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Providing Continuity of Care for Chronic Diseases in the Aftermath of Katrina: From Field Experience to Policy Recommendations

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Abstract

This study sought to elicit challenges and solutions in the provision of health care to those with chronic diseases after Hurricane Katrina in coastal Alabama and Mississippi. In-depth interviews with 30 health and social service providers (key informants) and 4 focus groups with patients with chronic diseases were conducted. Subsequently an advisory panel of key informants was convened. Findings were summarized and key informants submitted additional feedback. The chronic diseases identified as medical management priorities by key informants were mental health, diabetes mellitus, hypertension, respiratory illness, end-stage renal disease, cardiovascular disease, and cancer. The most frequently mentioned barrier to providing care was maintaining continuity of medications. Contributing factors were inadequate information (inaccessible medical records, poor patient knowledge) and financial constraints. Implemented or suggested solutions included relaxation of insurance limitations preventing advance prescription refills; better predisaster patient education to improve medical knowledge; promotion of personal health records; support for information technology systems at community health centers, in particular electronic medical records; improved allocation of donated medications/medical supplies (centralized coordination, decentralized distribution); and networking between local responders and external aid.

The treatment of acute injuries, management of environmental risks, and prevention of the spread of infectious diseases take precedence in most disaster response models.¹ As made painfully evident by Hurricane Katrina, such models should be augmented to include the

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provision of continued care to patients with chronic conditions (eg, diabetes, HIV/AIDS, cardiovascular disease, cancer).^{2–4} Estimates of the proportion of Katrina-affected individuals with 1 or more chronic illness diagnoses range from 41%⁵ to 74%.⁶ Continuity of care for chronic diseases (CDs) has been identified as the major health care provision issue in the storm's aftermath.^{1,5,7–12}

Disasters have the potential to damage the health care infrastructure, which is the basis for the provision of continued care to patients with CDs. Indeed, Katrina crippled the medical care fabric of the Gulf Coast.^{13,14} Federally funded community health centers (CHCs)—the safety net of the region's underinsured and uninsured—sustained an estimated \$65 million damage in Louisiana and Mississippi. Of the estimated 288 health center sites operating in those states in 2004, 32% were lost or severely damaged.¹⁵ Health and social service providers were displaced, with an estimated 28% drop in the number of board-licensed primary care physicians in Louisiana alone between 2005 and 2006.¹³

We sought to identify major elements of disaster preparedness and response that should be integrated in the formulation of models that incorporate provisions for continuity of care to patients with CDs in the aftermath of a disaster. We used qualitative research methodology to document and analyze the experiences of individuals and institutions involved in the delivery of health care to Katrina-affected populations. We report a data-driven, collective assessment of the problems faced, strategies used, and policy recommendations formulated to effectively prepare for and support adequate care for chronically ill people in the aftermath of a disaster.

METHODS

Interviews, work groups, focus groups, and electronic communications were used to collect qualitative data in 3 phases from July 2006 to June 2007. Semistructured, in-depth key informant (KI) interviews were conducted with 30 health and social service providers from organizations in coastal Mississippi and Alabama (Table 1). Four focus groups were conducted with patients with CDs (n = 28 participants). Two of the focus groups were made up of HIV/AIDS patients, recruited from support organizations; the other 2 included patients with various CDs recruited from CHCs. Facilitators used an open-ended question guide to elucidate from participants the chronic diseases deserving priority and their post-disaster management needs. Sessions were recorded and professionally transcribed for analysis. Written informed consent was obtained from all of the participants, in accordance with institutional review board protocol.

In phase II, 1 KI from each organization was invited to participate in an advisory panel (AP) workshop. Panel members (n = 11) were divided into 2 work groups and discussed topics that were unclear or unaddressed in KI interviews: the critical components of postdisaster CD management, resources needed, and actions that could streamline patient care across organizational boundaries. In a plenary session, each group presented a summation of findings to the project's external advisor, a New Orleans-based physician who worked after Katrina in both the hospital and CHC settings.^{16–20} Work groups and the plenary session were recorded for transcription and analysis.

