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Insuring continuity of care for chronic disease patients after a disaster: key preparedness elements

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Abstract

Background—Care for patients with chronic diseases is a challenge after a disaster. This is particularly true for individuals from health disparate populations as they are less likely to evacuate, have less financial resources and often depend on resource-strapped institutions for their care. The specific aim of the study presented here was to elicit challenges and solutions in the provision of health care to those with chronic diseases after Hurricane Katrina in coastal Alabama and Mississippi.

Methods—Focusing on agencies providing care to health disparate populations, a qualitative methodology was employed using in-depth interviews with health and social service providers. Participants identified key elements essential to disaster preparedness.

Results—Pre-disaster issues were patient education and preparedness, evacuation, special needs shelters and health care provider preparedness. Post-disaster issues were communication, volunteer coordination and donation management.

Conclusions—Lessons learned from those on the ground administering healthcare during disasters should inform future disaster preparations. Furthermore, the methodological approach used in this study engendered collaboration between healthcare institutions and may enhance future inter-agency disaster preparedness.

Keywords

disaster preparedness; chronic disease; continuity of care; health disparity; Hurricane Katrina

INTRODUCTION

Disaster preparedness and response models prior to Hurricane Katrina were grounded in the perceived risk of (bio)terrorism as the major potential threat to public safety and stressed preparation for mass casualties. Tertiary health care (Emergency departments and hospitals) is the critical piece in the response to such threats.¹ Hurricane Katrina was indeed responsible for an increased death toll in affected areas,^{2, 3} but the major brunt of its effects was in the destruction of infrastructure (homes, businesses, health care) and the internal displacement of residents.^{4, 5}

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Providing continuity of care for chronic diseases to affected and displaced persons became a major challenge post-storm.^{5–12} The proportion of Katrina affected persons with 1 or more chronic illness diagnoses was estimated between 41%⁶ and 74%,¹¹ whereas an extreme increase in mental illness was also observed.^{11–20} Against such a scenario, primary, rather than tertiary, care is posed as the most effective health care model to meet many patient needs.⁷ The safety net infrastructure of community health centers (CHCs), tasked with providing medical care to the under or uninsured, is the cornerstone of primary care delivered to health disparate populations.²¹

The Gulf Coast's CHC infrastructure was severely damaged in the aftermath of Katrina.^{18, 22, 23} While most CHCs already had and regularly updated disaster preparedness plans,^{24, 25} most of these plans did not include strategies for handling a substantial surge of patients and other chronic disease management challenges. Chronic diseases that required significant attention after Katrina included mental health, diabetes mellitus, hypertension, respiratory illness, end-stage renal disease, cardiovascular disease, and cancer.²⁶

Providers on the “front-lines” after the storm have a wealth of knowledge regarding procedures and strategies that allowed them to respond to the disease management needs of the local and influx patients. We capitalized on the experiences of such safety net medical providers by documenting key elements for the revision and expansion of disaster preparedness models in primary care. We specifically focused on CHCs as they provide care to the populations most at risk for health disparities.

METHODS

We hypothesized that a network approach to chronic disease management would be best in the aftermath of a disaster like Katrina, especially for health disparate populations. We utilized a qualitative methodology that would begin building this collaborative network by bringing providers together to discuss issues during data collection. The study methodology has been described in-depth elsewhere.²⁶ In brief, data were collected in 3 phases from July 2006 to June 2007. In Phase I (July – October 2006), 30 key informants (KI) were interviewed, including health and social service providers from 14 Mississippi and Alabama hospitals, community health centers, pharmacies and HIV/AIDS support organizations. We specifically selected agencies that provide healthcare to the under and uninsured along the Mississippi and Alabama Gulf Coast. In-depth interviews were semi-structured to glean information about chronic disease management issues and solutions.

In Phase II of data collection (November 2007), selected KI (n = 11) formed an Advisory Panel. Phase II served as a “member check,” giving participants the opportunity to summarize preliminary findings, correct misinterpretations and volunteer new information. Phase I data were then analyzed for emerging themes using Atlas.ti software.²⁷ The authors drafted an exhaustive report describing findings, which was circulated among all KI and other external consultants during Phase III (May – August 2007). Their comments and recommendations were incorporated into the final report.

As the ultimate goal of the project was to facilitate improved care of patients with chronic diseases after a disaster, the report was disseminated to KI and key policy and decision makers for emergency preparedness and healthcare along the Mississippi and Alabama Gulf Coast, as well as to the local press.²⁶

RESULTS

Critical pre- and post-disaster fundamentals discussed by study participants are summarized in Table 1. It is important to recognize that response within the first 48 hrs after a disaster is likely to come almost exclusively from institutions indigenous to the disaster area.

