

# Personal Disaster Preparedness of Dialysis Patients in North Carolina

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## Summary

**Background and objectives** Dialysis patients are among the most vulnerable patients during a disaster because they are sensitive to a lapse in treatment. Although thorough preparation could mitigate disaster effects, we hypothesized that dialysis patients' personal and medical disaster preparedness was inadequate.

**Design, setting, participants, & measurements** This prevalence study surveyed mentally competent adults requiring care at six regional dialysis centers. We asked questions regarding demographics, general disaster preparedness utilizing Homeland Security recommended item lists, dialysis-specific preparation for an individual to shelter in place, and preparatory steps for a forced evacuation. To determine if preparedness differed by demographic variables (gender, race, age, and education) chi-squared tests were used.

**Results** Four hundred forty-two patients were approached, and 311 (70%) completed the survey. Participants were 54% male, 60% black, average age was 58 ( $\pm$  15) years, and although 79% completed high school, 50% of our sample had marginal or low health literacy. Although all units had a disaster preparedness program in place, the general disaster preparedness of most participants was poor. Age, gender, race, education, literacy, and socioeconomic status did not affect general disaster preparedness. However, home peritoneal dialysis patients were significantly more likely to be prepared for a disaster compared with hemodialysis patients. No other significant associations were noted.

**Conclusions** Irrespective of sociodemographic characteristics, most subjects were unprepared for a disaster. Dialysis patients were poorly prepared to shelter in place or to evacuate in the face of a disaster. Education regarding personal and dialysis-specific disaster preparedness is warranted.

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## Introduction

Patients requiring dialysis are dependent on technology to sustain their lives. Interruptions in critical infrastructures (e.g., water, electricity, or transportation systems) may translate into a life-threatening event for dialysis-dependent patients (1). Man-made and natural disasters are frequent precipitants of infrastructure interruptions, as evidenced by Hurricane Katrina in 2005, which caused 94 Gulf Coast dialysis centers to close for at least 1 week. Of 5849 affected dialysis patients, 148 died within a month after the storm (2). Dialysis-dependent patients typically make detailed arrangements in advance of traveling away from their home dialysis units. As a consequence of the Katrina evacuations, many patients arrived in communities with little medical or insurance information and without prescheduled services (3).

In 2006, the Kidney Community Emergency Response Coalition developed a strategic plan for disaster responses addressing the particular needs of dialysis patients, including implementation and dissemination of best practices at the state, local, and individual level (4). This organization, along with the National Kidney

Foundation (NKF), published and disseminated information to dialysis clinics and patients regarding the necessary steps for disaster preparedness.

Disaster scenarios fall along two lines of response. For disasters such as tornados or hurricanes, citizens must evacuate their homes and seek shelter in other locations. Other events such as severe ice or snow storms require citizens to shelter in place (*i.e.*, in their homes). Each of these situations requires a different approach to preparedness (5).

The Kidney Community Emergency Response Coalition recommends identification of alternative dialysis facilities, renal emergency diet education, and early evacuation plans including medical documentation and medications as predisaster evacuation preparation (6). Steps necessary to shelter in place such as renal emergency diet knowledge and adherence; a strict fluid intake regimen; stockpiling of proper foods; storage of 2 weeks of extra medical supplies; acquisition and storage of a potassium-binding resin; and notification of local police, fire, electric, water, and emergency services (5) are recommended to prolong survival time without a dialysis treatment.

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Our objectives were (1) to examine the disaster preparedness for dialysis-dependent patients in a region of North Carolina, (2) to explore associations of preparedness with demographics or health literacy, and (3) to assess the disaster preparedness activities of dialysis centers.

Materials and Methods

Study Design

We conducted a cross-sectional survey of persons requiring dialysis care between June and August 2009 to determine general and dialysis-specific preparedness. We interviewed dialysis administrators to ascertain their centers’ disaster preparedness activities.

Study Setting and Population

Patients receiving dialysis care at six regional dialysis units managed by three different dialysis organizations in the central region of North Carolina were eligible for participation. The University of North Carolina Kidney Center nephrologists provide medical services to these units. Excluded subjects were younger than 18 years of age or unable to comprehend the informed consent process. The University of North Carolina Institutional Review Board and the dialysis management companies approved the study.

Study Protocol

Study participants were approached during dialysis care, informed of the study’s purpose, and provided written informed consent. The survey was completed by the participant or read to them by a research assistant depending on participant preference. Spanish-speaking participants were approached by a fluent Spanish speaker and all documents were provided in Spanish.