Using a grounded theory approach,²¹ 2 research team members (R.D.F., M.L.I.) independently analyzed and coded phase I transcripts for emerging concepts using Atlas.ti software version 5.2.9.²² The use of emergent (as opposed to predetermined) coding promotes the inductive identification of patterns among the responses from which conceptual hypotheses are developed without forcing the data into preset categories or theories. Instead, identified patterns in the data are grouped into categories, which

summarize the underlying thematic constructs and provide explanations of the experiences of participants.²³

Code families, or groups of salient themes, were used to generate lists of quotations relevant to each theme. This computer-generated narrative was then analyzed for content and summarized by a multidisciplinary team composed of a medical doctor (E.D.C.), a medical anthropologist (RDF), and a doctor of business management (M.L.I.). The team wrote a comprehensive report compiling phase I and II findings for distribution to all KIs.

In phase III, advisory panel members were invited to submit electronic feedback on the report, and other KIs were invited to join work groups. A questionnaire designed to identify perceived gaps or flaws in the report draft was distributed to all phase III participants. Results presented below focus on comments, opinions, and proposed solutions regarding CD management after a disaster. Findings specific to HIV/AIDS will be reported in a forthcoming manuscript.

RESULTS

Chronic Diseases of Priority

Chronic diseases identified as medical management priorities by KIs are mental health (n = 93 times referenced in transcripts), diabetes mellitus (n = 83), hypertension (n = 53), respiratory illness (including chronic obstructive pulmonary disease, asthma) (n = 49), end-stage renal disease (n = 27), cardiovascular disease (n = 20), and cancer (n = 5). A summary of diseases and comments related to their postdisaster management is presented in Table 2. CDs discussed by patients were mental health (n = 35), respiratory illness (n = 19), diabetes (n = 15), hypertension (n = 13), cardiovascular disease (n = 2), and cancer (n = 1).

Chronic Disease Management Issues

Aside from the specific needs of oxygen-dependent patients and those requiring dialysis, CD management needs revolved around maintaining the continuity of medication regimens. One KI stated, “Diabetics could not get their insulin. Or they could not keep their insulin refrigerated. Then blood sugar was a big problem. Appropriate food—and so they are eating 4000-calorie Meals Ready to Eat with no insulin. For hypertensives, it was getting medicines and keeping control of their blood pressure. Getting medicines. Keeping medicines.” Specific problems encountered, strategies that worked in solving those problems, and policy-related recommendations are detailed below.

Medical Records

Accessing medical records onsite (lost to flood waters) or at a distance (for displaced patients) was virtually impossible after Katrina (n = 115 + 47; KI mentions plus focus group mentions). Lack of appropriate medical records required providers to run new diagnostic tests, causing delays in resumption of treatment regimens. KIs agreed that electronic medical records would solve this problem. Providers recommended that portable or distally accessible personal electronic health records should be made available to patients (eg, central server, jump drive, DVD). An alternative is to encourage patients to carry a card containing frequently updated health and medication information. See Table 3 for representative statements.

Medication Issues

Medication-related problems (n = 333), particularly medication procurement (n = 183 + 68), were the most frequently mentioned challenges to CD management by both patients and providers. Factors affecting the provision of medications included the system’s appropriate

supply of medications (n = 75 + 0), the patient's knowledge of medications (n = 53 + 11), patients' financial abilities (n = 25 + 10), and the regulations that govern the dispensing of medications (n = 15 + 5) (Table 4).

Many patients arrived at new provider facilities without their prescriptions or bottles, and with inadequate knowledge of their medical histories or medication names and dosages. Providers had to be creative in helping people remember: "One of our nurses, our case manager (glued) our top 100 medicines on a peg board and said, 'Point to your medicines.'" To circumvent financial barriers, many providers and some pharmacists reportedly distributed small supplies of medications free of charge or pharmaceutical samples to their patients. Churches, pharmaceutical companies, and large drugstore franchises dispensed and accepted medication vouchers.

KIs thought patients should have at least a 1-month extra supply of medications to avoid therapy interruptions postdisaster. Regulations dictating the periodicity of refills in Medicaid and some private insurance policies, however, prevent patients from stocking more than the usual monthly allowance (n = 46 + 8). In such cases, KIs recommended overrides with patient education for appropriate storage. Immediate action by public authorities—such as relaxing Medicaid regulations to permit claims to be transmitted across state lines, and allowing pharmacists to refill up to a 30-day supply of medications as long as patients had some proof of current prescriptions—went a long way in facilitating the dispensation of medications (Table 3).

