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Improving Health through Community-Based Participatory Action Research:

Giving Immigrants and Refugees a Voice

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Abstract

Community-based participatory action research (CBPAR) gives people a voice in identifying and solving the health problems affecting their communities. Researchers from the University of Minnesota, health care professionals from West Side Community Health Services, and members of the Somali, Latino, and Hmong communities in St. Paul are using CBPAR to identify and study health-related problems in those communities and design initiatives to solve them. This article describes CBPAR and four projects that are currently underway within West Side's SoLaHmo Partnership for Health and Wellness: *Caafimad - Salud - Kev Nyob Zoo*.

As a primary care physician working in an inner city clinic, you see three patients on your schedule whom you have treated before and wonder how you will be able to help them today. One is a 62-year-old Hmong man with type 2 diabetes whose A1C levels have been consistently above 10. Another is a 23-year-old Latino woman who has scheduled well-child checkups for her 2-year-old girl and 3-year-old boy, both of whom have a body mass index (BMI) at the 85th percentile. The third is a 56-year-old Somali woman, who is following up for her hypertension but who has previously refused to have a breast exam, mammogram, and Pap smear.

Physicians regularly encounter patients who struggle with medical problems that are affected by their lifestyle choices, socioeconomic situation, and the environment in which they live and work. Being an immigrant or refugee can add to a patient's clinical complexity. In order to appropriately address immigrants' and refugees' medical needs, providers need to understand their lifestyle choices not only within a socioeconomic context but also within a cultural context.

Although clinical research has explored the health needs and practices of immigrants and refugees in Minnesota and the reasons why they do not get medical care, it has not always led to improvements in the overall health of these groups. Community-based participatory action research (CBPAR) has emerged as one way to improve the health of immigrants and refugees. This article describes our efforts to initiate and implement CBPAR projects aimed at improving the health of the Hmong, Latino, and Somali communities in St. Paul.

Community-Based Participatory Action Research

In CBPAR, researchers and community members work together in collaborative, nonhierarchical partnerships to try to improve the health of a community.¹⁻⁴ Using this approach, they can generate research that is informed by the experiences of community members and, therefore, is more valid and relevant to them. The findings then can be used to design health-improvement projects that build on people's cultural strengths, are attuned to the community's needs, and are more effective.^{1-3,5} Because of its focus on community engagement, CBPAR:

- Allows community members to identify health problems affecting their communities and work with academic partners to solve them;

- Fosters social connections that can lead to change; and
- Produces knowledge that can lead to action.^{2,6}

As University of Toledo sociologist Randy Stoecker, Ph.D., wrote in his book *Research Methods for Community Change*, “CBPAR is not a research project. It is a social change project of which the research is one piece. As such, it has three goals: learn relevant knowledge and skills; develop relationships of solidarity; and engage in action that wins victories and builds self-sufficiency.”⁷

During the last 30 years, research has shown that there is a connection between community engagement and health and well-being, as individuals who are engaged in their communities have been found to recover more quickly from life-threatening events, have fewer illnesses, live longer, and experience less disability than those who are not as engaged.⁸ The CBPAR approach, which relies on the involvement of community members, has been shown to be effective in promoting health within communities and in efforts to identify health indicators and social determinants of health.⁹

CBPAR in St. Paul

With the belief that CBPAR can reduce health disparities, health care providers from West Side Community Health Services in St. Paul along with members of the Hmong, Latino, and Somali communities in that city, and researchers from the University of Minnesota’s Program in Health Disparities Research (UMN PHDR) and School of Public Health created the SoLaHmo Partnership for Health and Wellness: *Caafimad - Salud - Kev Nyob Zoo*.

SoLaHmo’s mission is to build on the unique cultural strengths of the Somali, Latino, and Hmong communities to promote health and wellness through research, education, and policy. The idea is that members of these communities need to work as equal partners with researchers and health care professionals to make it happen. To date, the partnership has identified four priority areas related to health: 1) preventing chronic diseases; 2) promoting healthy youths and families; 3) improving mental health; and 4) increasing culturally competent health care delivery. In 2008, SoLaHmo received a National Institutes of Health grant to support CBPAR projects. With support from the grant, a project management team made up of representatives from West Side, the University of Minnesota, and the community created and piloted two CBPAR curricula: one for 22 University of Minnesota faculty members and one for 10 community members who were trained as CBPAR community research scholars. Each of the community scholars (four are Hmong, three are Latino, and three are Somali) described a health-related topic of interest to their community and sketched out a plan for research that could lead to activities to improve their communities’ health. The project management team then connected these individuals with faculty members who had research experience in those areas. The community scholars worked with academicians to design seven CBPAR projects. Six applied for and three were awarded pilot grant funding from UMN PHDR last year.

The CBPAR Projects

The following are descriptions of four CBPAR projects that are being conducted by SoLaHmo and West Side Community Health Services. They exemplify the range of topics that CBPAR can address—from community medicine to biology. The first three were funded by UMN PHDR in the fall of 2009; they received approval from the University of Minnesota's Institutional Review Board in 2010 and are now beginning. The fourth project was funded by UMN PHDR in 2007; data collection and analysis have been completed and results are being presented and published.

