B. PROJECT OVERVIEW

Project Name:
Los Cuidadores Unidos: United Latino Caregivers
HWPP Project Number:
2011D-28

Without exceeding this one (1) page, briefly describe your project and partnership.

Los Cuidadores Unidos (United Latino Caregivers) will improve the health of Latino community members in Wisconsin through the development of an intervention to relieve the burdens of those caring for people with Alzheimer's disease (AD) and other dementias. As the US prepares to ensure health services to a rapidly aging “baby-boomer” generation, significant racial and ethnic demographic shifts and shortages in Medicaid and family care funding continue to impact our national concerns. Caregivers of people with AD and other dementias have become recognized not only as valuable extensions of clinical care, but also as a cultural resource to delay institutionalization, increase quality of life, and perhaps most importantly, save billions of healthcare dollars. AD is the fastest growing cause of death from major disorders in the US and estimates project that the nation’s annual cost of AD related care will exceed $1.1 trillion per year by 2050. Overall, the epidemic has profound economic and social impacts. Wisconsin has approximately 200,196 AD and dementia caregivers who represent 227,982,824 hours of “unpaid” care annually; the report quantifies the value of this care at $2,621,802,480. While it is clear that caregivers have a strong positive impact on the health of an aging society, research has demonstrated that caregivers themselves are at risk for poor health outcomes.

The overall goal of this study is to develop and implement an innovative, personalized intervention to improve the health of participants responsible for providing care to Latino family members who suffer from AD or other dementias. The project also aims to increase caregiver levels of social connectedness via social activities, workshops, support groups, telephone and video calls with counselors, and to decrease caregivers' signs and severity of depression and stress, and improve reported quality of life. The specific objectives of the study were developed based on previously collected data from focus groups conducted at United Community Center (UCC) with caregivers of family members with AD. The multi-pronged intervention will take place within the established operations of the Latino Geriatric Center (LGC) of the UCC, and will utilize a family systems approach. Our aim is to pilot a replicable intervention that is geared towards the unique needs of the growing US Latino population. While the intervention only lasts six months, our project team will use both qualitative and quantitative assessments to measure the effects of the program on caregiver burden and stress.

The project has four specific aims: Specific Aim 1: Develop a pilot caregiver intervention, “Los Cuidadores Unidos,” for Latinos. Specific Aim 2: Deliver Los Cuidadores Unidos to 40 caregivers and their family members at the UCC LGC. Specific Aim 3: Evaluate Los Cuidadores Unidos. Specific Aim 4: Disseminate lessons learned to a wide community of stakeholders.

Our intervention is holistic because it integrates six primary components using a family systems approach. The overall work plan will begin when the study team starts to meet and schedule the program. All key personnel will receive Behavior Activation training through the University of Wisconsin-Milwaukee psychology department. Recruitment efforts will start in the third month and continue to enroll families up until the 18th month. Over a six-month period, the protocol will include: 1) Two family and spousal dementia education sessions; 2) Four individual counseling sessions; 3) Follow-up visits in person, via telephone, or video phone calls (e.g., Skype); 4) A respite day for caregivers with activities for self-care (e.g., Yoga, massages, guided imagery, nutrition education, and spiritual activities); 5) Peer network with mentors to provide support and guidance; and 6) Availability of educational sessions on-line or via DVDs according to the caregiver’s preference. Data will be collected at baseline, 3 months and 6 months using tested measures translated into Spanish. Instruments include: (1) Quality of Life (Medida del Calidad de Vida) measure, (2) Social-connectedness measure, (3) Zarit Caregiver Burden Assessment, (4) Patient Health Questionnaire (PHQ)-9, and (5) case notes from family sessions. Summative evaluations of the program will be developed for participants. Our dissemination phase targets community stakeholders, educators and academic publications and presentation.