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We submit this application in response to RFA-NR-13-001 “Addressing Needs of Informal Caregivers of Individuals with Alzheimer’s Disease in the Context of Socio-demographic Factors (R01)”. Hispanics are a rapidly growing population who suffer disproportionately from dementia, including Alzheimer’s dementia, and related caregiving burdens compared to Non-Hispanic Whites. Little is known about the key characteristics and needs of these caregivers and how they influence long-term outcomes, the effectiveness of interventions, and the management of information critical to their health and that of persons with dementia. We propose to address these questions by creating the New-York-City Hispanic-dementia-caregiver Research Program (NHiRP), a multifaceted, novel research program designed to understand the particular needs of and tailor evidence-based clinical interventions to Hispanic caregivers of persons with dementia. We are uniquely positioned to respond to this RFA because our multidisciplinary team is conducting the Northern Manhattan Caregiver Intervention Project (NOCIP, clinicaltrials.gov ID NCT01306695), a randomized trial of 6-months duration testing the effectiveness of the New York University (NYU) Caregiver Intervention in 160 Hispanic relative caregivers of persons with dementia. The NHiRP will build on the resources of NOCIP and will be coled by multiple PIs, Jose Luchsinger, MD, MPH, Roberto Lucero, RN, PhD and Mary Mittelman, DrPH, who will merge their complementary areas of expertise in epidemiology, clinical trials, minority health, mental health, medical bioinformatics, and caregiving research to achieve its 3 main goals: 1. Conduct a longitudinal follow-up of caregivers in NOCIP; 2. Create a registry of Hispanic caregivers in order to study the relation of sociodemographic factors with their caregiving-related needs; 3. Adapt and test a web-based personal health information management system intervention, working with registry members, tailored to their sociodemographic characteristics and needs. NHiRP will achieve its goals through the following specific aims: 1. To compare caregiver change in depressive symptoms and burden between the NOCIP study arms in a 5-year observational study phase 1 and 5 years after NOCIP enrollment; 2. To examine the interplay of key sociodemographic characteristics, caregiver burden, stress, and depressive symptoms in 300 members from our newly formed registry-Key characteristics include sex and family position, employment, acculturation, socioeconomic status (SES), social support, and coping; 3. To iteratively develop, refine, and test a web-based health information system with caregivers in the registry.