Donated Medications and Supplies

Although providers received helpful donations of medications, many—often cut off from communication channels—reported receiving large quantities of unrequested, inappropriate, and expired medications from unidentified sources. Classifying medications and disposing of unusable items was a burden on providers already struggling to dispose of disaster-related debris. In some instances, providers were forced to let surpluses become ruined in inclement weather due to lack of storage space. Others sorted donated medications and networked to redistribute surpluses to facilities in need. KIs recommended increased communication between potential donors and target health care facilities to assess needs. When the power supply returned, e-mail communications in conjunction with volunteer-run databases worked well for some KIs, linking potential donors, volunteer pools, and sites in need.^{24,25}

Critical Medications Needed

KIs stressed the need for antibiotics, antihypertensives, oral glucose-lowering agents in addition to insulin, medications for anxiety and depression, lipid-lowering agents, and asthma medications: "Our main focus is on maintenance medications for chronic-type conditions like high blood-pressure, high cholesterol, heart disease, diabetes. There was (also) quite a spike in demand for anxiety medications (and) various forms of heart disease. Probably (also) a considerable spike in asthma medication (and) for pulmonary conditions." With regard to medical supplies, the most pressing need was for oxygen and oxygen tanks.

Provider and Patient Disaster Planning

KIs identified planning and preparedness as essential elements to effective natural disaster response (n = 186 + 19). Provider's recommendations include: backing-up of medical records, stocking and protecting essential medications, ensuring that all staff know the disaster plan and their roles, and preparing back-up communications systems in case of telephone and Internet outage.

KIs believed that patients should take a more proactive role in the management of their disease. Cultivating patient responsibility requires enhanced patient education and empowerment. This is a challenge among at-risk populations with unstable housing, employment, and transportation situations. Providers also stressed the importance of using multiple media to reach patients (eg, newspapers, radio, provider letters, television).

Operational and Networking Issues

KIs (n = 153 + 11) believed that aid from volunteers, aid agencies, and governmental groups was vital to disaster relief and recovery. They stressed that it is crucial, however, that outside aid groups coordinate efforts with local organizations and work alongside local organizations and providers to meet the community's needs (n = 26 + 9). Coordinated efforts need to start predisaster if possible. Response/recovery efforts with leadership (or co-leadership) originating from within the disaster area worked well to ensure that aid reached the community (n = 23 + 2). Moreover, such efforts had a greater likelihood of sustainability, some transcending short-term outcomes to continue to affect the health and recovery of the community today (Table 5).

Providers emphasized the importance of centralized receipt and sorting followed by the decentralized distribution of medicines, medical supplies, and basic necessities. KIs proposed that a community-based group in constant contact with the local emergency operation center and with local and state officials should be responsible for such coordination. Predisaster, the group should network with faith-based groups, relief organizations, and even pharmaceutical companies. Networking predisaster ensures familiarity of entities with the local health care infrastructure. In the event of a disaster, the group would assess and communicate to the network the medical supply and medication needs of health care entities and facilitate the movement of these to areas of greatest need.

Table 6 provides a summary of the policy-related solutions proposed by KIs to the problems discussed in the sections above.

DISCUSSION

This study recorded and analyzed the experiences and perceptions of frontline medical care responders in the aftermath of Katrina. We systematically documented the CD management challenges experienced by indigenous health care providers, administrators, pharmacists, and community-based support organizations in the Mississippi and Alabama Gulf coasts. Challenges included inadequacy of predisaster preparation; lack/loss of medical and prescription medication records; insufficient patient knowledge of CD medications; regulatory, financial, and insurance barriers to medication purchase; inadequate and/or insufficient medication supplies; and lack of an effective structure to coordinate internal and external operations. Furthermore, we recorded field strategies used to provide continuity of care after Katrina and, through qualitative analysis, extracted policy recommendations formulated by study participants.

