

Compounded stress: Providing tools in Spanish for dementia caregivers

Change AGENTS Initiative

The John A. Hartford Foundation's Change AGENTS Initiative was a three-year effort dedicated to improving the health of older Americans, their families, and their communities through practice change. The initiative harnessed the collective strengths, resources, and expertise of the foundation's interprofessional community of scholars, clinicians, and health system leaders. The Change AGENTS Initiative was managed by The Gerontological Society of America.

The 34 projects funded through the Action Awards grants program showcased the improvements that interprofessional teams can bring to light by implementing evidence-based programs into targeted care settings in local environments.

These one-year grants for up to \$10,000 were available to interprofessional teams led by Change AGENTS for the purpose of achieving meaningful change to practice or policy that will improve the health and wellbeing of older adults and/or their families.



Imagine an older adult, Maria, doing everything possible to care for a lifelong partner with Alzheimer's disease—while coping with her own multiple conditions and medications. She hears about the CareHeroes app and website, created for caregivers just like her. The app has tools to help take care of her loved one, more efficiently communicate with her partner's physician, and track any emerging symptoms of depression or caregiver burden.

Maria excitedly downloads the app—and it is in English. She knows only Spanish.

That was the situation Nicole Ruggiano, PhD, MSW, and Ellen Brown, EdD, MS, RN, FAAN, of Florida International University (FIU) in Miami, sought to change with their grant through the Hartford Change AGENTS Initiative. “Lots of caregivers are just like Maria,” Ruggiano said. “They're older adults having many of the same issues—managing their own health when they're trying to help manage the health and well-being of someone they care about. It's all this compounded stress.”

Grant in hand, Ruggiano and Brown are meeting the needs of Hispanic caregivers in culturally competent, 21st century ways. In addition to creating Spanish language versions of the CareHeroes app and supporting website, the team created videos that provide important information in a different medium—and are also available in both English and Spanish.

Administered by The Gerontological Society of America, the Hartford Change AGENTS Initiative accelerated sustained practice change to improve the health of older Americans, their families, and communities. The initiative harnessed the collective strengths, resources, and expertise of the John A. Hartford Foundation's interprofessional community of scholars, clinicians, and health system leaders so they could learn from and support one another while they adopted, evaluated, and sustained changes in practice and service delivery. The Change AGENTS Action Awards grants program was designed to support Change AGENTS in implementing promising ideas in practice change.

The situation

CareHeroes is an Android app and website (www.careheroes.org) originally developed with funding from the Florida Department of Health. Brown, faculty member in FIU's Nicole Wertheim College of Nursing and Health Sciences and principal investigator on the project, said the app's purpose is to improve health care delivery and reduce state costs for dual-eligible beneficiaries by coordinating care, improving communications, and reducing nursing home admissions. The product is different from other dementia caregiver apps in that it allows health providers to seamlessly manage care delivery for community-based individuals with dementia.

The website and app have many features that save caregivers time, as well as connect them to useful resources. For example, caregivers can take an assessment for an individual with a neurocognitive disorder. The system produces a color-coded chart that is faxed to the physician's office, decreasing the time caregivers need to spend in reporting what is happening at home while giving the physician reports in real time.

"One of the problems in dementia is that the caregiver and patient might get 4 to 7 minutes with the primary care physician," Ruggiano said. "That's not enough time to talk about all the issues someone is experiencing with dementia. The CareHeroes system really tries to facilitate communication and collaboration."

Using the system, caregivers can assess their own depression symptoms and burden—and receive feedback encouraging them, for instance, to seek medical care, talk with the case manager, or reach out to their support communities. Medication management is another function, along with caregiver education and links to community resources. Caregivers also have access to a self-efficacy tool for managing dementia.

The pilot version of CareHeroes was well received, but Ruggiano and Brown saw quickly the need for a Spanish version. Feedback also showed the researchers how they could improve people's comprehension and understanding through use of videos—but that meant they needed both English and Spanish language versions.

That is where the Change AGents Action Awards grants program came in.

The solution

During 2016, Ruggiano and Brown used their grant funds to translate the website and app into Spanish, working with their nurse practitioner doctoral students—including some who were physicians from South America and the Caribbean—as well as with computer information science graduate students supervised by Peter J. Clarke, PhD, and language consultants. Brown, experienced in creating health education videos, worked with local talent agencies and led the three-member team in screening and casting bilingual actors for the roles (caregivers and health care provider).

One video showed how caregivers can recognize when they need help. The second one described how to prepare for a physician visit for an individual with dementia or Alzheimer's disease.

The translation effort—which seemed simple enough—was complicated by the multicultural nature of Miami's Hispanic communities. Spanish is not just Spanish; Ruggiano and Brown learned

from consultants that even the term used for the word *caregiver* varies depending on a family's country of origin.

Making the videos was even more complicated. "It sounded very simple, but in creating the videos, we had to work with grad students on the scripts and find a talent agency," Ruggiano said. "We had casting calls, auditions, even dress rehearsals. There was a lot of time and effort involved in creating these videos."

How the grant improved outcomes

As the grant wound down at the end of 2016, the researchers were preparing for focus groups to assess what their target audiences thought of the Spanish adaptations of the CareHeroes tools. With that feedback, they will tweak the materials and launch the Spanish versions. Future projects will add several innovative features to the CareHeroes prototype and evaluate its impact on caregivers and health care delivery, Brown said.

Ruggiano in the meantime has moved north, to the University of Alabama in Tuscaloosa. There she is seeking funding for a larger test of CareHeroes. She is in a perfect situation to do so. Having left the urban centers of the Sunshine State, she is learning that rural residents in Alabama and the state's African American caregivers have their own concerns and, in some cases, have new words or terms that they prefer. The diseases and burdens may be universal for patients and caregivers, but finding optimal, culturally competent ways of communicating seems more like traveling a road that holds surprises around every bend.