

Disaster Preparedness for Veterans With Dementia and Their Caregivers

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Survival in a natural disaster is difficult enough for people without any functional or mental impairment; consequently, older adults with dementia and their caregivers are even more challenged to survive. This article describes the evolution of an educational intervention pilot program at the VA Palo Alto Health Care System that resulted in improved natural disaster preparation and response for this population.

Natural disasters, such as Hurricane Katrina in 2005 and more recently Hurricane Sandy in 2012, underscore the need for disaster preparedness in older adults impacted by or diagnosed with dementia.

Dementia is defined as an acquired impairment in memory associated with impairment in 1 or more cognitive domains, including executive functions (eg, judgment, reasoning); language; complex motor skills; and the ability to recognize objects, faces, or other sensory information. Dementia must be severe enough to interfere with individuals' work, usual social activities, or relationships with others.¹

Individuals with dementia are at particular risk of isolation and injury due to cognitive impairment. Yet, planned, broad-scale community-level efforts to aid in their response and survival in a disaster are few.

The Veterans Health Adminis-

tration (VHA) mission statement highlights prevention and population health and addresses education targeted to national emergencies, all of which support excellence in veterans' health care. This article describes the development of the Disaster Preparedness Education Pilot, designed to address complex needs among veterans with dementia and their family caregivers who are served in the VA Palo Alto Health Care System (VAPAHCS).

DISASTER PLANNING FOR VULNERABLE OLDER ADULTS

Older adults need assistance to survive and recover from a disaster. Economic, social, environmental, physical, and functional constraints and variable decision capacity in older adults with dementia increase vulnerabilities during and after disasters. There has been previous interest and planning by geriatric researchers in the area of disaster preparedness

for older adults and the disabled, particularly in the aftermath of the 9/11 terrorist attacks. Interest in disaster planning for "special needs" children and adults as well as older adults expanded following Hurricane Katrina in 2005, in which 70% of the 1,464 known disaster-related fatalities were aged ≥ 60 years.^{2,3} An estimated 7% of the 8.4 million veterans who now receive VA health care or benefits are affected by dementia, which translates into 588,000 veterans and at least 1 million family caregivers nationally.³ A majority of veterans with dementia, like the nonveteran older adult population, are noninstitutionalized and living in community settings.

Sensory, cognitive, and physiologic changes in older adults can result in barriers to awareness, communication, help-seeking, and help-finding. In an oral communication to the author, geriatric researcher and educator Nina Tumosa, PhD, stresses that the 1 or more functional limitations that affect one-half of all people aged ≥ 65 years can impede key disaster response and adaptation behaviors. Disasters can promote agitation and behavioral disruptions in individuals with dementia and cre-

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ate additional response demands for caregivers. All older adults can be deeply affected by the interruption of community and support services essential to their community-based living. These vulnerabilities, in turn, guide an essential aim of disaster preparedness: to prepare older adults with dementia and their caregivers to seek and receive immediate disaster assistance in their homes and neighborhoods.

DEVELOPMENT OF DISASTER KIT

The concept for the disaster kit(s) for older adults was developed by Nina Tumosa, PhD, in VISN 15, based on her previous research. In 2010, the VISN 21 medical director demonstrated the disaster kit prototype at the VAPAHCS's annual Geriatric and Extended Care Conference. The clinical nurse specialist (CNS) at the VAPAHCS Geriatric Research Education and Clinical Center (GRECC) identified the disaster kit concept as an opportunity for devising a quality improvement (QI) project to improve care of patients with dementia. She envisioned the disaster kit concept as a key adjunct to providing disaster preparedness education to community-dwelling patients with dementia and their caregivers—a population vulnerable to stress and health risks in and following a disaster.

