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Increasing Research Literacy in Minority Communities: CARES Fellows Training Program

Melody S. Goodman,
Stony Brook University, School of Medicine

Janice Johnson Dias, and
CUNY/John Jay College of Criminal Justice

Jewel D. Stafford
Stony Brook University, School of Medicine

Abstract

The community alliance for Research Empowering Social Change (CARES) is an academic-community research partnership designed to: (1) train community members about evidence-based public health, (2) increase community members' scientific literacy, and (3) develop the infrastructure for community-based participatory research so that local stakeholders can examine and address racial/ethnic health disparities in their communities. Nineteen community members enrolled in the CARES training. The training consisted of 11 didactic training sessions and 4 experiential workshops, taught by a multidisciplinary faculty from research institutions. Results suggest that the training increased research literacy, prepared community members for collaborative work with academic researchers, and empowered them to utilize scientific research methods to create social change in their communities.

Keywords

community-based participatory research; public health training; academic-community partnership; research literacy; evidence-based public health

Residential segregation has been referred to as the “structural linchpin” that maintains structural inequality in the United States (Bobo, 1989) and is one of the many causes of disparities in health (Acevedo-Garcia et al., 2003). Prior research has found associations between residential segregation and poor health status, poor birth outcomes, infectious diseases, exposure to toxins, and mortality (Yankauer, 1950; LaVeist, 1989, 1993, 2003; Polednak, 1991, 1996a, 1996b; Bell et al., 2006; Osypuk & Acevedo-Garcia, 2008; Morello-Frosch & Jesdale, 2006). Residential segregation shapes socioeconomic conditions not only at the individual and household levels but also at the neighborhood and community levels (Williams & Collins, 2001), affecting access to healthcare services, quality jobs, education, safety, and social networks (Charles, 2003).

Long Island, New York, with a land area of 1,401 square miles and approximately 3 million residents (79% white, 9% Black, and 12% Hispanic), is the third most residentially segregated suburb in the U.S. With a non-white population increase of 56% between 1990

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Address correspondence to: Melody S. Goodman, Division of Public Health Sciences, Department of Surgery, Washington University in St. Louis School of Medicine, 660 S. Euclid Avenue, Campus Box 8100, St. Louis, MO 63110, Phone: 314-362-1183, goodmann@wudosis.wustl.edu.

and 2000 (US Census Bureau, 2000; Iceland et al., 2002), as Long Island is becoming more diverse, it is *not* becoming more integrated. Regardless of their income, Blacks and Hispanics on Long Island tend to live in segregated communities (Powell, 2004); these communities tend to have higher poverty rates, lower median income, poorer schools, older housing stock, and lower home ownership rates (Powell, 2004). Based on 2000 U.S. Census data for Long Island, on a scale of 0–100, where 0 represents complete integration and 100 represents total apartheid, the Black-White Index of Dissimilarity is 74 and the Hispanic-White Index of Dissimilarity is 47. In other words, almost three-fourths of Blacks and approximately half of Hispanics on Long Island would have to move into predominately white communities to have integrated neighborhoods (Rusk, 2002). This physical isolation from opportunities and vital resources poses unique public health challenges for many underserved communities in the region.

The history and ongoing practice of racism, classism, and residential segregation have engendered mistrust between marginalized communities and the institutions designed to serve them (e.g., police, medical), which may explain the slow progress in eliminating health disparities. Community-based participatory research (CBPR) has been shown to be effective in ameliorating or abating some of these issues by engaging underserved communities as partners in the research process (Viswanathan et al., 2004; Pinto, 2009), and has emerged as a promising approach in public health providing the missing link between research and practice (Baker et al., 2001). CBPR is a collaborative approach to research that focuses on the development of an academic-community partnership with the principles of co-learning, mutual benefit, and community participation (Minkler & Wallerstein, 2003; Wallerstein & Duran, 2006); researchers elucidate and address identified public health concerns, working collaboratively *with* communities as partners, not *on* communities as subjects (Tumiel-Berhalter et al., 2007). Moreover, community-based interventions have demonstrated the potential to be powerful tools in reducing health disparities (Baker et al., 2001), particularly when they address the systematic, environmental, and community-level factors that impact health. Developing a community health collaborative that addresses health disparities requires community engagement, transdisciplinary collaborations, and innovative research and intervention approaches (Schulz et al., 2002).

