Commentary

Genetic/metabolic health care delivery during and after hurricanes Katrina and Rita

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Abstract

Provision of health care to patients during and after events like those which occurred in association with hurricanes Katrina and Rita poses particular difficulties for rare disease patients, including those with genetic/metabolic diseases. In this summary, we recount the obstacles encountered in attempting to maintain and restore essential medical care to these patients, and offer proposals which may mitigate future such events.

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Background

Louisiana has three academic centers that have clinical genetics programs: Tulane, LSU, and LSU-Shreveport. Tulane and LSU, both centered in New Orleans, have outreach programs sited in public health clinics where genetics patients are seen, and where samples for laboratory testing are obtained. Tulane’s responsibility includes clinics in Baton Rouge, Alexandria, Lafayette, Hammond, and the major site at the Tulane/HCA facility in New Orleans. At that site the Hayward Center operates a typical biochemical genetics laboratory, performing analyses for amino acids, organic acids, carbohydrates, and various other specialized tests. The sample volume is about 2000/year. Adjacent to that is a cytogenetics and molecular lab that serves the needs of other genetics patients. Patients are referred from across Louisiana and the southeastern region, and in some cases travel considerable distances to be seen.

In Louisiana, the Office of Public Health provides support for patients with inherited metabolic disease. This includes coverage for the cost of formula, medications, clinical visits, and most laboratory testing. Formula and medications are dispensed from the Louisiana State Genetic Disease Program, which is housed in New Orleans, to health units throughout the state. In addition, this program is responsible for follow-up to newborn screening. The Louisiana Newborn Screening Program is also located in New Orleans. This system centralizes a hub of genetics care in the New Orleans area that serves the entire state.

On August 29th, 2005, hurricane Katrina came ashore as a Category 4 hurricane, passing over the city of New Orleans. Hurricane Rita followed closely, flooding a primary evacuation area, and further hindering recovery efforts. In their aftermath, close to 1000 people are known dead in Louisiana, and essential services, including provision of medical care, were disrupted. Communications within New Orleans and the southwestern Louisiana areas were severely compromised.

Many of the Tulane genetics personnel took shelter in the Medical School, which had proven to be a secure haven during previous hurricanes. The usual expectations for hurricane evacuation include dislocation for 3–5 days, and preparations were based on that premise. After Katrina
passed, the building lost power, but was structurally intact, and the people sheltering there anticipated a brief stay before returning home, and resuming work. However, when storm surge into Lake Ponchartrain caused the 17th St and Industrial Canal levees to fail, the city flooded, and genetics personnel were trapped in the medical school, ultimately being evacuated by helicopter from the top floor of the parking garage 4–5 days after Katrina. At this time, cell phones in the 504 area code were non-functional, due to loss of cell towers, and an enormous volume of calls which overwhelmed the residual capacity. The Tulane computer servers were also down for over 4 weeks, eliminating email and internet as means of communication. The result was an inability to communicate with each other, or with our patients.

**Problems in providing genetic care after a major catastrophic event**

In this context, the challenges were: (1) to find the members of the Tulane Center, (2) to contact our patients, (3) to arrange for alternative laboratory testing, and (4) to provide critical drugs and formula for our metabolic patients. This task was complicated by failure of essential services at many levels that rendered travel unsafe due to diminished police presence, and uncertain, due to shortages of gasoline, potable water, and traversable roads. Further complicating recovery was lack of housing for people, including medical personnel, in the affected areas.

The immediate task was to locate one another. This took approximately 1 week. As those of the Center who had evacuated from the affected area emerged, many purchased new cell phones in different area codes, which provided a reliable means of communication, but no easy way existed to inform each other of the new number. The same process hampered the use of alternative email systems, as members quickly signed up for Yahoo, Hotmail, and other providers, with no means to inform each other of the new email addresses.

One early solution came in the form of text messaging, which functioned even though telephone service in the area did not. Sending new contact information by text messaging to people still in the 504 area code made it possible to re-establish viable phone contact with people outside the region. Contact was greatly assisted by a series of conference calls mediated by the SouthEastern Regional Genetics Group, which allowed the Center personnel to regroup and plan on a weekly basis.

