Fam Community Health
Vol. 38, No. 1, pp. 12–21

Empowering Immigrant Youth in Chicago

Utilizing CBPR to Document the Impact of a Youth Health Service Corps Program

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Community-based participatory research (CBPR) is an approach that engages community residents with a goal of influencing change in community health systems, programs, or policies. As such, CBPR is particularly relevant to historically marginalized communities that often have not directly benefited from the knowledge research produces. This article analyzes a youth empowerment program, Chicago's Youth Health Service Corps, from a CBPR perspective. The purpose of this work was (1) to discuss Youth Health Service Corps as a health promotion program, (2) examine the use of CBPR within the immigrant community, and (3) discuss preliminary findings using a model on critical youth empowerment. **Key words:** *critical youth empowerment, immigrant youth, youth health service corps*

ALTHOUGH the Affordable Care Act is certainly the most significant expansion of the health care safety net since Medicare and Medicaid were introduced in the 1960s, the act omits entire categories of people from coverage, particularly 11 million undocumented immigrants in the United States.[1,2] Illinois is 1 of the 8 states in the United States that houses the bulk of these immigrants—many of them Latino and densely populated in Chicago. Undocumented Latino immigrants are at great risk for lack of health insurance coverage with roughly 430,000 undocumented Latino immigrants in Illinois alone.[3] Although undocumented people may receive emergency medical care, they have no rights to any other type of treatment. As a result, many low-income, undocumented immigrants face significant barriers to comprehensive, high-quality medical care.

The Chicago area Youth Health Service Corps (YHSC) program was established, in part, to address barriers to care and improve health literacy (ie, the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions)[4] in undocumented communities. In addition to significant barriers to care, many immigrants struggle with language and educational challenges that affect

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The authors give special thanks to all study participants who have shared their story. They also thank DePaul's Steans Center for Community-Based Service Learning, Center for Latino Studies, and the University Research Council's Public Service Grant for supporting this research, and Aracely Galvan, Bernadette Muloski, and Durrell Sheppard who have provided hours of research assistance on this project.

The authors declare no conflicts of interest.

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DOI: 10.1097/FCH.0000000000000058

health literacy, which has been linked to poor health outcomes.[5] A recent study found that Latino immigrants often are unaware of local public health programs and other health resources.[6] Hu and Covell[7] also found that bilingual or primarily Spanish-speaking adults are less likely to experience general physical, visual, and dental checkups, satisfaction with health care, insurance coverage, having a self-perception of excellent health, and adequate medical treatment. This is also true for less "acculturated" Latino groups.[8]

Although the Affordable Care Act is an incredible opportunity to expand health care to the previously uninsured, many people in the immigrant community are legitimately afraid of being more easily identified and deported, as more low-income citizens are required to either participate in the government-run Medicaid program or purchase private insurance. Immigrants may avoid basic and preventive health care screening, as seeking care in certain health care facilities may be seen more as a risk.[9] US-born children of such immigrants are also vulnerable, given that an estimated 4.5 million children are part of a family that is of "mixed status" (eg, one parent is undocumented, whereas the child is a citizen).[10] Many of these children may not participate in government-sponsored health insurance programs, for example, the State Children's Health Insurance Program, for fear that a family member will be deported according to US Department of Homeland Security regulations, which require verification of the child's residency status.

In addition to inequities in health care access, many young people in immigrant and/or mixed-status families struggle with social, emotional, and educational outcomes that are often worse than those of their first-generation immigrant parents.[11] For example, having at least one undocumented parent has been associated with increased developmental risks, including higher levels of anxiety and depression among youths.[10,12] Despite these vulnerabilities, critical social theory of positive youth development emphasizes factors that contribute to adolescent resilience. The YHSC program combines these strategies, that is, engaging individual- and community-level empowerment, developing competencies within the health care field, etc, which illustrate the tenets of the positive minority development framework.[13,14]

This study examines the YHSC program, which embodies the elements of positive youth development and provides an important contribution to the literature on immigrant youth and community resilience. The following sections (1) describe the YHSC program and its community partners; (2) outline the rationale for assessing the program through a community-based participatory research (CBPR) model; and (3) discuss preliminary findings from the study.

