# **ORIGINAL RESEARCH**

# Disaster Preparedness Among Older Japanese Adults With Long-Term Care Needs and Their Family Caregivers

Tomoko Wakui, PhD; Emily M. Agree, PhD; Tami Saito, PhD; and Ichiro Kai, MD, MPH

# **ABSTRACT**

**Objective:** In the 2011 Great East Japan Earthquake, as in Hurricanes Katrina and Rita in the United States, older individuals were at the greatest risk of mortality. Much concern has been raised about developing plans to reduce these risks, but little information has been provided about preparedness, and the key role played by caregivers has been largely unexplored. The aims of this study were thus to examine the preparedness of family caregivers of older adults with long-term care needs and to identify the characteristics of older adults and their caregivers that are associated with poor preparedness and greater concern about disasters.

**Methods:** Shortly after the Great East Japan Earthquake, the second wave of the Fukui Longitudinal Caregiver Study was administered to the family caregivers of older Japanese individuals with long-term care needs. The sample included 952 caregivers from 17 municipalities in Fukui prefecture. Logistic regression analyses were used to identify the factors associated with self-assessed preparedness, evacuation planning, and caregivers' concerns about preparedness.

**Results:** The majority (75%) of the caregivers had no concrete plans for evacuation in an emergency, and those caring for persons with dementia were 36% less likely to have any plan. In multivariate models, caregivers who were more experienced and wealthier and who reported more family and community support were more likely to feel well prepared. Caregivers with poor health or limited financial resources or who were responsible for older persons with mobility difficulties reported higher levels of anxiety about their disaster preparedness.

**Conclusions:** This study indicates that most caregivers are ill prepared to respond in emergencies and that caregiver resources, community support, and the needs of older care recipients influence both preparedness and concern about disasters. Education for caregivers and the development of community support programs could provide important sources of assistance to this vulnerable group. (*Disaster Med Public Health Preparedness*. 2017;11:31-38)

Key Words: disaster preparedness, family caregiver, older adults, Japan, community support

he Great East Japan Earthquake of 2011 highlighted a key challenge faced in aging societies: older people with limited mobility and other impairments are especially vulnerable to disasters. Japan, a country that has been frequently struck by earthquakes, is well prepared for disasters. Drills are held at schools and companies and in communities throughout the country every year, and guidelines concerning preparedness for vulnerable populations, including older people, were established a decade ago. 1 Nevertheless, during the Great East Japan Earthquake, 65.8% of those who died were aged 60 years and older, and of those who died of shock, stress, or damage-related injuries after the earthquake, approximately 90% were aged 65 years and older.2

Previous tragedies, such as Hurricanes Katrina and Rita in 2005 or the heat wave in Chicago in 1995, have revealed older people's vulnerability to natural disasters.<sup>3,4</sup> In fact, older adults are at greater risk during all phases of an emergency. Prompt evacuation can be hindered by physical conditions such as difficulty hearing, seeing, or walking or by a lack of transportation.<sup>5,6</sup> Additionally, older people who depend on formal or informal care may not have access to the help that they need during an emergency. 7 Chronic health conditions may also make older adults vulnerable after a disaster owing to a lack of medication or because of conditions that go untreated or are aggravated by either the evacuation process or the experience of personal loss resulting from the disaster. 6-9

Preparedness is the first step in ensuring the survival, independence, and health of those affected by disasters. <sup>10,11</sup> However, older people and those with chronic diseases are less likely than those without special needs to prepare for disasters or to have an evacuation plan. <sup>12,13</sup> Additionally, women and those with less wealth or education are reportedly at increased risk of being unprepared for disasters. <sup>12</sup> Cognitive impairment and dementia also make it more difficult for an older person not only to independently evacuate but also to judge the severity of an emergency and to form a plan for where and how to evacuate. <sup>14</sup> Nevertheless, emergency and disaster planning is often a distant priority for families organizing care plans. <sup>15</sup>

Enhancing the preparedness of older people living in the community is crucial from a public health perspective. Hyer and Brown suggest the possibility that older adults living in the community may be more vulnerable in terms of their disaster preparedness and response than their counterparts who live in nursing home settings. <sup>16</sup> Since Hurricane Katrina, research has examined the adequacy of evacuation planning in nursing homes and residential care facilities as well as home care agencies; <sup>17–22</sup> however, fewer studies have examined the needs of older persons in the community. Most Americans want to grow older in their own homes, <sup>23</sup> and approximately 70% of older people in Japan expect to stay in their homes, even after they become frail. <sup>24</sup>

