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Brief Report:
Lessons from the Field

Addressing Neurocognitive Disorders, Dementias, and Alzheimer's Disease in Colonias of the Lower Rio Grande Valley: Establishing a Research Foundation Using Promotores

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Several Texas communities along the Mexican border, including the Lower Rio Grande Valley (LRGV), are home to low-income Hispanic populations, many of whom live in underserved communities known as colonias. These areas have high incidences of neurocognitive disorders, dementia, and Alzheimer's disease (AD); health care strategies that are culturally and linguistically appropriate for the area are needed. We aim to build capacity to reduce risk, facilitate treatment, and provide caregiver support for affected individuals. However, gaining trust of communities and presenting information about research studies in a way that is culturally appropriate is critical for engagement of underserved communities.

This brief report examines our work with local community health workers (CHWs), promotores in Spanish, to establish contact with, engage, mobilize, and educate the Hispanic communities of the LGRV. Lessons from the succesful experience of training promotores in autism spectrum disorder in the LRGV highlight the importance of specifically addressing outreach in health fairs, clinic vists and referral as well as adequate selection, training, management, and support of the promotores as critical aspects. To initiate and sustain recruitment of older adults and care partners in research studies of AD and other dementias in the RGV, we have incorporated these aspects as components of the promotores training and engagement model, which has been developed and implemented by researchers and their colleagues at the School of Medicine at the University of Texas Rio Grande Valley. *Ethn Dis*. 2020;30(Suppl 2):775-780; doi:10.18865/ed.30.S2.775

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Introduction

The Texas Hispanic population represents more than 50% of the state's poor, and their poverty rates are twice as high as that among non-Hispanic Whites. The Lower Rio Grande Valley (LRGV) is the poorest region in the state, and the McAllen area has the highest rate (42.4%) of child poverty.[1] Most low-income Hispanics in this area live in areas called colonias, which often lack basic necessities, such as clean water, sewage systems, electricity, paved roads, or safe and sanitary homes. Colonias exist in Arizona, New Mexico, and California, but Texas has the greatest number and largest population (approximately 500,000).[2] In the United States, 28.2% of the population aged ≥25 years has a college degree or higher (26.1% in Texas), but only 5.5% of the colonias residents do.[2] Years in school and quality of education affect cognition across lifespan, particularly in older individuals,[3] suggesting that school attrition, educational opportunities, and educational quality are important risk factors for dementia and Alzheimer's disease (AD) in colonias, thus they are also key targets for prevention of cognitive deterioration.

Neurological disorders account for 6% of disabilities and 12% of deaths worldwide.[4] Many are progressive, and their rates increase with age. Around 5.7 million Americans have dementia, including 390,000 Texans. In Texas, the prevalence of AD is 13%

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among Medicare Fee-For-Service beneficiaries aged ≥65 years, while the national rate is 11.4%. However, the prevalence in the LRGV is even higher (Starr County: 20.7%, Cameron County: 15.7%, Hidalgo County: 19%, Willacy County: 17.7%).[5]

Hispanics have a greater risk of developing AD[6] and experience symptoms 6.8 years earlier than non-Hispanic Whites (mean age of initial symptoms: 67.6 vs. 73.1 years, respectively).[7] Aging Hispanics need improved health care and AD care, but the related infrastructure and research to advance it, are underdeveloped and insufficiently diverse with respect to ethnic representation. Thus, we focused on building capacity for advancing AD research and health care by leveraging health care and community networks and establishing the LRGV AD-Resource Center for Minority Aging (AD-RCMAR). However, gaining trust in communities and presenting information about research studies in a way that is culturally appropriate is critical for engagement of underserved communities. This brief report examines our initial work with local community health workers (CHWs), *promotores* in Spanish, to contact, engage, mobilize, and educate the Hispanic communities of the LGRV, with a special focus on colonias along the Texas/Mexico border.

