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The Formation of a Community Academic Partnership to Address Health Disparities and Improve Outcomes for Latino Family Caregivers Living in a Rural Community

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In 2008, the World Health Organization (WHO) initiated the Mental Health Gap Action Program (mhGAP) and identified dementia as a priority public health issue (WHO, 2017). Almost 10 years later, dementia remains a serious and rapidly growing health concern and recognized health disparity for minority groups (USC, 2016; WHO, 2017). Alzheimer's disease (AD), the most common type of dementia, currently impacts 5.5 million Americans (Alzheimer's, 2017). Latinos are 50% more likely to develop AD compared with non-Latino whites and it is estimated that 3.5 million Latinos will be living with AD by 2060, with costs to society exceeding two trillion dollars (USC, 2016). AD is an incurable neurodegenerative condition that causes progressive loss of cognitive and functional abilities along with adverse behavioral changes (Alzheimer's, 2017). Individuals affected by AD will experience significant memory loss and eventually lose the ability to communicate, make decisions, and perform basic activities of daily living, such as walking, bathing, and eating. In addition, patients with AD and their family members experience stigma resulting from gaps in awareness and understanding of dementia (Alzheimer's, 2017, Flaskerud, 2009). Specifically, Latinos are less likely than non-Latino whites to receive timely and comprehensive treatment and more likely to depend on informal, unpaid caregivers, typically family members or friends, to provide care (Flaskerud, 2009, USC, 2016). As a result of this caregiving role, family caregivers experience negative mental, physical, and socioeconomic outcomes. In a meta-analysis, Pinquart and S rensen (2003) found that caregivers had higher levels of stress and depression and lower levels of subjective well-being, physical health, and self-efficacy when compared with non-caregivers and that differences were more pronounced among those caring for family members with dementia. Consistent with earlier studies, Herrera et al. (2013) found that Mexican American informal caregivers had a greater risk of depressive symptoms and cognitive impairment than Mexican American non-caregivers, controlling for sex, age, and physical and mental health functioning.

Although evidence-based strategies have been shown to effectively support family caregivers' mental and physical health and improve quality of life, the extent to which these

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interventions successfully meet the unique needs of ethnically diverse family caregivers, especially those living in rural settings, has not been well-established (Nápoles, Chadiha, Eversley, & Moreno-John, 2010). Based on current projections there is a pressing need to engage the Latino community in developing culturally appropriate interventions to increase awareness of AD and support the 1.8 million Latino family caregivers who provide care to a loved one with AD or other dementia (USC, 2016). The National Institute of Mental Health (NIMH) encourages researchers to conduct investigations that improve access, quality, and equity of mental health care in real-world communities (NIMH, 2017). The purpose of this paper is therefore to describe the development and work of a community academic partnership that was formed to better understand existing assets and needs of family caregivers of relatives with AD living in a rural region of South Texas, populated predominantly by Latino persons. Findings from this initial phase will help to inform the development of sustainable interventions that are meaningful and accessible to this community.

This project evolved from a long standing partnership between the University of Texas Health Science Center (UTHSCSA) and the Frio County Translational Advisory Board (TAB), with support from the South Central Area Education Health Center (AHEC). The mission of the South Central AHEC is to facilitate community academic partnerships that address health disparities by improving access to quality care through educational interventions. The Frio County TAB, which consists of a representative body of citizens from a rural region in South Texas, was established in 2008 to collaborate with researchers from UTHSCSA in conducting community based participatory research with the goal of improving health outcomes in this community through educational outreach. Since 2009, community and academic partners have been meeting monthly to identify priority health concerns and develop programs to address these issues.

In the spring of 2016, community members attending a TAB meeting described the challenges associated with being a family caregiver and voiced a desire to improve services for family caregivers in their community. Subsequently, faculty from the UTHSCSA School of Nursing (SON) were approached to explore opportunities to partner with the Frio TAB in better understanding caregiver needs and facilitating support in this community. At this time, SON faculty were in the process of developing the Caring for the Caregiver program to support family caregivers of relatives with AD and other dementias as a component of the Biggs Institute for Alzheimer's and Neurodegenerative diseases being established at UTHSCSA. The core values of the Caring for the Caregiver program, family-centered care, community engagement, equal access, and social justice, were very much in line with partnering with the Frio TAB to improve services for caregivers living in a rural, predominantly Latino region of South Texas.

Nursing faculty were invited to attend an upcoming TAB meeting to discuss community concerns related to family caregiving. Several TAB members at this meeting described their experiences caring for a relative with AD and identified this area of caregiving as a significant health issue within their community. With support from the TAB and SON, two community members organized a gathering, inviting all interested community members and stakeholders, to further explore family caregiving issues. In addition to two TAB members,

15 family caregivers, two individuals with AD, and two healthcare professionals who had worked with dementia patients attended, along with three faculty from the SON and one nursing student. The meeting was co-facilitated by a community member and a faculty member. The majority of family caregivers were Latino.

