Virtual Mentor

American Medical Association Journal of Ethics August 2007, Volume 9, Number 8: 547-551.

Journal Discussion

Tools for Culturally Effective Care Gleaned from Community-Based Research Maria Luisa Zuniga, PhD

Sullivan M, Kone A, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW. Researcher and researched-community perspectives: toward bridging the gap. *Health Educ Behav.* 2001;28(2):130-149.

Minorities and other underserved populations are frequently overrepresented in disease morbidity and adverse health outcomes when compared to mainstream, insured populations. To effectively address these disparities, the field of public health has sought to increase meaningful participation of diverse communities in research and health promotion activities. Engaging community members as mentors of physicians-in-training and as active participants in the physician training and feedback process also appears to have a positive impact on the ability of physicians-in-training to deliver culturally effective care, especially when they are provided with opportunities to be active learners within community settings [1, 2]. Involving communities in the physician training experience, therefore, may be one of many opportunities for drawing upon the field of community-based participatory research (CBPR) for guidance in improving delivery of culturally effective care.

In the report cited above, Sullivan and colleagues provide insight into differences between investigators and community member perceptions about research that are also relevant to understanding how physicians and patients perceive health and health care [1]. This qualitative study conducted in Seattle used semi-structured interviews to assess the experiences of persons involved at varying levels of CBPR that had taken place between 1992 and 1996. Study participants included community members who were familiar with community-based public health projects in their region, study investigators, and project staff.

Study results indicated problem areas that had also been found in prior communitybased research, including researchers' misinterpretation of the cultural context of study participants, propagation of negative stereotypes in communities, and perceived power imbalances between community members and researchers. Although this was a small study that suffered from limitations common to other small studies (e.g., limited generalizability to other populations and cultural contexts), many of its findings suggest recommendations for improving opportunities to teach delivery of culturally effective care. Following are selected topics based on the work of Sullivan et al. that promote discussion about delivery of culturally effective care and the potential for culturally *in*effective care with examples relevant to the medical encounter that are drawn from this author's observations and specific examples derived from a community-based clinic.

Understanding the Patient's Cultural Context

Sullivan et al. report that study respondents voiced concern that researchers had misinterpreted the cultural context of some health-related behaviors. Drawing on the experiences of communities in studies, we find that clinician messages must be relevant to the realities of patients. For example, promoting use of condoms among patients living with HIV requires more than the patient's knowledge about how to use a condom properly. Clinicians must also consider the potential culture- and gender-specific implications of condom use in a given community. Teaching patients how to negotiate condom use in some cultures requires knowledge not only of the individual's perception of her or his power in the relationship, but also how she or he views use of condoms in the broader context of participation in risk behavior or acknowledgement of a partner's risk behavior.

In an ongoing study of barriers to participation of Latinos living with HIV along the U.S.-Mexico border in HIV/AIDS clinical trials, we heard from focus group members that access to research sites was difficult because of their reliance on public transportation. Public transportation, for example, involves considerable travel time [3]. Another group mentioned that, in an era of heightened sensitivity to immigration issues, persons of Mexican origin felt anxiety and fear over potential interactions with U.S. Border Patrol agents, who frequented public transportation stations in San Diego and requested identification of persons who fit certain profiles. These concerns were perceived as having a very real influence on patient participation in clinical trials.

Understanding the contextual reality of patients also forces us to figure out when we are doing the wrong thing for the right reason. Colleagues in a community-based HIV/AIDS clinic located in Southern California taught us an important lesson in caring for patients living with HIV. The red ribbon that has come to symbolize support for persons living with HIV/AIDS was worn by many staff and clinicians. When clinic leadership convened a community advisory board to get patient feedback about the clinic, they discovered that some patients felt uncomfortable because they were called from the waiting room by clinic staff members who were wearing the red ribbon. This reaction to social stigma was subtle yet poignant and real in the lives of persons living with HIV/AIDS. The lessons here are that care and clinician expectations must be firmly grounded in the patient's realities and that making opportunities to understand these realities can foster improved communication between clinicians and patients.

Reinforcement of Stigmatizing or Negative Stereotypes

Sullivan et al. found that some study participants felt as though negative assumptions about communities of color permeated the research project. This perception can indeed have an impact in the patient-clinician relationship. In our HIV clinical trials

participation study, for example, Latina focus group participants discussed how they had felt stereotyped by staff who made statements such as, "You Latinas tend to only eat *fritangas* (fried foods)," which some women found discounted their efforts to eat nutritiously and their earnest concerns about weight and body image [4].

Language Competence

Sullivan et al. do not mention overcoming language differences as a component of cultural research and clinical care arenas, perhaps because they take it for granted. Having health care workers who are able to speak with patients in their own language continues to be a priority among English-language learners. Among clinicians who are concerned about the limitations of using phone-based interpreter services, one realized that having an interpreter who is of a different gender than the patient can make the patient feel uncomfortable and can negatively impact the patient-clinician encounter.