Community engagement is a powerful vehicle for bringing about changes that can improve community health (Fawcett et al., 1995). Engaging communities to collaborate with researchers to address identified health concerns requires establishing a rapport, building trust, and maintaining a consistent presence (Ford et al., 2007). As an initial step in community engagement, the Center for Public Health & Health Policy Research (CPHHPR) at Stony Brook University invited community leaders, public health professionals, and faith-based and community-based organizations to participate in Mini-Summits on Minority Health (Stafford et al., 2010). Mini-summits are unique community forums and strategic planning sessions with key informants designed to elucidate and address health concerns. Three mini-summits were held over the course of a year, each with a different theme: (1) race, class, and public health, (2) CBPR, and (3) coalition building (Stafford et al., 2010). At the second mini-summit, participants were given a presentation on CBPR and then worked interactively in small groups to determine how CBPR could be used to address minority health concerns in the region. Through this process, participants recognized the potential in university-community partnerships. However, they were hesitant to participate in such partnerships without being on an equal footing with university researchers; therefore, they requested formal research training. Community members asserted that being trained was an essential step in becoming empowered to participate in the research process.

Concurrent with these mini-summits, the National Institutes of Health (NIH) Public Trust Initiative launched the Partners in Research program to encourage scientists and community

stakeholders to develop partnerships to increase scientific literacy and communicate needs of communities (NIH, 2007). This unique funding mechanism mandated that grant funding be divided equally between the academic partner and community-based organization; a member of the community-based organization is the Community Principal Investigator on the grant. CPHHPR, in collaboration with Literacy Suffolk, Inc., responded to the Partners in Research request for proposals to form the Community Alliance for Research Empowering Social Change (CARES), an academic community-based public health initiative designed to examine and address health disparities among minority and medically underserved populations in the region. The CARES leadership team consisted of the Director (Principal Investigator) and Project Manager from CPHHPR, and the President of the Board of Directors (Community Principal Investigator) and Executive Director (Project Manager) of Literacy Suffolk, Inc. Having equal representation from academic and community partners on the leadership team was essential for establishing and maintaining CARES as an equitable partnership.

CARES provided CPHHPR with the opportunity to respond to the community's request for training on research methods, to build trust, and to increase community capacity to partner with academic researchers on projects that had the potential for community empowerment and exchange of capital. CARES was designed to train community members about evidence-based public health, develop the infrastructure for CBPR, and examine and address racial/ethnic health disparities on Long Island using CBPR. Developing the infrastructure for CBPR through community training provides an opportunity for community members to learn the language and processes of research and affords faculty (academic researchers) the chance to learn the language and concerns of community. The specific aims of CARES are to:

1. Unite key community stakeholders to improve health outcomes by pooling member resources into a single, comprehensive community-based research network;
2. Enhance the community's knowledge and understanding of public health and research methods;
3. Build the infrastructure for CBPR that explores and addresses community health concerns;
4. Develop culturally appropriate interventions; and
5. Create a pool of trained community members who can serve on institutional review boards and community research advisory boards.

Methods

The CARES Fellows training was a comprehensive 15-week evidence-based public health research training course for community members on Long Island. The curriculum and goals, designed by the CARES leadership team, were developed based on a standard Masters of Public Health (MPH) curriculum (see Table 1). Each CARES session was a condensed, 3-hour version of an entire MPH course. Topics included: health literacy, ethics, cultural competency, epidemiology, quantitative and qualitative research methods, and grant writing. The training was designed to implement culturally appropriate ways to increase scientific literacy among community members. The goal was to train community members to: (1) become good consumers of research; (2) understand the utility of research in improving health outcomes in their communities; and (3) increase their understanding of how to work with academic researchers.

Human subjects approval for the CARES project was granted by the Stony Brook University Committee on Research Involving Human Subjects.