For older persons living at home, family caregivers are the first to provide guidance in an emergency, 16 and they have both the responsibility and the opportunity to assist older family members when a disaster strikes. 25-27 Therefore, a better understanding of disaster preparedness not only among older adults themselves but also among their caregivers will help to make it possible to design programs that can improve the survival of older persons with disabilities. Government and voluntary agencies have begun to target caregivers as key figures in the development of disaster plans for older people with long-term care needs by providing preparedness tips to caregivers, <sup>28,29</sup> although there is insufficient evidence of the best practices for enlisting family caregivers at this time. In any case, it is known that social networks, such as those that include family, friends, coworkers, and neighbors, are crucial resources for assistance during disasters. 10,25 Furthermore, family, friends, and neighbors can improve preparedness by sharing information and exchanging assistance with one another to influence disaster preparedness activities. 11,30 However, the ways in which caregivers of older adults with long-term care needs can better contribute to effective planning are less well known.

Disaster preparation for older people with physical and cognitive disabilities who are living at home relies upon the identification and understanding of informal resources, including family and the community. Clarifying both the degree to which family caregivers contribute to the

preparedness of older adults with long-term care needs in communities and the role of community support could also aid in the accumulation of evidence regarding public health preparedness.

Our research focused on the characteristics of older people, their caregivers, and community support networks, which are factors that might affect vulnerability to risk during natural disasters, as evidenced by difficulty in preparing for emergencies. Moreover, caregivers' general evaluation of their preparedness, the presence of evacuation plans, and their concern about disaster preparation were assessed in our survey.

# METHODS Study Site

Japan is a rapidly aging country, with 29.8 million people aged 65 years and older (ie, 23.3% of the population).<sup>2</sup> In total, 16.2% of these older people need long-term care (ie, 4.7 million people),<sup>2</sup> and approximately 10% were estimated to have dementia in 2012. The current study was conducted in Fukui prefecture, which is located in northern central Japan. This region has over 410 km of coastline bordering the Sea of Japan, which faces a potential danger from tsunamis.<sup>32</sup> The population size of this prefecture is 806,314, with a population density of 192.4 people per km<sup>2</sup>. Additionally, the proportion of people aged 65 years and older is 24.9%, and approximately 14% of this older population has long-term care needs. 33,34 Fukui prefecture experienced a disaster caused by torrential rains in July 2004, leaving 4 people dead, 1 person missing, and property damage to 14,157 households.<sup>35</sup> The prefecture also has 13 nuclear plants<sup>36</sup>; the people of Fukui prefecture are aware of the potential danger from a variety of disasters.

### Study Design

This research is part of the Fukui Longitudinal Caregiver Study in Japan. The Fukui Longitudinal Caregiver Study aimed to examine the effects of community characteristics on caregiving within communities using two-wave panel data on the family caregivers of 5639 randomly selected adults aged 65 years and older. These older adults were certified as having long-term care needs within the Japanese long-term care insurance system. For the first wave of the study, a selfadministered questionnaire was mailed between April and June 2010. The response rate was 51.4%, although several of the older persons sampled might have had no family caregivers; thus, the nominal response rate may have been underestimated. In December 2011, the second wave of self-administered questionnaires was distributed to 1769 caregivers who had participated in the first wave and who had agreed to be re-contacted for the second wave of the survey. Former caregivers (those whose care recipients were known to have been institutionalized, to have died, or to have moved out of the area) were not contacted. Questions on disaster

preparedness were included in the second wave of the survey, which occurred after the Great East Japan Earthquake. The effective response rate was 62.2%. Cases missing data for key variables were also excluded from the analyses. The final sample size for analysis in this study was 952. This study was consistent with the Declaration of Helsinki and was approved by the Research Ethics Committee of the Graduate School of Medicine at the University of Tokyo, Japan (#2913).