Study Instruments

The survey consisted of four parts: (1) general disaster preparedness, (2) dialysis-specific disaster preparedness, (3) health literacy, and (4) demographics. The survey was piloted on a small sample of dialysis patients and modified based on feedback and responses.

General Disaster Preparedness

General disaster preparedness was assessed using the 15-item list (Table 1) established by the Department of Homeland Security (7). We also asked whether all of the recommended items were together in a bag ready to evacuate.

Dialysis-Specific Disaster Preparedness

Thirteen questions were constructed using the NKF-recommended dialysis-specific disaster preparedness items (8). Eight questions dealt with preparedness for forced evacuation and the rest were related to shelter in-place preparedness. For peritoneal dialysis (PD) patients enrolled in the study, we asked an additional four questions related to their disaster preparedness.

Health Literacy Assessment

The Short Test of Functional Health Literacy in Adults (S-TOFHLA) was used to measure participants’ health lit-

Table 1. Department of Homeland Security 15-item checklist

- |   |
|---|
| <ol style="list-style-type: none"><li>1. First-aid kit</li><li>2. Working flashlight</li><li>3. Working battery-powered portable radio</li><li>4. Spare batteries</li><li>5. Mess kit or paper cups, plates, plastic utensils</li><li>6. Cash or traveler’s checks</li><li>7. Nonelectric can opener or utility knife</li><li>8. Antibacterial wipes or gel</li><li>9. Personal hygiene items</li><li>10. Toilet paper or towelettes</li><li>11. One change of clothes per person</li><li>12. Blanket or sleeping bag per person</li><li>13. Essential medications</li><li>14. Extra keys for house and car</li><li>15. List of emergency phone numbers</li></ol> |
|---|

eracy. The 7-minute exam, comprising narratives, measures an individual’s ability to read and comprehend health information. The S-TOFHLA Spanish version was administered to Spanish speakers. Research assistants timed the S-TOFHLA and directed participants to proceed to the next survey section at the end of 7 minutes. S-TOFHLA is scored on the number of correct answers for 36 questions. A score of 0 to 16 describes inadequate health literacy, 17 to 22 marginal, and 23 to 36 adequate. Marginal health literacy indicates that the individual will not only have difficulty reading, understanding, and interpreting most health materials but is likely to take medications incorrectly or fail to follow prescribed diets or treatment regimens (9).

Because the S-TOFHLA requires vision of at least 20/50 to complete the exam, vision was tested using the Snellen Pocket Eye Chart (10) before survey administration. If a participant’s vision was worse than 20/50, the S-TOFLA was excluded from the survey.

Clinic Preparatory Steps

A single research assistant interviewed managers for three of the six dialysis clinics to assess facility disaster preparedness and educational initiatives for patients and staff. Interviews were semistructured with template questions to guide discussion while allowing for unexpected responses and clarification of answers.

Data Analysis

For general preparedness, “prepared” was defined as having food and water for all members of the household for a minimum of 3 days and at least 75% of the additional items included on the Department of Homeland Security readiness checklist. To determine if preparedness differed by gender, age, socioeconomic status, race, education, or health literacy, chi-squared or the Fisher exact test was used. Data are presented as frequencies with percentages.  $P < 0.05$  was considered statistically significant. All analyses were performed using SAS statistical software (version 9.2, SAS Institute, Cary, NC).

Results

Of 443 persons approached, 30 were excluded (28 [5%] could not provide consent and 2 [ $<1\%$ ] were  $<18$  years).

Of the 413 eligible participants, 311 (75%) completed the survey, 88 (20%) subjects refused, and 14 (3%) subjects failed to complete the survey. The S-TOFHLA was completed by 238 (77%) subjects. Thirty-five patients had inadequate vision, 14 refused, 12 professed illiteracy, and 12 claimed to be unable to see the printed font despite an adequate vision test. Participants were predominantly middle-aged and English-speaking with a fairly even male/female distribution. Most were high school graduates earning less than \$50,000/yr. (Table 2) The mean S-TOFHLA score ( $n = 238$ ) was  $23.1 \pm 10.9$ .

General disaster preparedness was inadequate. Only 169 (54%) respondents stored ample food and water according to published guidelines, 152 (49%) stored 75% of checklist items, and 94 (31%) stored all items in a bag or kit for easy retrieval during disaster (Figure 1).

