LESSON 4-1
WORKING WITH CAREGIVERS
Lesson: Working with Caregivers

Authors: Carlo Rossi MDCM MTM&H CCFP
Major, Canadian Armed Forces
Royal Canadian Medical Service (RCMS)
Uniformed Services University of the Health Sciences (USUHS)

Brian A. Altman, PhD
Education Director, HJF
National Center for Disaster Medicine and Public Health (NCDMPH)
Uniformed Services University of the Health Sciences (USUHS)

Kelly Gulley
Project Coordinator, HJF
National Center for Disaster Medicine and Public Health (NCDMPH)
Uniformed Services University of the Health Sciences (USUHS)

Kenneth Schor, DO, MPH, FAAFP
Acting Director
National Center for Disaster Medicine and Public Health (NCDMPH)
Uniformed Services University of the Health Sciences (USUHS)

Intended Audience of Learners
A broad range of health professionals who may work with the older adult population.

Competencies
This lesson supports learning related to the following competencies, with regard to working with caregivers:


Core Competency 1.0 “Demonstrate personal and family preparedness for disasters and public health emergencies.”
Subcompetency 1.1 “Prepare a personal/family disaster plan.”
Subcompetency 1.2 “Gather disaster supplies/equipment consistent with personal/family plan.”
Subcompetency 1.3 “Practice one’s personal/family disaster plan annually.”
Subcompetency 1.4 “Describe methods for enhancing personal resilience, including physical and mental health and well-being, as part of disaster preparation and planning.

Subcompetency 2.2 “Prepare a personal professional disaster plan consistent with one’s overall agency, organizational, and/or jurisdictional plan.”

Core Competency 3.0 “Demonstrate situational awareness of actual/potential health hazards before, during, and after a disaster or public health emergency.”

Subcompetency 4.1 “Identify authoritative sources for information in a disaster or public health emergency.”
Subcompetency 4.3 “Identify strategies for appropriate sharing of information in a disaster or public health emergency.”

Core Competency 5.0 “Demonstrate knowledge of personal safety measures that can be implemented in a disaster or public health emergency.”
   Subcompetency 5.1 “Explain general health, safety, and security risks associated with disasters and public health emergencies.”
   Subcompetency 5.2 “Describe risk reduction measures that can be implemented to mitigate or prevent hazardous exposures in a disaster or public health emergency.”

Subcompetency 7.1 “Discuss common physical and mental health consequences for all ages and populations affected by a disaster or public health emergency.”

Core Competency 8.0 “Demonstrate knowledge of public health principles and practices for the management of all ages and populations affected by disasters and public health emergencies.”
   Subcompetency 8.1 “Discuss public health consequences frequently seen in disasters and public health emergencies.”
   Subcompetency 8.2 “Identify all ages and populations with functional and access needs who may be more vulnerable to adverse health effects in a disaster or public health emergency.”
   Subcompetency 8.3 “Identify strategies to address functional and access needs to mitigate adverse health effects of disasters and public health emergencies.”
Subcompetency 8.4 “Describe common public health interventions to protect the health of all ages and populations affected by a disaster or public health emergency.”

Subcompetency 10.1 “Describe legal and regulatory issues likely to be encountered in disasters and public health emergencies.”
Subcompetency 10.2 “Describe legal issues and challenges associated with crisis standards of care in a disaster or public health emergency.”

Core Competency 11.0 “Demonstrate knowledge of short- and long-term considerations for recovery of all ages, populations, and communities affected by a disaster or public health emergency.”
   Subcompetency 11.1 “Describe clinical considerations for the recovery of all ages and populations affected by a disaster or public health emergency.”
   Subcompetency 11.2 “Discuss public health considerations for the recovery of all ages and populations affected by a disaster or public health emergency.”
   Subcompetency 11.3 “Identify strategies for increasing the resilience of individuals and communities affected by a disaster or public health emergency.”
   Subcompetency 11.4 “Discuss the importance of monitoring the mental and physical health impacts of disasters and public health emergencies on responders and their families.”

