In Their Own Words: Lessons Learned From Those Exposed to Anthrax

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Objectives. We evaluated perceptions of workers at the US Postal Service Brentwood Processing and Distribution Center and US Senate employees regarding public health responses to the anthrax mailings of October 2001. We generated recommendations for improving responses to bioterrorism on the basis of the perceptions we recorded.

Methods. Transcripts from focus groups conducted with Brentwood and US Senate employees were examined, and qualitative analysis identified common domains.

Results. Brentwood focus groups consisted of 36 participants (97% African American and 19% hearing impaired). US Senate focus groups consisted of 7 participants (71% White and 0% hearing impaired). The focus groups revealed that participants' trust in public health agencies had eroded and that this erosion could threaten the effectiveness of communication during future public health emergencies. Among Brentwood participants, lack of trust involved the perception that unfair treatment on the basis of race/ethnicity and socioeconomic status had occurred; among US Senate participants, it derived from perceptions of inconsistent and disorganized messages.

Conclusions. Effective communication during a public health emergency depends on the provision of clear messages and close involvement of the affected community. Diverse populations may require individualized approaches to ensure that messages are delivered appropriately. Special attention should be given to those who face barriers to traditional modes of communication. (*Am J Public Health.* 2005;95:489–495. doi:10.2105/AJPH.2004.038349)

On October 15, 2001, a letter containing *Bacillus anthracis* was opened at Senator Tom Daschle's Capitol Hill office, triggering a series of events that revealed serious gaps in the nation's ability to respond to bioterrorism. By November 20, 2001, 22 cases of anthrax had been identified in the United States, and a wide spectrum of individuals had been exposed in the Washington, DC, area.[1] Although the first reports of positive anthrax exposures in Washington, DC, occurred at the Hart Senate Office Building, no actual cases were reported. The effect on the United States Postal Service facility on Brentwood Road, Washington, DC, through which the letter passed just days before it was opened, was more severe. Four cases of inhalational anthrax originated from this facility, resulting in 2 deaths. It was recommended that approximately 2743 people from the Brentwood population and 600 people from the Hart building take at least 60 days of antibiotic prophylaxis based on a presumed high risk for inhalational anthrax.[2–4]

Since that time, there has been much discussion about improving systemwide responses to bioterrorism. Recommendations have largely focused on surveillance for and management of biological agents, including medical treatment, containment, and decontamination.[5,6] Few empirical data regarding communication with potentially exposed individuals have been provided.

This issue is critical. Effective communication during a public health emergency can have profound effects, ranging from increased compliance with recommended treatment to decreased development of long-term psychological sequelae. A basic goal of public health communication is to provide accurate, accessible information that establishes a bond of trust between those in a position of responsibility and those potentially exposed to a bioterrorist agent.[7] This trust depends on perceptions of competence, objectivity, fairness, and consistency and on the general belief in the good will of those responsible for communication.[8]

The events surrounding the anthrax exposures required communication by various public health entities to a highly diverse audience during a period of sustained uncertainty. Screening and treatment recommendations changed as knowledge about the infection and its treatment evolved. Although the Daschle letter came through the Brentwood facility on October 12, Senate workers on Capitol Hill were initially thought to be the primary exposed population, resulting in rapid testing and prophylactic treatment of that population on October 15 (Table 1). Medical and public health agencies did not immediately recognize that fatal doses of anthrax could disseminate through unopened envelopes, resulting in little initial recognition that postal employees might also be at risk.[1] Thus, workers at the Brentwood facility were not screened or treated until October 21, after anthrax cases had been confirmed in their coworkers. By that time it was recognized that all employees from the Brentwood facility would need postexposure prophylaxis; nasal swabbing for diagnosis was felt to be both unreliable and unnecessary.[9,10]

Intense media coverage highlighted the delays in testing and treatment of the Brentwood workers, often making references to race and socioeconomic status; approximately 92% of Brentwood's employees were African American, as opposed to the predominately White staffers of the US Senate.[11,12]

