' did not capture the scope of what these individuals did in the HIV medical care setting (Table 3). About half of the participants felt undervalued by the health care professionals in their medical settings. All participants described what they perceived as "an exceptional ability" to connect with patients and believed that such a connection was a key contribution of peers in the HIV medical care setting that led to "gaining that trust" of patients. The participants' personal struggles in living with an HIV

TABLE 3. THEMES AND SUBTHEME

More Than An Educator
A Connection Like No Other
Gaining That Trust
Professionalize Us!
<i>Attributes of Successful Peers (subtheme)</i>

diagnosis drove their strong passion to "keep it real" for others, especially newly diagnosed patients and those struggling with medication adherence, addiction, or emotional health problems. The two participants who had a peer in their own medical care setting highly valued that service. The remainder all wished they had had a peer, again, particularly early after their HIV diagnosis or at times when they had struggled to stay engaged in their own self-care. Finally, there was an overwhelming aspiration for the peer role to be professionalized. Hence, a subtheme emerged as part of the discussion about professionalization—the personal attributes necessary for success as a peer working in the HIV medical care setting.

### *More than an educator*

The overarching theme in all the transcripts was that the peers felt that the title 'peer educator' captured neither the scope of the peer role nor the contributions peers bring to the HIV medical care setting. Providing education was only a part of what peers did in their day-to-day work with patients. Participants referred to their work as "peering," a newly coined verb in the vein of 'nursing'. 'Peering' did, of course, include an educational component, such as teaching patients "HIV 101" and instructing them about the need to adhere to their HIV medications. But 'peering' also meant being a role model, a motivator, an advocate, and a source of social support for patients. In addition, 'peering' encompassed often serving as a liaison between patients and their health care providers. Peers modeled a myriad of healthful behaviors, not just those behaviors directly related to medical care such as taking HIV medications as prescribed. Peers modeled how to "take care of the whole body and the spirit." Peers aimed to empower patients and addressed a wide range of topics that included relationships (both sexual and family relationships), disclosure of the HIV diagnosis, healthy socialization, exercising, healthy eating, how to access available community resources, navigating the health care system, and knowing when and why to get help for problems such as alcohol and substance abuse. Peers perceived that they helped patients to feel "good about themselves" and "to get motivated" about their health. Peers also described how they helped facilitate linkage to services. For example, one participant told the story of a patient with whom he had worked who needed help asking for, and accepting the need for, counseling to address his emotional health problems. The peer realized that the patient was "essentially trying to use me (the peer educator) as his therapist. I knew he needed professional help. But the patient wasn't telling his doctor the things he was telling me". The peer was then able to talk to the provider, serve as a link and help the patient obtain the mental health services he needed. Other components of peering included helping patients to transcend the stigma and myths that surround an HIV diagnosis by modeling the fact that living a long, happy and healthy life is

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS (N=15)

Characteristic	No. (%) / mean
Gender	
Female	6 (40%)
Male	9 (60%)
Ethnicity	
African American	7 (47%)
Hispanic/Latino	3 (20%)
Caucasian	5 (33%)
Years of education	
Range: 11–20 years	13 (mean)
Age	
36–45 years of age	4 (27%)
46–50 years of age	4 (27%)
Over 50 years of age	7 (46%)
Years living with HIV	
Range: 4–26 years	16 (mean)
Years working in medical care setting	
Range: 1–10 years	4 (mean)
Volunteer or paid position	
Volunteer	1 (07%)
<sup>a</sup> Paid	14 (93%)

<sup>a</sup>8 paid peer educators began as volunteers.

possible. As one participant explained: *"What I do is model the fact that yes, I have HIV, but HIV doesn't have me"*.

#### *A connection like no other*

Peers described a "personal connection" that forms between a peer and a patient. Many of the participants in this study used the exact same words to explain why this peer-patient connection was so powerful: *"we've walked...we're walking...in their shoes"*. Peers were certain that patients were more comfortable communicating honestly with a peer, than with a health care provider. Hence, patients would generally be more forthcoming with a peer. In particular, at initial diagnosis or at the onset of the patient's relationship with a new HIV medical care setting, talking with a peer felt 'safe'.