Learning Objectives
At the end of this lesson, the learner will be able to:
4-1.1 List the types of potential caregivers for older adults and their roles in the day-to-day context.
4-1.2 Apply clinical, psychological, and social considerations for preparedness and mitigation to the context of older adults and their caregivers.
4-1.3 Describe at least 3 unique impacts of disasters on the caregiver and care recipient relationship and offer strategies for addressing them in the post-disaster setting.

Estimated Time to Complete This Lesson
120 minutes

Content Outline
4-1.1: Health care professionals and elderly adult caregiver competency in disaster planning
   I. For the purposes of this lesson, a caregiver (CG) is defined as any person who has accepted the responsibility of helping older adults who are living in the community to
Caring for Older Adults in Disasters: A Curriculum for Health Professionals
Module 4: Caring for older adult populations during the disaster cycle
Lesson 4-1: Working with caregivers

continue to do so.¹ This definition includes any person who regularly looks after an
older adult and provides some level of assistance or protection (Table 1). Healthcare
professionals should be conscious of the fact that an individual patient’s situation may
involve several persons fulfilling different types of caregiving roles. Identifying who is
providing which caregiving service(s) and actively engaging them is critical to ensure
that all stakeholders are included in planning initiatives.

Table 1: Types of Caregivers.

| Informal: spouse, immediate family, extended family, friends or neighbors |
| Formal: home helpers, personal care aides, homemakers, companions |
| Health Professionals: certified nurse’s aides, home health aides, nurses, physical
  therapists, occupational therapists, speech therapists, social workers |

Adapted from the National Care Planning Council’s Caregiver’s Handbook.²

II. CGs are common in the United States; in fact, the majority of elderly Americans
report they receive some level of assistance from a CG.³ The scope of this care and
the intensity of the support provided may be substantial. The National Alliance for
Caregiving reports that the average CG spends over 20 hours a week providing care.⁴
Generally, these are not short-term commitments. The average length of care
provided by a CG is 4.6 years but can be much longer among select groups (e.g., one-third
of CGs to veterans report providing care for more than 10 years).⁵

a. CGs often accept the responsibility of helping care recipients perform complex
medical and technical tasks. The dynamics of these shared-responsibility care
models may become more difficult as care recipients become increasingly
dependent on their CGs as their medical situation deteriorates. Research
suggests that as task complexity increases, CGs benefit from explicit
instruction on how to best perform their role and ensure favorable outcomes
for care recipients.³

b. More than 4 out of every 5 self-identified CGs do not feel sufficiently trained to
provide the level of technical skill required or perceive that they are not
sufficiently connected to the community services they are expected to
arrange.⁶ When CGs feel they lack the competency to perform a required task,
the majority turn either to Internet resources or to their health care
professionals as sources of additional information.⁷ Over 60% of CGs reported
specifically asking for additional information from a physician and identified
that resources for “helping older adults deal with life-changing events” are
generally lacking.⁸ Health care professionals should leverage their positions as
primary sources of information for CGs to encourage this preparedness dialogue throughout the disaster cycle.

III. A review of the literature suggests that active support and assistance provided by health care professionals to CGs is associated with an improved ability to meet the needs of care recipients. Effective information sharing about disaster preparedness is likely to independently benefit both the care recipient and the CG. In fact, providing accurate and timely information has been shown to decrease CG stress responses in the event of a crisis and is associated with CGs making better personal health-related behavior choices.

a. In order to provide such information, health care professionals must have an appreciation for the types of disasters that might affect their communities as well as the potential impact of these events on elderly adults. An older adult’s vulnerability to disasters (inability to withstand the effects of an uncertain and often hostile environment) depends on the complex interactions of the physical environment with individual clinical, psychological, and social considerations. These interactions will be the focus of other sections of this lesson. On a basic level, however, health care professionals must recognize that all disasters disproportionately affect elderly adults—especially those with medical or mobility concerns and those who require specialized assistance.

b. Health care professionals should be familiar with which types of disasters are most likely in their specific geographic location to ensure that the preparedness recommendations they provide to CGs is relevant. The Disaster Assistance Improvement Program with the Federal Emergency Management Agency (FEMA) as its managing partner, lists 15 categories of disasters that health care professionals should familiarize themselves with and prioritize planning initiatives to those events with the highest likelihood of occurrence. Providing CGs with useful disaster-preparedness information relevant to their place of residence can certainly be considered an additional resource for “helping older adults deal with life-changing events.”