Recruitment and Study Participants

The CARES leadership team decided that 20 participants would be ideal for a pilot program and sought to recruit community health workers, leaders of community- and faith-based organizations, and other community members working to improve health among minority groups in the region. In an attempt to “go green” and to save on cost, we sent e-mails to Suffolk County Minority Health Action Coalition (SMHAC) members and requested that they forward our solicitation to their networks. Our previous outreach experience showed that e-mail distribution is an effective way to contact community-based organizations, many of whom have begun to distribute their newsletters electronically. To supplement the e-mail distribution, we held an informational session at the Suffolk County Minority Health Summit (an annual conference hosted by SMHAC and CPHHPR) and distributed recruitment brochures at local health fairs and community events. The CARES leadership team worked diligently to assure that recruitment materials were written in everyday conversational language.

Although SMHAC members originally requested the training, many of them were unable to participate. They were extremely active in the community and many could not make the time commitment required of the CARES Fellows training. We addressed low initial recruitment numbers through increased recruitment efforts, which took almost 6 months; we originally had expected to complete recruitment in 3 months. Despite these challenges, we were able to recruit a cohort of 19 CARES Fellows.

Once the full cohort of community members agreed to participate, a survey was sent requesting their availability. The day and time of the training was selected based on survey results. Before the first training session, two orientation sessions were conducted. These sessions provided participants with information on the CARES project, including the training program, goals and expectations, as well as ground rules for the training sessions and experiential workshops. Participants were asked to sign a CARES’ participant agreement which required that they not miss more than 2 of the 11 training sessions. Attrition of the Fellows was due to this attendance policy (32% attrition rate).

The majority of the 19 CARES Fellows were female (79%) and born in the U.S. (79%). Ten (52%) were black, four (21%) were white, three (16%) were Hispanic, and two (10%) were Native American. The CARES Fellows ranged in age from 22 to 78, with a mean age of 51. The majority of Fellows were members of community-based organizations and community health workers (at academic institutions, hospitals, and health departments); all had completed some college coursework. Table 2 displays the demographic characteristics of the CARES Fellow cohort.

Selection of the Faculty

Careful consideration was given when recruiting faculty to train the CARES Fellows. The faculty were chosen based on their level of expertise and ability to communicate complex public health topics in an accessible format and language. The result was a diverse, multidisciplinary faculty that included social and behavioral scientists from the National Human Genome Research Institute/NIH, a sociologist from the Department of Sociology, City University of New York/John Jay College of Criminal Justice, an epidemiologist, a biostatistician, a physician, a sociologist, and several social workers from the Graduate Program in Public Health, Stony Brook University School of Medicine and the School of Social Welfare at Stony Brook University. All members of the CARES leadership team also served as CARES faculty.

Training

The training consisted of 11 didactic training sessions, and 4 experiential workshops. (For an outline of the 11 sessions and 4 workshops, see the supplementary material posted at <http://caliber.ucpress.net/doi/suppl/10.1525/jer.2010.5.4.33>.) Our limited resources did not allow us to offer payment, transportation, or childcare. We were, however, able to provide refreshments at each training session. Classes were held at Suffolk County Libraries. The CARES leadership team identified libraries as a community asset and felt it was important for the training to take place in the community environment outside of the university setting. These trusted community institutions provided access to valuable resources including literature, computer access, and meeting spaces. Twenty Suffolk County Libraries signed on to be designated CARES sites; each site was accessible via public transportation and had a designated CARES librarian who was knowledgeable about the CARES project and worked to assist Fellows with their research. One librarian taught a training session on how to use the library and library research resources, and created a website specifically for the CARES project.

CPHHPR and Literacy Suffolk staff worked collectively to develop training materials, which were distributed at each session. Each training module contained materials that included background information and interactive exercises, as well as case studies and examples based on demographics of communities in the region and previously identified health concerns and issues.

In the experiential workshop sessions, CARES Fellows and faculty worked collaboratively to develop a CARES demonstration project. This experiential learning experience guided CARES Fellows through the steps of developing and implementing a pilot study in collaboration with academic researchers. The group worked together to develop and implement a web-based community health assessment of Long Island residents. The IRB-approved demonstration project has been completed and preliminary analysis is in progress; the group will reconvene to complete the analysis and interpret study findings. At the last workshop session, Fellows and faculty discussed grant writing, an ideal topic to transition from training into research.

