

Caregiver stress: Teaching core concepts, creating a supportive community

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.



Although it takes a village to provide adequate care to older patients with physical and cognitive limitations, the load is frequently borne by unpaid in-home caregivers who tend to a loved one's everyday needs. Given the immense stress of that commitment, the staff at MedStar Washington Hospital Center in Washington, D.C., wanted to do something to help those caring for the 600 people in their [Medical House Call Program](#).

“Caregivers must understand that they’re doing real work, that the work is hard even if you love the person you’re caring for, and that you have to take care of yourself in order to take care of others,” said Stephanie R. Bruce, MD, practice director of the program and assistant professor of medicine at Georgetown University in the nation’s capital. “Our goals in this program are to improve overall health and quality of life and to ‘unneed’ the need for nursing home placement. To accomplish those, we have been dependent since day one on the unpaid relatives and lifelong friends who provide the care.”

Using a Change AGENTS Action Awards grant to fund new activities in the program, Bruce and her team of medical personnel and social workers have been able to enhance the support they offer to caregivers. “If these loved ones are going to be able to age in place in their homes despite what might seem like overwhelming needs, we have to have talented, healthy, and motivated caregivers,” Bruce said.

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

The District of Columbia is “very lucky,” Bruce explained, to have home-care resources that cover many of the costs of aging in place for low- and moderate-income elders. Still, caregivers are needed; almost no one gets around-the-clock, 24/7 care through the services funded by the federal and local governments.

The Washington Hospital Center Medical House Call Program was launched in 1999 by Eric De Jonge, MD. From the beginning, the program has had a medical eye, with physicians and nurse practitioners literally making house calls to care for the medical needs of older adults in the primarily African American community of the District of Columbia. Bruce, who joined the group in 2004, said the founders quickly realized the need for social support, adding a social worker as the team’s fourth member. The program is now a member of the Independence at Home (IAH) demonstration, a national consortium of medical practices that are part of a CMS Innovation Center project.

The house-call group now has five physicians, six nurse practitioners, one licensed practical nurse, and four social workers. They work with people like Veronica Butler, a daughter who promised her dad before he died that she would take care of her mother after he was gone. With no idea what that commitment would entail, Butler began a 20-year journey as a caregiver, eventually having to quit working and, for the last 12 years of her mom’s life, providing total care.

Yet Butler never “stressed out,” said Ruth Shea, LICSW, social worker with the program and one of the principal investigators on the grant. The needs of Butler and many other caregivers made Shea and Bruce want to do more to support caregivers and to address the stresses they feel every day.

Even with a strong group of embedded social workers, the practice had more need than it had social worker time, Bruce said. “We thought, why not kind of spread some skills amongst the team so that we can help with the caregiver work, without having to involve the social worker?”

The Solution

“As a practice, we hadn’t really ever thought to ourselves, can we do better in teaching, educating, helping, supporting the caregivers who do the work of caring for their family members?” Bruce said. “When things went well, it was because caregivers did their part well, and when things fell apart, it was because the caregivers were falling apart. It took a while to recognize we should get upstream of this and really think about what we could do before the caregivers were in crisis. What can we do to support them? What can we do to educate ourselves—the medical staff?”

This realization had crystallized by the time the Change AGENTS Action Awards grant became available. Program staff outlined three goals for their 2015 grant year: reduce caregiver stress, improve clinician readiness to assess and mitigate caregiver stress, and demonstrate readiness of this model so the practices could be disseminated to the IAH group.

Baseline surveys of caregivers and staff helped identify problems and determine the kind of support that would best help caregivers. Based on the findings, Shea spearheaded development of two caregiver conferences, including one that focused on spiritual renewal, a monthly support group (where Butler and those with years of caregiving experience were particularly helpful to others), and a weekly prayer call.

At the caregiver conferences, 20 to 30 caregivers meet for 6 hours, sharing food and hearing speakers. “One expert was an author of a caregiving book that we had used in our group,” Shea said. “With the author, caregivers reviewed techniques for self-care, ways to be advocates for themselves, and ways to build circles of support when family members aren’t able to step up to the plate. That’s kind of a common thread of caregivers who have felt isolated—that they were selected by family members to be the caregiver.”

Shea also recalled one caregiver at the spiritual conference who had the opportunity to speak with one of the hospital chaplains. “She did not know it at the time, but that prepared her to deal with a hospice situation and the eventual death of her own sister,” Shea said.

Religion and spirituality is an important part of caregivers’ lives in this community. “A constant issue is that people lose their church connections either with their caregiving duties or because the patients themselves are no longer able to get out,” Shea said. “On our weekly telephone call, I offer the prayer. Even though participants’ lines are muted, the call offers people a way to feel that they’re joining together with others in prayer.”

The staff survey showed a surprisingly high level of confidence in addressing caregiver burden, Bruce said. “Two of our nurse practitioners had nursing backgrounds, so they were probably better skilled in this area,” she added. “Still, some providers perceived lower levels of competence than our social workers.” Addressing the needs of staff was delayed during the grant period by turnover among the social workers, but that is next up on the program’s priority list, along with a follow-up survey of caregivers to assess the impact of the program interventions. The model is about to be expanded to Baltimore hospitals in the MedStar system and then will be shared with IAH participating institutions.

How the Change AGents Action Award improved outcomes

The Change AGents Action Awards grant enabled Washington Hospital staff to conduct surveys of caregivers and set a baseline for caregiver stress, bring in speakers for the caregiver conferences to address needs and, especially, to “hook people up and link our caregivers with services to ameliorate their stress,” Bruce said. “We also sought to teach our caregivers to recognize and deal with stress.”

Bruce recalled a recent state-of-the-art talk on the topic of Alzheimer’s disease delivered at the 2016 American Geriatrics Society meeting by Christopher Callahan, MD, of the Indiana Alzheimer Disease Center. Callahan, also part of the Hartford Change AGents Initiative, spoke for an entire hour not on new drugs or gene therapy but on caregivers—“on the need for them, how practitioners rely on them, how they are the crux and the core of the future of care of the disease,” Bruce said. “Hearing that after we had launched our caregiver efforts really resonated with me and reassured me that we are on the right path in our Medical House Call Program.”