HISTORY

In August 2010, under the leadership of the VAPAHCS GRECC CNS, a disaster kit planning committee was developed. Members included a geriatrician, a GRECC team member, a GRECC research health science specialist, a nurse practitioner in the VAPAHCS Home-Based Primary Care (HBPC) program, the clinical registered nurse manager of the VAPAHCS Adult Day Health

Center, and a doctorally prepared registered nurse Health Services Research Fellow at the GRECC. The GRECC director served as special advisor to the project committee as well. Committee members were selected for their skill and expertise in program development for older adults or clinical operations and evaluation.

The committee employed the Plan-Do-Study-Act (PDSA) QI model, endorsed by the VHA, and an array of accrediting and health care industry organizations. As its name implies, the PDSA is a 4-step iterative model used for process improvement.^{4,5}

ASSUMPTIONS

The preparation of older adults with dementia and their caregivers for disasters is based on several assumptions. Disasters of all kinds affect older adults disproportionately, particularly those with chronic diseases, disabilities, or conditions. These conditions complicate the disaster response for those affected, requiring targeted planning and supplies as well as additional time and resources for these individuals to evacuate and recover from a disaster event.⁶ Community preparation efforts for older adults need to address the special needs and capabilities of community-dwelling older adults with dementia and their caregivers. The disaster kit concept assumes that patients with dementia and their caregivers can benefit from guided disaster preparation educational interventions and physical tools to aid in disaster response. Planning assumptions also acknowledge that caregivers of individuals with dementia can be engaged in preparing for a disaster with anticipatory guidance, and a disaster start-up kit developed through this project.

INSTITUTIONAL REVIEW

In September 2010, the pilot project was designated as a QI project by the VAPAHCS Office of Research, and the quality management director approved the project as well. The VAPAHCS chief of staff's office was kept apprised of the project start-up and progress.

DEVELOPMENT OF EDUCATIONAL TOOLS

In the initial stages of the project, committee members first evaluated peer-reviewed literature as well as disaster and health educational material from local, state, and federal disaster response and health agencies concerning disaster response strategies for older adults. A limited subset of the information specifically addressed needs of older adults with dementia and their caregivers. The literature and health education information review provided basic tips for selecting and storing supplies in anticipation of a disaster and organizing emergency contact information.

Mindful of the most likely regional natural disaster to occur in California, earthquakes, the committee selected a 1-page tip sheet for seniors from the California Department of Aging on earthquake preparedness and response that appeared on the first side of a doubled-sided information sheet. The reverse side of the tip sheet addressed guidelines for the food and supplies recommended for inclusion in the veterans' and caregivers' disaster bags (Figure 1). The committee decided that both veterans and caregivers needed separate bags with unique items in each, acknowledging the importance of engaging and purposefully equipping both parties in the educational intervention.

Guidelines for caregivers addressed both the committee-supplied and committee-recommended com-

VETERAN & CAREGIVER DISASTER KITS

VA & PAHCS

Veteran's Disaster Kit	Caregiver's Disaster Kit
<p>Items Provided</p> <ul style="list-style-type: none"> • coil bracelet whistle • hand sanitizer/face mask • flashing reflector light • first aid kit • notepad and marker • safety education handouts • photo/ID album (see below) <p><i>Add the following to the photo/ID album:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> individual photo of the Veteran <input type="checkbox"/> copy of health insurance card(s) <input type="checkbox"/> completed contact card (inside the photo album) <input type="checkbox"/> copy of healthcare directive(s) <ul style="list-style-type: none"> - Living Will - Durable Power of Attorney for Health Care - POLST 	<p>Items Provided</p> <ul style="list-style-type: none"> • coil bracelet whistle • hand sanitizer/face mask • flashing reflector light • first aid kit • notepad and marker • safety education handouts and DVD • photo/ID album (see below) • crank radio with flashlight <p><i>Add the following to the photo/ID album:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> individual photo of the Veteran and caregiver <input type="checkbox"/> copy of health insurance card(s) <input type="checkbox"/> completed contact card (inside the photo album) <input type="checkbox"/> copy of healthcare directive(s)
<p style="background-color: #e91e63; color: white; padding: 2px;">Recommended items to add to both disaster kits</p> <ul style="list-style-type: none"> <input type="checkbox"/> water: one gallon of water per person per day for at least three days (for drinking and sanitation) <input type="checkbox"/> food: at least a three-day supply of non-perishable food with a flip-top opener or add a can-opener if adding canned food <input type="checkbox"/> medications: a three-day supply of key medications and/or a list of current medications <input type="checkbox"/> eyeglasses (extra pair), hearing aid batteries <input type="checkbox"/> blanket <input type="checkbox"/> cash - \$20 (in small bills) <input type="checkbox"/> garbage bags for personal sanitation <input type="checkbox"/> activity for the Veteran (examples: puzzle, family photos) 	<p style="background-color: #e91e63; color: white; padding: 2px;">Caring for your disaster kits</p> <ul style="list-style-type: none"> • Review every year or when changes occur. • Check the expiration dates of your supplies; replace items as needed. • Replace your medication list with a new list whenever there are changes. • If you are keeping a three-day supply of medications, be sure they have not expired. • Keep your emergency contact information up to date.