The major challenges to CD management were availability and affordability of prescription medications.^{7,8,26,27} Strategies that could ensure the immediate availability of medications postdisaster are predisaster stockpiling coupled with safe storage, and the staging of supplies in locations just outside the perimeter of a potential disaster area under imminent threat.^{8,27,28} Coordination of the receipt and distribution of medical/medication supplies is a key operational element in adequate CD management postdisaster. KIs advocated for a centralized structure for receiving supplies and medications, but a decentralized access model with patients retrieving medications at multiple community sites. Such a model is a recommended standard for the management of international drug donations.²⁹

Given the added financial stressors after major disasters, the affordability of medications becomes a key barrier to CD management, especially for subpopulations living in poverty.^{19,26} Goodwill solutions (eg, free samples, cash vouchers) can solve immediate needs. Broad and equal access to free or reduced-cost medical care and prescription medications for underserved populations can be realized only through legislative channels, a point made by KIs. Emergency expansion of Medicare/caid coverage that allows for transstate coverage and shields individual states from matching fund contributions has been discussed by Congress.^{30,31} Institutions such as the Kaiser Family Foundation³² and the Children's Health Fund³³ continue advocating for a comprehensive legislative solution to affordable medical care for underinsured or uninsured populations affected by disasters.

Donated medications increased the availability and affordability of prescription drugs after a disaster. Antihypertensives, glucose-lowering agents, medications for anxiety and depression, asthma medications, and antibiotics were identified as the most useful medications for major CD management needs. A formulary should be developed to guide medication donations postdisaster and should be widely circulated among potential donating institutions.²⁹

Some of the problems regarding donations sent to Katrina-affected areas have also been widely experienced by international recipients of aid.³⁴ These have given rise to the formulation of 4 core principles for drug donations: maximum benefit to the recipient, respect for the wishes and authority of the recipient, no double standards in drug quality, and effective communication between donor and recipient.²⁹ Although we can trace many of our study participants' recommendations back to each of those principles, effective flow of communication stands out as one of the most important elements advocated by KIs in this study. A potential communication solution is programs such as "Rx Response," designed to create a single forum for medication suppliers, community volunteer relief organizations, and local, state, and federal agencies responding to major disasters.³⁵

To circumvent patients' inability to remember the names and doses of their medications, our study participants advocated for a personal health record or continuity of care record, preferably in electronic format but alternatively in a paper copy. Patient-based medical information data repositories become mandatory in disaster situations in which patients need to access health care away from their usual providers. There are several major initiatives—from the centers for Medicare & Medicaid Services, the Department of Veterans Affairs, and the private sector—to implement the use of standardized, interoperable personal health record functions in medical care.^{27,36} Primary care clinics in the Gulf Coast should be supported with funding to educate patients and staff on the use of personal health records or continuity of care records and to secure the technology infrastructure and supplies for incorporating these into day-to-day operations.

Another major area of system improvement considered critical by KIs was the use of information technology to record patient information, facilitate medical record sharing within and across institutions, support access to information at a distance, and ensure routine and emergency storage of data. The Department of Veterans Affairs health record system provides a model for such a system and it proved successful in support of evacuee health care after Katrina.³⁷ The Department of Health and Human Services has stated its commitment to the formation of a national health information network.^{36,38,39} The Gulf Coast region should be slated as a priority in establishing the local, state, and regional platforms of such a network.

The seminal elements in effective disaster response identified by participants in the present study and by other investigators are provider and patient disaster planning and the

establishment of strong networks to support collaboration and synergy among the multiple response actors.^{40–42} Achievement of their translation into operational practices hinges on 2 major facilitating streams: explicit policies that address the legal and liability roadblocks (eg, licensure reciprocity for volunteer health professionals, liability protection, interjurisdictional coordination, privacy) and appropriate funding to ensure that critical personnel and resources are available to develop, rehearse, and implement plans, as well as to create and sustain the necessary networks.^{10,28,40,42–45}

Limitations

The present study is limited in that many other disaster response actors involved directly in or making decisions that affect the provision of health care were not included as participants. We are confident that the majority of institutions involved in providing care to underserved Gulf Coast inhabitants (the focus of the present study) were represented. By design, we limited data collection to the Gulf Coast counties of Mississippi and Alabama. Therefore, our results do not provide direct information on health care challenges experienced in Louisiana, but likely encompass the CD management needs of displaced Louisianans who sought refuge in Alabama and Mississippi.