A crucial measure of the training's success was the Fellows' ability to develop their own pilot projects. During the first workshop, CPHHPR released a Request for Proposals (RFP) to fund small CBPR pilot projects. The purpose of the RFP was to encourage CARES Fellows to work collaboratively with academic faculty on developing pilot CBPR projects for their communities. CPHHPR provided a list of Stony Brook University faculty who agreed to participate as collaborators on the pilot projects; many of these faculty members taught the training sessions and thus were familiar to participants. The Fellows developed a research topic with specific research hypotheses; CARES faculty assisted with study design. Each application required CARES pilot CBPR project teams to generate the following information: project title and summary, performance site, specific aims, background and significance of the public health problem to be addressed, a research and evaluation plan, and a detailed budget. This process provided a unique opportunity for Fellows to demonstrate their understanding of research concepts and apply new research skills.

Evaluation of the CARES Program

We collected both quantitative and qualitative data to assess Fellows' learning experience during the CARES training program. The quantitative data measured change in research knowledge from baseline to follow-up, while the qualitative data measured program satisfaction. We administered a baseline survey at the beginning of the first training session that consisted of 26 questions: 10 demographic questions and 16 assessment questions. The

assessment questions were open-ended and measured participants' existing knowledge and understanding of CARES training topics including research ethics, health literacy, cultural competency, evidence-based public health, CBPR, and community health, as well as quantitative and qualitative research methods. Additionally, we administered a pre- and posttest for each training module. In addition to assessing their knowledge of the training content, we also administered evaluations at the conclusion of each module that asked Fellows to provide feedback about content and presenter(s). After the 11 training sessions, we administered a follow-up survey. The follow-up survey consisted of 39 questions: 26 questions from the baseline survey, and 13 new questions about the training program. The 16 assessment questions that were measured at both baseline and follow-up were graded by two people (each assigned to the same group of questions on the baseline and follow-up to ensure that all test and questions were graded consistently). The baseline and follow-up test scores are the percentage of the 16 questions that Fellows answered correctly on each assessment respectively. We used SAS/STAT Software Version 9.2 for Windows to analyze the quantitative data.

Results

Thirteen (65%) Fellows completed the face-to-face training, 10 of whom submitted pilot grant proposals. All proposals were reviewed by CPHHPR and returned to Fellows to address critiques and resubmit. Although Fellows were encouraged to work in groups based on the principles of CBPR, three Fellows submitted individual proposals. None of the Fellows who submitted individual proposals responded to the comments or revised and resubmitted their proposals. However, the Fellows working in groups responded to comments and were ultimately funded. The two CBPR pilot research projects have received IRB approval; one project is a door-to-door community health assessment of a predominantly Hispanic community, and the other project is an educational intervention about obesity, followed by focus groups, for black women on Long Island.

Nineteen CARES Fellows completed the baseline survey and 12 Fellows completed the follow-up survey. Based on the responses to the 16 assessment questions taken at baseline and follow-up, the CARES Fellows showed improvement in their test scores. The average score on the baseline test was 38.8% and the average score on the follow-up test was 63.5%. Results of a paired t-test demonstrate an average increase in score of 26%, a statistically significant increase ($p = 0.0016$), indicating improved knowledge of public health research topics.

In addition, we compiled responses to the open-ended evaluation questions and examined responses for recurring phrases and themes regarding satisfaction with the training. We categorized answers into positive and negative responses. We also queried participants for information on their previous and current knowledge of research methods. Overwhelmingly, the Fellows agreed that the training was well structured and had excellent faculty; one Fellow's comment, that the "training sessions overall [are] excellent, and speakers are knowledgeable," is representative of the comments we received related to satisfaction with the training. We expected to observe greater variety in the tenor of responses, but the data suggest that CARES Fellows overwhelmingly valued and appreciated this unique training opportunity.

Critiques of the training fell into two categories: the need for more group activities and the need for additional time for future training sessions. Reflecting the sentiments of other Fellows, one CARES Fellow suggested that we include "more group exercises and sharing diverse experiences during training sessions." Another stated that s/he needed "more time at sessions to digest the information." Three respondents commented that training sessions

were intense but provided a great deal of information. One suggestion was to include the use of “back-up distance learning if sessions are missed.” We also gathered the perspectives of those who dropped due to attendance. They also recommended web-based distance learning options for those who are unable to attend the in-person training sessions.