For dialysis-specific preparedness, 244 (80%) respondents had insurance information and a listing of their medications accessible in case of forced evacuation. Only 129 (43%) knew of alternative dialysis centers and 128 (42%) had sufficient medical records at home to provide a dialysis center with treatment information. Although most had friends or family

to stay with during a disaster, only 121 (40%) had explicitly discussed this possibility with their friend or relative. Lastly, 47 people (15%) had an identifier that they could wear such as a bracelet or a necklace to alert health care providers of their chronic conditions (see Figure 2). Dialysis-specific preparedness to shelter in place demonstrated that although more than half (169 [63%]) maintained an extra supply of medicines and 177 (57%) understood a renal emergency diet, only 19 (6%) respondents had a potassium-binding resin at home (see Figure 3).

All home PD patients ( $n = 27$ ) knew how to order extra supplies (100%), but only 40% had an extra supply of antibiotics, 38% had notified the local power company of their health condition, and 20% notified the local water company. Age, gender, race, education, literacy, and socioeconomic status did not affect general disaster preparedness ( $P > 0.1$ ; Table 2). Home PD patients were significantly more likely to be prepared for a disaster than hemodialysis patients (63% versus 37%,  $P = 0.01$ ).

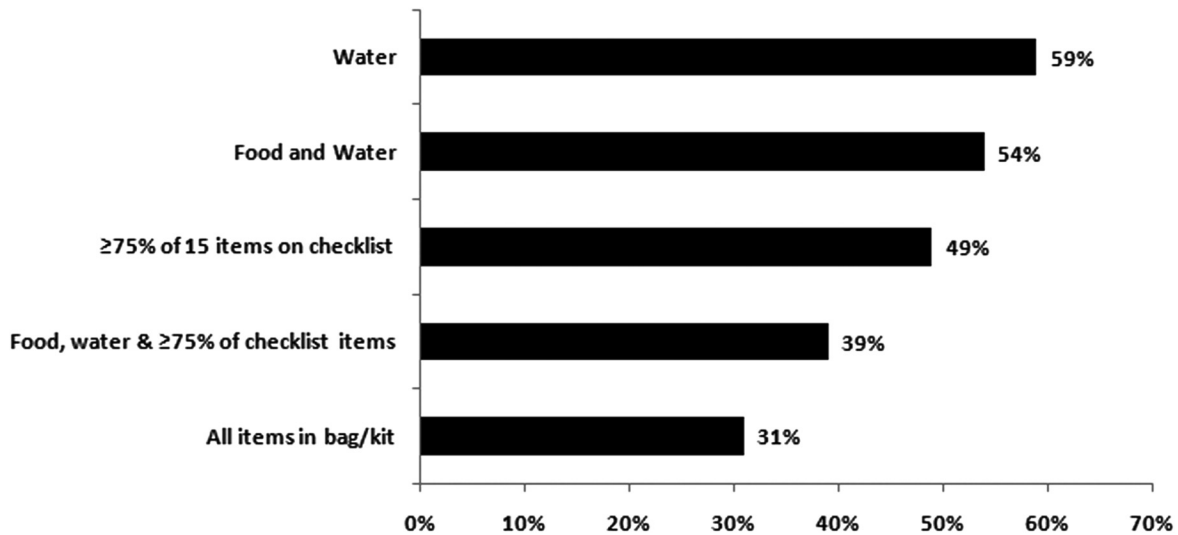
All three interviewed dialysis managers maintained accurate and constantly updated patient contact information. All used electronic health records; however, these systems