Following the initial diagnosis, employees at both facilities who were deemed to be at highest risk received prophylactic antibiotics for 60 days. Subsequent recommendations for postexposure prophylaxis extended the suggested length of antibiotic prophylaxis to 100 days or

TABLE 1—Timeline of Events Associated With Anthrax Exposures: 2001, Washington, DC[2,9,25,26]

October 12, 2001	Two letters addressed to Senator Daschle and Senator Leahy, mailed or postmarked from Trenton, New Jersey, were processed at the Brentwood Road postal facility
October 12	A letter addressed to NBC news anchor Tom Brokaw was found to be positive for anthrax
October 13	Two New Jersey postal workers who apparently processed anthrax-contaminated letters reported suspicious skin lesions to New Jersey state health officials
October 15	Staff worker in Senator Daschle's office in the Hart Senate Office Building opened a letter containing *Bacillus anthracis*
October 15	Environmental sampling initiated in Hart Senate Office Building
	Nasal swab testing and prophylactic antibiotics begun for staffers in area of exposure
October 17	Hart Senate Office Building closed and remainder of staff received nasal swab testing and prophylactic antibiotics
October 18	Cutaneous anthrax was confirmed in New Jersey postal workers
October 18	USPS contractor conducted private field tests at Brentwood as a result of suspicions in New Jersey population
October 19	State of New Jersey urged postal employees at Hamilton and West Trenton facilities to contact their private doctors or area hospitals and to initiate a regimen of antibiotics
October 19	Brentwood postal worker admitted to hospital with suspected inhalational anthrax
October 20	CDC team visited Brentwood
October 20–22	Three additional cases of anthrax were identified in Brentwood postal workers
	During this period, 2 of the cases resulted in death
October 21–22	Brentwood postal facility closed; nasal swab testing and initial treatment of Brentwood postal workers begun
October 23	Extensive environmental sampling of Brentwood postal facility by CDC and USPS contractor begun

USPS = United States Postal Service; CDC = Centers for Disease Control and Prevention.

receipt of a vaccine, classified as investigational, to further reduce the chance of acquiring inhalational anthrax.[13] Antibiotic adherence was similar at both sites, with 64% of Brentwood and 58% of Senate workers completing at least 60 days of antibiotics.[3] However, the 2 groups differed sharply in their response to the vaccine recommendation. Thirty-eight percent of high-risk Senate workers chose to receive the anthrax vaccine, as compared to only 2% of Brentwood workers.[14]

To date, there has been a paucity of information about how individuals exposed to anthrax perceived and responded to public health information, or how this may have affected subsequent health behaviors. There has been even less focus on communication with particularly vulnerable groups, such as African Americans or those with hearing impairments, both of whom are disproportionately represented in Brentwood's population.[15] We studied the experience of Brentwood and Senate employees in order to better understand, from the perspectives of those affected, their response to these events. Our goal is to generate suggestions for improvement that will help improve communication during a public health emergency.

METHODS

We conducted a series of 2-hour focus groups to gather detailed, qualitative information about the events surrounding the anthrax exposure. At Brentwood, focus groups were scheduled to accommodate all work shifts. Because postal facilities typically employ a relatively large number of hearing-impaired individuals, we included a focus group composed primarily of persons with hearing impairments. Attendees were recruited from flyers distributed at labor union meetings and posted at local facilities and through a local support group. In addition, we conducted a focus group of Senate employees from the Hart Senate Office Building. Attendees for the Senate focus group were recruited through an e-mail announcement to individuals in the Hart building.

All Brentwood participants were paid $50 for participation, and either breakfast or dinner was provided. Senate ethics rules preclude Senate staff from accepting cash payments; lunch was provided. All study methods were reviewed and approved by the RAND Human Subjects Protection Committee.