IV. Health care professionals must acknowledge that involving CGs in disaster planning may differ from engaging them in other aspects of support required by elderly adults. This is because accepting the responsibility of assisting with disaster planning implies a willingness to balance a CG’s own personal obligations during a disaster (which may be significant) with the needs of care recipients during a disaster. Determining if this is feasible for an individual CG-care recipient dyad may be difficult. Health care
professionals should assess the level of CG engagement with their individual patients before engaging in a discussion about involving the CG in disaster planning.\textsuperscript{13}

a. Directly asking elderly patients to identify their primary CGs may be an appropriate first question to help assess engagement.\textsuperscript{14} Determining the actual level of engagement, however, may be more nuanced than simply determining who the primary CG is. One potential method to acquire additional information about the CG-patient relationship is to pay close attention to the CG’s interactions with the older adult during a formal encounter. A recent systematic review that examined the nature of these interactions reported that the majority of CGs will function as “decision-making aids,” but the manner in which this assistance is provided may vary.\textsuperscript{15} Table 2 provides a selection of contextual questions that might assist a health care professional in assessing the level of CG engagement.

Table 2: Contextual questions to assist in determining CG engagement.

<table>
<thead>
<tr>
<th>Contextual Questions</th>
<th>Potential Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who initiated the CG’s participation?</td>
<td>The patient.</td>
</tr>
<tr>
<td></td>
<td>The clinician.</td>
</tr>
<tr>
<td></td>
<td>The CG himself or herself.</td>
</tr>
<tr>
<td>What type of information is the CG providing?</td>
<td>Small talk only.</td>
</tr>
<tr>
<td></td>
<td>Clarification of patient responses/provides counter observations.</td>
</tr>
<tr>
<td></td>
<td>Information about the patient’s values/preferences.</td>
</tr>
<tr>
<td>How did the CG assist in decision-making?</td>
<td>Did not assist.</td>
</tr>
<tr>
<td></td>
<td>Exerted pressure.</td>
</tr>
<tr>
<td></td>
<td>Offered support/provided advice.</td>
</tr>
</tbody>
</table>

Adapted from Boehmer et al.\textsuperscript{13}

b. Identifying engaged CGs will facilitate shared disaster planning decision making between elderly adults and their health care professionals.\textsuperscript{16} Knowledge of the CGs role in the patient’s life may help shape the clinical conversation and ensure that decisions made truly reflect patients’ personal values.\textsuperscript{17}

V. In this section, we defined CGs and highlighted the services they provide to elderly adults, a subset of the American population especially vulnerable to disasters. We discussed how the majority of CGs receive little formal support or education on how to best care for elderly adults and that this can impact the quality of care provided.\textsuperscript{18} Health care professionals are ideally suited to provide CGs information
about disaster planning, because the majority of CGs believe health care professionals to be reliable and accurate sources of information. We reviewed the importance of providing disaster preparedness information relevant to individual geographical risk profiles and suggested basic methods to help to identify engaged CGs that may be more likely to actively participate in disaster planning. Section 4-1.2 will discuss specific recommendations that health care professionals may make to CGs to assist them with preparedness initiatives applicable to the pre-disaster phase.

4-1.2: Assisting CGs with Pre-Disaster Planning

I. In the previous section we defined who CGs are and highlighted some of the services they help provide to elderly adults. We reviewed that CGs receive little formal education on how to best care for elderly adults, including how to prepare for disasters, and that this can impact the quality of care provided.\(^{18}\) In this section (4.1-2) we will focus on specific pre-disaster recommendations that can be provided by health care professionals to CGs in order to facilitate preparedness initiatives for older adults.

