

Post-Disaster Lessons Learned: Dialysis Patient Management

October 11, 2017

ASPR TRACIE staff compiled resources and references related to post- disaster dialysis operations in response to numerous requests for technical assistance. We have also attached a previously completed technical assistance response on the post-Sandy improvements to dialysis patient management for additional reference.

Specific Post-Disaster Lessons Learned for Dialysis Patient Management

Pre-disaster Preparedness

- Prepare the facility – place flood barricades if possible, wrap delicate equipment in plastic, other event specific mitigation activities
- Prepare the patients – pre-dialyze as many patients as possible, send patients home with 3-day diet instructions, medical records and a number to call to coordinate post-storm care, per communication plan
- Prepare the staff – instruct staff how to report to work or check in following a disaster, have an emergency communication plan in place, ensure the staff have personal preparedness plans and family preparedness plans

Post-disaster Actions

Affected Facilities

- Survey the facility as soon as possible and report operating status per local, state, and federal protocols
- Communicate open/close status with patients per communication plan
- Prepare to open
- Coordinate additional supply deliveries
- Check on status availability to work and consider emergency housing resources for staff

Shelters

- Ask people who check in to a shelter to identify as a dialysis patient
- Coordinate with the health component of shelters to ensure they are aware of all dialysis patients in the shelter. Shelter health components must coordinate with the ESF 8 personnel in the local area to ensure coordinating to provide dialysis care

Hospitals

- Hospitals receiving dialysis patients should coordinate with local shelters and local/open dialysis clinics to ensure only patients requiring acute care are managed in a hospital and patients that can be managed as outpatients are referred appropriately.
- Provide hospital emergency department staff with “PREparing Emergency Personnel in Dialysis (PREP-D)”, a just-in-time training program designed for healthcare personnel with limited experience or knowledge of the basic steps of dialysis to support routine dialysis staff during a disaster
- Ensure additional dialysis supplies are on hand to treat a surge of patients

Accommodating Dialysis Patients

- When looking to accommodate displaced dialysis patients, shelters, hotels, and other locations must be able to support their needs. They need wheelchairs, walkers, and other mobility aids, they need elevators or ramps for ease of movement. They need additional medical equipment, such as oxygen.
- Consider ADA requirements when placing patients.

Other Issues

General

[This article](#) by Kopp et al. provides an in-depth analysis of positive and negative lessons learned following Hurricane Katrina. Table 2 on page 818 provides a detailed review of functions and performance with indicators of ways to mitigate or improve in the future.

Specifically, the following factors were noted:

- Evacuation
 - Early evacuation was helpful, but a more coordinated dispersal of dialysis patients to ensure they were sent to shelters or locations that could support dialysis treatment is necessary.
 - Patient personal evacuation plans need to include information on medications, comorbidities, and infection status
 - Early hospital discharge of dialysis patients opened space for those that were critical during the storm.
- Shelters
 - Designated “special needs shelters” had dialysis capability in house to facilitate referrals, but not all shelters could support dialysis patients and communication among the shelters was insufficient to coordinate care
 - Poor care coordination led to some dialysis patients being sent to area hospitals without acute illness tying up limited resources
 - Unique bracelets were used to identify dialysis patients in shelters
 - Some shelters lacked additional medical supplies that are often used with dialysis patients, such as supplemental oxygen and wheelchairs
 - Some shelters did not have the ability to support dialysis patients other needs, such as infection control and special diet

- Patient Care
 - Mobile medical units were helpful in providing surge medical care in concentrated areas
 - Advance prescriptions and pharmacy chains coordinating prescriptions helped across state lines
 - Access to medical records across the region was impaired, so often providers had to rely on patient histories and an assessment in real-time
 - Vascular access problems occurred including infection of existing access sites and thrombosis of vascular access, so specialized care was needed, but not always available
 - Lack of translators for non-English speaking patients

Transportation

Even in the event a Dialysis Clinic is able to open, the local transportation and para-transit system must also be coordinated to ensure patients can physically get to the clinic for treatment. Coordination with local Emergency Operations Centers is key to prioritize limited transportation resources to those patients who critically need transport. Security check points must have a way to verify healthcare staff who need to pass into restricted areas.

Wrap Around Care

Dialysis patients who have been evacuated due to a disaster require support beyond just ensuring they receive their dialysis treatments. Case workers need to ensure these patients have kidney diets, can be transported to dialysis, receive care for any other co-morbid diseases, and can be returned home as soon as safe and practical to resume their regular health care.

Return to normal Operations

Community infrastructure must be in place to support Dialysis Center operations. Power, water, transportation, and security must be in place to support opening centers. In addition Dialysis Centers need adequate supplies and staff that are able to return to work.