Focus groups were conducted by 2 moderators (J.B., Y.H.). Two specially trained interpreters attended the focus group for the hearing-impaired. Participants were assured anonymity and confidentiality of responses. Sessions were taped for later transcription.

We asked open-ended questions designed to assess a number of key issues relating to communication and trust surrounding the public health response to the anthrax exposures. Recordings were transcribed and coded using ATLAS.ti version 4.2 software (Scientific Software Development, Berlin, Germany). Major domains and subdomains were identified by 2 of the authors (N.L., J.B.) on initial review of the transcripts. Statements were then coded independently by 2 authors (J.B., Y.H.), and differences in coding were settled by consensus agreement. An individual statement was defined as a contiguous discussion around a subdomain by an individual speaker. Some statements had overlapping themes and thus could be assigned more than 1 code.

RESULTS

Thirty-six Brentwood postal workers participated in 4 focus groups; 7 of the participants (19%) were hearing-impaired and 35 (97%) were African American, with equal proportions of men and women. Seven persons participated in 1 Senate focus group; 5 individuals (71%) were White, 2 were African American, and 6 were female.

A total of 716 statements were identified and coded into individual subject domains/subdomains—573 from Brentwood and 143 from the Senate (Table 2). The distribution of issues was similar in all 4 Brentwood focus groups, although the predominately hearing-impaired group provided additional information specific to this impairment.

TABLE 2—Frequency of Statements by Domain and Subdomain in the Focus Groups

	Mentions		
	Brentwood, n (%)[a]	Senate, n (%)[a]	Total, n (%)[a]
Source of information			
Media	33 (40.7)	4 (9.5)	37 (30.8)
Physicians or personnel from the military/Navy	5 (6.2)	8 (19.0)	13 (10.6)
Coworkers/friends	6 (7.4)	7 (16.7)	13 (10.6)
Capitol Physician's Office		9 (21.4)	9 (7.3)
USPS management staff	9 (11.1)		9 (7.3)
Internet	4 (4.9)	4 (9.5)	8 (6.5)
Centers for Disease Control and Prevention	5 (6.2)	3 (7.1)	8 (6.5)
District of Columbia Health Department	1 (1.2)	1 (2.4)	2 (1.6)
Personal physician	3 (3.7)	1 (2.4)	4 (3.3)
Family	2 (2.5)		2 (1.6)
Scientific journals/books	1 (1.2)	1 (2.4)	2 (1.6)
Sergeant at Arms (at Capitol)		1 (2.4)	1 (0.8)
National Institutes of Health		1 (2.4)	1 (0.8)
World Health Organization	1 (1.2)		1 (0.8)
Other	2 (2.5)	1 (2.4)	3 (2.4)
Unidentifiable source	9 (11.1)	1 (2.4)	10 (8.1)
Subtotal	81	42	123
Attitudes/problems with the information			
General absence of information	32 (40.5)	11 (52.4)	43 (43.0)
Lack of clarity/confusing information	16 (20.3)	5 (23.8)	21 (21.0)
Delay in communication	19 (24.1)	0	19 (19.0)
Problems with communication specifically involving hearing impaired	9 (11.4)	0	9 (9.0)
Poor quality of information	3 (3.8)	5 (23.8)	8 (8.0)
Subtotal	79	21	100
Attitudes toward the source of information (those who delivered information)			
Mistrust	83 (33.5)	6 (14.0)	89 (30.6)
Felt agencies treated them with disrespect	39 (15.7)	5 (11.6)	44 (15.1)
Treated groups differently based on race/socioeconomic status	40 (16.1)	1 (2.3)	41 (14.1)
Treated them as experiments	30 (12.1)	1 (2.3)	31 (10.7)
Did not have the proper knowledge to provide adequate information	20 (8.1)	8 (18.6)	28 (9.6)
Felt personal physician/community medical facilities lacked information or were prevented from giving information	26 (10.5)	2 (4.7)	28 (9.6)
Lack of organization	7 (2.8)	11 (25.6)	18 (6.2)
Advocates/lack of advocates	3 (1.2)	9 (20.9)	12 (4.1)
Subtotal	248	43	291
Attitudes toward treatment options (medications/vaccine)			
Feeling that information about treatment not complete	21 (27.6)	7 (33.3)	28 (28.9)
Concern about side effects	20 (26.3)	5 (23.8)	25 (25.8)
Recommendations by public health expert/health provider	14 (18.4)	3 (14.3)	17 (17.5)
View that treatment was part of experiment	9 (11.8)		9 (9.3)
Fear of anthrax if medication not taken	5 (6.6)	2 (9.5)	7 (7.2)
Perceived risk/lack of risk of medication	3 (3.9)	3 (14.3)	6 (6.2)
Recommendations by family/friends/non–health expert/other	4 (5.3)	1 (4.8)	5 (5.2)
Subtotal	76	21	97
Recommendations for future improvement			
Better communication	43 (48.3)	12 (75.0)	55 (52.4)
Better leadership	21 (23.6)	3 (18.8)	24 (22.9)
Provide advocate	14 (15.7)		14 (13.3)
Eliminate disparities in treatment	11 (12.4)	1 (6.3)	12 (11.4)
Subtotal	89	16	105
Total	573	143	716