# **Outcome Variables**

The primary outcomes were the overall levels of disaster preparedness, evacuation planning, and caregivers' concern about preparedness. Caregivers were asked to rate their overall preparedness in response to the following question: "How would you rate the level of overall preparedness for you and your care recipient in the case of emergency?" The possible answers were "not at all prepared," "a little unprepared," and "somewhat to well prepared." The participants were also asked about the older adults' evacuation plans: "Do you have an evacuation plan for your care recipient in the case of an emergency, such as how and where to evacuate? (Y/N)." Finally, the participants were asked to rate their concern about their preparedness: "Do you worry about your disaster preparation?" The possible answers were "Not very worried," "Somewhat worried," and "Very worried."

# **Independent Variables**

Four types of independent variables were considered: care recipient characteristics, caregiver characteristics, aspects of the caregiving situation, and community support. The care recipient characteristics included age, gender, mobility, and symptoms of dementia. Mobility was assessed by caregivers as dependent, partially dependent, or independent on the basis of the mobility domain of the Katz activities of daily living (ADL) scale.<sup>37</sup> The presence or absence of dementia was reported by caregivers as the presence of any symptoms or problematic behaviors due to dementia.

Caregiver characteristics included age, gender, perceived health, financial status, and relationship to the care recipient. The caregivers' age was dichotomized at age 65, whereas age 75 was used for the care recipients. Additionally, the care duration was dichotomized at 5 years of experience. Care situations were assessed based on co-residence, the duration of caregiving, and the presence of another family member who assisted with caregiving.

The level of community support was constructed from 3 self-reported indicators: daily conversations, care-related community support, and availability of emergency support. We classified community support into 3 types. First, care-givers who reported having no caregiving support from the community, even if they had a daily conversation network, were coded as "no support/daily conversation only." Second, if they reported at least one care-related source of support but

no one available for support in emergencies, they were categorized as having "care-related support." Third, those who reported having at least one person in the community who they could call on when they needed help in an emergency were categorized as having "emergency support." In this case, emergency support did not refer exclusively to support that is necessary because of disasters; it also referred more generally to the availability of help in unexpected circumstances.

# **Statistical Analyses**

Logistic regression models were estimated by using IBM SPSS Statistics 20. We first described both the demographics of the respondents and disaster preparedness among family caregivers. Odds ratios (ORs) with 95% confidence intervals were also reported for multivariate logistic and ordinal logistic regression analyses of the associations between the 3 outcomes (being prepared, having evacuation plans, and being worried) and both care recipient and caregiver characteristics and community support.

#### **RESULTS**

Table 1 shows the descriptive characteristics of the caregivers and their care recipients. The mean age of the older care recipients was 86 years, and 71% were female. In total, 67% of the care recipients had dementia, and more than 80% reported a degree of difficulty with their mobility. Meanwhile, the mean age of the caregivers was 64 years. In total, 74% of the caregivers were female, and daughters-in-law were the main care providers in our sample. Fewer than 30% of the respondents evaluated their financial situation as either poor or relatively poor. Nearly 80% reported a degree of support from family, whereas 21% had no support network in the community. Very few (5%) were completely isolated; most had at least one person with whom they could talk (data not shown).

Table 2 shows the distribution of preparedness. In total, 26% of the caregivers reported being "somewhat to well prepared," and more than 75% of the caregivers reported that they had no evacuation plans for their care recipients. More than 65% worried about their preparedness situation to a certain extent, with one-quarter expressing a great deal of concern.

Table 3 shows the ORs from the logistic and ordinal logistic regression models predicting overall preparedness, evacuation planning, and the level of worry. Care recipient characteristics were not significantly associated with either evacuation planning or preparedness, with the exception of dementia, which was associated with evacuation planning. In particular, the caregivers of individuals with dementia were 36% less likely than the caregivers of individuals who were not cognitively impaired to have evacuation plans for their care recipients. In contrast, older caregivers were relatively more likely to report being prepared for disasters. Although this