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Community Health Workers/Promotores

The American Public Health Association defines a CHW as "a frontline public health worker who is a trustworthy member and/or has an unusually close understanding of and trust from the communities they serve." CHWs enable the development of individual and community capacities regarding general health[8] in diverse roles, sometimes performing many tasks that may be preventive, curative, or developmental, while in other cases, their role is very specific. In Hispanic communities, CHW are also known as *promotores*, short for ´Promotores de Salud'; they positively impact research at many levels especially by facilitating recruitment and retention of participants.

History of Community Health Workers/Promotores in the Lower Rio Grande Valley

The LRGV *promotores* model, "Mano a Mano," was created in April 1991 in response to three infants with anencephaly who were born 36 hours apart in Brownsville, Texas. This unusual cluster caught the attention of health workers, particularly Ms. Paula Gomez, executive director at Brownsville Community Health Center (BCHC), and Dr. Carmen Rocco, who started a binational campaign for local citizens to locate pregnant women needing prenatal care. The focus was training volunteer *promotores* to disseminate prenatal-health care knowledge. In 1999, the Promotor(a)/CHW Training and Certification Advisory Committee in Texas was charged with implementing standards related to the training and regulation of *promotores*. The committee continues to review applications from sponsoring organizations or training programs and to recommend certification.[9]

The University of Texas Rio Grande Valley's School of Medicine (UTRGV/SOM) was founded in 2015 and members of the Inaugural Department of Family and Preventive Medicine forged a community-academic partnership to address inter-professional education and integrated care training in the LRGV with support from the United Health Foundation. This partnership focused on the World Health Organization's priorities in Mental, Neurological and Substance use disorders (MNS) disorders and the Mental Health Gap Action Programme's (mhGAP's) curriculum[10] to create the CHW Consortium, which included the Texas A&M National CHW Training Center, University of Texas School of Public Health, and South Texas College. In 2017, the Center for Brain Health was founded,

which formed the basis of the Institute for Neurosciences (IFN) and included an outreach component based on collaboration with *promotores*.

Training of Community Health Workers/ Promotores

Texas *promotores* are certified by CHW Training Programs by the Texas Department of State Health Services (DSHS) Promotor(a)/CHW Training Certification Program. Courses are at least 160 hours, and continuing education units (CEU) are required to renew CHW certification every two years. The CHW/ Promotor(a) training for Mental Health GAP is a 12 CEUs course delivered by the Texas A&M School of Public Health, CCHD's National CHW Training Center. The program provides basic training in mental health screening and referral to primary health care personnel trained in mhGAP along with training for monitoring and following-up with people with mental illness and their families. The following are core competencies[9] with a specific module for MNS[10]: 1) communication skills to enhance abilities to exchange information with community members and health and human-services agencies; 2) interpersonal skills to improve abilities to communicate and build relationships, particularly when cooperation is required; 3) service coordination skills to strengthen abilities to assist individuals and families through planning, coordinating, identifying, accessing, and monitoring services and support to achieve the best quality of life and full community participation; 4) capacity building skills to enhance abilities to promote individual and organizational capabilities to obtain, improve, and retain skills, knowledge, tools, equipment, and other resources needed to pursue community goals; 5) community needs assessment skills to teach participants skills to systematically collect, analyze, and use information to educate and mobilize communities; develop priorities and action plans, and demonstrate the need for funding proposals; 6) advocacy skills to enhance abilities to effectively communicate, negotiate, or assert interests, desires, needs, and rights of the community; 7) teaching skills to develop abilities to teach and evaluate behaviors to facilitate learning in one-on-one or group settings; 8) organizational skills to improve abilities related to creating structure and order, boosting productivity, and prioritizing tasks; 9) knowledge on MNS to gain and share basic knowledge of mental health and mental, neurological and substance use services, social determinants, mood disorders, psychosis, alcohol and substance abuse, developmental disorders, self-harm and danger, cognitive disorders, stroke, epilepsy, movement disorders, and chronic pain; and 10) conflict resolution skills to enhance abilities to identify conflicts, acknowledge different opinions, and build consensus around actions needed to address community needs.

