2013 WEBINAR SERIES
STATE OF THE SCIENCE:
DEMENTIA EVALUATION AND MANAGEMENT
AMONG DIVERSE OLDER ADULTS AND THEIR
FAMILIES

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American Geriatrics Society, California Area Health Education Centers,
& Community Health Partnership

April 18, 2013

GERIATRIC EMERGENCY PREPAREDNESS AND RESPONSE (GEPR) WEBINAR SERIES
SESSION ONE
DEMENTIA AND PREPAREDNESS PLANNING FOR ETHNIC ELDERS AND CAREGIVERS

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April 18, 2013

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“Dementia and Preparedness Planning for Ethnic Elders and Caregiver”

Melen McBride, PhD, RN, FGSA

Dr. Melen McBride, Associate Director, Emerita, and Ethnogeriatric Clinical Nurse Specialist at Stanford Geriatric Education Center (SGEC), School of Medicine, Stanford University, Palo Alto, CA. She has over two decades of experience in ethnogeriatrics, using Internet technology. She designed the Cohort Historical Analysis Tool (CHAT) currently used in graduate psychology and nursing programs and has published in these areas. She provides leadership (since 2001) to infuse ethnogeriatrics into inter-professional emergency preparedness training of health professionals through the Geriatric Emergency Preparedness Response (GEPR) Collaborative of six HRSA funded GECs, one of which is SGEC, and co-coordinates the SGEC Faculty Development Program in Ethnogeriatrics and Health Literacy.

National Association of Geriatric Education Centers Initiative
Geriatric Emergency Preparedness, Response (GEPR) Collaborative

- 2001-02: National Association of Geriatric Education Center (NAGEC) surveyed GECs; presented position statement to HRSA on the need for geriatric emergency preparedness training
- 2004—now: HRSA funded 6 GECs (CA, KY, MD, NY, OH, TX), initially called the Bioterrorism Emergency Preparedness in Aging (BTEPA), developed inter-professional training for health professionals; continues its work today as the GEPR Collaborative ~ Consortium of NYGEC, Ohio Valley Appalachia Regional GEC, University of Kentucky, Saint Louis University Gateway GEC of MO & ILL, Stanford GEC, Stanford University, Texas Consortium GEC, and University of New England, Maine GEC.
National Association of Geriatric Education Centers Initiative
Geriatric Emergency Preparedness, Response (GEPR) Collaborative

- **2010-2015**: GEPR committed to offer inter-professional geriatric preparedness programs through GECs HRSA funded educational activities.
- **2010-2015**: Three members of the Collaborative formed a national consortium to provide a Webinars Series on Geriatric Emergency Preparedness hosted by Stanford GEC. The Ohio Valley Appalachia Regional GEC, University of Kentucky, the University of New England, Maine GEC, and Stanford GEC has offered four session and will have two more this year and six others on various topics in geriatric preparedness through the SGEC/GEPR Webinar Series program.

National Consensus

When resources are stretched thin, the needs of vulnerable populations are left unmet in all phases of preparedness.

The Centers for Public Health Preparedness (CPHP), 2007 (http://www.cdc.gov/phpr/cphp/centers.htm)

Learning Objectives

- Identify risk factors that heighten the vulnerability of ethnic elders specific to the Hispanic/Latino American and Vietnamese American elders with dementia and relate these factors to preparedness planning.
- Differentiate the unique needs of Hispanic/Latino and Vietnamese elders with dementia and their caregivers that are important to developing a plan for disaster preparedness and recovery.
Learning Objectives (continued)

- Identify at least one helpful strategy in emergency preparedness planning and response that clinicians and service providers can adapt to increase safety and survival of the cognitive impaired ethnic elders and their caregivers during a disaster.
- Identify at least one gap in evidence-based, culturally appropriate services for preparedness planning and recovery specific to elders with dementia from Hispanic/Latino and Vietnamese communities.

Background

- 2007 CPHP Report on vulnerable populations.
- Vulnerability defined as "the inability to access and use the standard resources offered in disaster preparedness and planning, response, and recovery".
- Eight vulnerable populations: ethnic and racial communities, older adults, children, the disabled, mentally ill, rural communities, economically disadvantaged, and Spanish speaking populations.