Pre-Disaster Fundamentals

Patient education and preparedness—KI emphasized that disaster preparedness should become ingrained in the fabric of Coastal communities via consistent channels to insure that residents have the knowledge necessary to prepare for severe weather endemic to the area. They stressed that standard literature dissemination was ineffective and that more innovative methodology was necessary. For example, disaster preparedness principles could be introduced early and reiterated frequently if incorporated into K -12 school-based curriculums.

KI also pointed out the important role health providers can play in educating chronic disease patients on avoiding interruption of medication regimens. A major concern was the lack of patient's knowledge of their prescription medications. Preparation training must emphasize the need for keeping portable (waterproof hard copy, CD, DVD, jump drive) medical and medication records, as well as a stockpile of at least a 10–14 day supply of medications (preferably one month). KIs also recommended that patients link prescriptions to at least one large franchised pharmacy with a central electronic database and distribute copies of medical information to trusted family or support agencies. In addition attention must be paid to special dietary needs, and the safe storing and packing of important documents.

The ability to obtain advanced prescriptions—which would facilitate patients' stockpiling of medication when a disaster is anticipated—was also considered an important element in disaster preparation. Participants suggested that public and private insurance regulations limiting the frequency of refills should be temporarily relaxed in communities likely to be affected by a natural threat. However, the group also acknowledged that not all patients would make appropriate use of an extra supply of medicines stocked pre-disaster.

Evacuation—Key Informants also addressed the vital role of patient evacuation, particularly for special populations: patients on dialysis and/or in nursing homes, hospice and assisted living. If not evacuated, these patients often require special needs shelters or turn to local hospitals that have severely limited resources. KI stressed the need for institutions caring for special populations to have a defined disaster plan in place, including exact knowledge of to where patients may be evacuated (eg, mutual aid agreements), as well as an evacuation transportation system. Such provisions should be legally mandated.

Many members of health disparate populations, especially those who lack personal transportation, have difficulty planning for evacuation. Moreover, language, cultural beliefs and strong community ties such as those among the Vietnamese, Laotian, and Cambodian communities of the Gulf Coast create barriers to evacuation. It is necessary to establish linguistically and culturally sensitive transportation plans to aid those without resources (eg, Greyhound buses, public transportation). Evacuation should be facilitated through improvement or expansion of evacuation routes and ensuring a continued supply of fuel on routes—gas stations should be required to have generators and remain open as long as fuel is available.

Communication between health care facilities will insure that patients who need to be evacuated reach institutions that are ready to care for them. Mutual aid agreements are needed to secure such arrangements. Information Technology solutions, such as the Alabama Incident Management System - a web-based forum through which facilities can communicate their

patient, personnel and supply capacities in real time²⁶—can also greatly enhance the ability of facilities to communicate at all stages of disaster response and ensure that patients are evacuated as close to home as possible.

Special needs shelters—Also prominent among KI suggestions were the establishment and operation of special needs shelters, designated for people whose age, frailty, mobility, functional or medical disability make them vulnerable in disaster situations.²⁸ KI provided explicit advice on operational aspects of special needs shelters (Table 2). It is important that information regarding shelter location and rules of entry are distributed widely and reviewed periodically. Providers should educate their patients who may need these shelters and stress the importance of pre-registration, if available. Patients should then determine what to bring with them, usually durable medical equipment (eg, walkers, wheelchairs, oxygen tanks), medications, and a caretaker.

Emphasis was given to special needs shelter staffing and training. In some localities there are now plans to have a minimum of five key, paid personnel on-site: environmental services (team leader), medical staff (nurse practitioner with a physician on call), clerical staff (record-keeping) and a social worker (discharge planning). KI stressed the need for proactive discharge planning, (both for special and mass care shelters) as in many cases, shelters lacked 1) plans for transfer of special needs patients to appropriate care facilities after the storm, 2) resources to ascertain whether patients' homes were viable before the patient was discharged, or 3) transportation to facilitate their return home.

"...We're...staffing the medical needs shelter with... social workers who will...do a full assessment of the patient upon admission... [We will ask], "Where are you going to go? Do you have a place to go back home?" So our hope is to [create] an actual medical record at the shelter for each patient so we already know, "This patient can go home as soon as the power company tells me the power is back on." Key Informant Transcript (KIT) 14:4

Health care organization preparedness—KI acknowledged that their experiences after Hurricane Katrina should help to formulate effective preparedness plans.

"I think you need really clear-cut policies on what to do in every area...when to call, where to go, if this building is destroyed, we will do this, this is our secondary plan... I think you need concrete policies in place. And having been through this disaster, there's no reason why you can't have concrete policies, based upon what we've already experienced. So that doesn't mean we will (not) experience something (new) next time (but) at least we can cover what we know." KIT 10:80

They also stressed the value of well articulated plans that can be rehearsed and implemented, and believed that preparedness holds the key to an appropriate response in a disaster.