Because the majority of health care institutions included in the study are primary care clinics, the information recorded relates to CDs usually managed in such settings and provides limited information on diseases typically managed in specialty clinics (eg, cancer, end-stage renal disease). Likewise, our study does not provide information on the postdisaster management of less prevalent diseases (eg, sickle cell disease). Another limitation is the small size and scope of the patient sample. Our sampling method—provider nomination for participation in focus groups with an emphasis on patients with HIV/AIDS—precluded the gathering of a broadly representative sample of CDs. Furthermore, we focus only on the adult population, given that KIs interviewed were mainly devoted to adult care. We oversampled patients with HIV/AIDS to document specific circumstances and strategies related to HIV/AIDS management; for example, issues of confidentiality and maintenance of complex highly active antiretroviral therapy regimens. Findings pertaining to HIV/AIDS are described in a separate article.

CONCLUSIONS

In addition to documenting and describing the most pressing CD management needs in the aftermath of a disaster—especially those burdening the underinsured and uninsured—the present study describes field strategies that effectively maintained continuity of care after Hurricane Katrina, documents major challenges faced, and lists policy-related recommendations to streamline health care response in the event of future disasters. Although some steps have been taken to improve the system's response 4 years after Katrina, the challenge still lies in ensuring the political will and resource commitment that are necessary to systematically implement such recommendations.^{10,28,42,43}

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TABLE 1

Participating Types of Institutions and Job Descriptions of Key Informants

Institution Type by State	AL	MS	Key Informants by Job Description	
Hospital	1	1	Administrator	3
			Medical director	1
Community health center systems	2	1	Administrator	2
			Medical director	1
			Nurse	1
			Nurse practitioner	3
			Social worker	1
			Research/risk coordinator	1
County health department	1	1	Clinic administrator	1
			Director of social services	2
			Director of nursing	1
			Emergency management	1
AIDS support agency	1	1	Executive director	2
			Case/program manager	2
Nonprofit pharmacy	1	1	Executive director	2
Retail pharmacy outlets (6 locations of 2 major corporations)	3	3	Administrator	3
			Pharmacist	1
			Pharmacy technician	1
Closed door pharmacy	0	1	Administrator	1
Total no. locations	9	9	Total no. key informants	30

TABLE 2

Management Issues for Specific Chronic Diseases

Condition	Participant Comments
Mental health (N = 93)	<p>Increase in anxiety and depression for patients and providers</p> <p>Exacerbation of existing cases and onset of new cases</p> <p>Mental health problems perceived to adversely affect status of chronic diseases</p> <p>Substance abuse (particularly alcohol) and suicide rates perceived to be on the rise</p> <p>Shortage of mental health professionals, both indigenous and volunteer</p> <p>Needs unmet in immediate aftermath and have reached epidemic proportions 1–2 y postevent</p> <p>Providers report that when counseling is recommended, many patients fear the stigma of being labeled as mentally ill</p>
Diabetes mellitus (N = 83)	<p>Insulin difficult to access and store (power out 4–6 wk or longer in some areas)</p> <p>Difficulty maintaining special diets</p> <p>Difficulty monitoring glucose due to lack of supplies and proper sanitation</p> <p>Reported poststorm increase in insulin usage among diabetics</p> <p>A few patients, particularly with preexisting hypertension, reported being newly diagnosed with diabetes and associated it with poststorm nutrition imbalances</p>
Hypertension (N = 53)	<p>Noted fluctuation in previously managed blood pressure</p> <p>Disruption in medication treatment due to severed supply channels and inoperable pharmacies in the immediate aftermath</p> <p>In the long term, difficulty affording medications due to financial burden</p>
Respiratory illness (N = 49)	<p>Worsening of asthma, COPD, and allergy problems</p> <p>Inadequate oxygen and portable tank supplies</p> <p>Nebulizers and ventilators inoperable due to power outage</p> <p>Noted increase in upper respiratory infection, sinusitis, persistent coughing, and pneumonia</p> <p>Most respiratory problems perceived related to mold, debris in air, and contaminated/stagnant water</p>
ESRD (N = 27)	<p>Loss of power and inadequate water supply makes dialysis impossible</p> <p>Hospitals ill-equipped to accommodate increase in dialysis needs</p> <p>Urgent need to transport many dialysis patients to distant locations</p>
Cardiovascular disease (N = 20)	<p>Noted increase in episodes of chest pain and fluctuation of blood pressure</p> <p>Disruption in medication treatment</p>
Cancer (N = 5)	<p>Disruption of chemotherapy and other treatment regimes</p> <p>Loss of biopsy records and delay in treatment and surgery</p>

Multiple comments regarding HIV/AIDS are not included in the present article. Other conditions less frequently mentioned: dyslipidemia, hepatitis (especially in conjunction with HIV), and tuberculosis (concerns for spread in shelters poststorm). N, number of coded key informant quotations; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease.