★ ★ ★

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TIPS FOR SENIORS

Before an Earthquake

- ⓪ Eliminate hazards. Make it as easy as possible to get under a sturdy table or desk for protection.
- ⓪ Secure special equipment such as telephones and tanks of oxygen.
- ⓪ Keep a list of medications, allergies, special equipment, names and numbers of doctors, pharmacists and family members. Make sure you have the list with you at all times.
- ⓪ Keep an extra pair of eyeglasses and medication with your emergency supplies
- ⓪ Keep walking aids near you at all times. Have extra walking aids in different rooms of the house.
- ⓪ Put a security light in each room. These lights plug into any outlet and light up automatically if power goes out. They operate for four to six hours and your can turn them off by hand.
- ⓪ Make sure you have a whistle to signal for help

- ⓪ Keep extra batteries for hearing aids with your emergency supplies. Remember to replace them annually.
- ⓪ Keep extra emergency supplies at your bedside
- ⓪ Find two people to check on you after an earthquake. Tell them your special needs, how to operate equipment you use and where you keep emergency supplies.
- ⓪ Prepare to be self sufficient for three days

During & After an Earthquake

- ⓪ If you are in bed or sitting down, do not get up
- ⓪ If you are standing, duck and cover or sit down. You could be thrown to the floor if you are standing.
- ⓪ Turn on your portable radio for instructions and news reports. For your safety, cooperate fully with public safety officials and instructions.
- ⓪ Prepare for aftershocks by staying in a safe location
- ⓪ If you evacuate, leave a message at your home telling family members and others where you can be found

For information and assistance in your area call 1-800-510-2020

Last Updated: November 2010

Figure 1. Disaster kit information insert, front/back.

ponents of each of the 2 kits; the caregiver kit contained more supplies and documentation than the veterans' kit did. The committee sought to minimize burden and limit veteran and caregiver information overload by limiting information to the 1-page, 2-sided information insert and 1 informational CD developed by the American Public Health Association, summarizing the importance of disaster preparedness. Written information was designed to maximize readability and was aimed at a 5th- to 6th-grade reading level.

VETERANS' AND FAMILIES' INVOLVEMENT IN THE PLANNING

With input from the VAPAHCS director of performance improvement, the committee developed a

simple survey to query patients and caregivers about what they considered important supplies in a disaster kit. The survey was deployed in the GRECC Team Clinic as well as in HBPC patient/caregiver populations in November 2010. A total of 16 patients and family caregivers were interviewed. The survey responses included veteran/caregiver recommendations such as first-aid kits, water and food, hand sanitizer, emergency contact information, games, and writing supplies. Responses confirmed the disaster kit item selection endorsed by the committee.

KIT DEVELOPMENT

The committee spent considerable time discussing the rationale for inclusion of VA-provided supplies for

the kits, differentiating between essential and secondary items needed for veterans and caregivers. Several components were not included in the kits, because of safety concerns expressed by committee members; these concerns included unintended ingestion or self-injury hazards for veterans with dementia, involving alcohol-based hand sanitizer liquids (sanitizer wipes were substituted) and other ingestible supplies and hand tools.