II. The intimate nature of the CG-care recipient relationship discussed in the previous section translates into CGs being well positioned to help health care professionals assess the clinical, psychological, and social considerations that can make older adults particularly vulnerable to disasters.\(^{19}\) For a detailed discussion of how preexisting conditions can influence the vulnerability of elderly adults to disasters, readers are directed to review Module 2: “Conditions present in the older adult population that impact their disaster preparedness, response, and recovery.”

a. For the purposes of this lesson, health care professionals should be aware that this increased vulnerability is compounded by the tendency for older adults to be suboptimally prepared for disasters. In the Health and Retirement Study, for example, only one-third of older adults (mean age 70 +/- 9.3y) had participated in an educational program or read reference materials about preparing for disasters.\(^{20}\)

b. In another analysis, data from the CDC’s Behavioral Risk Factor Surveillance System (BRFSS) revealed that adults most likely to be receiving CG services (fair/poor perceived health, activity limitations, three or more chronic diseases) were found to be significantly less likely to have completed disaster preparedness activities than their healthier counterparts.\(^{21}\) Health care professionals can help to bridge this preparedness gap by helping CGs understand the value of pre-disaster planning.
III. In this section, *pre-disaster planning* encompasses all actions undertaken before a disaster strikes that have the intended goal of improving an older adult’s resilience to a disaster.\(^\text{22}\) Evidence shows that inadequate pre-disaster planning, when combined with the increased baseline vulnerability of geriatric populations, may lead to poorer health outcomes post-disaster. As an example, consider that after Hurricane Katrina, the inability to provide medications (a surrogate marker for co-morbid medical complexity compounded by planning deficiencies) was identified as the key obstacle to continuity of medical care for older adults.\(^\text{23}\) Health care professionals should also be aware that a lack of pre-disaster planning has been associated with deterioration of acute health status in older adults after a disaster.\(^\text{24}\)

IV. The reality of these increasing demands on finite CG resources is that CGs must prioritize the needs of their care recipients. Recommendations to tackle preparedness tasks (to include pre-disaster planning) may be assigned a lower priority than other day-to-day issues, particularly if the risk of a disaster is perceived to be remote.\(^\text{25}\) Health care professionals can help to address the perception that disasters “won’t happen to me” by providing CGs and care recipients specific, relevant, and timely information about the true risk of disasters given their specific regional context and probabilities. Discussing preparedness across the wide spectrum of repeated interactions between CGs, care recipients, and their health care professionals may help to reinforce the importance of planning. Health care professionals seeking further information may refer to the content of Module 3: “Disaster types: Special considerations for the older adult population in disasters.”.

V. While the day-to-day demands on CGs can be seen as an obstacle to pre-disaster planning, the nature of the CG-care recipient relationship also presents an opportunity for more effective preparedness. By leveraging a CG’s intimate knowledge about the elderly adults they assist, health care professionals can shift from a “one-size-fits-all” paradigm of preparedness and advocate for initiatives tailored to the specific needs of individual older adults. In this way, preparedness is less of a top-down exercise in medical paternalism and becomes more of a cooperative process incorporating the views, attitudes, and beliefs of older adults to the fullest extent possible. A model for thinking about the individual clinical, psychological, and social considerations involved in creating person-specific pre-disaster plans is provided for health care professionals in Table 3. This table approaches CG preparedness by broadly addressing the clinical, psychological, and social domains in 2 of the 4 disaster management phases—preparedness and mitigation.
Table 3: Matrix to assist health care professionals in engaging CGs of older adults in pre-disaster preparedness activities.