TABLE 3

Medical Records and Prescription Medication Issues: Representative Quotes

<p>Medical records (N = 115 + 47)</p> <p>Loss and/or lack of access</p> <p><i>“We had record storage (but) I had to destroy all the records because they were soaked clean through. And that was a nightmare. We took the pharmacy computer, one of the backups, home. We lost all the other records.”</i> KIT 7:106</p> <p><i>“I admitted tons and tons of patients from New Orleans who (had come in) say a week before Katrina and had a breast biopsy done. And said, ‘This is my doctor’s name.’ When we called the doctor, the office was completely destroyed. We had to repeat the breast biopsy. We had to repeat the colonoscopy. We had to repeat a brain biopsy. That is, in my opinion, inexcusable.”</i> KIT 26:227</p> <p>Need for electronic medical records</p> <p><i>“People came with no health records no prescriptions, no medicines. Certainly having an electronic version of the health record at some point, would help.”</i> KIT 12:55</p> <p><i>“There needs to be some type of product, some type of chip, CD, DVD with your medical history, and people could take it with them. That would be so helpful.”</i> KIT 26:32</p> <p>Ways in which clinics are implementing electronic systems components</p> <p><i>“We have kept all our records on jump-drives. We have a safe coming by in 2 days (to store them), so you know you don’t have to worry about privacy. We’ll remove them when we have to evacuate. But the rest of the records, the paper records are all about people’s finances. And basically, if we lose those we have to start over.”</i> KIT 7:94</p> <p><i>“We budgeted for a new system. When the information comes in you put it in the computer and it goes out to the pharmacies. It will give us back a list that we could reconcile with this patient. Medication records are a really big challenge. If you can tell what medications they are on, it would be like clock work.”</i> KIT 25:92</p> <p>Patient knowledge of medications (N = 53 + 11)</p> <p><i>“I had lost (my) medication. I had to go to the hospital and try to remember what all my medication and how much I was taking.”</i> FGT 3:12</p> <p><i>“The people who were coming from Louisiana and Mississippi. (Some) showed up and they had no medication. And they did not even know what they were taking. They said, ‘Oh, I take the blue pill and the green pill and the yellow pill.’ They didn’t even have their bottles or even a list of what they were taking.”</i> KIT 1:39</p> <p><i>“(We’ve tried) dispensing 2 weeks of medicine that you could take with you in case of emergency. My clientele won’t do that—they’ll just use their medicine. Because you’re asking people who have chaotic life-skill to plan for the future, and what they end up planning is, ‘I don’t have to go in, I can miss my appointment, I could make it last. I don’t have gas money so I’ll just use that medicine.’ (So instead) we copy their medicine down, all the dosages that they actually take, give them a printout to keep it in their wallet or purse, and if they evacuate, they’ll have the complete list.”</i> KIT 7:93</p> <p>Advance prescriptions (N = 46 + 8)</p> <p><i>“If insurance companies would work with their customers. In a catastrophic event go by your ZIP code. If your ZIP code is in that area of the projected path (allow early refills) enough for a month so that people could go and get their prescriptions.”</i> KIT 29:39</p> <p><i>“(So) you would not have problems sending claims to the insurance companies. There could be a hurricane override where if your prescriptions were 15 days early, hurricane override would allow that to go through the system, (and) the patient could get their meds before they evacuated.”</i> KIT 24:9</p>
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N, number of coded statements by key informants plus number of coded statements by patients; KIT, key informant transcript; FGT, focus group transcript.