[a]Percentage of times theme presented as a fraction of total subdomain.

The domains identified were source of information (the origin of basic information, such as the media or Centers for Disease Control and Prevention [CDC], regardless of the perceived quality of this information), attitudes or problems with the information itself (whether participants felt information was available for both hearing and hearing-impaired groups, was delayed, was clear, or was of good quality), attitudes toward the source of information (participants' opinions about agencies/groups who were responsible for delivering information or interacting with relevant groups), attitudes toward treatment options, including antibiotics and vaccines, and recommendations for future improvement. Findings for each domain are described below.

Source of Information

For the Brentwood participants, the most commonly cited source of information was the media (Table 3). Thirty-three statements cited the media as the initial source of information that anthrax had been identified at the participants' workplace. Participants also cited US Postal Service (USPS) management as a source of information disseminated through organized meetings. Senate workers also cited the media, but they more frequently cited internal channels of communication, such as the Capitol Physician's Office and a Navy physician who worked closely with the physician's office, and coworkers and friends. Other sources identified included the Internet, the CDC, and the District of Columbia Department of Health. One Brentwood employee stated, "I read the description and saw the pictures in the newspaper of what the anthrax virus looks like, and I thought, I could be exposed to this?"

Attitudes Toward the Information

Over half of the statements in this domain by both Brentwood and Senate groups expressed frustration with the lack of information about anthrax (Table 3). Participants at both sites felt that the information they did receive was unclear, inconsistent, and in many cases, inaccurate. Many of the Brentwood workers felt that the information they received was not timely, and they expressed concern about the fact that they were never told the results of their nasal swab testing.

TABLE 3—Representative Statements From Identified Domains

Sources of information
- I was talking with my friend on the Internet and she let me know to watch the news about what was happening at the post office. So I turned on the TV and was watching the news and the captioning was telling me that I needed to go and get checked out. (Brentwood, hearing impaired)
- I think that, well for [our] office, information on anthrax came from the Navy and from [the Capitol Physician's Office]. The information on the side effects to the medication mostly came from your peers. (Senate)

Attitudes/problems with the information
- It was no communication. It was sit down, shut up, take this, you can go. (Brentwood)
- The CDC would say things or there would be an announcement from the Public Health Service. . . . You always left every meeting more confused than when you went in. (Senate)
- I don't know with some of the other people what happened. How they got a hold of them to let them know that their group was leaving [the building]. But I felt like I was being left out and it wasn't until later that someone was writing me a note [that I learned I should leave]. (Brentwood, hearing impaired)