Awareness of the possible influence of limited education on communication can help clinicians remember to use terminology that patients understand. In our research studies we have learned, for example, that terms including "stigma" (which is the same word in English and Spanish); "sexual orientation;" and "ethnic identity" may be foreign to patients or others who are unfamiliar with research terminology.

Different Perspectives on the Same Issue

In a recent study of barriers to HIV clinical trials participation, we observed a distinct difference in perception of barriers to participation between Latinas living with HIV and caregivers who serve them [4]. Latina participants' primary concerns were about HIV-related stigma (e.g., concern that someone might find out they were HIV-positive if they participated in a study). HIV clinical staff and social services workers on the other hand, described the barriers to participation as more structural in nature, citing problems such as lack of child care and transportation. HIV stigma was not raised by any of the clinic staff interviewed. That perceptions of the same phenomenon—e.g., low participation in clinical trials—can differ drastically, has implications for a variety of clinical concerns, from medication adherence to patient willingness to discuss certain topics with their physicians and other caregivers.

Providing Clinicians-in-Training with Tools for Culturally Effective Care

Providers and physicians-in-training can create many opportunities to improve the delivery of culturally effective care through a variety of approaches. They can *promote patient-provider trust* through mitigating sometimes adverse circumstances faced by patients. We heard from recent focus groups that patients feel frustrated when they lose continuity with their clinicians or feel that clinicians are rushed. Often these structural and environmental forces are beyond the clinician's control. Drawing from experiences in conducting CBPR, however, we can approach these situations by being honest and up-front with patients, letting them know that we are aware that a circumstance is not ideal, empathizing with them, and asking for an opportunity to work with them within the given circumstances. As Sullivan et al. put it, "To facilitate the development of trust, researchers were urged [by community

members] to be honest about their agendas, to follow through on promises, and to implement research findings" [5].

Physicians-in-training can *learn how to reflect on new experiences* and apply this reflective technique throughout their professional careers. To be effective, physicians must be comfortable with thoughtful reflection on why certain behaviors or poor adherence to clinical recommendations are occurring, even if they can't do anything about it. In our study of before-and-after effects of a block rotation in community pediatrics [2], we found that prompting medical residents to reflect on their community experiences allowed them to express their understanding of culture and delivery of culturally effective care in community settings.

Drawing both from the fields of anthropology and CBPR, clinicians can also recognize how to approach patient encounters with cultural humility. In the context of CBPR, we approach our community experts as learners with sincere interest in working alongside the person or agency. The community is often a very willing teacher when asked for its expertise. Extending this to the patient-clinician relationship, expressing one's sincere desire to learn from and about patients, may contribute to building trust.

In working with colleagues who are clinicians and researchers in CBPR projects, we know that physicians and other health professionals who are passionately devoted to improving opportunities for delivery of culturally effective care have raised some thoughtful questions that can indeed help us on our way to improve patient health: How do I help my patient feel comfortable if I do not speak her language and need to use a phone interpreter? How do I engage the community in a meaningful way? How do I provide feedback to the community? These are thought-provoking examples of the very nature of building relationships, reflective thought, and cultural humility, that can lead us to provide better care.

References

- 1. Sullivan M, Kone A, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW. Researcher and researched-community perspectives: toward bridging the gap. *Health Educ Behav.* 2001;28(2):130-149.
- 2. Zuniga ML, Sidelinger DE, Blaschke GS et al. Evaluation of residency training in the delivery of culturally effective care. *Med Educ*. 2006;40(12):1192–1200.
- 3. Zuniga ML, Organista KC, Scolari R, Olshefsky AM, Schulhof R, Colon, M. Exploring care access issues for HIV+ Mexican-Origin Latinos living in the San Diego/Tijuana border region. *J HIV/AIDS and Soc Serv.* 2006;5(2):37-54.
- 4. Zuniga ML, Blanco E, Martínez P, Strathdee SA, Gifford AL. Perceptions of barriers and facilitators to clinical trials participation in HIV-positive Latinas. *J Women's Health.* In press.
- 5. Sullivan et al., 140.

Further Reading

Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health.* San Francisco, CA: John Wiley & Sons, Inc; 2005. This publication provides insights and practical guidance on approaches to improving communitylevel participation in research, from conceptualization of a study, to implementation to dissemination of findings.

Maria Luisa Zuniga, PhD, is an assistant professor and epidemiologist in the Division of International Health and Cross-Cultural Medicine at the University of California, San Diego (UCSD) School of Medicine and is also affiliated with the UCSD Division of Community Pediatrics and San Diego State University Graduate School of Public Health. She specializes in behavioral health and access to care in Latino populations living with HIV, particularly those living in the U.S.-Mexico border region.

Acknowledgements

The author gratefully acknowledges the essential contribution of San Ysidro Health Center and surrounding communities, from which many of the learning experiences for this work were drawn. This project was partially supported by the National Institutes of Mental Health (Grant Number K01 MH072353) and the San Diego EXPORT Center, National Center of Minority Health and Health Disparities, National Institutes of Health (P60 MD00220). Its contents are solely the responsibility of the author and do not necessarily represent the official views of the National Institutes of Health.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2007 American Medical Association. All rights reserved.