Within 7–10 days almost all Center personnel were located, and a core of members still in Louisiana had begun the process of patient identification and location. This was greatly facilitated by one member (A.C.) who had previously established a list of metabolic patients and their contact information which was retrieved from another center member’s laptop. Despite having no access to patient or treatment information contained in patient charts or on medical school computers, we were able to begin contacting patients the day after the hurricane to assess their location and immediate needs. HIPPA issues did not arise as only members of the Tulane genetic clinic or authorized referral laboratory personnel were involved.

Patients were triaged by metabolic status, diagnosis, age, and location—contacting each by phone or e-mail. A new database containing formula and medication dosages, estimated time before more would be needed, and new contact information was compiled. The nutritionist contacted formula companies, while the physicians contacted possible sources of medications and dispensing pharmacies. FEMA assisted by providing emergency approval to pharmacies for purchase of critical medications. As each patient’s status was assessed, these sources were contacted and asked to ship emergency supplies.

Metabolic nutritionists rely on a national professional list-serve sponsored by Emory University Department of Genetics. Through this list-serve, and the PKU and OA (Organic Acidemia) family list-serves, patients who had evacuated to other states were found, referrals to other genetic centers for dislocated patients were made, and family-to-family sharing of metabolic formula and medications was coordinated. Contact was also made with nursing and nutrition staff at the state health units where the patients are normally seen, and they were invaluable in locating patients and arranging for care. The Director of the LA Genetic Disease Program was located, and work was begun to coordinate with him regarding ongoing Newborn Screening follow-up and emergency protocols for sending laboratory samples for analysis.

The geneticist on call at the time of Katrina was evacuated by helicopter to Louis Armstrong airport, and then to Lafayette for decontamination. Once in an area with stable services, communications were quickly restored to permit consultations with the core clinical faculty outside the disaster area. The local library offered free high speed internet, which made it easy to quickly establish a group (Hayward_Genetics_Center_at_Tulane@yahoogroups.com), which served as a quick means of disseminating information.

The state health unit staff were reassigned to shelters around the state to deal with the unprecedented numbers of refugees. A clinic at Lafayette Women and Children’s Hospital (W&C) was able to continue operations and permitted us to see genetics patients there.

The State Pharmacy in New Orleans normally supplies citrulline, biotin, hydroxycoabalin, and other medication required by metabolic patients free of charge, however, it was incapacitated by Katrina. A specialty pharmacy in Lafayette able to meet these patients needs’ was identified.

Three of our patients required hospitalization. One patient with MSUD suffered a ruptured appendix immediately after Katrina. The second patient was a newborn with cobalamin responsive methylmalonic acidemia, who was admitted to the University of Mississippi at Jackson. The third patient was a 10-month-old female with citrullinemia who developed an infection around her g-tube (Escherichia
coli). She was admitted to W&C for nasogastric administration of her urea cycle medications, and a 7-day course of iv antibiotics. All three patients recovered and are doing well.

Rare disease patients are disadvantaged, often living in areas remote from appropriate care providers, lacking availability of, or accessibility to specific medicines, and lacking information about their conditions. In this sense, they are similar to common disease patients in third world countries, even though they are located in the United States [1]. These problems are exacerbated during a mass catastrophe such as witnessed during the Katrina/Rita episode. There were no providers, no access to lab tests, and no essential medicines. For a while, courier service, on which the “send out testing” and medicine and food delivery depends, was unreliable. With the assistance and good will of many in the genetics community, our Center worked to re-build genetic care in Louisiana. Emergency formula distribution was arranged with assistance from the manufacturers and distributors. Private pharmacies were identified who were willing to provide medications. Alternative sources for laboratory analyses, and protocols for sending samples were distributed to sites unaccustomed to this activity. In addition, we have diagnosed and began treatment for one PKU patient identified by newborn screening, and are in the process of determining the status of several individuals with putative positive galactosemia results.

Louisiana was uniquely impacted by this disaster because of the centralized provision of genetic services from the medical schools and the state programs—all housed in New Orleans. Because of this, the hub of genetic services upon which Louisiana patients depend was abruptly ablated.