THE DISASTER PREPAREDNESS SURVEY

One of the goals of the project was to enhance the awareness and knowledge of caregivers about key elements of disaster preparedness and response. Another goal was to trans-

Caregiver Disaster Preparedness Survey

Please circle Yes, No, or Don't know for each of the following questions:

1. It is important to prepare in advance in case a disaster (such as an earthquake, fire, flood, etc) occurs near my home/neighborhood.
Yes No Don't know
2. Have written name(s) and phone number(s) for our neighbor(s) in case of an emergency.
Yes No Don't know
3. I have written name(s) and a phone number(s) for our family members in case of an emergency.
Yes No Don't know
4. I have a disaster kit ready in our home and available for use for myself/veteran if needed.
Yes No Don't know
5. Home disaster kits should have a 3-day supply of food, water, medications, and other supplies.
Yes No Don't know
6. Having a photo of the veteran in the home disaster kit is important.
Yes No Don't know
7. Please check (✓) all items in the following list that should go in a home disaster kit:

<input type="checkbox"/> A list of current medications	<input type="checkbox"/> Sanitation supplies/plastic trash bags
<input type="checkbox"/> At least a 3-day supply of medications	<input type="checkbox"/> Hand sanitizer
<input type="checkbox"/> Whistle to call for help	<input type="checkbox"/> Recent photo of veteran
<input type="checkbox"/> Hearing-aid batteries	<input type="checkbox"/> Flashing reflector light
<input type="checkbox"/> Notepad and pen	<input type="checkbox"/> First-aid kit
<input type="checkbox"/> Crank radio/crank flashlight	<input type="checkbox"/> Face mask/latex gloves
8. In an emergency, people with dementia can become agitated. Please check (✓) all the actions in the following list that may help calm a person with dementia:
 - Watch for signs that the person may be overwhelmed, such as fidgeting, pacing
 - Reassure the person by holding hands/putting arm on his/her shoulder
 - Tell person that things are going to be fine
 - If possible, move the person to a safer, quieter place
 - Redirect the person's attention if she or he becomes upset
 - Make sure that the person takes medications as scheduled
 - Provide information using brief explanations and concrete terms
9. Please rate your level of preparation for a disaster at this time (circle only 1 answer).

Not at all prepared	Somewhat prepared	Prepared	Well prepared	Very well prepared
1	2	3	4	5

Source: VAPAHCS Disaster Kit Planning Committee, 12/2010.

fer important knowledge to caregivers about behavioral management strategies for patients with dementia, which would enable caregivers to reduce theirs and their patients' stress during and after a disaster. Preparedness instruction specific to behavior management of patients with dementia is often limited or nonexistent in educational material targeted to older adults. To address this gap, the project offered an opportunity to target educational interventions to current VAPAHCS patients with dementia and their caregivers. Veterans with confirmed clinical diagnoses of dementia were identified in HBPC, GRECC clinics, and Adult Day Health. In this process, > 250 veterans were identified along with 278 primary caregivers, mostly family. Caregivers were contacted in person or by letter and asked to participate in the survey process and disaster kit intervention. Veterans were asked to participate in the pilot if no primary caregiver was identified.

As part of the PDSA model, an assessment of caregivers' knowledge regarding disaster planning and response was considered to be a core component of the project. A 9-question English-language, self-report survey was developed by committee members and designed for a 6th- to 8th-grade reading ability, using the Flesch-Kincaid (Microsoft Word 2007) readability and reading level scales (Figure 2). The committee selected a pre- and posteducation test survey design to quantify caregivers' disaster preparedness awareness and knowledge, hypothesizing that caregivers' awareness and knowledge would significantly increase 3 months after receiving the disaster education and kits. The committee concluded that mailing the survey would be the most practical and efficient method of distribution in the

Figure 2. Disaster Preparedness Survey.