A number of the CARES Fellows agreed that the training increased their critical thinking, collaboration, and cultural sensitivity. Echoing the comments of the CARES Fellows, one Fellow stated that as a result of the training, “I am better able to collaborate.” Similarly, another Fellow stated that training improved their practice through “Better communication with members of my community.... now I know that even in Suffolk County some people cannot read even though everyone pretends to speak English better than me.” When asked how the training may help them utilize research to address problems in their community, one of the CARES Fellows who applied for the pilot grant said, “It will help me apply for a grant to implement my research project.” Another interesting observation was from a Fellow who stated that the training “helped me to be more critical of an issue and its possible solutions and to consider limitations to actions before I act.”

Discussion

Based on the data collected from the CARES Fellows, the CARES training was successful, useful, and provided substantive details about evidenced-based public health research topics. The consistent weekly format, while intense, was beneficial to the Fellows. Although the training sessions were structured lecture-style, Fellows were actively engaged, asked in-depth questions, and requested additional time for discussion at each session. The training reframed complex public health topics, moving beyond the theoretical framework, introducing the practical application of the topics in underserved communities. A diverse and knowledgeable faculty was crucial to the success of the training. The Fellows indicated that the faculty was well organized, prepared, and provided great detail on their topics. To this end they enjoyed their increased communication with and access to academic faculty, and felt prepared to move into the research phase of the CARES program.

The CARES training program achieved its goal to enhance the community’s knowledge and understanding of research, as well as increase their capacity to participate in research as partners. Fellows’ increased mean scores from the baseline to follow-up demonstrated increased comprehension of public health topics, while their qualitative responses provided a greater understanding of how the training influenced their experience. The results of the CARES program, particularly the process of applying for a pilot CBPR project grant, suggest that comprehensive evidence-based public health research training can prepare community members for collaborative work with academic researchers and empower them to utilize research to create social change in their communities. This transformative process increased communication, and developed a common language to form equitable community-academic partnerships. Developing culturally appropriate, region-specific public health training requires both art and science and may prove beneficial to improving research literacy for community stakeholders who desire to engage as equal partners in the research process.

CBPR is time-consuming, and it was challenging to meet grant timelines. However, our approach, including the composition of the leadership team, truly reflects the principles of CBPR. The academic leadership team of the CARES project was uniquely positioned to bridge the gap between community health needs and public health research. As scholars of color, we are both insiders and outsiders, members of both academia and minority communities in the region. We represent a key constituency typically missing from many

CBPR studies. We believe this diversity was integral in the success of CARES and will be vital in ending health disparities.

Best Practices

We identify seven best practices for the development and implementation of a master's-level public health training course for community stakeholders and health professionals. (1) The purpose of the course should be to create a common language between community members and academic researchers. Developing a common language is integral and enables a co-learning experience that bridges the gap between community health needs and academic research. (2) Through this framework, community members are empowered to partner with academic researchers, and develop and implement research projects designed to address identified concerns. CBPR through its collaborative and interdisciplinary approach provides the infrastructure to examine population health issues through an evidence-based culturally competent lens. (3) Training faculty should be chosen based on their ability to explain complex topics clearly and to work with and treat community members as research partners; in this case, credentials do not provide creditability or legitimacy. (4) Training should be conducted in a structured format accessible to nontraditional learners. (5) Training should be located in a community setting outside of the academic institution to reduce the hierarchy traditionally found in university-community relationships. Having the training take place in a community environment helps to shift the power dynamic between faculty and Fellows and allows for a bidirectional exchange of knowledge that is imperative for meaningful outcomes. (6) Fellows should have opportunities to recognize that they have knowledge and expertise to contribute, and thus to educate the faculty about their community and its needs. No one knows a community better than the people who live there. (7) Community engagement by the faculty is a prerequisite for ensuring that community members trust their academic partners and feel comfortable sharing this expertise with faculty. In CARES, the community benefited by participating in research that addressed their identified needs, while researchers gained invaluable knowledge and enhanced the quality of their projects.

Research Agenda

Future work should address economies of scale and attend to how training a larger cohort of community members would impact learning and program satisfaction. We were able to recruit a multi-ethnic cohort that was diverse in age; however, the number of participants limits the generalizability of our findings.

