Setting the stage for community based participatory research: Lessons learned from the Latino mental health survey

Lauren Gilchrist, BA, MPH Candidate; Carolyn Garcia, PhD, MPh, RN; Centro Campesino; Nancy Raymond, MD; Sandy Naughton, BA

1Center for Adolescent Nursing and Densford Center for Nursing Leadership, School of Nursing, University of Minnesota; 2Deborah E. Powell Center for Women’s Health, University of Minnesota, 3Neighborhood House, 4Center for Adolescent Nursing, School of Nursing, University of Minnesota, 5Health Start, 6West Side Community Health Services

Lessons Learned

**Research Process**
- Community identified research priorities
  - Through community-academic dialogues, rural and urban community stakeholders identified specific research topics
- Literature review
  - Based on community priorities, University partners identified existing measurement instruments validated in Spanish
- Formation, translation & revision of survey instrument
  - Extensive revision by partners ensured cultural validity of the instrument
- Preparation for survey administration
  - Human subjects protection training provided to community research staff as needed
- Data collected by community organizations
- Data analysis in progress
- Some preliminary results disseminated to local communities

**Background**
- In Minnesota, growth of the Latino population surpasses national demographic trends.
- Barriers to mental health care services include language, insurance, immigration status, cultural beliefs, lack of services and awareness.
- Limited data available on nature/prevalence of mental health problems in Minnesota’s Latino communities or knowledge of existing services

**Project Aim**
Use community-based participatory research methodology to develop a cross-sectional instrument assessing the mental health status, beliefs, and knowledge of resources among rural and urban Latinos residing in a mid-western state.

**Results**
Community-based participatory research methods were successfully utilized to develop a culturally-relevant, 100-item bilingual Emotional Health Survey (adult and youth versions)

**Next Steps**
Data analysis for rural and urban communities has begun. Results will be disseminated through community partners for interpretation and planning action steps. Results will be submitted for peer-reviewed publication.

**Acknowledgements**
This project was supported, in part, through a University of Minnesota Academic Health Center Faculty Seed Grant (PIs: Raymond & Gilchrist); Densford Clinical Scholar Program (Director: Disch, Clinical Scholars: Garcia & Hunt), the Adolescent Health Protection Research Training grant number T01-DP000112 from the Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (DHHS) (Director: Bearinger, Fellow: Garcia) in the Center for Adolescent Nursing, School of Nursing at the University of Minnesota, a Research Grant from Zeta Chapter of Sigma Theta Tau International (PI: Garcia).

Special thanks to our Research Assistants, Amy Leite and Rachel Hardeman.

**Lessons Learned**
- **Relationship building**
  - Relationships based on shared power are imperative and take time. Initially, collaborators agreed on principles of partnership such as open communication, respect and shared ownership of data.
  - Frequent communication builds strong relationships. In-person meetings at least monthly and frequent e-mails enabled our partnership.
  - New partnerships require time to develop trust and shared vision. It was valuable that partners had a previous history of working together on other projects.
- **Community participation in all stages of research**
  - Community members should initiate and lead development of the research question. Ex: The rural survey was initiated by community members who anecdotally identified local unmet mental health needs.
  - Even minor decisions in the research process, such as word choice in the survey instrument, can have greater implications in the project.
  - Dissemination of results to communities works best when led by community members, especially sensitive topics like mental health.

- **Flexibility of timelines**
  - Factors such as grant submissions and unexpected leadership changes within community organizations created delays in our original timeline.
  - Adaptable timelines are critical to respond to unexpected situations and enable collaborative decision-making.
  - Fluidity of timelines can be challenging to University processes.
  - Funding agencies must consider the time-intensive nature of CBPR in planning grant mechanisms to support this type of research.

- **A facilitative University infrastructure is optimal**
  - University infrastructure to facilitate coordinated interdisciplinary and community research could minimize redundancy, enhance efficiency. Collaborators from schools of medicine and nursing discovered each other through a coincidental encounter.

- **CBPR is an opportunity to build capacity & knowledge**
  - All partners bring distinctive knowledge and skills to the research dialectic. University partners provided knowledge of current literature and opportunities for community to train in human subjects research. Community members shared insider perspective of community norms, values and priorities

---

**What is Community-Based Participatory Research (CBPR)?**
- CBPR in public health is a partnership approach to research that equitably involves stakeholders including community members, organizational representatives, and researchers in all aspects of the research process.
- Partners engage in the research process by:
  - Contributing expertise on the topic
  - Sharing responsibility and ownership to enhance understanding of the topic at hand
  - Translating knowledge gained into action to improve the health and well-being of community members. (Israel, 2001)

**Project Aim**
Use community-based participatory research methodology to develop a cross-sectional instrument assessing the mental health status, beliefs, and knowledge of resources among rural and urban Latinos residing in a mid-western state.

**Background**
- In Minnesota, growth of the Latino population surpasses national demographic trends.
- Barriers to mental health care services include language, insurance, immigration status, cultural beliefs, lack of services and awareness.
- Limited data available on nature/prevalence of mental health problems in Minnesota’s Latino communities or knowledge of existing services

**Community-University Partners**
Centro Campesino, Owatonna, Minnesota
West Side Community Health Services, St. Paul, Minnesota
Neighborhood House, St. Paul, Minnesota
Health Start, St. Paul, Minnesota
School of Nursing, University of Minnesota
Powell Center for Women’s Health, University of Minnesota
Khahil Beal, University of Minnesota
Parents & adolescents from Minnesota’s Latino communities

**Results**
Community-based participatory research methods were successfully utilized to develop a culturally-relevant, 100-item bilingual Emotional Health Survey (adult and youth versions)

**Next Steps**
Data analysis for rural and urban communities has begun. Results will be disseminated through community partners for interpretation and planning action steps. Results will be submitted for peer-reviewed publication.

**Acknowledgements**
This project was supported, in part, through a University of Minnesota Academic Health Center Faculty Seed Grant (Pis: Raymond & Gilchrist); Densford Clinical Scholar Program (Director: Disch, Clinical Scholars: Garcia & Hunt), the Adolescent Health Protection Research Training grant number T01- DP000112 from the Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (DHHS) (Director: Bearinger, Fellow: Garcia) in the Center for Adolescent Nursing, School of Nursing at the University of Minnesota, a Research Grant from Zeta Chapter of Sigma Theta Tau International (Pl: Garcia).

Special thanks to our Research Assistants, Amy Leite and Rachel Hardeman.