TABLE 4

Medication Procurement Issues: Representative Quotes

<p>Medication procurement (N = 183 + 68)</p> <p>Financial and insurance issues (N = 31 + 25)</p> <p><i>“Our normal systems were down; we could not transmit claims. We were not prepared; we did not have a back up plan. If a patient wanted prescriptions, they had to pay for them. We could not do any kind of third party. We could not get in touch with casinos to make sure the (insurance) contract was still there. We had to fill what we could and the only way we could guarantee that we could get reimbursed for what we were dispensing was (for patients) to pay cash. I mean you had to (make exceptions) in certain cases. Every situation was different.”</i> KIT 24:6</p> <p><i>“Across the whole coast (the price of) everything has shot up everything that they are building is going to be extremely high. But the wages are not being increased. So people are having to give up stuff struggling from paycheck to paycheck. You are going to have to let something go. And a lot of times people are letting their medications go. You know my depression might not be a top priority. Or people will stop taking their HIV meds. You have to decide whether you want to eat, or you want to take medication. And most of the time you are going to decide that you want to eat and that you want to feed your family.”</i> FGT 1:874</p> <p>Samples and vouchers (N = 18 + 6)</p> <p><i>“Most of the time everybody was given their medication for free, if it was available, or a prescription if it wasn’t. We had one drugstore that was open there. If they didn’t have the money, the churches provided patient assistance for medications.”</i> KIT 10:19</p> <p><i>“We try and have some vouchers for medication from drug companies. We just take these vouchers to the drug companies like Wal-Mart, CVS Drugs, Rite Aid.”</i> KIT 4:62</p> <p>Regulations (N = 15 + 5)</p> <p><i>“The governor of Alabama allowed pharmacists to (give refills) for (up to) 30 days. The liability was off of me. It was probably the best thing that happened because when people walked in that I had never seen before, and need some help without prescriptions I was taking care of people’s medications. I was giving people controlled substances, but I used what I figured was the best judgment that my 40 years of experience had given me. Basically, harmless type medications, things for chronic illnesses. If you walked in here and told me that you were diabetic and that you needed insulin, I sold you the insulin and the paraphernalia to use it. Everyone who came through our doors got help. I just took a note pad and had one of the staff people writing down as fast as they could what people needed and the disposition of it said they were Medicaid, if they said they usually give a \$2 co-pay, I let them put a \$2 co-pay in a cigar box. (We) would give somebody enough medication for 24 hours, and tell them that if you are going to continue, you need to convince whoever will see you here.”</i> KIT 19:6</p> <p>Donated medications and supplies (N = 75 + 0)</p> <p><i>“But regular diabetic medicine, not insulin, wasn’t coming in. Antihypertensives, you couldn’t find them, you couldn’t find the antidepressants. What you could find, and what we still have is 2 types of antibiotics with short shelf-life. Our facility was destroyed, (so) the lady who does our staffing took an informal survey of the clinics that opened up and who were dispensing medicine, and the stuff that started coming in to us she began to ship around to those clinics. It was hard to go out and find who was dispensing the medicine, because there was no central place that kept up, or registered the people that were doing it.”</i> KIT 7:5</p> <p><i>“Some of the stuff was really inappropriate, just not what we need. We did need antibiotics but a lot of what came had already expired (and) we can’t use it if it’s expired. Some stuff got wet. We were in that motor home—there wasn’t anyplace to put anything.”</i> KIT 8:12</p> <p><i>“We went through and just destroyed tons of medication. We had our Health Department nurses and physicians sit in a room, go through boxes and boxes and boxes of medication. We would use what we could use and throw away what we couldn’t use. All the (donated) meds now have to come through the Department of Health, and we’re going to manage all the medications.”</i> KIT 6:90</p>