<table>
<thead>
<tr>
<th>Preparedness</th>
<th>Mitigation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical</strong></td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Physical/mental health needs.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Mitigation</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Dependency on medical devices.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Need for personal assistance services.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Mobility limitations.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Use of service animals.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
<tr>
<td>Communication difficulties.</td>
<td>Plan for transitions of care (create and regularly update medical problem lists, medication lists, allergy information, medical provider contact information, insurance information, etc). Plan for common disaster-associated conditions (e.g., hypo/hyper-thermia, minor trauma). Organize in-home improvements for mobility and emergency access (keep entrances clear). Have communication aid backups (hearing aids, visual aids, contact information for interpreters, etc).</td>
</tr>
</tbody>
</table>

VI. Selected examples of how health care professionals can address clinical, psychological, and social aspects of pre-disaster planning with CGs.
a. Optimizing transitions of care planning (clinical)
Health care professionals should be prepared to assist CGs with planning for transitions of care in the aftermath of a disaster. A key element of this preparation is to ensure that a comprehensive medical needs assessment (to include the required durable and consumable medical supplies) is conducted and updated regularly. Several checklist-type tools are available to help CGs with assessing the clinical baseline of older adults.\textsuperscript{26,27} Health care professionals may consider augmenting CG assessments with clear, concise, and current clinical information. Generally speaking, health care professionals may provide written medical information specific to an individual, directly to that individual, with the individual’s consent. Should a health care professional require further guidance, the Department of Health and Human Services HIPAA Decision Tool addresses the issue of maintaining appropriate levels of confidentiality in disaster settings, particularly when and to whom protected information can be disclosed.\textsuperscript{28} The tool can be found at the following website: http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/decisontoolintro.html.

b. Reducing stressors caused by disasters (psychological)
Disasters are stressful events for all survivors. Difficulties with understanding instructions or making themselves understood may exacerbate stress for older adults after a disaster. In nondisaster situations, CGs will often provide \textit{ad hoc} interpreter services or act as communication assistants for elderly adults to optimize interactions. In the context of a disaster, however, the communication assistance provided by CGs may not be immediately available. Assessing communication difficulties and taking concrete measures to address them (preplanning contacts who may provide some translating abilities, visual aids, extra hearing aids, etc) are therefore valuable strategies for reducing anxiety. In fact, FEMA suggests that health care providers who support preparedness efforts can minimize stress by establishing and testing predetermined key actions beforehand.\textsuperscript{29} One method health care providers can employ to help CGs establish and test key actions is to ask those CGs providing \textit{ad hoc} interpretive assistance what the contingency plan is for their care recipient in the event of an emergency and then provide CGs with appropriate community resources to engage with.

c. Using CGs to assess social isolation (social)
By virtue of their relationships with care recipients, CGs are key members of many older adults’ networks of social support and can help health care professionals assess the care recipient’s level of interaction with available community social
services. In many cases, older adults suffer from social isolation as adult children move away and medical or mobility issues progressively limit other social engagements. In the context of a disaster, social isolation can be a significant obstacle for receiving advance warning information about disasters and can reduce the ability of some older adults to ask for help after a disaster strikes. CGs may have additional strategies to contact long-distance relatives unknown to their health care professionals. Health care professionals can routinely ask the CGs they encounter about additional ways of contacting older adults’ loved ones in the event of a disaster. This information should be recorded in the medical record and added to emergency contact information. By establishing and exercising an effective communication plan and by helping CGs link older adults with available social services, health care professionals can actively assist with tailoring pre-disaster planning to the specific social situation of their patients.

d. In this section, we have reviewed how the unique CG-care recipient relationship can help to inform disaster preparedness initiatives when supported by health care professionals. Section 4.2: “Access and functional needs” will provide more specific information on the tools and resources that are available to help health care professionals and/or CGs conduct the needs assessments that are crucial to pre-disaster planning. We focused on how health care professionals can engage CGs to provide experience-informed perspectives on their care recipients to optimize pre-disaster planning and offered 3 concrete examples of how this might happen. The next section will concentrate on how health care professionals can work with CGs to maximize the effectiveness of the response and recovery phases of the post-disaster period.