Attitudes toward the source of information

Mistrust
- I think it was a general mistrust. . . . I didn't like the way everything was going down, with them not getting us out of the building. I just didn't feel comfortable with it. (Brentwood)
- The public health community seems to feel like we should just do what they say because they say it. And we don't have that kind of trust in them anymore. (Senate)
- [We could trust the media] more than anyone else. . . . If the post office said they had cleared the building and the media says they haven't cleared the building, I'm going with the media. (Brentwood)

Disparities based on race
- They should have treated us like we were Hart [Senate Office building] people. I mean they should have treated us all equally. (Brentwood)
- Look at the Hart building. When they go up to that Hart building, what's 90% of that color inside—White folks . . . the color of that post office at Brentwood is black—97%. So the racial thing you knew right away. They can't call that coincidence. That's why CDC knew. They closed down the Hart building but [did] nothing for us. (Brentwood)
- They gave [us] preferential treatment because [we] were in Congress. And if that was readily apparent to us, it was probably apparent to the community, people living in DC and Virginia and Maryland also. That was a tragedy, because they waited so long to close the Brentwood facility. (Senate)

Experimentation
- People kept saying they're using us as guinea pigs. We heard all kind of things . . . they came back down to the post office every so often with questionnaires, you know, to fill out. They were very interested, but it was only for research. (Brentwood)
- We're all being used. Everybody's benefiting but us. (Brentwood)

Did not have the proper knowledge to provide adequate information
- They didn't know. There'd never been a case like this before. (Senate)
- I think that they were just in the dark . . . the CDC didn't know the seriousness of the situation. Because I'm quite sure if they knew they would have shut it down. (Brentwood)

Attitudes toward treatment options
- If [a Navy physician] had walked in off the street and I'd never met him and he said, "We think you should take this experimental vaccine," I don't know that we would have. But at that point we'd built up a level of trust with him. (Senate)
- I asked [the CDC representative] what made them want to give us the vaccine, what constituted us needing it. And they talked about a study with some monkeys how they had 3 subject groups. . . . One group didn't get any treatment. . . . So I figured for all I know [we] could have been the ones who didn't get [any treatment,] and they were using us. (Brentwood)

Nine of the Brentwood statements specifically address problems related to those with hearing impairments. Comments addressed the lack of qualified interpreters able to communicate about issues related to the anthrax emergency, including evacuation of the Brentwood facility and recommendations about antibiotic prophylaxis. One hearing-impaired Brentwood employee (hereafter, speakers of the quoted material are identified only by focus group location and as "hearing impaired" if applicable) said, "I know the hearing people got more information than me. . . . I know they could at least talk with the people sitting behind the desk, whereas I couldn't."

Attitudes Toward Sources of Information

Two hundred forty-eight of the 573 statements from the Brentwood groups and 43 of the 143 statements from the Senate group addressed attitudes toward the agencies responsible for providing information (Table 3). Both groups made statements noting that the CDC and the District of Columbia health department provided very little useful information. In addition, Brentwood workers stated that information provided by the USPS, mainly through management, was incomplete or inadequate.

Both groups expressed negative opinions, and particularly mistrust, of many of the sources of information, such as from the USPS and the CDC, although the underlying reasons for mistrust differed by location. Among the Brentwood participants, mistrust was linked to the delay in evacuating the facility and initiating nasal swab testing and treatment and to feelings that they had been treated differently because of their social class and race/ethnicity. In contrast, the mistrust and negative opinions expressed by the Senate group were linked to inconsistency of information and poor organization of the public health representatives responsible for communication. Although these concerns were mentioned in the Brentwood group, they were secondary to the recurrent themes of mistreatment and disrespect. At both sites, participants stated that before the anthrax emergency, their opinions of the CDC and the local health department had been either neutral or favorable, but the views expressed in the focus groups reflected that their opinions of these organizations changed during the crisis:

> I thought the CDC was something regarding the concern for public health. . . . I had a most high respect, but right now they're just a part of the government to deceive (Brentwood).