Background

- 2012 CDC Guide "Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During All-Hazards Emergencies: A Cross-Sector Guide for States and Communities".
- "vulnerable older adults": require additional help in an emergency such as those with limited English proficiency (LEP)
- "at risk individuals": for persons who have major difficulty in accessing needed public health and medical services after an emergency event (Office of the Assistant Secretary for Preparedness and Response [ASPR])
- "four functional needs": CMIST, an acronym for Communication, Medical care, Independence, Supervision, and Transportation.
Background

- 2012 CDC Guide “Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During All-Hazards Emergencies: A Cross-Sector Guide for States and Communities”
- “special needs populations” populations with additional needs before, during, and after an event including but not limited to the CMIST functional areas (FEMA)
- “Individuals in need of additional response assistance may include those who have disabilities; who live in institutionalized settings; who are elderly; who are children; who are from diverse cultures; who have limited English proficiency or are non-English speaking; or who are transportation disadvantaged.” (FEMA)

Ethnogeriatrics Emergency Preparedness

The functional needs of ethnic elders who have dementia fall into almost all of these classifications of vulnerability.

There are many gaps in scientific knowledge about culturally appropriate geriatric preparedness for all-hazards emergencies.

Donna Benton, PhD

Dr. Donna Benton is assistant research professor at the University of Southern California, Davis School of Gerontology and Executive Director for the Caregivers Support Program based at USC. Her major research is on elder abuse and is widely published in this area. She works closely with the LA County Area Agency on Aging and the CA Commission on Aging.
Thuan D. Ong, MD, MPH

- Dr. Thuan D. Ong, Assistant Professor, Division of Gerontology and Geriatric Medicine, University of Washington is board certified in Internal Medicine and Geriatric Medicine. His teaching and supervisory responsibilities involved interns, residents, and fellows in internal medicine, geriatrics, and hospice care. His research activities involve the development of depression education resources for Vietnamese American older adults, assessment for hospice admissions and development of physician home visit program for internal medicine residents. Dr. Ong received the HRSA Geriatric Academic Career Award (2010-2015) and has completed in 2012, the SGEC Faculty Development Program in Ethnogeriatrics and Health Literacy.

Reference


Learning Objectives

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High Risk Populations During Disasters

- High risk populations (Enarson & Walsh 2007)
  - Older adults
  - Low-income
  - Low health-literacy
  - Persons with disabilities
  - Medically dependent
  - New immigrants and cultural minorities
  - Children and youth
- Many of these attributes cluster together hence exacerbating risk

Emergency Preparedness: Layers of Complexity

- Older adults
- Dementia
- Vietnamese Identity
- Emergency Preparedness
- Meaning and Process
  - Cultural
  - Community
  - Individual
Case Study: Hurricane Katrina, New Orleans, 2005

- Over half of evacuees seen in medical units were ≥65y/o.
- Of the approximately 1,200 who died
  - Nearly 75% were >60y/o
  - 50% were ≥75y/o


Predisposing Characteristics of Older Adults

- Chronic health conditions

Kario K et al. Increased coronary heart disease mortality after the Hanshin-Awaji earthquake among the older community on Awaji island. J Am Geriatr Soc 1997; 45: 610-13

General Characteristics of Older Adults That May Magnify Impact of Stressors (Disasters)

- Chronic health conditions
- Physical limitations
- Sensory impairment
- Fixed incomes
- Paucity of social support
- Age-related changes


General Characteristics of Older Adults That May Magnify Impact of Stressors (Disasters)

- Chronic health conditions
- Physical limitations
- Sensory impairment
- Fixed incomes
- Paucity of social support
- Age-related changes
- Cognitive impairment
Dementia and Impact on Emergency Preparedness

- Impact on emergency preparedness dependent on:
  - Disease severity
  - Primary residence

Functional Assessment Staging Tool (FAST)*

<table>
<thead>
<tr>
<th>Level</th>
<th>Stage</th>
<th>Assessment</th>
</tr>
</thead>
</table>
| Moderate-severe | MMSE = 10-9 | 6A: Improperly putting on clothes (requires assistance or doing).
| Severe     | MMSE = 0   | 7A: Speech limited to 3-6 different words or fewer during any day. |

*Score is highest consecutive level of disability.