# TABLE 1

# Demographic Characteristics in the Fukui Longitudinal Caregiver Survey During the 2nd Wave $(n = 952)^a$

	Percentage (%				
Older persons					
Age, years (mean ± SD)	$85.9 \pm 7.1$				
Female sex	71.0				
Mobility					
Independent	13.6				
Partially dependent	41.3				
Fully dependent	45.2				
Dementia, yes	66.8				
Caregivers					
Age, years (mean $\pm$ SD)	$63.9 \pm 10.6$				
Female sex	73.5				
Relationship					
Wife	17.4				
Husband	8.4				
Daughter	23.2				
Son	17.3				
Daughter-in-law	31.6				
Other	1.9				
Perceived health	4.7				
Very unhealthy	4.7				
Unhealthy	29.4				
Neither	19.3				
Healthy	42.9				
Very healthy	3.7				
Financial status	8.3				
Very poor	8.3 20.1				
Somewhat poor Neither	20.1 43.5				
Somewhat wealthy	23.8				
Wealthy	4.3				
Care-related factors	4.5				
Coresident, yes	93.9				
Care duration	55.5				
<5 years	48.5				
≥5 years	51.5				
Family support, yes	79.2				
Community support	75.2				
No support/daily conversation only	21.1				
Care-related support	30.7				
Emergency support	48.2				
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<sup>&</sup>lt;sup>a</sup>The percentages may not add to 100% due to rounding.

difference was not significant in terms of having evacuation plans, they were nearly twice as likely to feel better prepared for a disaster. Additionally, caregivers with 5 or more years of experience were 1.3 times as likely to be better prepared for disasters overall and were 1.7 times as likely to have evacuation plans. However, whether the caregiver lived with the older person did not have a significant relationship with overall preparedness or evacuation plans. Perceived financial status and family and community support were important both for having evacuation plans and for overall preparedness; in particular, emergency-specific support in communities was much more likely to increase the level of preparedness and the frequency of evacuation plans for older adults.

# TABLE 2

Distributions of Preparedness in the Fukui Longitudinal Caregiver Survey During the 2nd Wave ( $n=952$ )								
	No.	%						
Level of disaster preparedness								
Somewhat to well prepared	247	25.9						
A little unprepared	396	41.6						
Not at all prepared	309	32.5						
Has evacuation plan for care recipient								
Yes	234	24.6						
No	718	75.4						
Level of worry about disaster preparedness								
Very worried	236	24.8						
Somewhat worried	386	40.5						
Not very worried	330	34.7						

In contrast to the results for actual planning, concern about preparedness was significantly associated with the care recipient characteristics. Caregivers of older people with mobility limitations expressed greater worry, and the more severe the dependency, the greater the concern. In contrast to the findings for actual preparedness, dementia was not a significant predictor of worry about preparation. Caregivers who were female, who were older, and who described themselves as being in worse health were more worried about being prepared for disasters, whereas wealthier caregivers were less likely to worry. However, in this case, family and community support were not significantly related to concerns about preparation.

#### DISCUSSION

The present study focused on the disaster preparedness of community-dwelling older people with long-term care needs and their families and identified the most vulnerable subgroups. Despite the substantial levels of disability among the care recipients studied and the temporal proximity of the Great East Japan Earthquake, the levels of disaster preparedness were relatively low, and the caregivers to those recipients with dementia were less likely to have an evacuation plan. In addition, the key role that caregivers play in older people's disaster preparedness was highlighted in this research. In particular, disaster preparedness is enhanced when individuals comprehend the risks of emergencies. 15 Sufficient knowledge to recognize a hazard, to believe that it is avoidable, and to understand the importance of preparedness is therefore required to take preparedness actions. 11,38 However, useful information targeting older Japanese individuals with dementia and their families is limited. In fact, in Japanese preparedness manuals, older adults and those with special needs are recognized as requiring support, but tailored preparedness tips for those with each specific need are lacking.<sup>1,39</sup> In contrast, in the United States, detailed tips for those with chronic diseases, mobility impairment, and

TABLE 3

# Odds Ratios (ORs) and Confidence Intervals (CIs) for Logistic and Ordinal Logistic Regression Models of Preparedness Outcomes (n = 952)