*"Sometimes we (people living with HIV) don't feel comfortable talking to our doctors or our case managers. But, another person that's dealing with the same thing I'm dealing with, yes, we (are) able to talk to them. It helps a lot (!) to have somebody else that's going through this because that's how everybody feels when they are first diagnosed. They the only one. Ain't nobody else out there cause they ain't met nobody else. And to be able to talk to someone that's going, been through it, and living, it makes you feel, you know....so (having) a peer (in the medical care setting) is VERY important to us who are HIV-positive."*

Peers felt strongly that they understood patients' feelings. Peers frequently knew the "real" reasons, which were often not shared with health care providers, why a patient might not be taking his/her HIV medications. Finally, peers also felt that **some** patients would be much more likely to believe a peer than their own doctor/health care provider.

*"Peers aren't 'white coat' people. Peers understand how society discriminates. Peers understand that the reason HIV-positive people are not engaged in care is because maybe they don't have a place to stay, they are dealing with substance abuse, they are dealing with mental abuse, they are dealing with physical abuse...."*

Peers also talked about another reason that they were able to make such a strong connection with patients. Peers simply had much more available time to spend with a patient in the HIV medical care setting than any of the other professional health care providers. Extensive conversations between the peer and patient were perceived to result in a deeper level of communication and understanding. Hence, peers often found themselves in the role of a liaison between a patient and his/her health care provider(s). However, perhaps the strongest reason that participants gave for their ability to form such a meaningful connection with patients was their belief that only a person living with HIV can truly understand another person living with HIV's feelings.

*"A (HIV) positive person doesn't believe that a non (HIV) positive person can really understand what they're going through. You might say 'well, you don't have to be a diabetic to understand diabetes'. But it's the stigma, the associated stigma with this particular situation that throws people for a loop. I've seen people (choose to) die because of the stigma. When I talk to another (HIV) positive person, I say 'we're in the same boat together, we're bailing water for each other. I bail for you and you bail for me and together we're going to get through this'."*

#### *Gaining that trust*

Peers spoke repeatedly about "gaining that trust" and how they felt this was a critical component of successful

peering. Peers also believed that trust helped to engage patients in care and helped to prevent them from dropping out of medical care. The participants in this study had successfully lived with an HIV diagnosis for many years and this success with healthful behaviors was perceived as the primary mechanism of peers' ability to gain the trust of patients. Almost every participant gave the same explanation and described how the trust felt almost instantaneous: *"When I walk in and say 'hi, my name is Mary and I've had HIV for 19 years (snaps fingers)."*

Participants also believed that their own experiences and struggles dealing with the myriad of societal barriers, high degree of stigma, and many myths associated with HIV disease helped them to gain the trust of patients. Peers shared with patients the fact that they had been "through the same things," had "felt the same feelings," and had "survived." Peers also stated that they "know what patients are thinking." Such sharing and the ability to tell patients what they were thinking, even when the patient may not have yet verbalized their feelings, further contributed to the trust patients had in the peers. Peers perceived that this high level of trust also facilitated the ability of peers to empower patients by modeling healthful behaviors. According to the participants, the fact that patients witnessed the peers functioning at a high level in an environment where everyone knew their HIV status, in and of itself, modeled the ability to transcend stigma. All of the peers believed that stigma is the number one reason why patients do not take care of themselves.

Every participant felt strongly that a peer should be present for every patient at the initial diagnosis, or if this was not possible, then at the first visit with an HIV health care provider. All participants were convinced that the time around the initial diagnosis is the critical moment when trust with the medical care team must be established, or if not, there is a risk that the patient could be lost to care. Peers believed that the presence of a peer at the time of diagnosis might enhance a patient's trust in the medical care team/system.