Can Individuals with Dementia Remember Disasters?

- Kobe, Japan earthquake on January 17, 1995
- 7.2 magnitude, >6,300 deaths
- 51 subjects, mean age = 74y, MMSE = 17, ADAS = 26
- MRIs given after earthquake
- Semi structured interviews 2 months later

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Emotional Memory is Present in Individuals with Alzheimer's Disease

- Fear reinforces memory retention of an event.
- Experience of a catastrophe induces strong mental reactions.

![Graph showing memory retention and Alzheimer's disease severity](image)


Vietnamese Culture: Generalizations

- Beliefs:
  - Folk religion
  - Confucianism/Taoism
  - Buddhism
  - Catholicism/Christianity

Source: www.Lonelyplanet.com

Vietnamese Culture: Generalizations

- General Characteristics:
  - Diverse socioeconomic/education levels
  - Mostly monolingual, with regional dialects
  - Emphasis on filial piety
  - Trust in authority figures
  - Multiple traumas: physical, emotional, psychological

Source: www.Lonelyplanet.com
Vietnamese Culture and Dementia

- “Normal aging” (Braun et al. 1996)
- Stigma, shame, self-isolation (Braun et al. 1996) [Hinton et al. 2005]
  - Asian Americans (53%) endorsed “Alzheimer’s is a form of insanity more than Anglos (16%)” [Ayalon L & Arean PA. Int J Geriatr Psychiatry 2004; 19: 255-61]
  - “Loss of face” [Yang L. Singapore Medical Journal 2007]
- Cultural idioms
  - Confused, crazy, loss of intellect/mind

Vietnamese Explanatory Models of Dementia

Perceived Barriers to Mental Health Services Following a Disaster

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Barriers to mental health services among individuals in need of services following a disaster</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Did not believe they had a problem or that the problem was severe</td>
</tr>
<tr>
<td>2.</td>
<td>Lack of knowledge about where to obtain help or lack of available services</td>
</tr>
<tr>
<td>3.</td>
<td>Believing they can solve the problem on their own</td>
</tr>
<tr>
<td>4.</td>
<td>Concern about stigma associated with mental illness</td>
</tr>
<tr>
<td>5.</td>
<td>Problems with transportation and other problems accessing services</td>
</tr>
<tr>
<td>6.</td>
<td>Concerns about the cost of services</td>
</tr>
<tr>
<td>7.</td>
<td>Belief that treatment is ineffective</td>
</tr>
<tr>
<td>8.</td>
<td>Fear of treatment</td>
</tr>
<tr>
<td>9.</td>
<td>Do not have time to seek treatment</td>
</tr>
<tr>
<td>10.</td>
<td>Belief that others need services more than they</td>
</tr>
</tbody>
</table>

Older Vietnamese-Americans: Vietnam War

- Trauma & PTSD continue to affect mental health of displaced Vietnamese from the Vietnam War
  - 50% of Vietnamese compared to 19% of Australian-born population


Older Vietnamese-Americans and Cohort Analysis: Impact on Emergency Preparedness

<table>
<thead>
<tr>
<th>Years</th>
<th>Historical Events: Vietnamese American</th>
<th>Age</th>
<th>55-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>1970</td>
<td>1st wave: former elite South Vietnamese. 2nd wave: diverse cross section from unified Vietnam. 1979-80, 100K Vietnamese enter the U.S. 1975, 130K Vietnamese refugees to U.S. 1975-79 of Vietnam.</td>
<td>Adolescents &amp; Young Adults</td>
<td>Middle aged &amp; Young Old</td>
<td>Young old &amp; Old</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1980</td>
<td>Continued influx of immigrants. Immigration, 2nd wave, many after long periods in refugee camps. Increased diversification of population.</td>
<td>Young adults &amp; Middle aged</td>
<td>Middle aged &amp; Young Old</td>
<td>Young Old &amp; Old</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1990</td>
<td>↑ immigration of elders as “followers of children.” Stereotyped as freeloaders receiving special benefits. Victims of anti-refugee sentiments.</td>
<td>Young adults &amp; Middle aged</td>
<td>Middle aged &amp; Young Old</td>
<td>Young old &amp; Old</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Vietnamese Culture: Emergency Preparedness

- Impact – Frame of reference
  - Floods from typhoons
  - Earthquakes
  - Tsunamis
  - Superstitions
    - Belief or practice based on the operation of supernatural or magical forces
  - Fatalistic
  - Beliefs

[Ca VT & Nguyen ND. Tsunami risk along Vietnamese coast. J Water Resources Planning Engineering 2008; 134(1).]