Caregivers were initially asked to describe their caregiving experience and then to discuss needs related to this role. Prior to the beginning of this discussion, permission to audiotape the session was granted by all community members. Consistent with input previously provided by TAB members, caregivers discussed the need for a local caregiver support group, more information related to Alzheimer's disease, and respite services. Participants envisioned the support group to be a forum for emotional support (an opportunity to vent among others who understand), information sharing, and co-learning. In addition, they requested opportunities to receive specific educational information on topics such as the stages of Alzheimer's disease, strategies to manage and cope with behavioral, cognitive, and functional changes, early detection, approach to diagnosis, genetic risk factors, and legal, financial, and advance care planning. Lastly, caregivers were asked how they would like to receive educational information and were notified of and invited to attend an upcoming Alzheimer's conference. Caregivers preferred that TAB members and researchers attend and share information at future meetings. Caregivers were also interested in learning about on-line resources, but requested that these resources be presented in person to accommodate those caregivers who did not have access to the internet or lacked health/technology literacy. Attendance and engagement at this initial meeting demonstrated the importance of this topic to the community and created a strong foundation for next steps.

Subsequently, a team of community members and nursing faculty and students applied for and received a community engagement grant. This grant has helped to support the development of relationships among family caregivers and community and academic partners and allowed our team to more comprehensively examine this topic. Early input from our community co-investigators was invaluable in getting this project off the ground. Our community partners not only provided us with a unique understanding of the community, but they also shared important insights related to being a family caregiver for a loved one with AD.

The project was deemed non-regulated research for community outreach by our institutional review board. As a first step, beginning in the summer of 2016, caregiver support group sessions were initiated and scheduled based on the preferences of the community members. Early on participants suggested that a structured educational component be incorporated into each session and that the sessions be opened up to individuals providing care for relatives with other chronic illnesses. Dementia caregivers felt that other caregivers within their community were most likely experiencing some of the same challenges and would benefit from the support and services being offered by our team. As a result, since January of 2017, faculty have facilitated education or invited experts to present on topics that caregivers prioritized as beneficial to their role as a caregiver and/or to the health of their community. These sessions were therefore opened up to all caregivers and interested community members. Experts have presented and provided resources on AD, caregiver burden, benefits and legal resources, heart health, and stroke awareness and prevention.

In conjunction with these events, to better assess existing assets and needs, community and academic partners conducted an informal assessment of caregiver services in the area and developed a comprehensive caregiver survey. Prior to implementing the survey, TAB members were asked to review the survey on two separate occasions to improve the survey's suitability to this community. The survey assesses demographics, caregiver/recipient health information, service utilization, assistance with activities and instrumental activities of daily living, positive and negative reactions to caregiving and quality of life. Survey collection is ongoing. In addition, a follow-up focus group was conducted in the summer of 2017 to build on the findings from the initial focus group held at the onset of this collaboration. This follow-up focus group was again facilitated by a SON faculty and community member. Participants were asked to describe the challenges that they have experienced as a family caregiver, assets and resources within their community that have been helpful to them, and ways in which services or programs could be improved. The following themes resulted from this focus group: *confusion and challenges surrounding access to services to support family caregivers, emotions surrounding accepting changes and assistance, and finding strength and resilience in the caregiving role.*

Although we continued to have a core group of caregivers and community members attend events, in general, as is common in the early stage of community work, participation began to decline. Community and academic partners were utilizing several strategies to promote participation and engagement; events were being advertised in the local paper, flyers and announcements were provided at monthly TAB meetings, the local hospital, and health fairs, and a committed community champion continued to informally share information throughout the community. Caregivers who agreed to complete a survey or participate in the focus group received a gift card as a small token of our team's appreciation. Refreshments and free resources were offered at each event. Throughout this process members of our team sought input from community members during events and at scheduled TAB meetings. This feedback informed future content as well as changes in scheduling of events (times and locations) to improve our reach within the community.

Efforts over the last 18 months have supported the development of positive working relationships among family caregivers and community and academic partners enabling our team to generate a better understanding of caregivers' needs and assets within this community and develop programs to begin to address needs. Although at the onset of this project we were initially focused explicitly on family caregivers of persons with dementia, based on community feedback, our focus has expanded to include all family caregivers. We continue to have a core group of dementia family caregivers participate in this work, and, as we analyze and reflect on findings, our team will pay attention to variations among caregiver groups. Awareness and understanding of AD and other dementias remains an important priority for this community and members have recently voiced interest in a virtual dementia simulation, which we are in the process of coordinating. Trained facilitators from the SON will provide community members with attire and equipment that will alter participants' sensory abilities as they are asked to complete a variety of everyday tasks. This simulation will allow community members to experience first-hand what it is like to live with dementia, to gain a better understanding of the needs of individuals impacted with dementia, and to discuss strategies to address what is often perceived as *abnormal* behaviors.

In conclusion, this is the first time to our knowledge that family caregiving has been examined in both a systematic and collaborative way within this community. Progress has been shared by community and academic partners at local conferences and meetings. Findings from the follow-up focus group and survey, in addition to ongoing input from community members, will inform next steps and future projects. We believe that this community academic partnership and the community based participatory approach that we have adopted to explore family caregiving in this region of south Texas will allow us over time to develop culturally tailored interventions that best meet the unique needs of this group and support health outcomes within this rural community. Through this work, we hope to begin to address health disparities of family caregivers in this largely Latino rural community.

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