4-1.3: Assisting CGs through the post-disaster period

I. In the previous section we reviewed how health care professionals might involve CGs who work with older adults across the spectrum of disaster preparedness. We provided concrete examples within a proposed clinical, psychological, and social preparedness matrix to assist health care professionals in engaging CGs in readiness activities. In this section, we shift our focus from the preparedness and mitigation phases of the disaster cycle to the post-disaster period.

II. Disasters can disrupt established habits and routines (e.g., timing of medication administration, substitution of medications owing to procurement challenges, not having a relationship of trust with temporary health care professionals, etc). In some
cases, disasters can trigger vulnerable older adults to be temporarily relocated into emergency shelters or other temporary living arrangements. This substitution of the familiar with the unfamiliar, the routine with the less well known, may lead to confusion, disorientation, and clinical deterioration.31

e. In the non-disaster setting, health care professionals may already be familiar with the isolation and disorientation experienced by some elderly adults who are brought to an unfamiliar medical clinic or emergency departments (ED). In an effort to minimize the challenges of these environments, some health care organizations have sponsored companion and temporary CG programs for older adults in the ED. One such program, the Care and Respect for Elders in Emergencies (CARE) volunteer initiative, was designed to improve the care of older adults with cognitive deficits and emotional distress in the ED. The program involves bedside interventions, conversation/companionship, and short activities and tools to assist in orienting older adults to their new surroundings.32 Although volunteer CGs are not familiar with their assigned patient’s medical issues, programs such as CARE have been shown to improve the experiences of older adults in emergency medical situations.

f. In a disaster context, CGs and health care providers should anticipate the impacts of unfamiliar settings on older adults and should not minimize their significance. This would be especially true for older adults who become separated from their primary CGs, and this separation may be long-lived. In some cases after Hurricane Katrina, care recipients were only reunited with their primary CGs after more than 6 months had elapsed from initial evacuation.33 Health care professionals should expect that in the aftermath of a disaster, CGs will be separated from the elderly adults they care for. There is insufficient evidence to discuss the effect of this separation on older adults. One group in whom this has been studied in the post-disaster context is the pediatric population. In this population, separation from primary CGs has been identified as a stronger predictor of persistent psychological distress than the extent of first-hand exposure to the disaster or trauma itself.34 One could postulate that the same may be true in elderly populations.

g. In light of the success of volunteer temporary CG programs like CARE, many volunteer and community organizations have committed to providing temporary volunteer caregiving services in the aftermath of a disaster. Health care professionals can assist in reducing the stress of CG separation by helping to engage these temporary CGs in the post-disaster period. Many citizens who have volunteered their time to assist older adults may have little experience
with how to provide care or assist with complex medical tasks. When contacted by emergency shelters providing care to elderly adults, health care professionals can advocate for just-in-time training programs that may improve the comfort levels for both volunteers and older adults.35

III. Health care professionals should also advocate for the maintenance of elderly adults’ confidentiality and dignity during assisted personal care, despite the reality of temporary shelters having few engineered protections for privacy.36 At every opportunity, health care professionals should share information on emergency contact information for older adults (including the contact information of their usual primary CGs). Reuniting older adults with loved ones and familiar care providers may help to improve health outcomes in this population. Health care professionals should be aware that some older adults with cognitive impairment may have relied upon their CGs to provide consent for medical procedures.37 If older adults are separated from their designated proxy decision-maker(s), health care professionals may have difficulty determining who has the authority to provide informed consent. By encouraging temporary CGs to reach out to preidentified emergency contacts as soon and as repeatedly as possible, health care professionals may help to avoid difficult ethical scenarios such as health care surrogate decisions before they occur.