Opening Pandora's Box: Somali Women, Sexuality, and HIV/STD Prevention

African-born Americans including Somalis have higher rates of HIV/AIDS than any other ethnic group in the United States, and Somali women are at higher risk for HIV infection than Somali men. In spite of the high infection rates, only a handful of studies have been done on HIV/AIDS in Africans in the United States. This has contributed to the fact that few HIV/AIDS prevention programs are aimed at the Somali community. Concerned about the need for better prevention efforts, Somali community members Fatima Jama and Amira Ahmed and University of Minnesota researcher Bean Robinson, Ph.D., designed a study to examine Somali women's knowledge of and attitudes about HIV and AIDS, and behaviors that might contribute to the transmission of HIV or prevention of infection. The project is in its early stages and will involve face-to-face interviews with 30 Somali women of all sexual orientations in order to develop methods for collecting sensitive sexual and HIV/STD-related data; learn how to increase the HIV/STD testing rate among Somali women; and learn about the women's knowledge of, attitudes toward, and behaviors related to their risk for and transmission of HIV and STDs. The ultimate goal of the project is to develop culturally appropriate HIV counseling and testing services for Somali women.

Improving Nutrition and Physical Activity among Latino Youths

Concerned about the growing number of overweight Latino children, two members of the Latino community, Rosaura de la Torre and Maria Navas, together with University of Minnesota researcher Jamie Stang, Ph.D., M.P.H., designed a study to determine how to improve nutrition and physical activity among young children in order to prevent obesity and diabetes. They are forming a coalition representing health care, social services, educational services, childcare, and other organizations from St. Paul's Latino community to guide their research. The partners will then interview leaders of key health care and social service organizations in the community and conduct six focus groups composed of parents of 3- to 5-year-old Latino children who are overweight or obese. The goal is to learn about the parents' knowledge of obesity and diabetes risk factors, perceived community strengths and barriers around prevention of obesity, and their preferences for intervention strategies to improve nutrition and physical activity among their children. This project will lead to the development of a culturally appropriate community-based obesity- and diabetes-prevention program for Latino children and their families in St. Paul.

Intimate Partner Violence in the Hmong Community: Tackling an Old Problem in a New Way

Members of immigrant and refugee communities are often limited in their ability to access resources that can help repair the damages caused by intimate partner violence (IPV) because of their limited language proficiency, cultural and social isolation, misunderstandings about the law, and lack of economic and social resources. Two Hmong community members, Mikow Hang and Thomas Tou Yang, and Tai Mendenhall, Ph.D., a social scientist at the University of Minnesota, are working with Hmong community members and professionals to tackle the problem of IPV using CBPAR. The goals of the project are to identify the Hmong community's unique challenges to and assets for preventing IPV; identify resources that are needed for treating victims of IPV; explore methods for connecting community members with available resources; and make the initiative sustainable over time. Ultimately, they will apply their findings to the design of new community-based interventions that will have a greater likelihood of successfully addressing IPV within that community than interventions designed by outsiders who do not have the appropriate language, cultural knowledge, and social connections.

Hmong Pharmacogenomics Research

Since 2007, West Side's Hmong Pharmacogenomics Research Board has been conducting a CBPAR project that includes Hmong people in genomics research. Members of ethnic communities are often not included in genomic research and thus cannot fully benefit from results. The board first conducted qualitative research to elucidate traditional and current ideas about heredity and genetics and identify factors that would encourage or discourage community members' participation in genomics research. That information was used by University of Minnesota and West Side researchers Robert Straka, Pharm D., Pachia Vue, M.P.H., and Kathleen Culhane-Pera, M.D., M.A., who subsequently collected saliva samples from 237 Hmong adults and analyzed them for known genetic mutations that can increase the risk for developing type 2 diabetes (*CDKN2A*) and that can influence the metabolism of warfarin (*CYP2C9*3*) and effectiveness of warfarin (*VKORC1*). Of the 236 analyzable samples, 44% have a mutation in the diabetes gene that could increase the risk of developing diabetes by 20% to 30%. Also, 30% of the samples have mutations in one or both of the genes involved in the metabolism of warfarin. The rate of mutation in one gene (*CYP2C9*3*) in the Hmong participants is higher than the rate in Caucasian populations and four times higher than the rate in a Han Chinese population.¹⁰ These findings indicate that the Hmong could be at higher risk for hemorrhage when taking warfarin than other populations. Physicians may need to 1) monitor their Hmong patients sooner and more closely when starting warfarin; 2) consider ordering genetic tests before starting warfarin to determine whether a patient has these genetic variations; and 3) consider starting a lower initial dose of warfarin and covering with low-molecular weight heparin for a longer period of time until the genetic test results are available or until the INR is in therapeutic range.

Conclusion

West Side Community Health Services in St. Paul, in partnership with researchers from the University of Minnesota and members of the Somali, Latino and Hmong communities, is

using CBPAR to better understand health problems from the perspectives of members of those communities. Clinicians from West Side are using this newfound knowledge to improve both their medical practices and the health of their patients. This work has the potential to help immigrants and refugees address the most pressing needs of their communities, thereby improving their own health and wellness.

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What CBPAR Participants Say

Ten members of St. Paul’s Somali, Latino, and Hmong communities were trained in CBPAR and are conducting research for projects on behalf of SoLaHmo. The following are comments from three of them about their experiences with this type of research:

“Having the community member, faculty, and health care professional share one common goal and vision that is culturally appropriate for the targeted community increases the understanding about the root causes of the health problem and the opportunities to improve health. It is a great opportunity for my community to have our expertise valued in the research process and for us to be continuously engaged through the development of community health programs.”

—Amira Adawe

“I am drawn to CBPAR because it empowers communities to be proactive in improving their current situation. It gives the community a sense of ownership, and building sustainable programs becomes more feasible. Conventional research sees the results interpreted from the researchers’/health care professionals’ perspectives only, while CBPAR involves the community’s voice, painting a more accurate portrait of the situation.”

—Mikow Hang

“The actual medical and scientific findings are one goal of CBPAR research. Another goal is to afford the opportunity for our community members to bring cultural strengths and practical questions to the table. The next goal is to have more physicians and researchers hear what community members are asking and not ignore our important perspectives and experiences.”

—Luis Ortega