Future research should compare structure, format, and content across research training programs to identify the most successful approaches. The structure of our training program (weekly in-person sessions) was a major reason for attrition of participants. As a result, the CARES leadership is considering distance learning as an alternative training format. However, the development of a web-based training raises new questions about the transfer of knowledge between community members and academic researchers. Can the knowledge provided during the in-person session be obtained in a web-based format? Can trust and mutual respect be developed in a distance learning setting? Is there a web-based format that would allow for bidirectional communication and co-learning between community members and researchers? Would faculty gain as much insight about the community and its needs through online instruction?

Educational Implications

Researchers can only address health disparities with participation, insight, and input of community members. Therefore, we have a responsibility to educate community members about research. Asking communities to participate in research is like asking a novice card

player to partner with an expert in a card game. The first thing the expert must do is teach the novice the rules of the game and give the novice the opportunity to use their talents and practice what they have learned in a comfortable practice setting. As researchers it is our job to first train our community partners in research, so they know the rules of the game, build on their strengths, and give them the opportunity to practice what they have learned in a comfortable learning environment. If done correctly, these community partners will become invaluable resources to the research process.

Training community members on complex public health research topics requires moving beyond the theoretical realm, introducing practical application through regionally and culturally relevant examples and a demanding but flexible curriculum. Faculty engaged in training community members must be engaging, accessible, and open to learning from community members in order to meet community members of varied education levels where they are and bring them to a level necessary for equitable partnership. The training framework should: (1) prepare community members to form equitable partnerships with researchers, (2) empower community stakeholders to use scientific research methods to create social change, and (3) develop region-specific community driven interventions to address health disparities.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Biography

Melody S. Goodman is Principal Investigator of the CARES grant and Project Director of the SMHAC grant. Dr. Goodman was involved in developing the necessary partnerships that created the infrastructure for CARES, including giving presentations at the mini-summits and securing funding for SMHAC. She developed the CARES syllabus, recruited the CARES faculty, helped recruit participants for the CARES training, taught training sessions (data and quantitative research methodology), co-taught two workshops, and graded assessments. She is currently working with a subgroup of Fellows as they implement their pilot projects.

Janice Johnson Dias is a member of the CARES training faculty and taught the training session on qualitative research methodology. She has subsequently worked with a subgroup of CARES fellows in the development of a community-based collaborative focusing on ending health disparities among young black girls on Long Island.

Jewel D. Stafford is the Project Manager of the CARES and SMHAC grants. She facilitates the logistics of CPHHPR community-based research projects including: communicating with community members, professionals, and faculty; planning and implementing evidence-based strategies; and developing training materials. She has worked to build community capacity and has assisted in the development of the Suffolk County Minority Health Action Coalition (SMHAC) and CARES. For the CARES project, she participated in recruitment of participants, graded assessments, conducted orientation sessions, taught training sessions

(Introduction to Research, Cultural Competency, and Community Health), and co-taught two workshops.

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TABLE 1**CARES Fellows Training Cohort I Syllabus.**

Session/ Workshop	Topic
Session 1	Introduction to Research
Session 2	E-Health and Health Literacy
Session 3	Ethics
Session 4	Research Methods
Session 5	Library Resources/Data/Cultural Competency
Session 6	Qualitative Methods
Session 7	Census 2010: Stand Up and Be Counted/Quantitative Methods
Session 8	Community-Based Participatory Research
Session 9	Community Health
Session 10	Introduction to Epidemiology
Session 11	Workforce Assessment and Health Literacy
Workshop 1	Research Synthesis
Workshop 2	Culminating Experience
Workshop 3	Culturally & Linguistically Appropriate Services (CLAS) Standards
Workshop 4	Grant Writing and Pilot Survey Development

TABLE 2

Characteristics of Participants. * (N = 19)

		n	%
Gender	Female	15	78.95
	Male	4	21.05
Race	non-Hispanic Black	10	52.63
	non-Hispanic White	4	21.05
	Hispanic	3	15.79
	Native American	2	10.53
Education	Some College or Associate's Degree	2	10.53
	College Degree	9	36.84
	Graduate Degree	1	47.37
	Doctoral Degree		05.26
Country of Birth	Born in United States	15	78.95
	Foreign Born	4	21.05
Affiliation	Community Health Worker	6	31.58
	Community-Based Organization	6	31.58
	Community Member	7	36.84
Age	Mean Years	51.2	
	STD Deviation	15.5	

* Respondents were asked to participate in a baseline assessment at the first training and provided demographic information.