	Level of 0	verall Prepared	ness (1–3)	Has an Evacuation Plan (0-1)			Level of Worry (1-3)		
	OR	95% CI			95% CI			95% CI	
		Lower	Higher	OR	Lower	Higher	OR	Lower	Higher
Older persons									
Age									
<75 (Ref)	-			-			-		
≥75	1.34	0.81	2.22	0.95	0.51	1.75	0.95	0.57	1.57
Sex									
Male (Ref)	-			-			=		
Female	1.09	0.82	1.45	0.89	0.62	1.27	1.18	0.89	1.58
Mobility									
Independent (Ref)	-			-			-		
Partially dependent	0.90	0.62	1.31	0.87	0.54	1.40	1.71	1.16	2.51
Dependent	0.83	0.57	1.21	0.81	0.50	1.31	2.41	1.64	3.56
Dementia									
No (Ref)	-			-					
Yes	0.84	0.65	1.10	0.64	0.46	0.89	0.91	0.70	1.18
Caregivers									
Age									
<65 (Ref)	-			-					
≥65	1.89	1.45	2.48	1.20	0.85	1.69	1.52	1.16	1.99
Sex									
Male (Ref)	-			-			=		
Female	1.10	0.82	1.46	1.20	0.83	1.74	1.70	1.27	2.27
Perceived health <sup>a</sup>	1.01	0.89	1.16	1.02	0.86	1.21	0.79	0.69	0.90
Financial status <sup>a</sup>	1.35	1.18	1.55	1.20	1.01	1.42	0.79	0.69	0.90
Care-related factors									
Co-resident									
Yes (Ref)	-			-			=		
No	1.28	0.77	2.11	0.76	0.38	1.52	1.00	0.60	1.66
Care duration									
<5 years (Ref)	-			-					
≥5+ years	1.34	1.05	1.71	1.71	1.25	2.35	1.20	0.94	1.53
Family support									
No (Ref)	-			-			-		
Yes	1.47	1.08	1.98	2.11	1.37	3.24	0.88	0.65	1.19
Community support network									
No support/daily conversation (Ref)	-			-			-		
Care-related support	1.45	1.03	2.04	1.66	1.03	2.69	0.95	0.67	1.33
Emergency support	1.66	1.21	2.29	2.29	1.47	3.58	0.98	0.71	1.35

<sup>&</sup>lt;sup>a</sup>Higher is better.

cognitive impairment have been distributed by such organizations as the American Public Health Association, and the importance of condition-specific preparedness in communities has been highlighted. <sup>29,40,41</sup> A guide similarly aimed at preparedness based on specific disabilities would be useful in Japan, which is facing a rapid aging of the population, with longer lifespans indicating an increasing population with disabilities. In addition, local guidance is important because communities vary in their challenges and resources, such as social capital or social networks<sup>42</sup>; thus, more general recommendations should be supplemented by guidelines that are specific to local areas. Furthermore, the importance of the family's role in preparedness suggests that information that is

targeted toward caregivers would also increase the usability of these recommendations.

This study validates earlier findings that social resources in communities are important; even a family's social resources affect the disaster preparation of older adults with care needs. In particular, the involvement of the family in helping a care recipient improves the likelihood of having evacuation plans; therefore, this involvement would help the preparation for emergencies overall. In addition, even controlling for family help, support networks in the community are strongly associated with better preparedness. In the present study, we measured the presence of community support networks

on which caregivers can rely for care-related support and emergency support for unexpected support needs. We found that the more community networks that are involved in helping a family's care recipient, the better that family is prepared, both via having an evacuation plan and via overall preparedness. Older people with long-term care needs require other people's help during disasters: those with mobility impairment require people to help them with evacuation, whereas those with cognitive impairment require people to help evaluate the situation to determine whether they should evacuate or stay in place. Community assistance also provides backup assistance for primary caregivers in cases in which the caregiver may not be available because the caregiver is, for example, injured or away from home at the time of the disaster. 11 Having an emergency support network in communities would thus help caregivers believe that their care-needing family member could survive a disaster through assistance by people in the community during emergency situations.