Primary Sources

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Kopp, J. (2007). [Kidney Patient Care in Disasters: Lessons Learned from the Hurricanes and Earthquake of 2005](#). Clinical Journal of the American Society of Nephrology.

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Technical Assistance Response 2015

ASPR TRACIE developed a technical assistance response in 2015 related to post-Sandy improvements in dialysis patient management. That response, along with the resources is provided below, as additional information on dialysis patient management in disasters.

General Themes, Key Points, and Examples

Public Health/ Healthcare Coalition/Emergency Management/ESRD Engagement

Key Points

- Healthcare coalitions are engaging dialysis facilities and kidney networks to ensure coordinated planning and delivery of disaster clinical care
- Using de-identified data and mapping CMS data to pre-identify End Stage Renal Disease (ESRD) dialysis dependent populations in the affected area to anticipate and plan for dialysis facility and hospital surge planning and transportation needs
- Identification of facilities that can handle dialysis walk in patients or patients experiencing an exacerbation of ESRD
- The disaster related needs of the ESRD community are now being discussed in the broader emergency management and healthcare preparedness community

EXAMPLES

- In 2015, the ESRD National Coordinating Center's Kidney Community Emergency Response (KCER), in partnership with ASPR, conducted the webinar **Emergency Shelters: Medical Triage Considerations for ESRD Patients** during FEMA's Prepare-A-Thon Service on April 30, demonstrating the enhanced engagement of the ESRD community with public health and emergency management. [16]
- KCER sponsored national level exercises in 2013, 2014, and 2015 that engaged all 18 ESRD Networks. The ESRD Networks engaged large and small dialysis organizations, and State and local emergency management, public health, and utility partners. These exercises engage the whole community approach and have facilitated local partnerships and awareness of the ESRD community needs during disasters. By planning together both emergency management agencies and public health departments can understand any gaps and expectations from local dialysis facilities. Utility companies and dialysis facilities can also plan to communicate about disruptions during a disaster or even disruptions that occur during normal operations. [22]
- Since 2013, CMS and KCER have worked to build stakeholder relationships, specifically engaging federal agencies, kidney associations, large and small dialysis organizations, dialysis supply manufacturers and others. KCER has sponsored national Stakeholder Meetings to discuss current issues, including the KCER Summit, which brings together a wide variety of stakeholders in the ESRD Community to discuss and brainstorm

emergency preparedness and response improvements and to foster new ideas for resiliency and redundancy. [22]

- ASPR and KCER have collaborated on national conference calls and webinars, including the webinar ***Emergency Shelters: Medical Triage Considerations for ESRD Patients*** and the Healthcare and Public Health Sector Coordinating Council Critical Infrastructure Protection Webinar on Dialysis Patients in Disasters (December 2013). [9, 22]
- ASPR, in partnership with CMS, has developed de-identified data and mapping capabilities for dialysis populations at the state, territory, county, and zip code levels as well as facility locations. Both have significantly increased state and local public health ability to anticipate, plan for, and better respond to potential needs in an emergency or disaster. ASPR's mapping system, [GeoHEALTH](#), can [17, 25]:
 - Map the number of persons that use dialysis services at the state, territory, county, and zip code level through the use of the CMS claims data
 - Locations of the facilities from:
 - CROWNWeb Data provided by KCER
 - In the future, ASPR would like to display facility operating status and will work with the ESRD community on that initiative.

ESRD Community Preparedness (KCER, Large Dialysis Organizations, ESRD Networks, Dialysis Facilities)

Key Points

- Emergency response plans and procedures for dialysis facilities that include:
 - Emergency communication plans for facilities
 - Ability to accommodate immediate pre-event dialysis
 - Agreements in place for sharing and moving staff and resources within the same organization, same State, same Network
 - Emergency generator with fuel and fuel re-supply process
- There is still a need for redundant communication to patients, to other facilities, to hospitals, to emergency operations centers, and their networks
- All ESRD Networks and Several Large Dialysis Organizations have developed comprehensive emergency management programs

EXAMPLES

- Large dialysis organizations have engaged in the development of comprehensive emergency management programs that address institutionalizing incident management, creating emergency response teams, both within the corporate management structure and deployable response teams. [21] Supplies, generators, and personnel were all organized and deployed to various communities throughout the Sandy affected area. Fresenius, Medical Care, DaVita, and Dialysis Clinic, Inc. have all developed disaster resources and vendor relationships that can activate in a disaster to support patient treatment.