"We had an excellent staff, [but] the details of the plan really made a difference. The highest [level] is the national emergency plan... you have all these people designated to operate the various departments and that really worked... everybody knows you have your Incident Command Center, your commander, your operational chief, your different chiefs... That way you know who to call and who to contact for what... because they have very specific job actions... Our staff is very well educated on our plan. We have drills quite often. When you have a drill... it does not really seem live, but people perform at such a high level when it is the real thing. It's kind of like a war zone. People can go and (perform their roles)...and it's just kind of automatic." KIT 25:12

However, preparedness levels are not uniform across institutions. Some organizations are still wrestling with recovery issues, and may not have the resources—financial, human capital, and time—to invest in disaster preparedness.

Post-Disaster Fundamentals

Communication—Immediately after Hurricane Katrina, communication was severely limited, impacting interactions between providers, providers and their patients, and provider agencies and governmental agencies. Word of mouth was often the only form of reliable interaction. Personal cellular phones were used for work communication, frequently limited to text messaging due to cell tower outages. Although some hospitals and CHCs recognized the usefulness of satellite phones; however, their staff often did not know how to use them. Recommended solutions for improving provider—patient communication post disaster are presented in Table 1.

System-wide information dissemination and coordination: Post Katrina, the collapse of the communication infrastructure made it difficult or even impossible for entities both within and outside disaster-affected areas to coordinate activities. Participants repeatedly iterated that improved communication was the key to the coordination of health and social services and to the efficient use of limited available resources.

While local Emergency Operation Centers (EOC) are usually tasked with coordinating activities in all sectors, participants suggested that the medical sector should remain in constant contact with, but separate from, the EOC (eg, move to the local health department). It was their feeling that a local group would be more efficient in coordinating medical relief efforts. This local group would also create (preferably pre-disaster) an electronic registry of all local public health providers, public mental health providers, clinics, pharmacies, agencies, faith-based organizations, social services agencies and churches that provide care and services for the chronically ill. Effective coordination from this local entity would help prevent the duplication of services, improve the distribution of incoming medical supplies and medications and allow both local and external entities to collaborate instead of compete.

Volunteer coordination—Post-Katrina, a surge of nurses, physicians, pharmacists, allied health professionals and lay persons came to the Gulf Coast to volunteer their time and expertise. Volunteers were vital to relief efforts in the immediate storm aftermath and for many months thereafter. Opportunities noted by participants to maximize volunteer efforts included better coordination among the volunteer and local groups and credentialing of volunteers to maintain public trust in services.

Key Informants felt that the invaluable support provided by health care volunteers needs to be integrated within a framework that strengthens the ‘host’ health care system. It was observed that many unaffiliated individuals arrived on the disaster scene without clear directives and sometimes without the supplies needed to be self sustainable. Pre-registration with sanctioned volunteer groups is one solution. Another is the pre-disaster selection and training of local volunteer coordinators to oversee that incoming volunteer organizations register with a central local agency and describe their plans so efforts across organizations can be coordinated.

Credentialing of Healthcare Volunteers: Healthcare is highly regulated, with healthcare providers having to meet societal, state and national standards and requirements of licensure. Our participants raised concerns that aptly trained professionals could not be used most effectively because of the lack of an efficient credentialing process for nurses, doctors and others from out of state. Credentialing volunteer healthcare providers should occur in a timely fashion so as not to delay relief efforts. On-line registration of volunteers pre-storm would

greatly improve this process, as Alabama is now doing. Fees to credentialing bodies should be waived to facilitate ease of entry and eliminate disincentives. However, credentialing was thought to be critical as a quality control. A formal system to verify credentialing would 1) provide a means to assess whether volunteers are formally trained to provide medical services and 2) insure that authorized personnel could shut down individuals or clinics lacking proper licenses.

An unexpected suggestion from KI was that volunteer healthcare providers and organizations should be mindful of how long they remain in the area. They felt strongly that some agencies “overstayed” their welcome and delayed the return to normalcy that the area desperately needed. In many cases this also delayed the return of patients to their usual providers as they found free medicines and care at some of the volunteer clinics. A central credentialing and coordinating effort would also alleviate this problem: volunteers would be matched to the needs of the local system and relocated when regular providers returned.

Management of donations—Post- storm, there was a large influx of donated medical supplies. Such donations were critical as stockpiling medications pre-storm was both cost-prohibitive and even impossible for clinics due to time constraints as the storm approached. Moreover, clinics that did have stores of medications often lost their surplus to water damage or lack of refrigeration. KI identified several opportunities for improved efficiency and coordination of donations. While some KI did receive helpful donations of medication, most providers—many cut off from communication channels—reported receiving large quantities of un-requested and unsorted medications from unidentified sources. These medications were often expired, very close to expiration, or in some cases, half-used personal prescriptions. In other instances, providers received a surplus of medications and supplies, but lacked sufficient storage space.