THE YHSC COMMUNITY OUTREACH PROGRAM

The YHSC program model was originally created by the Connecticut AHEC (Area Health Education Centers) in 2004, where it was piloted in 4 regional centers. It has now been replicated in 30 states throughout the country. As a fairly new, nationwide program, more research is warranted on the uniformity with which the curriculum has been implemented and its impact on diverse communities. The Chicago area YHSC (also referred to as "5 + 1 = 20") program is a peer-to-peer health education and youth empowerment program, developed by the community-based organization Centro Sin Fronteras (CSF) in collaboration with staff from CAAAELII (Coalition for African, Arab, Asian, European, and Latino Immigrants of Illinois) and Rush University Medical Center in Chicago. The program uses health education, including information on nutrition and physical activity (which refers to the "1" in "5 + 1 = 20"), to address 5 major diseases—diabetes, hypertension, cancer, HIV/AIDS, asthma—that are reported to reduce overall life expectancy by 20 years.[15] The program's objectives are to (1) improve health literacy throughout the community; (2) provide structured services to youth including tutoring services, college counseling, and

health career exploration; and (3) participate in community organizing and advocacy efforts surrounding immigration and health care reform. The program builds on youth capacity to promote healthy behaviors and decrease risky behaviors. Medical students from Rush University Medical Center and other local hospitals provide weekly health education seminars to YHSC youth participants.

After completing the health education training, YHSC participants provide education outreach to at least 10 friends and family members. In the spirit of the de Madres a Madres Program, a peer health education model developed in Houston's Hispanic community, YHSC strives to "mobilize a total community for health."[16] YHSC participants are considered community "insiders," which allows them to become agents of change in their own communities. For example, given that many Latino immigrants only speak Spanish, language brokering, in which the children of immigrants often interpret and translate critical health information to their parents, is common.[17] As youth participants disseminate critical health education, health literacy in their social network and community may increase. Participants take an active role in coordinating and screening community members at quarterly health fairs. Social capital is developed, as they receive training on critical health information, gain exposure to mentors and the inner workings of the health care profession, and learn prevention strategies that address major diseases. YHSC participants also receive college counseling, one-on-one academic tutoring, leadership training, and multiple opportunities to participate in lobbying and advocacy efforts on local, state, and national levels.

METHODS

Using CBPR to assess the impact of the YHSC program

Through a CBPR approach that considers individual program participants, community-based organizations, and the community as a whole, this study examines the YHSC program by surveying and interviewing participating high school students. The goals of the study were to (1) document program impact and outcomes to enhance efforts to sustain and improve programming as well as seek further funding and resource support; (2) support individual- and community-level empowerment by providing regular progress reports that may inform advocacy efforts, enhance recruitment strategies, and promote positive youth development; and (3) better understand the challenges, strengths, and resilience of individual youth and their families.

Community assessment and diagnosis: Definition of the issue

A critical consideration in establishing a CBPR partnership is deciding how the "community" is defined, who represents the "community," and how partners are selected.[18] In this study, the community comprises individuals who are marginalized to various degrees and include group identity by immigration status (undocumented, generational), ethnicity or race, and geographic neighborhood. These multiple identities contribute to shared lived experiences, emotional connection to other members, common symbol systems, values and norms, shared interests, and commitment to meeting mutual needs.[19] The YHSC program was first implemented in the Pilsen neighborhood in Chicago, a community with many low-income, uninsured, new immigrant, or undocumented families of Latino descent.

The acting directors of the 2 partner organizations—CAAAELII and CSF, determined that the newest members of the community were more likely to be undocumented and uninsured, which necessitated urgent action to address their health care issues. An ecological systems framework has informed the developmental processes at play and the complex, systemic factors that influence them.[20,21] As immigrant families are embedded in a highly contextualized environment, the factors that contribute to their successful

settlement and adaptation in the United States are sociological, historical, political, and psychological in nature. In line with principles of CBPR, an ecological systems framework is critical to understanding the unique and varied determinants of health within the immigrant community.[18] Highlighting the importance of history, context, power, and agency[22] within a critical understanding of the ecological systems perspective places individual- and community-level empowerment, and the balance between participation, research, and action in the fore.[23,24]

Documentation and evaluation of the partnership process

Israel et al[18] have identified 9 principles of CBPR, including the facilitation of a collaborative, equitable partnership in all phases of the research that attends to social inequalities. To date, leaders from both CSF and CAAAELII have worked closely with the primary investigator on developing the goals, outlining the data collection process, and conceptualizing the questionnaire(s) that will be used with youth and program staff. Centro Sin Fronteras has implemented the program with 3 Chicago area high schools. The leaders of both organizations have been consulted throughout the study, including making decisions on how the data should be disseminated throughout the community. The leaders of these organizations have also ensured that research activities are true to the original aims of this study and are respectful of the confidentiality and privacy of the participants. A youth advisory board includes YHSC youths in the process of decision making regarding program implementation and data interpretation. Youths are asked to identify the strengths of programming, what they have most valued in specific programming activities (eg, youth leadership training, college counseling) as well as how day-to-day program activities can be improved.