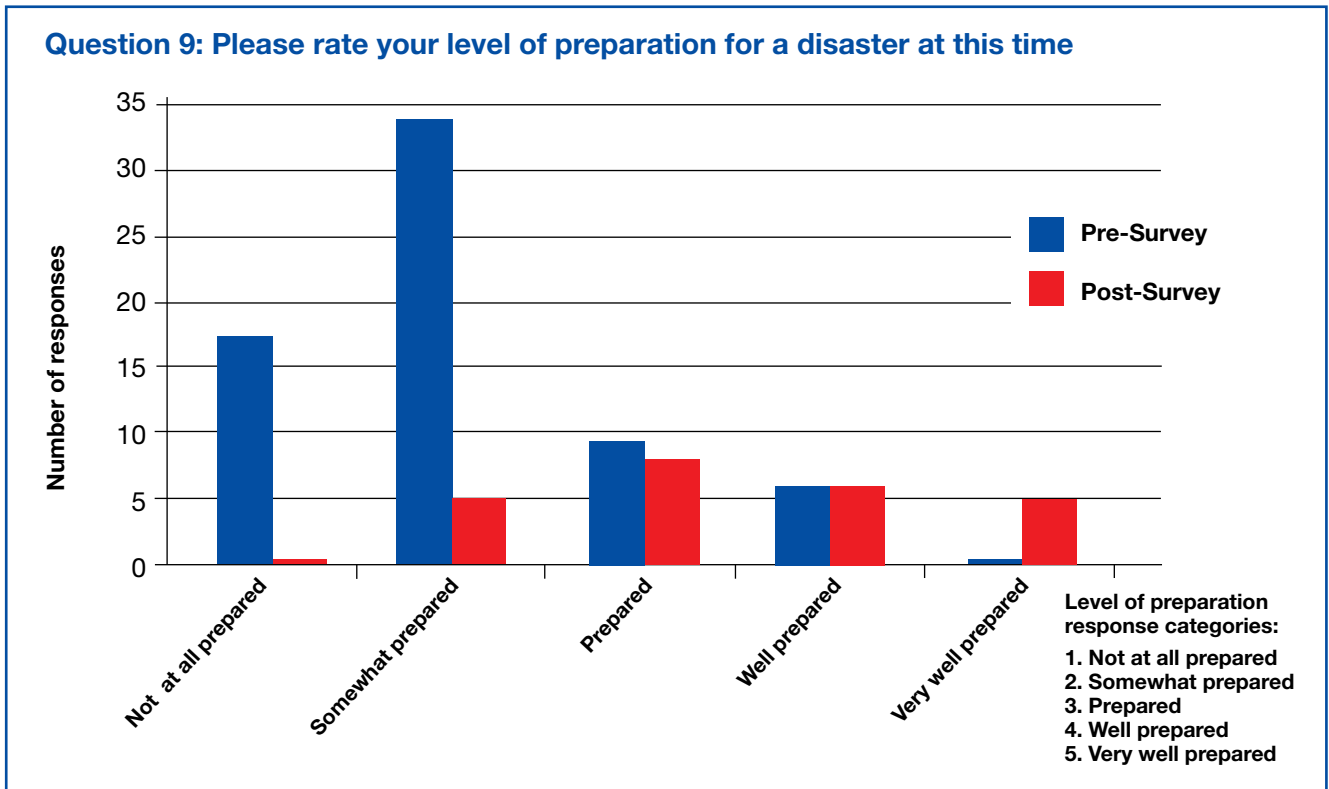


Figure 3. Disaster Intervention Pilot: Pre- and postintervention survey response results.

pre- and postintervention survey waves. Caregivers received the first self-report surveys to complete before they received the disaster preparedness information, and they received a second survey within 3 months after they received the disaster kit and educational material. Response data were coded and analyzed to quantify participants' awareness and knowledge at baseline and following preparedness education.