> I never had an opinion about the CDC before. And now [it's negative]. I assumed CDC was the expert. . . . And they had done all the testing. They knew it all. There was definitely an assumption that the federally funded Centers

for Disease Control knows all about diseases. (Senate).

The Brentwood groups reported predominately favorable impressions of their primary information source—the media—and expressed the opinion that the media in general were a better source of information than either USPS management or public health agencies. In contrast, some participants in the Senate group felt that the media did not report information accurately. They commented favorably on the Capitol Physician's Office, which, they felt, served as a major source of consistent and familiar information, as well as on a Navy physician who worked closely with the Capitol physician. Office managers at the Capitol often took responsibility for information dissemination among their staff:

> You're talking to one person from CDC and the next day you walk in the room and you get this new person. . . . And it was a different story [and] different person every day. Whereas, with the Navy, it was one person and he was consistent. If he'd been wrong on something, he would [update us]—you never heard conflicting reports from him with no explanation, which happened with all the other sources of information (Senate).

> My impression throughout this was that the Capitol [Physician's Office] . . . was truly concerned about us versus the CDC or other people who were just like, 'Isn't this a fascinating laboratory test' (Senate).

Although some participants did seek information from their personal doctor or from local hospitals, participants in both locations felt that these sources were limited in their ability to provide information because of a poor understanding of the natural history of anthrax infection. Furthermore, they believed that anthrax-related knowledge was not effectively communicated to community physicians and hospitals by the CDC or the District of Columbia Department of Health. Eight statements by the Brentwood participants indicated an impression that physicians and local hospitals were essentially "gagged" by the CDC and instructed not to provide care to Brentwood employees.

Seventy-nine of the statements from the Brentwood focus group referred to a perception that they were not treated with respect and that they were often treated differently from other groups (mainly those at the Senate) because of race and other socioeconomic reasons:

> We're just common black workers. We're poor black workers. . . . They're special. They work for the Senate, they work for the government. We're just poor, stupid people that don't get anything (Brentwood, hearing impaired).

> They tested the Capitol Hill police dogs before they tested the postal workers (Brentwood).

Thirty comments in the Brentwood focus groups referred to experimentation. The Tuskegee syphilis experiment was cited in discussing the anthrax events—a theme that permeated all 4 Brentwood focus groups. Some felt that the anthrax exposure itself was an experiment, and others remarked that once the exposure had occurred, the government and the CDC took advantage of the situation to observe its effects on them rather than to provide immediate treatment:

> I made it plain that I thought that it was a cover-up. . . . Because the government's done it before. They did it with syphilis (Brentwood).

Although the majority of opinions expressed an overall discontent with the quality and timeliness of information, some participants recognized that public health agency efforts were hampered by lack of available information about anthrax. They felt the major problem was not the lack of knowledge but how this deficiency was communicated to the public:

> They've had anthrax in mail before but it was never exposed to a group of people. . . . I can understand them not having the data (Brentwood).

Attitudes Toward Medications and Vaccines

Although many persons at both locations took most of their prophylactic antibiotics, some did not complete the entire course. Reasons included side effects and the recommendations of their personal physicians. Workers at both locations noted that lack of information about the medications, such as side effects and drug interactions, was a major problem (Table 3).

Two participants out of 36 in the Brentwood group elected to be vaccinated for anthrax. One stated that a family member had been vaccinated with no problems, and another cited previous experience with the military. Those who chose not to be vaccinated cited the facts that the vaccine was billed as experimental and that those who administered it did not appear want to take responsibility for any side effects. Three of the 7 Senate group participants chose to be vaccinated; however, others stated that they were not offered the vaccine because they were not at the highest risk of exposure. Those who did take the vaccine said information from a Navy physician as well as personal discussions with peers influenced their decision. These decisions were largely influenced by the level of trust in the recommending public health authority (Table 3).