Shared decision making is another critical element of CBPR.[18] The adjustment and ongoing reevaluation of the survey and interview guide and the determined need for a dialogue event among youths on assimilation are examples of shared decision making. For example, CSF recently implemented a YHSC program at 2 military academies where they observed a significant contrast in youth participation and engagement compared with implementation in the first nonmilitary school. The interview guide was then adjusted to better capture the unique context of the school that may have shaped their particular engagement with the program. In response to the identity struggles of immigrant youths who must negotiate US attitudes and policies that exclude or marginalize them, the primary investigator and CAAAELII staff facilitated a dialogue on ethnic identity and assimilation and integration that included YHSC participants, Northeastern Illinois University students, and other members of the community. On the basis of the discussion, the research team added questions about challenges youths face as immigrant youth/"dreamers" in the face of the new health care act and issues surrounding immigration reform; methods of coping and navigating developmental and sociopolitical challenges; areas of strength and resiliency; influences of contextual and environmental factors such as family support, school system, neighborhood, mentors, etc. This iterative process involving the constant exchange of information and building consensus throughout the tenure of the research process has encouraged reciprocity and mutual regard for community priorities.[24]

Feedback, interpretation, dissemination, and application of results

The primary investigator of the project presented preliminary findings related to the study's focus on the critical youth empowerment (CYE) model.[13] The findings were delivered in collaboration with the Executive Director of CAAAELII at the annual Health Disparities and Social Justice Conference at DePaul University, which focused on health disparities in the Latino community. As coauthors and community partners, this article also

serves as a vehicle for dissemination of the program's structure, progress, and impact. As more surveys are collected and in-depth interviews are transcribed, community partners and the youth advisory board will take on an increasingly active role in the interpretation of both quantitative and qualitative data. Commitment to translating research findings into community-relevant interventions and policies has been of utmost importance.

On the basis of the principles of CBPR, the principal investigator and leaders from the community-based organizations collaborated on the entire study including research design, respondent recruitment, data collection, and analysis. Using a mixed-methods approach, close-code surveys and semistructured interviews (averaging about an hour to an hour and a half in length) were conducted with high school students enrolled in the YHSC program. Participants were recruited with the assistance of the CSF health coordinator as well as snowballing.

Sample

Twenty-three participants in the YHSC program completed in-depth semistructured interviews in which they were asked to reflect on their experiences in the program and its impact on family and community, describe their engagement with the community, discuss their future plans, etc. All participants in the program were between the ages of 14 and 19 years who lived in Chicago. Ten participants were male and 13 were female. Twenty participants identified themselves as Hispanic, Latino, or Latino American (8 specified Mexican descent, whereas 1 identified Puerto Rican descent), whereas 3 identified as African American. Although they were not directly asked about their immigrant status, some participants voluntarily discussed their experiences living in a mixed-status family.

Data analysis

Given that many ethnic and racial minority groups have experienced historical trauma and oppression as well as exploitation as subjects in academic research, this study relies on a more culturally sensitive framework that emphasizes human agency, community empowerment, and critical consciousness raising.[25,26] This study uses critical social theory and interpretive frame analyses[27] to highlight the narratives of new and undocumented immigrant youths. Interpretive frame analyses hold sacred the cultural meanings and symbolism that underlie the language and interactive processes involved within ethnic communities, providing access to lived experiences and the complexity of intersectionality and marginalization, levels of strength, and potential areas of empowerment. Narrative theory allows for rich description of youths' experiences, as they make meaning of health care law, their own positionality, human agency, and development as ethnic minority youth. The CBPR approach facilitates efforts to achieve accuracy and cultural sensitivity in the interpretation of findings and results.[23] More culturally relevant codes will continue to be developed as well as an understanding of meaning behind language in transcripts. A thematic analysis of the transcribed interviews[28] will continue to be used to appreciate common experiences in the sample. Using an indigenous perspective has also underscored the influence of social, political, and historical contexts on participants and the dynamics of power in attaining and disseminating knowledge.[25] It is hoped that this research will optimize the capabilities of partnering community-based organizations in their advocacy efforts, policy development, strategic planning, and service delivery within immigrant communities.