Proposed solutions

Communication

The first element that must be restored post disaster is communication among health care personnel, and then between providers and patients. Redundancy of services and methodologies is essential to restore and to maintain communication. Two geographically distinct nodes within each region that can each establish a matrix of people with their working phone numbers and email addresses will ensure that at least one regional node will be unaffected by a catastrophe. This would be greatly facilitated by a previously established 800 number to which both patients and providers could be directed in the case of an evacuation or catastrophe. An easily remembered number—we suggest 1-800-911GENE would be staffed by people who would take relevant locator information from health care professionals and patients and make appropriate referrals and contacts.

Other methods of communication include ad hoc internet networks that can utilize a dedicated laptop with satellite wireless access to communicate with Voice-over-Internet-Protocol (VoIP), email and web site postings. This dedicated laptop could serve as a central communications node and be powered by accessory sources such as car electrical systems and portable generators. A radio transceiver, such as citizen band or ham radio could also be powered by accessory sources and would not require additional infrastructure for effective communication.

Backup laboratories

Specialty laboratories are the life blood of metabolic clinics. The National Institutes of Health made initial contact with us after the hurricanes and assisted us in contacting referral labs. Laboratories at the University of Maryland, The Children’s National Medical Center, and the University of Miami agreed to temporarily accept samples for monitoring the metabolic status of established patients, and to confirm putative positive newborn screens. The Louisiana OPH contracted with Iowa to resume newborn screening. This ad hoc arrangement worked well, but required a significant amount of coordination to arrange while coping with dislocation of staff and a disabled communication structure. A master plan with a hierarchy of laboratories willing to accept samples, initially at no charge, and distributed throughout the USA so that intact laboratories could be found regardless of the location of the catastrophe would appear to be an idea worth discussion. Trial runs to implement the plan and work out the logistics are clearly needed.

Orphan therapeutics

Medical foods and orphan products are sometimes difficult to obtain even under normal circumstances. The suppliers we contacted were uniformly anxious to help, cutting through red tape and ensuring un-interrupted supplies of various metabolic formulae. Nevertheless, as with the laboratory situation described above, a pre-existing plan with a pre-positioned stockpile of these items, in a central location, with dedicated courier service to ensure delivery to the correct location would mitigate some of the problems encountered. These would include metabolic formulas, treatments for urea cycle disorders (Buphenyl, Ammonul, Arginine, and citrulline) organic acidemias and aminoacidopathies (carnitine, B12, biotin, tetrahydrobiopterin), and Cystagon to treat cystinosis. Identifying dedicated pharmacies in all counties/parishes to provide products for neighboring regions would facilitate rapid access to rare and occasionally expensive medications.

Emergency patient instructions

Timely re-establishment of genetic services following an evacuation or catastrophe must include predetermined instructions for patients to follow. When communications have broken down, patients must be aware of a standard protocol for re-establishing access to care and medications. These written instructions should include contact numbers...
(e.g., 800-911-GENE), web addresses for further instructions and contact to their displaced caregivers, and a list of central pharmacies and medical centers where they can access care. Patient ID bracelets and durable (plasticized) treatment protocols could educate providers who are unfamiliar with the patients and their disorders.

**Personnel hierarchy**

A pre-determined hierarchy of responsible individuals in each region should be established with co-directors in separate regions who can activate the emergency response for genetic patients and centers. The hierarchy must be regional, subregional, metropolitan, and center-wide with a clear plan on the roles and responsibilities of each unit. Then units can then be further coordinated through the centralized communications centers (websites, telephone numbers, etc.).

**Summary**

In the broader context of a mass disaster it may appear to some that inordinate resources are required to care for these complex patients. That is precisely why planning and pre-intervention is required: the system is geared to the most common injuries and disabilities. Until now, no one has considered the special problems presented to such rare disease patients under such dire circumstances. Proper planning may afford significantly improved recovery after a national disaster with actual cost-avoidance because ICU admissions due to uncontrolled hyperammonemia or acidosis will be averted, as well as avoidance of remedial costs from the occurrence of preventable disabilities.

**Reference**