**Table 2. Demographics**

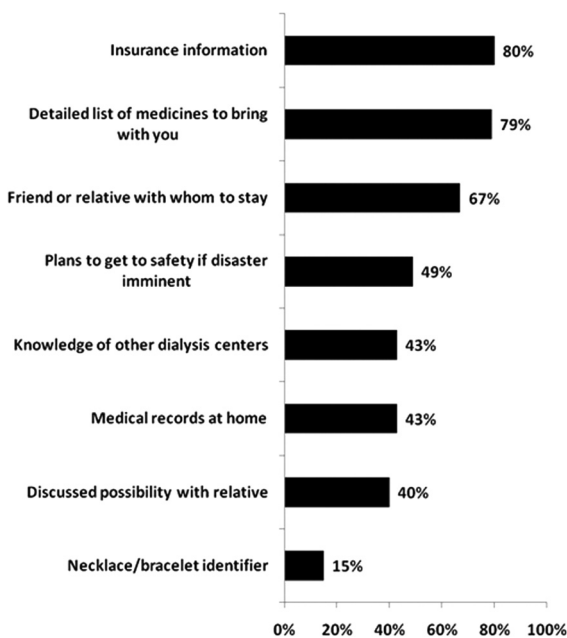
	<i>n</i>	Percent	General Disaster Preparedness		
			<i>n</i>	Percent	<i>P</i>
Gender					
male	167	53.7	65	38.9	1.00
female	144	46.3	56	38.9	
Age, years					
<53	104	33.4	33	31.7	0.14
53 to 66	109	35.1	49	45.0	
>66	98	31.5	39	39.8	
Language					
English	292	93.9	117	40.1	0.14
Spanish	19	6.1	4	21.1	
Racial identity					
African American/black	176	57.0	63	35.8	
white/Caucasian	95	30.7	43	45.3	
Hispanic/Latino	24	7.8	6	25.0	
other	14	4.5	7	50.0	
Education					
no high school	30	9.8	7	23.3	0.27
some high school	61	19.9	23	37.7	
high school/GED	134	43.7	57	42.5	
college/technical degree	82	26.7	33	40.2	
Household income, \$					
<\$10,000	45	20.2	17	37.8	0.19
\$10,000 to \$19,999	73	32.7	29	39.7	
\$20,000 to \$49,999	71	31.8	24	33.8	
≥\$50,000	34	15.3	19	55.9	
Type of dialysis					
hemodialysis in clinic	284	91.3	104	36.6	0.01
peritoneal dialysis	27	8.7	17	63.0	
S-TOFHLA					
inadequate	72	30.3	25	34.7	0.52
marginal	46	19.3	17	46.0	
adequate	120	50.4	51	39.5	

GED, General Educational Development test; S-TOFHLA, Short Test of Functional Health Literacy in Adults.

<sup>a</sup>General preparedness defined as having food and water for 3 days for each person and at least 75% of the 15 items on the Homeland Security checklist.



**Figure 1. | General disaster preparedness was assessed using the 15-item list established by the Department of Homeland Security.** We also asked whether all of the recommended items were together in a bag ready to evacuate. General disaster preparedness was inadequate. Only 169 (54%) respondents stored ample food and water according to published guidelines, 152 (49%) stored 75% of checklist items, and 94 (31%) stored all items in a bag or kit for easy retrieval during disaster.



**Figure 2. | Dialysis-specific preparedness for forced evacuation revealed that 244 (80%) of respondents had insurance information and a listing of their medications accessible in case of forced evacuation.** Only 129 (43%) knew of alternative dialysis centers and 128 (42%) had sufficient medical records at home to provide a dialysis center with treatment information. Although most had friends or family to stay with during a disaster, only 121 (40%) had explicitly discussed this possibility with their friend or relative. Lastly, 47 people (15%) had an identifier that they could wear such as a bracelet or a necklace to alert health care providers of their chronic conditions.

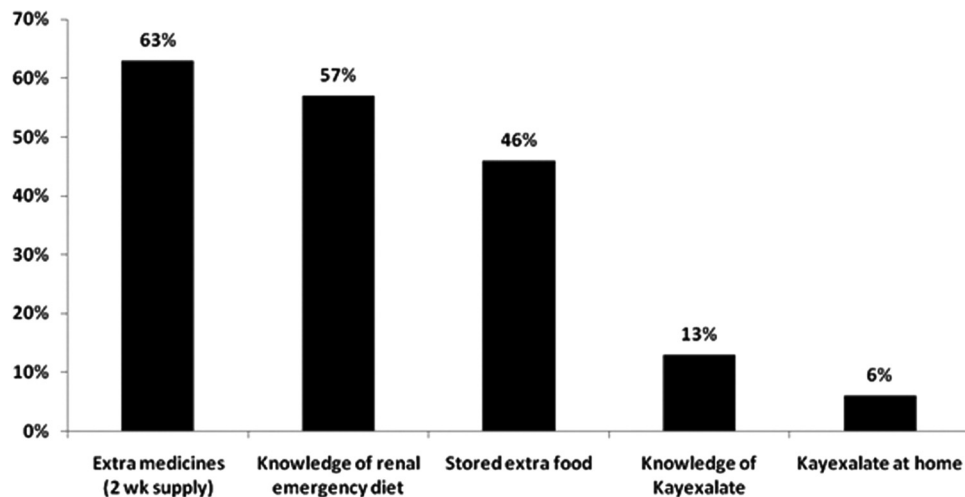
do not communicate with one another, diminishing their usefulness in a disaster. All have phone trees to facilitate prompt staff communication, and two of the three send

important information and updates for patients to local television and radio stations. One facility, the largest of the three, had a generator, but all three had easily accessible contact information for their water supply company, which is aware of their need for priority service restoration. All three also knew how many people they could potentially dialyze in a day.