Suggestions for Future Improvement

At the end of each focus group, participants were asked what they would have done differently had they been in charge of handling the response to the anthrax exposures. Most of the quotations (55 out of 105) involved improving communication, setting up identifiable contact persons who could serve as advocates, and making efforts to eliminate disparities in treatment between those affected. Representative suggestions are presented in Table 4.

DISCUSSION

Focus group results indicate the prevalence of issues associated with lack of communication and trust, disrespect, and disparities in treatment on the basis of race or social class. The focus groups also reveal the importance of a consistent, trusted advocate. When in doubt, many participants turned to their local hospitals and physicians, who unfortunately were often unable to provide informed advice. Many respondents felt that their own physicians had been "gagged."

Many of the concerns expressed in the focus groups may have been simply a result of miscommunication. Because of the lack of significant prior experience with anthrax, recommendations changed as new information became available. Public health messages may have been interpreted as being inconsistent or unreliable if the rationale for such changes was not made clear.

The references to mistrust and the parallels with the Tuskegee experiment expressed by

TABLE 4—Recommendation Quotes From Focus Group Participants

Provide better communication

- I'd have put all 2700 employees, told them what anthrax was, what was found in the building, why we closed the building, and after the swab test came, gave every individual . . . their results. . . . And I think from doing it I would have built up a rapport with every employee of trust and communication. (Brentwood)
- Get the most recent studies of everything . . . and then admit, we've never seen this before and this is the best recommendation that we can give you based on all these other studies. . . . But feel comfortable in saying we don't know. Because that's always more reassuring than hearing conflicting information from people, because then you don't believe anything. (Senate)
- You get all this information at you and some of it is medical or complicated terms that you don't understand. And there was nothing to take home with you and read over later when you were capable of understanding it. Or if you wanted to take information home and take it to your personal doctor, you didn't have that option because you had to try to remember what you had heard. For me the big personal lesson from this was communication. (Senate)
- They need to get a full-time interpreter that's available . . . somebody who's fully certified and qualified. When they're depending on just another employee in the post office who maybe can sign a little bit, they're not really qualified. (Brentwood, hearing impaired)

Provide better leadership

- They should appoint one person to be the face of it and then that one person continue to give the information . . . have that person speak with authority and give honest answers to questions. If they don't know, say "I don't know." (Senate)
- I would have public health have full-fledged preparation for the medical health community and the hospitals. . . . Have public health informed, [and] prepared to train the hospitals, personnel, doctors, train them so they can help people as well. Because people are going to be going to different places. They shouldn't be rejected and waiting for the CDC to come forward to give mass medication. (Brentwood)
- Have a representative . . . from CDC, to monitor all these groups who are doing this work. And not just have them monitor how they're handling this situation, but also be the support for them as well, instead of just monitoring the potentially exposed persons. (Brentwood)
- The first thing to do whether it's anthrax or any other kind of disease . . . you would err on the side of caution. . . . Soon as you know something is in the building, it's evacuated immediately. You err on the side of caution, not let's see what happens. (Brentwood)

Provide an advocate

- I would have a consultant liaison from the CDC accessible. . . . hotline 24/7, 365 days a year . . . only for the anthrax people. I would give everybody that was exposed to anthrax a PIN number. (Brentwood)
- [Have] a mediator. You get somebody from CDC, the employee, top management [to form a] panel. . . . And that's a good thing because then everybody's on the same wavelength. . . . And trust me, it will get filtered to the employees if you have somebody, like one of us, on that panel with them, because we're going to tell them the truth. (Brentwood)

Eliminate disparities in treatment

- Everyone needs to get the same information—that's the thing. When it's trickled down make sure everyone gets the same information. I think they're trying to do that now with sending the newsletters and things out, send them to your home. (Brentwood)
- First of all they could have remembered that all men are created equal. . . . treat us all the same. They should have put people's lives and health above productivity. (Brentwood)

the Brentwood postal workers raise serious concerns. In the Tuskegee experiment, over 128 deaths from syphilis or related complications occurred when 399 men remained untreated for the disease after enrollment in a study conducted by the United States Public Health Service.[16] Our findings are consistent with prior research that has documented minority group mistrust of the medical community.[17,18] In our sample, many reported an initial favorable or neutral opinion of public health agencies, indicating that during the emergency, trust eroded. This problem could potentially have been avoided with more effective communication from the start.