SURVEY RESULTS

Preintervention surveys were mailed to 278 caregivers (or veteran if no primary caregiver) in May 2011 (26% response rate, $n = 71$); the postintervention surveys were distributed in September 2011 (31% response rate, $n = 45$). Fewer respondents submitted postintervention surveys due to institutionalization, death, or

disability in the veteran or caregiver populations. Many of the surveys included notes of appreciation for the project from caregivers. Three-fourths of the pre- and postintervention surveys were completed by caregivers; the remaining were completed by veterans or nonprimary caregiver family members.

Preintervention, more than two-thirds of the respondents (68%, $n = 48$) reported not having a disaster kit, while 97% agreed ($n = 70$) that disaster preparation is important. A higher percentage of respondents reported having family emergency contact information than having neighbor emergency contact information (85%, $n = 60$ vs 66%, $n = 47$). Thirty-three percent (33%, $n = 23$) reported not having neighbor emergency contact information. Ninety-one percent of respon-

dents ($n = 64$) agreed that a 3+ day supply of food and water should be in home disaster kits; another 4% of respondents ($n = 3$) responded "Don't know" to this question.

When asked to rate their level of preparation for a disaster, 26% of respondents ($n = 17$) indicated that they were *Not at all prepared* for a disaster, and another 51% ($n = 34$) indicated that they were *Somewhat prepared*. Fourteen percent ($n = 9$) reported being *Prepared* for a disaster, and 9% ($n = 6$) reported being *Well prepared*. No respondents reported being *Very well prepared* (Figure 3).

The preintervention survey results revealed the opportunity for increasing caregivers' disaster preparation through the disaster kit distribution intervention, which included education related to including updated medication lists, veteran identifica-

tion documents, storage/updating of emergency supplies, and obtaining and preserving family and neighbor contact information.

Postintervention survey results (45/124, 36% response) indicated an expected shift in the respondents' disaster preparedness knowledge of key disaster preparation elements and perceived preparation and validated the expected impact of the educational intervention. Seventy-nine percent of 24 respondents (n = 19) reported that they were *Prepared*, *Well prepared*, or *Very well prepared* for a disaster; 21% reported that they were *Somewhat prepared* with none reporting *Not at all prepared* (Figure 3). Respondents also indicated an increase in documentation of emergency contact information for family (84% pre- vs 93% postintervention) and neighbors (66% pre- vs 93% postintervention). Respondents reporting having a photo of the veteran available for reference in an emergency increased from 75% preintervention to 97% postintervention.

Conclusion

Preintervention, few veterans with dementia or caregivers reported that they were fully prepared for a disaster. Postintervention, respondents reported much-improved disaster preparation. Disaster preparedness in a vulnerable veteran and caregiver population calls for anticipatory guidance and structured support such as that offered in this pilot.

SUSTAINABILITY

Project planning included the identification of long-term funding sources for the disaster preparedness education program expenses (outreach, education, and evaluation). A separate

process for identifying short-term funding for the initial purchase of 555 bags and the prescribed baseline supplies for veterans with dementia and their caregivers was conducted as well. Direct supply costs for the distributed 555 kits approximated \$25 per kit. Direct and indirect staff time for the project was estimated at 16 hours per month for the first 6 months and 20 hours per month for the subsequent 6 months of the project. To fund the direct costs, the committee sought and obtained donations totaling \$4,000 from veterans' service organizations and a local Internet entrepreneur supportive of veterans' organizations. The VAPAHCS GRECC, Adult Day Health Care, HBPC, and Palliative Care programs together allocated \$9,700 to the disaster kit project.

IMPLICATIONS FOR THE VHA

The demand for support services for community-dwelling older adults with dementia is surging. Within the next 50 years, the prevalence of all forms of dementia is expected to double in persons aged 75 to 85 years and quadruple in those aged ≥ 85 years.⁷ The estimated lifetime risk of dementia is 33% for women and 20% for men.^{8,9} The implications of growth in the dementia population are clear: Equipping veterans and caregivers with information and tools that they will need to manage community disasters will enable them to better respond to the disaster-related stresses and challenges that they may experience in their communities. ●

Author disclosures

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