Is The Threat Real?


Case Study: Hurricane Katrina, New Orleans, 2005

- 42% Vietnamese refugees and immigrants
- 1/3 living below poverty line
- 2nd forced displacement
- 7month post-Katrina structured interviews & self reported sociodemographic
  - Impact of Event Scale-Revised (IES-R)
  - SF36 version 2
  - History of Traumatic Event Exposure Scale
  - Perceived Social Support Scale


Vietnamese Americans & Hurricane Katrina

- Greater the impact of prior trauma, the poorer physical health
- Higher the financial hardship, the poorer mental health
- Less acculturated Vietnamese had greater PTSD symptoms and poorer physical health

Lessons Learned: Vietnamese Americans in Hurricane Katrina

- Low levels of PTSD
  - ‘it is harder leaving from your culture. Hurricane is nothing. In the hurricane, you have your family with you all the time.’
- Support came from family, friends, church
- Language proficiency an integral barrier to access
- Many evacuated with religious leaders
  - Proficient in Vietnamese & English language


Possible Needs of Frail Older Adults

- Functional impairments
  - Mobility
  - Sensory impairments
  - Environmental modifications
- Dietary needs
  - Dysphagia diets
  - Nutritional content
- Pre-existing medical conditions
  - Access to medications
  - Access to medical equipment (e.g., oxygen, catheters)
  - Access to medical records and contact information
- Update assessments annually
  - Enroll in MedicaAlert with those with cognitive impairment

Recommendations: Emergency Preparedness Planning for Frail Older Adults

- Hand-held two way radios for communication
- Assess and address the needs of older adults’ caregivers
  - Respite needs to fulfill other roles
- Urinary incontinence supplies
  - Adult pads
  - Gloves
  - Cleaning supplies
- Medications
  - Nutritiously balanced meals
  - Appropriately textured foods
  - Attention to sensory impairment
- Lanyard: Photo ID, primary language, medication list, medical problems, PMD, functional limitations, family/friend contacts
Conclusion

- Emergency preparedness requires understanding of
  - The individual
  - The community an individual lives in
  - Their beliefs and perception of threat

Donna Benton, Ph.D

Dr. Donna Benton is currently an assistant research professor of gerontology at the University of Southern California (USC) - Andrus Gerontology Center. She is Director for the Family Caregiver Support Program at USC Davis School of Gerontology. She works on issues related to caregivers, dementia and elder abuse.

Learning Objectives

- Participant will better understand the needs of Latino and African American caregivers for emergency preparation.
- Participant will be able to identify gaps in services for Latino and African American caregivers in their community.
Who is a caregiver?

- A caregiver is an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in helping someone with activities of daily living, and/or medical tasks and care.
- 65.7 million caregivers (29% of the U.S. adult population) provide care to someone who is ill, disabled or aged.
  - 43.5 million of adult family caregivers care for someone 50+ years of age

Caregivers at Home

- Caregivers perform medical & nursing tasks.
- Provided activities of daily living (ADL's) supports (e.g., personal hygiene, dressing/undressing, or getting in and out of bed) or
- Instrumental activities of daily living (IADL's) (e.g., taking prescribed medications, shopping for groceries, transportation or using technology) supports
- Combination of all of the above

Caregivers and Technology

- Caregivers are significantly more likely than other internet users to search for health information on behalf of the person they are helping.
- Caregivers under 50 are more likely to use caregiving technology.
- Racial and ethnic minorities 50+ are likely to rate technology as helpful (compared to non-minorities of same age)
- Caregivers more tech savvy, with most using cell phone and having internet access or seeking social support and medical information
**African American Caregivers**

- National study on caregivers suggest that African-American caregivers were on average older than their counterparts (48.0).
- More likely to be single or never married
- More than half of African-American caregivers find themselves "sandwiched" between caring for an older person, and a younger person under age 18
- Caring for more than one older person.
- More likely to live with the care recipient
- About 66 percent are employed full or part-time.