All patients from these three facilities were provided with a pamphlet, *Preparing for Emergencies: A Guide for People on Dialysis*, upon facility admission. This pamphlet has sections stickers with contact information for county emergency management offices, local hospitals, and sister dialysis units' contact information as well as patient medical history, personal information, insurance information, and current medications. It has information on how and where to obtain a medical emblem to indicate their ESRD condition, an emergency supply list, directions on how to disinfect water, an emergency food list, an emergency medication/medical supply list, and a specific 3-day emergency diet plan that provides step-by-step directions on what exactly to eat. One center reviews this pamphlet quarterly with patients, whereas the other two centers review the pamphlet at the onset of treatment and annually thereafter.

## Discussion

Our results indicate that dialysis patients in this study were largely unprepared for a disaster. This lack of preparation was independent of any demographic variable examined, including literacy, education, income level, race, gender, or age ( $P > 0.05$ ), with the exception that PD patients are better prepared than hemodialysis patients ( $P = 0.01$ ). Most have food and water for 3 days, but few have the remainder of the recommended items and even fewer still have all of the items collected in a bag or a kit for easy access, retrieval, and transport.



**Figure 3.** | Dialysis-specific preparedness to shelter in place demonstrated that although more than half (169 [63%]) maintained an extra supply of medicines and 177 (57%) understood a renal emergency diet, only 19 (6%) respondents had a potassium-binding resin at home.

During a disaster of significant magnitude, one can shelter in place or evacuate. The essential preparedness difference is that one action requires resource stockpiling to survive a prolonged interval when society will not be effectively distributing goods, utilities, or civil services, whereas the other requires an individual to leave home without much forewarning. When dialysis patients shelter in place, they must be prepared to prolong the interval between dialysis treatments. This means having extra medicine and eating foods that adhere to the renal emergency diet. The Council on Renal Nutrition of Northern California created a 3-day Emergency Diet Plan, the goal of which is to prolong the interdialysis interval by limiting protein, potassium, sodium, and fluid intake more strictly than a regular renal diet. The diet provides 40 g of protein, 1500 mg of sodium, and 1500 mg of potassium daily (11). Stockpiling the proper foods to adhere to this diet is an easily attainable measure that can significantly prolong the interdialysis interval for an end-stage kidney disease (ESKD) patient (12). Only 57% of those questioned had knowledge of a renal emergency diet, and 63% replied that they have a 2-week supply of extra medicines.

Individuals should maintain personal stores of potassium-exchange resins along with instructions for use to mitigate hyperkalemia. After the 1995 Kobe earthquake (Japan) and the 1999 Marmara earthquake (Turkey), physicians successfully utilized potassium-binding resins and sorbitol to treat hyperkalemia and to extend interdialysis intervals (13,14). Prescriptions could be provided for potassium-binding resins with instruction to use them in the setting of disaster when dialysis access is limited. Patients and their families could be instructed to watch for early signs of hyperkalemia such as intestinal cramping, diarrhea, nausea, and vomiting or late signs including muscle weakness, flaccid paralysis, and cardiac arrhythmias (15). However, we found that too few subjects have any knowledge of the medication (13%) and even fewer have the medication at their homes (6%).

Evacuation during disaster poses many complicated logistical issues for ESKD patients. Hurricane Katrina demonstrated that most ESKD patients evacuate without prear-

ranged dialysis services (16). During the Katrina evacuation, most patients did not wear an identification tag labeling them as a dialysis patient. In our study, only 15% had an identification tag. After the hurricane, hospitals and hemodialysis units that were not affected by the storm became inundated with evacuees, impeding their ability to deliver care for those in need (16). Preparedness measures could mitigate many of these threats. Having medical records, insurance information, and a list of medicines can expedite the process once a dialysis center is located. A plan of action including contact information for dialysis facilities near the homes of friends and family will facilitate getting to a clinic to receive treatment (4). In our study approximately 60% of respondents had not discussed the possibility of evacuation with a relative, had no knowledge of other dialysis centers, and did not have their medical records easily accessible to take with them on short notice.