FINDINGS

The following sections present findings using the 5 dimensions of CYE.[13]

Meaningful participation and engagement

All youths surveyed and interviewed (n = 23) indicated that they have had positive

experiences with the YHSC program, feel that it is a worthwhile program, and believe that it should be expanded within other schools. Sixteen-year-old participant, Ben,* shared the reasons why he is so motivated to engage in the program that he feels will help him become a physician when he talked about witnessing a family member become a victim of gun violence and feeling a sense of powerlessness. He stated: "Um, well I had a ... my uncle ... he was shot ... right by my house and I was little so I couldn't really do anything." This participant was motivated to become a doctor so that he would not experience that sense of helplessness again. He also noted that the mentorship he receives from the health coordinator sustains his engagement within the program. Most of the participants state that the main reason why they joined and stayed engaged with the program is because of Miriam, the main program coordinator, who has particularly been open about sharing her experiences growing up in the same neighborhood as many of the youths, having to be separated from family through deportation, and giving up a basketball scholarship to dedicate her life to the program. At least half of the sample participants expressed feeling consistently comfortable with program staff and participants and the sense that they have developed a personal and emotional investment in each other. As 16-year-old Elena describes the day-to-day experience of being in the program and the level of cohesion that has developed,

> ... We're always calling each other a family here. We're always looking out for each other. If we have a problem, if someone is mad or sad ... tired ... we would, you know, "if you're tired go home. If you're hungry, here is some money for food." ... We treat each other like a family. We respect each other.

At least 5 participants discussed their investment and their plans to stay actively engaged in the program after high school graduation and as some attend college locally.

Critical reflection on interpersonal and sociopolitical processes

Seventeen-year-old participant Jessica noted that the program helped shift the way she thought about herself as an individual, improved her sense of agency, and facilitated an understanding of how she may have a positive impact on her community. She stated that being part of the program has "gotten me self-confidence and showed me how to put myself out there ... like all this stuff going on in the world with like, the government and stuff I like never knew." Jessica talked about gaining more knowledge and awareness about and exposure to social and political issues that impact immigrant communities. Youths continue to participate in leadership trainings and action/advocacy-oriented activities that provide opportunities to interface with local and state legislators. As Jessica learned more about asthma and environmental racism, she began to think more critically about the placement of local factories and their impact on minority groups. She states,

> We had a whole thing [informational session] on the lead in factories. Asthma is a huge problem. There are a lot of things that happen to minorities. It's interesting ... minorities are the ones that really need help. We get exposed to a lot of stuff. Especially in Chicago, we don't have the money or insurance to take care of ourselves. Most people [would] be like, "I am ok," but it ends up being a bigger problem later on in life.

Community-level empowerment

Individual levels of empowerment have expanded to the community level. Across all 23 youths in the sample, they provided health education to approximately 800 individuals—through one-on-one conversations and speaking in front of groups at health fairs and community-based forums. Many friends and family members have been coping with some medical illness, including diabetes (n = 7),

*Pseudonyms were used for each participant quoted in this article.

obesity (n = 5), breast cancer (n = 1), high blood pressure (n = 17), cardiovascular disease (n = 2), and asthma (n = 3). Of the friends and family members with whom the participants are in touch, at least 50 sought follow-up health care (screening or medical treatment) as a result of their outreach (excluding those who received screening, medical attention, and information at the health fairs). The community health outreach continues as they organize additional health fairs. Approximately 500 families from across the community attended the most recent health fair hosted by one of the participating high schools. Participants discussed the impact of these health fairs and the program, with a few stating, "We save lives."

Some of the participants talked about either experiencing or identifying with the struggle as an undocumented immigrant. Two participants talked about their experiences sharing their personal stories with legislators, and several participated in rallies and lobbying efforts on the state and local levels, which are regularly organized by the program. A few participants stated that their family benefitted from the program because they received important health information to which they did not previously have access. One participant noted that family members have become more informed as a result of the program, stating, "They were informed of the conditions they were suffering from, which they had no knowledge about." Another participant stated, "We reach out to and help people in our community who don't have access to health care or medical attention." Cynthia, a 16-year-old participant, discussed how the program has taught her knowledge that would help her family in a very direct way. Her mother received a diagnosis of cancer and she wanted to learn more about the disease, and the process of learning about it connected her more with her mother, especially because her parents are undocumented and are often afraid to seek health care. In light of her mother's complex health needs, Cynthia stated, "Learning how to take blood pressure has been the most valuable skill to me because my mom has been diagnosed with what might be high blood pressure. Although it's not severe, she needs to check it every day and I help her do that."