In this study, experienced caregivers tended to be more prepared than were less experienced caregivers, which suggests that regardless of an older person's care needs, those with less experienced caregivers will be more vulnerable due to a lack of disaster preparedness. In particular, during the early stages of caregiving, focusing on providing care itself may leave little room for considering emergency preparedness for care recipients. Furthermore, a worse financial status among caregivers is a barrier to disaster preparedness, as previous studies have reported.<sup>43</sup> Specifically, poverty is associated with decreased willingness to evacuate owing to concerns about the cost of transportation, and limited financial resources likely hinder people's ability to maintain a stockpile of food or materials for possible disasters. 43 Enhancement of preparedness among caregivers who are poorer and in the early stages of caregiving would thus be the first action to prioritize to increase disaster preparedness among community-dwelling older people. However, the involvement of family caregivers in emergency preparedness activities, such as the development of community emergency plans, training sessions, and drills, may not always be easy due to a family's own health conditions and caregiving obligations. Therefore, providing sufficient information at early stages and expanding their knowledge, stockpiling supplies and equipment, and developing plans step by step will improve the target group's preparation.

In the present study, two-thirds of the family caregivers of older individuals worried about their preparation for disasters. Care recipient mobility was a crucial issue; older, female, unhealthy, and poor caregivers, who would be more vulnerable when in charge of helping care recipients evacuate, were more likely to be concerned about their preparedness. These findings suggest that regardless of their preparedness, caregivers may have a more limited ability to respond in an emergency when they are physically less

capable or when they need to overcome severe mobility problems during an evacuation. Evacuation-focused disaster preparation plans, such as clarifying who will help and where to go, should thus be the priority for disaster preparedness among those with care needs. Conducting a disaster drill would also make it easier to assess the adequacy of preparations, including determining whether each evacuation site is close enough for those with care needs and determining who would be available to help older adults with their evacuations, with or without family. Disaster drills can also help to reduce concern and provide suggestions for modifications to improve preparedness. Preparation, evacuation, and postdisaster responses must differ depending on the severity and type of disaster (eg, a tornado or earthquake), which may vary between communities. Locally oriented evacuation support focusing on those with care needs would also help to alleviate worry.

#### Limitations

The limitations of this study should be noted. First, the data were collected from a single prefecture, and the survey was distributed during the second wave of a longitudinal caregiver survey project. Therefore, the sample was not random, and the generalizability may be limited. However, the distribution of demographic characteristics in this sample (ie, the caregivers' age, sex, and relationships to the care recipients) was compared with that for national data on family caregivers from the Comprehensive Survey of Living Conditions, 44 and these 2 datasets were found to paint a demographically similar portrait of caregivers of older persons with long-term care needs in Japan. Second, because one of the aims of this research was to examine both care recipients' and caregivers' characteristics related to preparedness, older persons without family caregivers were not included in this survey, and these individuals' level of preparedness may be different. However, it is assumed that the negative impact of both physical and cognitive difficulties on the ability to survive a disaster and the positive impact of community networks on disaster preparedness should apply to that population as well. Finally, self-reported preparedness was measured, and neither details regarding preparedness (such as the preparation of 3 days of food and water supplies or medication) nor the types of possible disasters were specified. Different disasters require different types of preparedness, so future research must clarify this issue in further detail.

# **CONCLUSIONS**

Preparedness before a disaster is the first step in ensuring survival after a disaster. This study provides new insight into the most vulnerable subgroups of older people, thus allowing communities to prioritize preparation for disasters. The findings also highlight the critical role of the family and community in ensuring adequate preparation for a disaster. Education for caregivers and the development of community support programs could provide important sources of

assistance to this vulnerable group. However, disaster-related vulnerability among community-dwelling older adults occurs not only in the preparation phase but also during the evacuation and post-disaster phases. Further research is needed to acquire knowledge on all phases of disaster preparedness, but we expect that the current research will serve as a foundation for further research and for preparedness policies targeting vulnerable populations within communities.

## **About the Authors**

Human Care Research Team, Tokyo Metropolitan Institute of Gerontology (TMIG), Tokyo, Japan, and Hopkins Population Center, Johns Hopkins University, Baltimore, Maryland (Dr Wakui); Department of Sociology and Hopkins Population Center, Johns Hopkins University, Baltimore, Maryland (Dr Agree); Department of Social Science, National Center for Geriatrics and Gerontology, Obu, Japan (Dr Saito); and University of Tokyo, Tokyo, Japan (Dr Kai).

Correspondence and reprint requests to Tomoko Wakui, PhD, Tokyo Metropolitan Institute of Gerontology (TMIG), Human Care Research Team, Sakae-cho, 35-2, Itabashi-ku, Tokyo, Japan (e-mail: t-wakui@umin.ac.jp).

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