The identification of an advocate (the Capitol Physician's Office), as well as networking with individuals who took responsibility for informing others, seemed to help Senate workers cope with events. Neither the advocacy nor the networking appeared to be immediately available to Brentwood staff. Instead, many had to rely on the media and the rapidly changing information given to them by various groups, including the USPS, the CDC, and the District of Columbia Department of Health.

The focus groups suggested a set of recommendations. Many involved improving training and coordination in the medical and public health community. Others, summarized below, suggest ways to improve communication effectiveness.

- Consistency of messages across all groups affected is paramount to encouraging trust. Responsible parties should present an organized front and establish clear lines of communication to address unanswered questions.[8] In the event of uncertainty, it is important to be honest while at the same time providing reliable updates on changing developments.
- Communication efforts should closely involve people within the community of exposed individuals, preferably someone who is widely recognized and trusted and who can provide input as well serve as a spokesperson. Bioterrorism preparedness efforts in the workplace should involve identification and training of such potential leaders.
- The community of exposed individuals should be involved in helping to devise plans for intervention, treatment, and communication. Many nonacute public health interventions, such as immunizations and cancer screenings, have increasingly adopted such community-based involvement as effective models of care.[19–21]
- Future communication efforts must also consider the diversity of individuals who might be affected. Consideration should be given to an array of relationships to include not only persons of differing racial and socioeconomic backgrounds but also those with physical limitations that could hinder communication, such as those with hearing impairments.[22] For these populations, effective interventions require not only interpreters but interpreters specifically trained in health care communication who can be readily available

at community meetings and support groups.[23,24]

In an emergency situation, such as a crisis requiring mass vaccination or prophylaxis, it will be important for everyone to participate. Groups with a historical legacy of mistrust in government, and those who have difficulty communicating (resulting, for instance, from poor English skills or a hearing impairment) may not participate in such efforts, either by choice or because they do not understand the emergency. As a result, an emerging infection, whether caused by bioterrorism or a naturally occurring event, could spread widely before being contained.

Public health officials and others should begin now to develop the kinds of relationships necessary to communicate with a range of diverse groups. These relationships need to be nurtured and will take time to mature to a level of reliability that can be called on in times of crisis. Although we focused on African Americans and the hearing impaired in our sample, lessons learned from these groups can apply to other vulnerable populations as well.

Limitations

There are several limitations to our study. First, the focus groups were conducted 14–16 months after the initial exposures, and therefore many perceptions may have been distorted by the passage of time and by other public events that have occurred in the interim. Second, focus group participants were not selected at random, so persons more likely to have strong opinions about the events may have been more likely to participate. Finally, we were limited in the number of focus groups we could conduct.

Conclulsions

Effective public health emergency communication must recognize and respond to diversity. Trust requires a consistent message and open acknowledgment of limitations. Although approaches to different populations may vary, key messages must be the same. All parties should feel that they are treated fairly and without bias. In the words of a Brentwood employee, "Three words: honesty, diligence, and respect. We never got any of those three. If you treat, I don't care what color you are, a human being, like you care about that human being's well-being . . . that person will give everything up but their soul to say, 'Okay, that person cares about me. I'm going to listen. I'm going to work with you.'" ■

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Contributors

J. Blanchard supervised all aspects of the study, ran the focus groups, and completed the analysis. Y. Haywood ran the focus groups and completed the analysis. B. Stein, T. Tanielian, and M. Stoto contributed to writing. N. Lurie supervised the study and completed the analysis. All authors helped to conceptualize ideas, interpret findings, and review drafts of the article.

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Human Participant Protection

All study methods were reviewed and approved by the RAND human subjects protection committee.

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