Sixteen-year-old Rosa, who was born in Mexico, describes the constant sense of not feeling worthy because she was not born here, and the ease of internalizing the persistent message of, as she puts it, "You're not good enough because you were not born here." Sixteen-year-old Mexican participant, Amelia, talked about the need to counteract this message in order to increase health literacy in the Latino community and how the program seems to address this:

> I think that the program is making them knowledgeable; making them, the community, knowledgeable of these things. Because to be honest, they're not ... it's a Latino based community. And they're not aware of these things. They're not aware that they can go to non-profit places where it's ... where they can get these check-ups done. And because they don't have insurance, they don't have a social [social security number] so they're not aware that they can come to health fairs like at Juarez [participating high school] ... and that they could get these check-ups for free. And, um, and then follow up based on that, whatever they have. So I think that the program does a really good job ....

Amelia further noted that many members of the community were extremely afraid of seeking health services because of their undocumented status. Her peers, particularly, feel the palpable barriers of being undocumented, not having a social security number, not being able to apply for financial aid, feeling stuck, and unable to go to college. Amelia discussed how she has benefited from her experience with mentors she met through the YHSC program, who cultivated her dream of going to college and medical school, all of which counteracted her feelings of hopelessness. She also experienced being empowered to motivate others to do the same.

DISCUSSION

Community-based participatory research values voice and agency in ethnic minority and immigrant communities that normally are excluded from research or innovative programming. YHSC's coordinators provided optimal conditions for positive youth development through support, social capital, collaboration, and shared decision making among youths. The Chicago area YHSC program is distinct from other health promotion programs in that the founding organization is action oriented, with particular focus on assertive advocacy efforts on behalf of the undocumented and new immigrants who are not eligible to receive health care coverage. Programming is youth driven, focusing on the development of youth social capital (eg, leadership skills, knowledge of and preparedness for college and the health care field), capacity building, and health outreach through participants' social network in their communities. The integral role of the health coordinator cannot be underestimated, as many discussed being inspired by her as a member of their community and as a role model-mentor who understands the immigrant struggle with which they have come to identify. Youths in this study reveal that they experience the program in diverse ways that are empowering on both the individual and community levels. This wide array of distinct elements has contributed to sustained engagement and retention of participants in the program.

In line with the CYE model,[13] the YHSC program raises critical consciousness,[26] which is central to empowerment on both the individual and community levels. As youths participate actively and engage in shared decision making in the program, they experience a growing understanding of their position and how their circumstances are shaped by the constraints of broader social and historical forces. Empowered by this critical consciousness, youths increasingly become resources for community action as well as agents of social change and community development through health promotion. Considering the complex intersection of race, ethnicity, socioeconomic, and immigrant status together with social and political forces against the backdrop of immigration and health care reform, the YHSC program is a notable influence on individual- and community-level resilience and a catalyst for social change.

Study limitations

Time constraints are a clear challenge of this project. In keeping with the CBPR approach, it has taken several months to learn about the day-to-day work of both CAAAELII and CSF, the vision and forces behind the YHSC program, the logistics in implementing the program, as well as developing a trusting and working relationship with program leaders, staff, and youth participants. In turn, the community partners have demanding roles and are burdened with overwhelming levels of responsibility in the communities and organizations they serve. The process of hiring, orienting, and training research assistants on interviewing, transcribing, and data analysis is also time-consuming. Furthermore, investigators in this study are junior faculty concerned with promotion and tenure, a process that inevitably places other academic roles and responsibilities that can intrude on full-time investment in the CBPR endeavor. In addition to incorporating cultural humility, caution, and critical self-reflexivity,[29] researchers must consistently question their own privilege, power, and position throughout all the stages of this research by continuing to ask "to whom does this research benefit?" Recruitment and engagement of youths within the YHSC program has also been a challenge, which has impacted the number of respondents enrolled in the study. We have been sensitive to the potential fear and skepticism youths (and their parents who must provide consent) may have in participating in the study due to their immigration status or that of family members in their household. The lack of funding and limited resources[18] has also hampered programming and project activities. Finally, the study is limited to one large

metropolitan area, and the sample is relatively small, which may only represent participants who have sustained program engagement for at least 1 year.

CONCLUSION

Preliminary results from the evaluation of the YHSC program suggest that CBPR remains a relevant and effective research method, particularly when used in collaboration with strong community partners. Community-based participatory research facilitates a collaborative, nonhierarchical approach to learning about community-level challenges and resources and as such it should be considered more widely. Although the approach presents its own challenges, it ultimately generates successful partnerships between community-based organizations, community members, and researchers.

There is also strong evidence that positive youth development programs, particularly those that focus on health and health care, are beneficial to individual participants and the community as a whole. These models are relatively inexpensive to operate and have positive effects across vulnerable populations. As such, the findings of this CBPR impact study of the Chicago area YHSC suggest that replicating such models in other underresourced communities may be an effective health disparities and youth development intervention. Additional studies should be carried out to test the model on a larger scale.

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