- KCER, through the ESRD Networks, has developed and delivered training in the following areas **[22]**:
 - Emergency management principles, policies and plan templates
 - Hazard Vulnerability Analysis (HVA)
 - Incident Command System (ICS)
 - Exercises, After Action Report (AAR) and Improvement Plan (IP) with template
 - Pandemic training
 - Terrorism training
 - Viral Threat training
- KCER provided a standardized Comprehensive Emergency Management Plan template to all ESRD Networks, along with Pandemic and Terrorism Annexes. **[22]**
- Government Emergency Telecommunications Service (GETS) accounts were opened and training provided for ESRD NCC and all ESRD Networks to enhance emergency communications capabilities. **[22]**
- KCER takes a leadership role during disasters and shortage events, coordinating conference calls with necessary stakeholders. **[22]**
- KCER has established eight committees that provide their expertise in emergency preparedness and response, such as Nurse Licensure Compact Agreements, Nephrology medical expertise, monitoring of infectious disease and viral threats, review of the CMS proposed Rule for Emergency Preparedness, and incident reporting.
- KCER has developed a Hurricane Katrina 10th Anniversary Commemorative Video with handout that will be released in August 2015. **[22]**
- KCER and the KCER Communication Committee have completed the revision of the “Save A Life” brochure, and await approval from CMS leadership. This brochure was initially created in 2010 to introduce the kidney community to different stakeholders: government agencies (local and state), utility companies, water companies, suppliers and any other partner that would need to understand the serious nature of dialysis and the urgent need for recovery in dialysis.**[22]**

Patient Preparedness

Key Points

- Improved communication with patients in advance of a disaster including:
 - Diet for emergencies and the supplies needed on hand
 - Medical records on hand, including their dialysis prescription, medical records, and medications
 - Where they should go and how they should get there

EXAMPLES

- ASPR has developed three video Preparedness Tips, available via YouTube that address early treatment, prior to a pending disaster, the emergency diet, and preparing a dialysis emergency kit. [5, 6]
- KCER provides information and participates in National Preparedness Month activities and established Kidney Disaster Awareness Week in the fourth week of September. Preparedness materials and messages are sent to the ESRD community each day of the week (four days of adult material and one day for children). [22]
- Disaster-related information for patients and providers is being developed and promulgated by numerous sources. KCER has remodeled their website to be more client-focused and both patients and providers can access critical disaster preparedness information within 1 or 2 mouse clicks, including information translated into Spanish. [22, 24]
- KCER is currently revising the CMS Booklet, Preparing for Emergencies: A Guide for People on Dialysis. [22]

Hospital ED Preparedness

Key Points

- PReparing Emergency Personnel in Dialysis (PREP-D) is a just-in-time training program designed for healthcare personnel with limited experience or knowledge of the basic steps of dialysis to support routine dialysis staff during a disaster
- Emergency supplies for dialysis included in routine disaster caches

EXAMPLES

- In a study conducted by Adalja, Watson, et al., [1] the authors used a qualitative, interview-based method to study medical surge strategies used at hospitals receiving patients from evacuated healthcare facilities during and after Hurricane Sandy. One gap noted was a challenge associated with the increase in the number of dialysis patients and planning for the influx of these patient populations is critical.
- KCER developed and held training webinars for healthcare providers not formally trained or experienced in dialysis care, entitled **Emergency Preparedness and Response for the Dialysis Community: What You Need to Know!** [13]
- Authors Stoler, Johnston, et al., [14] detailed a collaborative, multi-disciplinary 5-module training program called PReparing Emergency Personnel in Dialysis (PREP-D), developed to provide just-in-time training for healthcare personnel with limited experience or knowledge of the basic steps of dialysis to support trained dialysis staff for surge in a disaster.

- Authors Lempert and Kopp [3] reviewed lessons learned from Hurricane Sandy as a kidney failure disaster and identified the following recommendations for healthcare facilities: preparedness to handle the influx of ESRD patients, transportation plans to assist patients in accessing dialysis, coordination with local dialysis facilities to potentially share medical records.
- In a study conducted by Lin, Pierce, et al., [4] the authors conducted a retrospective study on hospital dialysis services provided after Hurricane Sandy. They found challenges with: lack of dialysis documentation from transient dialysis patients (92.3%), staff shortage (50%), staff transportation (71.4%), and communication with other agencies (53.3%). The authors identified the following capabilities aided in successful dialysis surge events: having a larger inpatient dialysis unit, an associated outpatient dialysis center within the same health system, having extra dialysis machines in house, and just-in-time trained or extra workforce.