IV. Older adults with fixed or limited incomes may become concerned about the cost of medical care after a disaster. Health care professionals are well suited to provide CGs and care recipients information about Medicare coverage during this period of post-disaster uncertainty. Health care professionals should be familiar with 42 USC§1320b-5, Authority to waive requirements during national emergencies, which specifically addresses this issue for the 60 days following a federally declared disaster (may be extended). This measure allows for the provision of additional funding to ensure sufficient health care items and services are available to meet the needs of those enrolled in the Medicare program.38

V. In this section, we reviewed some of the challenges older adults face in the post-disaster period, which include the stress of unfamiliar environments, CG separation, issues of legal authority of consent, and concerns about out-of-Medicare financial obligations. In each of these cases, health care professionals can directly influence the experience of older adults after a disaster by interacting effectively with CGs. Health care professionals should take comfort in the fact that when elderly adults are well supported by health care professionals and their CGs, they self-report better emotional recovery scores after a disaster than do their younger adult counterparts. In a study of older adults evacuated after Hurricane Katrina (mean age of 60 y), each
additional year of life was associated with a significant improvement in emotional recovery when measured 2 years after the disaster.39

Suggested Learner Activities for Use in and Beyond the Classroom

This activity can be conducted either with learners working individually or with learners working in small groups. If learners are working in small groups, each learner should consider the discussion questions below from his or her perspective and share those thoughts with the group members. At the end of the discussion, a member of each group can share key takeaways from their discussion with the other groups.

Scenario
Frank is an 88-year-old retired industrial designer of Japanese descent. He lives by himself in a single-story detached home outside of Portland, OR. He has a worsening intention tremor in both hands and severe rheumatoid arthritis that limits his walking to less than 100 feet with the aid of a walker. He also has severe bilateral hearing loss that he accommodates through custom bilateral hearing aids. His daughter, Judy, is his primary caregiver and she lives about 45 minutes away in rural Oregon. They have hired a companion aid to help with meals and feeding as Frank’s tremor makes these tasks difficult. Increasingly, the companion has been assisting with personal care including shirt buttoning, hair combing, and teeth brushing. Today they have come to the occupational therapy clinic to discuss upgrading his walker since the tremor is making operating the wheel brakes difficult.

Discussion Question 1
Using the clinical-psychological-social matrix presented in section 4-1.2, develop a list of pre-disaster preparedness considerations that you can assist Judy (his primary CG) in thinking about and addressing.

Follow-on activity (if working in groups)

If the instructor notices that answers provided for question 1 seem to be focused on the elderly adult and not on the CG, instructors are requested to refocus attention towards CG actions specifically.

For example, if learners focus on creating “disaster kits” that elderly adults are to carry with them in the event of an evacuation, how would this specifically apply to Frank? Learners can imagine how difficult it might be to carry such supplies or equipment with a significant tremor while using a walker, even in optimal conditions.
Learners can be directed to imagine how much more difficult such a process would be when pathways are blocked by debris and lighting is difficult (as in the post-disaster setting).

If learners have difficulty with identifying tasks specific to CGs, guide them into thinking about actions that can be taken in advance of a disaster with CGs to minimize what an elderly adult would be expected to do when a disaster strikes. Applying Table 3 to Frank and Judy’s situation may provide some assistance in developing a list of actionable preparedness recommendations.

Discussion Question 2
In the aftermath of an earthquake, Frank is evacuated with his medical information, durable medical devices, and his medications to a FEMA shelter nearby. He has provided shelter staff with emergency contact information. His primary CG Judy cannot be reached. Shelter staff is able to contact you, his health care professional. Create a list of at least 3 anticipated challenges that Frank will face in this new environment without his primary CG and suggest ways his temporary CGs might address them.

Readings and Resources for the Learner

- Required Resources

- Supplemental Resources
Learner Assessment Strategies

1. Discussion question 1 (populate the clinical-psychological-social matrix) can also be used to assess the ability of learners to consider the aspects of disaster preparedness amenable to CG involvement.

2. Discussion question 2 (create a list of challenges related to CG separation) can be used to assess the ability of learners to understand the services CGs provide and how health care professionals can anticipate issues that will occur if CGs are unable to accompany evacuated elderly adults.

Readings and Resources for the Educators

- Required Resources

- Supplemental Resources

Sources Cited in Preparing Outline and Activities Above