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TABLE 5

Disaster Planning and Networking: Representative Quotes

<p>Provider and patient disaster planning (N = 186 + 19)</p> <p>Provider (N = 121 + 7)</p> <p><i>“We are never losing our medicine again. (We’ve gone through (it) all and got the most highly used drugs and most expensive. We’ll pack those up and haul them to—’s office because they only got 1 inch of water (with Katrina). And we’re stacking them up and securing them there.” KIT 7:110</i></p> <p><i>“We had no phone service. The Southern Link phone that we had, nobody knew how to work it. (Now) we’ve instructed the operators (to) do a weekly roll call with all the different sites in Alabama. (Personnel) from Southern Link came down and showed us how to use it.” KIT 16:11</i></p> <p><i>“We have what we call the emergency response team strictly on a volunteer basis. When there is a hurricane or any type of natural disaster, I activate the team. We will shelter here. We can open up immediately after a disaster. We make plans to be here for at least 2 days staying here along with our families. I am working on getting air mattresses; I got microwave food in our freezers. I have caps for us to wear and T-shirts so the patients can recognize us. (We also plan to) make contracts with vendors to ensure that they will re-supply us. We are going to have at least 25 staff members sleeping (here). I have a floor plan, guidelines, policies, and all that.” KIT 21:3</i></p> <p>Patient (N = 65 + 12)</p> <p><i>“We need to educate our patients here on the coast on an ongoing basis. Especially when it gets to be summertime: ‘Now do you have your medication? Don’t wait to the last minute. Keep gas in your car.’ Little things like that ”KIT 10:35</i></p> <p><i>“We’ve been talking to our clients how to plan if you have special needs, finding help if you need transportation to a shelter. We’ve been following up, ‘Have you done it yet? Have you phoned your number in, told them what you needed so you could be on the list to get picked up?’ Because you have to remind some of these folks a good deal. (But) the shelters are flexible about where they’re going to be (set up) so that’s been hard for our folks to plan. But we’ve made them call in at least and say, ‘I need electricity because I’m on this machine and so you need to count me in.’” KIT 7:43</i></p> <p><i>“We provided pamphlets with contact information. And there is an article in the ‘Connection’ of the local paper that comes out once a month. And we are putting our information in ahead of time, communicating with churches and the pharmacies and with our patients directly, to let them know what our plans are and what services will be available to them.” KIT 17:27</i></p> <p>Operational and networking issues (N = 153 + 11)</p> <p><i>“What they needed initially was some kind of registry or control. They didn’t need to stop (outsiders) from setting up, because that’s what made the difference. If you could be accessible, then people could use you. But you need some kind of standard for folks coming in or some way to move medicine and to move supplies. You need to be able to have those contacts. Initially after the storm, unless you had a satellite phone and somebody to call on a satellite phone, you were text-messaging for weeks and weeks. And I’m not sure unless you can go into a community and people can see you, whether you could’ve given out the medicine or not.” KIT 7:84</i></p> <p><i>“I’ve talked with the Red Cross. We’ve met a couple times. I think we both realized that it was more chaotic than it needed to be. So I’ve had a chance now to (fill) him (in) on our procedures. And I have a better understanding of how they work. So we won’t have incidents where people went to the Red Cross and (they sent them) down here (to get their medications), and then we couldn’t help them because they didn’t have the (documentation) that we needed. Or because they were sent down here for things that we couldn’t help them with, like narcotics.” KIT 15:44</i></p> <p><i>“What has to take place is better communication: with ourselves and the different pharmacies. Maybe even organizing a pre storm seminar where you have all the drug companies’ representatives sit down and decide the easiest way a patient can have access to medicines.” KIT 4:39</i></p> <p><i>“Whatever it takes to create a network, whether hospitals or clinics, pharmacies. (All) that are involved (in) health care, to facilitate sharing of information both about general services and patient specific information.” KIT 15:44</i></p>

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TABLE 6

Summary of Policy Recommendations

Issue	Policy Recommendation
Advance prescriptions	In the event of an imminent storm, relax public and private insurance stipulations on periodicity of medication refills.
Patient knowledge of medications	Support the provision by health providers to patients of summary health and medication information on paper or in electronic format; educate patients to know diagnosis and explicit treatment regimens.
Medical records	Support community health centers to attain electronic medical records capacity, with appropriate storage, transfer, and distant access capability. Move toward electronic medical records systems that can interact across institutional boundaries.
Medication and medical supplies	Support a centralized structure for the coordination of receipt and distribution of health care supplies and medications. Support a decentralized structure to facilitate patient access to distribution sites. Support predisaster networking among health care institutions, pharmaceutical companies, and community-based aid organizations—including the faith-based community—to define critical supplies needed and streamline distribution postdisaster.
Coordination of aid	Support a structure that will facilitate coordination of external aid to work alongside indigenous institutions, to promote a long-term impact on the health of the community.