Clinical Advancements

Key Points

- Early dialysis, in advance of a storm or other potentially disruptive event can reduce morbidity and mortality in ESRD patients
- Guidance for the rationing of critical supplies was developed by Institute of Medicine (IOM) (now called the National Academy of Medicine) and now adapted by the Association of State and Territorial Health Officials (ASTHO)
- Guidance for the use of water from tanker trucks and other non-public water sources has been promulgated for use in the event of a utility disruption
- Widespread use of the 3-day emergency diet

EXAMPLES

- In a study conducted by Kelman, Finne, et al., [2] the authors evaluated the storm impact to ESRD patients. Nearly half the study group patients received early dialysis prior to Sandy's landfall, however there were still increases in ED visits, hospitalizations and 30-day mortality among the study group, but not in comparison groups. An article by McGinley [28] quantified the cost of post-disaster hospital dialysis visits, "After Hurricane Ike, it was estimated that the cost of ESRD patients presenting to the ED for dialysis instead of their usual facility was, on average, \$6,997 per visit. Those ESRD patients who did not require dialysis were billed \$482 on average."
- Lurie, Finne, et al., [20] conducted a retrospective cohort analysis, using claims data from the Centers for Medicare and Medicaid Services Datalink Project. The authors found that patients who received early dialysis had 20% lower odds of having an emergency department visit or 21% hospitalization in the week of the storm and 28% lower odds of dying within 30 days. ASPR released this data along with recommendations to dialysis facilities to schedule early dialysis when possible prior to a storm or other disaster, when warning is available.

- In a study conducted by ASPR [7], the authors conducted an emergency drill and found that Medicare claims data was 93% accurate in identifying individuals using a home oxygen concentrator or ventilator. Authors concluded that the drill findings suggest claims data can be useful in improving preparedness and response for electricity dependent populations. HHS recently released the [emPOWER](#) mapping program that allows emergency managers and public health officials access to de-identified claims data to determine the population affected by utility failures.
- In an editorial authored by Hick, Hanfling, Courtney and Lurie, [8] the authors applied the emergency management cycle to supply shortage decisions and discuss the recent adoption of key stewardship actions, such as sharing, conserving, substituting, adapting, reusing, and reallocating. These are the key components of the IOM's standards of care guidelines for catastrophic emergencies and have been adapted by ASTHO for use during drug-shortage events, including the recent peritoneal dialysis solution shortage.

Legislative and Regulatory

Key Points

- A number of statutory and regulatory changes have been made since Hurricane Katrina that directly and indirectly affect the ESRD community.

EXAMPLES

- CMS issued a Final Rule April 15, 2008 that addressed numerous changes to their regulations, however a number of changes were made as a direct result of lessons learned in prior disasters, specifically Katrina and Rita. [29] (We have highlighted the changes in a separate summary document, attached.)
- CMS has a Proposed Rule currently in review that will expand the covered entities required to have emergency preparedness capabilities.
- The Pandemic and All Hazards Preparedness Act was enacted following Hurricane Katrina and among numerous changes to the Public Health Preparedness national landscape, the law requires planning for and coordination of the needs of at-risk individuals, including those with medical needs. [31,32]
- The Post Katrina Emergency Management Reform Act of 2006 specifically establishes a Disability Coordinator and developed guidelines to accommodate individuals with Disabilities, Access, and Functional needs, of which the ESRD community is included.[30]

Challenges and Future Areas for Engagement

There are three specific challenges for the ESRD Community in disasters – transportation, incident reporting, and interoperability of data.

Transportation

Patients use various methods to get to and from regularly scheduled dialysis appointments including private vehicles, local or state regulated Medi-vans and paratransit vehicles, public

transportation and other mechanisms. During a disaster, any or all of these mechanisms can become disrupted or unavailable due to cancellation of services, blocked or inaccessible roads, unavailability of drivers and other issues. These are primarily personal, local, or possibly State regulated issues and are challenging for the ESRD Networks and community to solve. Large dialysis organizations, providers, and patients do not control many transportation issues, therefore networking and pre-planning with the transportation sector in advance of a disaster is critical to ensure the ESRD community needs are addressed once a disaster strikes. [22-25]

Incident Reporting

During an emergency, information gathering is critical to support accurate decision making. Creating a standard Emergency Status Report, at the national-level would help standardize the data collection needed to determine the operational status of the ESRD Network in an affected community. Creating an electronic data gathering system with standard definitions for the following could create a real-time operational status board to support decision making:

1. Patient Census
2. Facility Status - Open
3. Facility Status - Closed
4. Facility Status - Altered schedule
5. Facility Status - Increased shifts at facility

Interoperability of Dialysis Patient Data

Studies have shown that during an emergency, patients will commonly seek access to dialysis care at any open facility or in the hospital. Unfortunately treatment can be delayed due to a patient not having a current treatment plan, hepatitis status, list of medication, and or any lab data. In many situations patients will commonly show up without knowing the name of their facility or have any information. The lack of information causes hospitals to have to conduct testing to develop a “just-in-time” dialysis plan that also can stress a hospital that is already responding to an emergency. Accordingly, enhancing interoperability of dialysis data between at dialysis facilities, hospitals, providers and labs would increase the ability of all to ensure continuity of care during an emergency. [4, 20]

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