The inability of cross-communication between electronic medical record systems is a ubiquitous problem within the health care system and affects the dialysis community's ability to respond to a disaster. If electronic medical record systems could cross-communicate, one could simply arrive at any facility with identification and a medical record number and would be able to safely and quickly receive treatment. Facilities could cooperate with one another to shunt patients to facilities operating below maximum capacity.

Twenty-seven peritoneal patients were enrolled in this study. All (100%) respondents had the phone number of a dialysis company, which is reflective of their knowledge of the process of ordering supplies. This would be useful in the event of forced evacuation. During Hurricanes Katrina, Rita, and Wilma, patients on PD fared better than those on hemodialysis (17). Accordingly, during these crises, most patients on PD who evacuated before the storm traveled with a 1-week supply of necessary items, and when they needed more supplies, they had the knowledge and experience to order them on their own. Also, a PD nurse was able to arrange emergency shipment of PD supplies in areas where transport had been restored from her location, thus helping with the provision of dialysis treatment from



a remote location (18). However, the fact that <40% of enrolled PD patients had extra antibiotics or had notified local utilities of their special needs indicates that PD patients, like the rest of the dialysis patient population, are largely unprepared to shelter in place.

Mitigating the effects of disaster on dialysis patients will require local, regional, and national leadership. Local dialysis center leadership requires educating patients and providing resources to ameliorate logistical issues surrounding disaster preparedness. Developing a plan that is well rehearsed and communicated to patients and staff is key (19). The NKF recommends that dialysis centers should maintain a current list of patient contact information and transportation needs including alternative emergency contact information. Communication channels should be established between staff members, physicians, patients, and local agencies such as police, fire, electricity, and water companies. Utility companies should be notified of the dialysis facility's special needs (4). Additionally, facilities should know how many patients they could potentially dialyze in a day and have plans to acquire food-grade-water (water tankers) and electricity (generators) when local water and power services are interrupted (20). Most importantly, facilities must ensure that patients are educated for disaster preparedness.

Regional leadership by large dialysis organizations includes standardizing plans throughout their extensive network of facilities, rehearsing plans on a regional level, and regularly and frequently reviewing patient education materials. Large dialysis organizations should provide patients with listings of their facilities so that patients will have treatment options during evacuations. National leadership by organizations such as the American Society of Nephrology and the Department of Health and Human Services are critical to disaster mitigation. Despite the availability of online and printed educational disaster preparedness material, more efforts are required to ensure the message is being received. Disaster preparedness education should be part of a comprehensive patient safety plan by the American Society of Nephrology and similar organizations.

### Limitations

A cross-sectional survey was determined to be the optimum method for determining the preparation level in North Carolina. This group of patients represents a snapshot in time of a portion of the dialysis community of North Carolina. It includes 311 persons from an area within a 50-mile radius of Chapel Hill. This introduces sampling bias, and thus the study is limited in terms of external validity and generalizability for other areas of the state and country. Because the study was conducted with a cross-sectional survey, we cannot comment on whether preparedness in this population is changing over time. Our sample could be biased because it required volunteering to participate. Furthermore, patients were approached while receiving dialysis, which may have artificially lowered the scores on the health literacy examination. However, these scores were not correlated with preparedness in our analysis.

### Conclusions

Adult dialysis patients in central North Carolina were largely unprepared for disaster. The primary intervention

needs to be more frequent and aggressive education and preparation at the level of the dialysis unit. It is evident that distributed brochures were not effective in ensuring adequate preparedness. Regular verbal reinforcement of the suggestions already written in these packets and provided to the patients may improve adherence to disaster preparation guidelines. The outcome of this investigation should be a quality improvement initiative that will address the shortcomings in disaster preparedness. Because disaster preparedness was not related to level of education, literacy, socioeconomic status, or age, it is evident that the lack of preparation is a systemic problem that will require coordinated efforts from dialysis facilities, large dialysis organizations, and national foundations. Assistance and instruction should be provided more frequently to create individual timelines on the basis of particular needs, local environment, and different kinds of emergencies, and plans should be rehearsed more regularly to ensure that people know well what to do when confronted with a disaster.

### Disclosures

None.

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