In 2018, the UTRGV AD-RCMAR was established to reduce impacts of AD and brain disorders among Hispanics and other minority groups. The organization embraces alliances with community members and organizations rooted in the Institute of Medicine's framework for collaborative public health action.[11] Within this scope, *promotores* pursue general primary care principles, recruit patients with memory disorders and dementia, refer patients to primary health care providers, monitor and support patients and families, and link them to community resources. Additional opportunities are offered to *promotores* via courses, conferences, reflective dialogue sessions, and introductions to different research teams and approaches. Concepts of responsible research conduct are discussed and embedded in training that includes discussions on designing, planning, implementing, and evaluating projects and post-project sustainability. The goal is to engage *promotores* in sustainability-enhancement efforts including broadening and deepening stakeholders' involvement.

The UTRGV/SOM and the UTRGV AD-RCMAR have initiated programs to study impacts of MNS including autism, AD and related brain disorders among Hispanics with the purpose of developing health care strategies to improve diagnosis, care, and prevention of these conditions. Embedded on the planning of these programs are strategies to respond to local socioeconomic conditions, culture, and educational levels. One of the mechanisms to promote community engagement is the implementation of alliances with CHW/*promotores* organizations, which resulted in community-academic partnerships (South Texas Promotores Association, BCHC Mano a

Mano, Proyecto Juan Diego, Red de Promotores, Migrant Health Promotion Salud, LGRV CHW Consortium, and Area Health Education Center Program) toward the implementation of programs for MNS led by *promotores* organizations.

Promotores are also research partners for the UTRGV AD-RCMAR pilot projects that offer them opportunities to participate at all stages of research, particularly in defining research questions, instrument development, participant recruitment, data collection, and research dissemination. Enhancing *promotores*' capabilities to implement interventions and data analysis is necessary before their involvement and UTRGV AD-RCMAR supports several mechanisms of interaction with them in which empowerment and commitment to developmental activities are explored through informational sessions and public trainings using social media, listening sessions and development of resources that facilitate visualization of information and data.

Promotores focus on the following: training and informing communities about behavioral health, dementia, AD, and related disorders; making home visits to detect potential issues affecting health or healing and identifying needed services; eliminating language barriers that affect health care access or treatment adherence; creating educational networks that extend deeply into communities; recruiting research participants; using the Mini-Cog[12] as a screening tool for referrals for individuals concerned with cogntitive-performance changes.

Efforts to Date

Since 2017, an average of 80 *promotores* have participated in each training. A clinical research certificate and stroke-care course are being developed. To conduct colonias research with *promotores*, we minimized course dropouts by simplifying learning experiences and adapting protocols and data-collection instruments to the languages and cultures; we further highlighted opportunities to access older adults by respecting the role of elderly people in colonias culture.

One of the few reports of using *promotores* on MNS in the LRGV was focused on training *promotores* to engage parents on early detection of autism.[13] Given the participation of one of the UTRGV AD-RCMAR´s members (NG) in that team, we have extracted the lessons and adapted to engage *promotores* in early detection of cognitive decline in older adults. The Hispanic Autism Research Center (HARC) developed a "train-the-trainer" program that included an educational intervention for CHWs, with a practicum (visits) and focus groups to identify perceived strengths and weaknesses of the curriculum. Two organizations that group a substantial number of *promotores* in the LRGV were invited to participate in the training: Proyecto Juan Diego in Cameron County and the South Texas Promotora Association in Hidalgo County.

Fifty-eight *promotores* out of the sixty invited received training using the Developmental Milestones and the Warning Signs of Autism: Promotora Training Guide developed by the Organization for Autism Research (OAR)[14] to identify normal childhood-developmental milestones and recognize delays. All but one self-identified themselves as Hispanic and there were four males in the group. More than half of the *promotores* (55%) were aged ≥50 years, and almost a third (39%) held 12 grades of education as their terminal degree (high-school). All 56 *promotores* completed the five sessions of approximately one hour: 1) introduction to developmental milestones; 2) developmental milestones; 3) outreach during a health fair; 4) outreach during clinic visits; and 5) referral information and review. Each participant completed a pre- and post-training survey that was also developed by OAR and modified by the HARC with the purpose of assessing gain of knowledges. Analysis of the responses revealed that *promotores* significantly improved their knowledge of developmental milestones and warning signs of autism after the training, (60.5 ± 16.4% vs 73.6 ± 18.2%, t= 5.7, P<.0001).[13]