Clearly, there is a need for better coordination of donated medications, to ensure that providers get the types and quantities of medications they need. KI formulated the following recommendations: 1) Establish pre-event relationships with potential donors, so donors understand the services provided by local organizations and the type of supplies that will be needed, 2) Insure back up communication with donors post-storm, 3) Network with local healthcare organizations to foster understanding of local needs, 4) Establish a local community-based group to coordinate the collection and distribution of healthcare supplies and medications, 5) Keep records of response time to supply request to inform future disaster planning, 6) Encourage donors to check medication expiration dates before shipment.

CURRENT CONDITIONS AND CONCLUSIONS

The institutions that participated in our study continue to care for the underserved population of the Alabama and Mississippi Gulf Coast. They are in varied states of preparedness for the next disaster, but all are acutely aware of the importance of developing a plan. Through this qualitative study, the group was able to reach a consensus on the most pressing issues to provide care for chronic diseases after a natural disaster. These issues are: availability of medication for patients, patient preparedness and self awareness of medical information, ability to access medical information, coordination of aid efforts, and communication and collaboration among indigenous institutions and private and public aid institutions.

CHCs’ key role in post-disaster health care was made evident by Katrina, and in some sectors, their importance in state-wide efforts to formulate response plans for the future is now being recognized. The exercise of the study enhanced communication between the groups involved. Area hospitals and CHCs are now more aware of the information technology available to facilitate evacuation and there is increased knowledge regarding resources available across the

region. While our goal was to develop a tangible network to assure post-disaster care of health disparate populations with chronic diseases, it is too early to tell if centralized coordination of efforts and the enhanced communication systems are in place. Standard policies should be enacted and reviewed regularly to ensure that the benefits of the collaborations formed and ideas exchanged through this exercise will be realized.

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Table 1
Pre- and post-disaster fundamentals identified by key informants.

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| <p>Pre-disaster</p> <ul style="list-style-type: none"> • Patient education and preparedness Basic safety information; awareness of health care options; location of shelters; improved health literacy regarding medications; communication regarding stocking special dietary needs and medications • Evacuation Communication regarding contents of evacuation "Kit," including medications; transportation options for the indigent; plan for special populations (eg, dialysis, nursing home); culturally and linguistically appropriate public announcements • Special needs shelters Widely distribute location and requirements; pre-register patients; train staff and hold drills • Health care provider and organization preparedness Back up medical records; stockpile necessary supplies, both basic (food, water, batteries) and medical (eg, trauma and emergency kits, medication kits including generic chronic disease medications); insure communication capabilities within and between organizations post-disaster; address health care staff needs, as they are also personally under the duress of the disaster situation; develop strong local networks across institutions responsible for disaster response and recovery, health care support institutions (ie, pharmacies) and community-based support and relief organizations |
| <p>Post-disaster</p> <ul style="list-style-type: none"> • Provider-patient communication Collect multiple means of emergency patient contact information, including one contact outside the local area; record patient disaster plans (eg, where they might seek shelter); use multiple media outlets (eg, TV, radio, internet) to disseminate information both pre- and post-disaster; establish a 1-800 number outside the local area for patient use; train staff on the use of emergency communication devices and on their expected role in disaster through frequent drills; disseminate medical/medication information at basic needs distribution points • Volunteer coordination Maintain registry of volunteers and match them with local entities (conducted at designated local entity charged with medical relief); ensure timely credentialing of healthcare volunteers and waive or reduce fees • Management of donations Funnel medications and medical supplies through designated local entity charged with medical relief; improve communications between donators and local groups (when possible, pre-disaster); discourage sending of expired medications; utilize local networks to share surpluses |

Table 2

Important considerations identified for special needs shelters.

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| • | <i>Establishment of facility</i> | Secure appropriate power supply; stock anticipated medical/general supplies; transportation plan for patients who cannot access the shelter on their own |
| • | <i>Gauge needed capacity</i> | Identify members of population who will need facility and seek alternate solutions if capacity is inadequate |
| • | <i>Inform Public (focus on likely users)</i> | Define and publicize criteria for entry; create pre-registration mechanism for potential users; send letters to potential users instructing them on locations of shelters and what they need to bring |
| • | <i>Staffing</i> | Formal health care personnel rather than volunteers; staff should be scheduled and trained well in advance |
| • | <i>Discharge planning</i> | Should start immediately after storm; develop plans if unable to return to destroyed or uninhabitable homes |
| • | <i>Other issues</i> | Keep records of care provided; individuals with special needs should be accompanied by a caretaker in most instances |