*"What I've been told by patients is that they wish I (a peer) was there when they were given the (HIV) diagnosis. That's their statements."*

#### *Professionalize us!*

All participants had received some type of training prior to their employment as peer educators. Some received formal training, some had received 'on the job' training, and some had received both. The most common formal training program was attendance at a People-to-People program ([http://peer.hdwg.org/pet\\_sites/peopletopeople](http://peer.hdwg.org/pet_sites/peopletopeople)). The number of days that participants had attended the People-to-People training program varied between 2 and 5 days. Some participants had also completed a program entitled L.I.F.E. (<http://www.uchaps.org/homegrown7.shtml>). Some of the participants considered the L.I.F.E. program to be part of their peer educator training. The 'on the job' training peers had received varied immensely by work setting. However, despite having had formal and on the job training, the majority of the peers stated that the bulk of their peer educator knowledge and training had come from "self-teaching on the Internet." All peers wanted more, and ongoing, training in a variety of topics, which included behavior change science and communication

techniques. Further, the peers yearned for the ability to interact with other peers who were doing the same jobs in other parts of the country, or even the world. Several peers stated that they would “love” to be able to attend a national or international educational conference dedicated to peers working in the HIV medical care setting.

The participants in this study liked their work, but some did not feel that the professional members of the health care team (i.e., physicians, nurses, pharmacists, social workers) understood what their role was or what they could ‘bring to the table.’ Many peers felt ‘under-utilized’ by the health care providers with whom they worked, leaving some with a sense of being undervalued.

Peers discussed this issue when training new peers:

“...make sure to have the buy-in from the doctors and nurses and pharmacists, because without that buy-in, you know you’d feel like someone was looking at you like ‘you’re stepping on my toes, you’re going outside your jurisdiction.’”

Peers also talked about a disconnect between themselves and some of the professional health care providers:

“...one provider said that they were afraid they were going to be undermined (by a peer), but no, we’re not there to undermine. We’ve gone through hell and high water. So we know some things. Peers bring a lot, especially in a multi-disciplinary (HIV care) team. Because when you get case manager, doctor, nurse, pharmacist and a peer together, I do feel like the patient gets the best customer service.”

“...peers don’t think they can save somebody. You can’t save anybody. All you can do is lead them to the water and hope that they bathe.”

#### Attributes of a successful peer

The 15 peers who participated in this study had a number of common attributes. This group of peers exuded confidence and felt highly successful in their jobs, based on the feedback they received from patients. All were enthusiastic about the peer role and were quite motivated to acquire more education and to build their skills in an effort to enhance their job performance. Many talked about the need to maintain a “professional relationship” with patients and not “cross that line.” As one participant explained, “peers are not friends—well...they are friends, but not exactly.”

The majority of the participants in this study had lived with HIV for a long period of time. Their longevity served them well when addressing the myths that surround an HIV diagnosis, and most felt it was important for a person to have had the disease for a period of time before stepping into the peer role.

“I feel newly diagnosed patients need to see somebody (a peer) that’s been living with it (HIV) a long time. That’s the way I feel because when you first diagnosed, you look at it (HIV) as a death sentence. You think—‘I’m dying, I can’t do what I want to do, and what am I gonna take medication for? I’m already dying.’ Having a peer that’s been living with HIV a long time let’s them actually SEE it’s not a death sentence. That’s what I think, no matter what a health care provider says, patients will look at it (HIV) as a death sentence.”

Yet, despite the fact that having lived with HIV for many years was seen as a positive attribute for a peer, many also talked about the fact that there was a need to recruit young people to be peers. Peers in this study were all over 40 years

old and they understood that “it can be hard for a 50-something to relate to a teen or a 20-something.” Another attribute that all of the participants in this study verbalized was the importance of having support outside of their workplace. All had long-term partners/spouses or a supportive family and many had both. These social support networks outside the workplace enhanced their abilities to stay motivated and to continue their work as peers. In addition, all the peers who participated in this study were active (e.g., church, social/family activities, exercise), were adherent to their HIV treatment and had suppressed HIV viral loads. Finally, almost all (14/15) were paid staff members at the time of the interview. There were several participants who had started as volunteers and then became paid staff members. Participants who began as volunteers felt that “getting paid” had served to increase their feelings of self-worth in the workplace.

#### Discussion

This study found some variation by setting with regard to the roles that peers have as members of the HIV medical care team. Most of the peers who participated in this study stated that their “job description” was to provide education with an emphasis on the importance of adherence to HIV treatment. However, all peers said that education was just a small part of what they did, and what they meant, to patients. Formal training for the role was described as brief, some had no formal training, and all had some type of “on the job” training. Most peers stated that they were “left to do their own thing” in the clinical setting. Some peers felt undervalued by many of the health care professionals with whom they worked and some felt that their medical settings created a “confining environment”. Peers yearned for more training and they strongly wished to be “professionalized.”