**Latino/Hispanic Caregivers**

- 12 percent of adults are family caregivers
- Latino/Hispanic caregivers more likely to rate their health as fair or poor compared to others
- Need family focused interventions
- Language appropriate materials

**What would you suggest?**

- A 58 year old Latina is caring for her mother with dementia. The caregiver works part-time from 9-1pm. The caregiver lives with her mother, who still is able to walk but often forgets to turn off the stove if she cooks. The mother also answers the phone but does not always remember who called.
- The daughter want to make an emergency plan, what would you suggest?
Disaster Preparedness Class for Caregivers

- Three telephone conference calls
  - All in English but one presenter able to present in Spanish
- Used materials from LA City Area Agency on Aging
- Provided caregiver focused tips for preparation
- Evaluation: simple survey asking pre and post call knowledge and planning for emergencies

Examples for Caregiver Focused C.A.L.M.®

- Have ICE* that includes that you are Caregiver
- Dual registration of self and care receiver
- More focus on medication and special diet needs in kits
- Have local emergency responders (fire fighters) know about the caregiving situation
- Have easy access to medical information by family and friends who are caregivers?
- Anticipate changes in cognition during an emergency

Evaluation Results: Pre-Post Survey

- There were 23 caregivers on three Preparedness phone calls.
  - 20% were Latino, 80% English (African American and non-minority)
  - 40% returned the evaluation of 4 questions
- Evaluation asked
  - Do you feel better prepared, did you know less pre talk, can you develop a plan, can you talk to others
  - 100% of those surveys (English and Spanish) agreed that they were more prepared, knew less pre than post, can make a plan and are better able to talk with others.
- This was a selective, very quick survey but suggest it is a good topic for caregivers.
Practice Tips for Care Professionals

- Work with local emergency responders to collaborate on adding content or a power point slide specific to diverse ethnic caregivers and other caregivers
- Have presentations available for limited English speakers
- Use low-tech information access like phone and local talks

http://www.deep.med.miami.edu/x21.xml

- “Disaster Preparedness Guide: Plan, Prepare, Practice, Protect”; “Cuando el Desastre LLega, estas preparado? Preparando a la familia ante un Desastre”
  A comprehensive guide to preparing one’s self and their family for a disaster written fully in Spanish. Includes various checklists for what materials to have during a disaster, emergency contacts for Broward and Miami regions, and what one should know after the disaster occurs. The guide is completely free and downloadable.

Resources: Spanish and English

- Just in Case: Emergency Preparedness for Older Adults and Caregivers
  This 12-page fact sheet provides step-by-step information on how older adults should prepare for a disaster/emergency. It includes helpful checklists, contact lists, and a medication list that can be filled in.
  - http://aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/docs/SpanishDisasterReadiness.pdf, Spanish
  - http://aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/docs/Just_in_Case030706_links.pdf, English

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Resources: Spanish and Other Languages

- http://www.healthyroadsmedia.org/topics/emergencies.htm has audios and videos on preparedness topics.
- National Resource Center on Diversity Preparedness, a clearinghouse of information on emergency preparedness in culturally diverse communities.
  - http://www.diversitypreparedness.org/
  - http://www.diversitypreparedness.org/Resources/23/resourceTypeID=7782/

References

- Fact Sheet: Selected Caregiver Statistics Family Caregiver Alliance with funding provided by the Administration on Aging (AoA). Copyright © 2012 Family Caregiver Alliance. All rights reserved.
- Home Alone: Family Caregivers Providing Complex Chronic Care, AARP with United Health Hospital Fund October 2012
  - http://aging.lacity.org/emergency-preparedness/

References

- Pew Research Center’s Internet & American Life Project, Family Caregivers Online, July 2012. Caregivers in the U.S.
- Pew Research Center’s Pew Internet & American Life Project: Family Caregivers Online: The Internet is an Integral Part of the Lives of People who Care for Loved Ones, July 2012
Q & A

- We now have some time to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, we would like to ask each of the participants to answer the short evaluation questionnaire.

Final Question
Thank You for Participating!

Reminder: Please complete our short survey. We appreciate your feedback.

NOTE: Continuing Education Participants must complete a final survey in order to receive CEU/CME credit.