Ten *promotores* volunteered to implement the OAR curriculum during home visits and provide families with materials from the CDC campaign, "Learn the signs. Act early."[15] Twenty-seven *promotores* participated in focus groups conducted after training, and they emphasized the effectiveness of the interactive workshop as opposed to strict lectures and that it prepared them well for their community outreach. They were also interested in reviewing material in another workshop or providing it to other *promotores*.

One of the most revisited themes in focus groups was the community's desire for more information regard-

ing childhood development and autism. Two other prominent topics were insufficient knowledge about developmental milestones and the stigmatization or emotionally challenging aspects of autism spectrum disorder (ASD) diagnoses. The *promotores* discussed limited education levels and resources as potential factors in recognizing autism in Hispanic communities. The overarching theme about the curriculum was that it was simple, clear, and understandable. The *promotores* emphasized the cultural versatility of the bilingual educational tools for their own education and community outreach. Some *promotores* requested additional resources because of the topic's importance to families. *Promotores* also found that families discussed their concerns about children's development with their physicians and shared the information with others. When asked about questions missed most frequently on post-training tests or the curriculum's weaknesses, many mentioned the topics' complexity and needing more time to study material. In every focus group, *promotores* disagreed with the OAR's recommended way of educating in health fairs. Some reasons were the cultural inappropriateness of asking about children's ages and that there should not be one set order for presenting material because each encounter requires adaptation. Lessons from this experience are used as guidance for the development and implementation of the Training Guides in MNS, including those focused on older adults.

Promotores are active stakeholders in developing strategies for establishing research foundations for studies of complex neurocognitive disorders such as ASD in the LRGV.

We now have 347 certified *promotores* in LRGV: 174 in Cameron County, 169 in Hidalgo County, 3 in Starr County, and 1 in Willacy County. Most of the *promotores* in LRGV are female, Spanish-speakers (98%) although half of them are also fluent in English and more than half of the *promotores* have five years or more as a state-certified CHW. *Promotores* know that they are valuable resources for the community, but they often feel undercompensated for their many roles and fear for their livelihood; most CHWs work for grant-funded projects that are temporary. Managers of CHWs describe the importance of providing support, monitoring and assessment of the activities of *promotores* as delivery agents for quality and adherence to agreed protocols. They also emphasized the importance of selecting and training those *promotores* who have a deep knowledge of colonias culture, able to keep confidentiality on many sensitive issues, including migration status. The translation of the knowledge gained from CHWs in an autism program to studies of MNS and AD and related dementias has facilitated the engagement of *promotores*.

Conclusions

Promotores are active stakeholders in developing strategies for establishing research foundations for studies of complex neurocognitive disorders such as ASD in the LRGV. *Promotores* provide services in locations with relatively inaccessible formal health care, contributing to community health and wellbeing, and also engage individuals residing in colonias to research studies. However, it is critical to frame engagement of *promotores* within community-academic partnerships that begin with genuine interest in addressing local health needs. Extension of lessons from the ASD study, and the incorporation of the mhGAP strategies in training of *promotores* support the feasibility of deploying CHWs to recruit older adults and care partners in research studies. The LRGV population's characteristics make early detection of AD and dementia and support for patients and caregivers high priorities, and working with *promotores* is an effective means of achieving them.

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Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Garza, Uscamayta-Ayvar, Maestre; Acquisition of data: Garza, Uscamayta-Ayvar, Maestre; Data analysis and interpretation: Garza, Uscamayta-Ayvar, Maestre; Manuscript draft: Garza, Uscamayta-Ayvar, Maestre; Administrative: Garza, Uscamayta-Ayvar, Maestre; Supervision: Garza, Maestre

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