This study discovered that peers have a wealth of frontline expertise and an insider perspective. Peers felt that they have much undeveloped potential and that their expertise and skills could be used to revolutionize behavioral strategies and enhance HIV health outcomes. The participants in this study felt that all individuals receiving care in the HIV medical care setting would benefit from being peered, but that especially those who are newly diagnosed and struggling to stay adherent to treatment would benefit. Specific attributes of the participants in this study (e.g., had lived HIV for many years, suppressed HIV viral load and on antiretroviral therapy, strong support system in own personal life) may be critical to the success of peers as members of HIV care teams.

The title ‘peer educator’ did not do justice to all that these individuals bring to the HIV medical care arena. This was a group of knowledgeable, insightful, sensitive, and compassionate individuals. “Peering” is a novel health care service, which has the potential to enhance the health outcomes of persons who are living with HIV.

This study had limitations. This study used a convenience sample of experienced peers with an average of 4 years of job experience as peers in HIV medical care settings. The inclusion criterion that participants must have at least 1 year of job experience would have excluded individuals who were less enthusiastic about the peer role and had left their position with less than a year of experience. Moreover, those who volunteered to participate might have been the peers who

were the most passionate about their work. Such passion could have resulted in the peers reporting overinflated perceptions about the positive impact of their role on patient outcomes. In addition, the investigators—despite their best efforts to stay neutral—are supportive of peer educators in the HIV medical care setting and their positive attitudes about peers could have biased the interpretation of the findings. Finally, because participants were recruited from a limited geographic area, ‘peering’ or the role of HIV peer educators may be different in other parts of the U.S. and other parts of the world.

Despite these limitations, findings from this study have important implications for research and clinical practice. ‘Peering’ needs to be defined and the impact of peering on HIV-related health outcomes must be rigorously examined and documented. Further, an evidence-based description of the type of background and training needed to be successful in the peer role would benefit clinical practice. A more extensive curriculum than the brief training that most of the peers in this study received seems warranted. In addition, ongoing continuing education is desired.

### Conclusion

This study contributes to better understanding of the role that peers have in the HIV medical care setting and their potential to enhance HIV-related health outcomes. Being ‘peered’ differs from being ‘doctored,’ being ‘nursed,’ or being ‘counseled.’ However, many unanswered questions remain about the peer role in the HIV medical care setting. This study demonstrated that training activities, role definition, and clinical activities of peers in the HIV medical setting are widely variable. Professionalizing peers who work in the HIV medical care setting through certification, or some other type of formal education and recognition, seems beneficial. In particular, professionalization might make the role more uniform, and elevate the value of peering in the eyes of other health care providers and key stakeholders. Demonstrating that peering has a significant positive impact on HIV health outcomes would also contribute to the value of peering and could lead to reimbursement for the services that peers provide in the medical care setting. Peers are unique and novel HIV health care providers. Findings from this study indicate that peers may have great potential to enhance HIV care and HIV-related health outcomes. Clearly, more research is needed to define the role and examine the impact that ‘being peered’ means in the long term. Anecdotal reports from the group of experienced peers who participated in this study suggest that peering has a positive and lasting impact.

*“I retired from peering. I just became a great-grandparent. But when I go to the clinic for my own care, and I see my old clients that I peered, they come up to me and say.... ‘you’re the reason why I’m alive.’”*

### Acknowledgments

The authors are grateful to the peer educators who participated in this study. This article is dedicated to the memory of Rev. James (Alex) Alexander who encouraged us to conduct this study and remains an inspiration. We thank Alicia Downs, MSW, LaTrischa Miles, BBA, and graduate research assistant Mary Kay Jeseen, RN, MSN, for their support of this

study, and David McKinsey, MD, FIDSA, for his thoughtful review of our article.

### Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Dr. Maithe Enriquez  
Sinclair School of Nursing  
University of Missouri  
Columbia MO 65211

E-mail: [enriquezm@missouri.edu](mailto:enriquezm@missouri.edu)