

## A Bitter Pill to Swallow: Nonadherence with Prophylactic Antibiotics During the Anthrax Attacks and the Role of Private Physicians

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### ABSTRACT

**To generate recommendations for improving adherence to public health advice during public health crises, we conducted semi-structured interviews with employees at the Brentwood Road Postal Facility and on Capitol Hill to identify key themes associated with decisions to adhere to recommended antibiotic prophylaxis during the 2001 anthrax attacks. Factors used in deciding to adhere to recommended prophylactic antibiotics and concerns about the official response were similar in Brentwood and Capitol Hill employees, and in adherent and nonadherent participants. All participants used multiple sources of information and support as they weighed the risk from anthrax against the advantages and disadvantages of antibiotics. We found that nonadherent participants were commonly following the advice of private physicians, whereas adherent participants commonly described ongoing support from multiple sources when discussing their decisions. Our findings highlight the need for better integration between the public and private health care systems during public health crises and the importance of equipping private physicians for their key role in aiding decision-making during a public health crisis. Special attention also should be given to enhancing support and information from multiple sources throughout the entire period of risk.**

**O**N OCTOBER 15, 2001, a letter containing weapons-grade anthrax spores was opened in the office of Senate Majority Leader Daschle in the Hart Senate Office Building (HSOB). His office and people nearby were quarantined as field tests quickly revealed positive results for anthrax. As investigators began nasal swab testing in order to determine zones of potential exposure, staff were treated with prophylactic antibiotics.<sup>1</sup> On October 17, the entire HSOB was closed, and public health

officials advised more than 600 Capitol Hill staffers to begin antibiotics to prevent potential infection.

On October 18, U.S. Postal Service officials reported that the Daschle letter probably had been processed at the Brentwood Road Postal Facility (BPF) in Northeast Washington, DC; however, officials thought it unlikely that spores had escaped from the sealed letter into the facility. Following confirmation on October 21 of inhalation anthrax in a postal worker from BPF, the facility was

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closed, and nasal swab testing and antibiotic prophylaxis of BPF postal employees began.<sup>1</sup>

The unfolding of these events was characterized by a great deal of uncertainty; communication with the public and with potentially exposed individuals was often confusing and misleading.<sup>1</sup> Emerging health crises are typically characterized by rapid changes in the available knowledge about the cause of illness and appropriate treatment options; however, the manner in which official communications and response efforts were implemented during the anthrax attacks (e.g., changing spokespersons, messages, etc.) compounded potential anxiety and confusion within affected populations. Many at-risk individuals learned of their possible exposure through the media rather than from employers or other more personal sources. Early reports about the source of the anthrax were wrong, and officials did not recognize the seriousness of the threat nor the degree of contamination to the postal system. As events unfolded and more was learned, there were changes in the recommended clinical treatment protocols and in the way the recommendations were communicated to local private health care providers. These rapid changes resulted in different messages and response efforts (e.g., building closings, use of nasal swabbing, prophylaxis choice and course, etc.) between the HSOB and the BPF. Deciphering and making sense of information became a challenge for both local medical personnel and for the at-risk individuals most directly in need of reassurance and care.

Ultimately, the mailing of several anthrax-contaminated letters resulted in 22 documented cases of anthrax, including 4 inhalation anthrax cases and 2 deaths in the Washington, DC, area. Public health officials instructed more than 10,000 people across the United States deemed to be at high risk of anthrax exposure, including approximately 2,700 individuals affiliated with BPF and 600 affiliated with the HSOB, to take at least 60 days of prophylactic antibiotics.<sup>2</sup> But despite extensive public health outreach efforts to at-risk individuals, rapid mobilization of the public health system, distribution of free medication, and national media attention, nationally only 44% of individuals at high risk of anthrax exposure completed the recommended course of antibiotics.<sup>2</sup> Rates of adherence were similar and somewhat higher among both Brentwood postal workers (64%) and HSOB Staff (58%),<sup>2</sup> but still low enough to be of great concern in the event of a contagious disease. Although anthrax is not contagious, understanding adherence rates during this event can help public health decision-makers build better response systems for future public health crises.

Over \$4 billion has now been allocated to states and communities to improve the capacity of the public health system to respond to a bioterrorism attack.<sup>3</sup> The early stages of a public health response to an emerging infec-

tious disease or bioterrorism event will almost certainly involve officials instructing the public to take actions to reduce or mitigate their risk. The success of such a response will likely be determined by the extent to which people follow these actions. But decisions to adhere to health recommendations often involve considerable uncertainty,<sup>4,5</sup> even in routine medical settings. During a bioterrorism event, there may be even greater uncertainty about critical factors that affect an individual's decision, such as the probability of exposure, susceptibility to the disease, the consequences of the disease, the options available to prevent or treat the disease, and the pros and cons of such options.<sup>6</sup> Adherence decisions will also be influenced by organizational and government responses, media coverage, and the response of family, friends, and other trusted individuals (i.e., the social environment in which people are embedded).

Others have begun to explore the reactions and major concerns of people exposed to anthrax and to examine the overall official response, including disparities in the HSOB and BPF response efforts.<sup>1,7,8</sup> There remains a paucity of information, however, regarding peoples' decisions about whether or not to follow actions recommended by public health officials after the anthrax attacks. To obtain such information, we interviewed Brentwood Postal Facility workers and HSOB employees about their perceptions in order to better understand, from the perspectives of those affected, how they made those important decisions. Our goal was to generate suggestions for improving adherence to public health recommendations during a future public health emergency.

## METHODS

### *Participants*

We used flyers and e-mail to recruit 54 individuals who had worked at the BPF or the HSOB during October 2001. Individuals were eligible if officials had advised them to take at least 60 days of antibiotic prophylaxis. We screened individuals to obtain a final study sample in which approximately half of BPF and HSOB participants were nonadherent with the recommended 60 days of antibiotic prophylaxis. Brentwood postal workers were paid \$50 for their participation; HSOB staff were not compensated because Senate Ethics Rules prohibit such payment. RAND's Human Subjects Protection Committee approved all study procedures.

### *Data collection*

We conducted 1-hour, semi-structured interviews between February and July of 2003 using well-established procedures.<sup>9-11</sup> Using open-ended questions, we asked

participants how they learned about their potential exposure to anthrax, how they assessed their personal risk from anthrax, what actions they took to protect their health over the subsequent weeks and months, and how they perceived the pros and cons of following the recommendations of public health officials. We sought clarification or elaboration of responses as required, probing specifically to learn how participants reached decisions and what source and type of information participants used. Interviews were audiotaped and transcribed. Interviewers also recorded their own personal notes and observations immediately after each interview.

### *Analysis*

Drawing on the literature on risk perception and decision-making, we identified major themes, including adherence to public health recommendations, perceptions of the official response to the crisis, individuals' perceptions of risk to their well-being, sources and types of information used to make adherence decisions, and perceptions of public health recommendations. Trained coders reviewed transcripts using qualitative software (Atlas.ti. In.4.1 ed., Scientific Software Development, Federal Republic of Germany) to mark sections of text for each major theme. Next, quotes pertaining to each major theme were pasted on index cards with participant characteristics (e.g., adherence status, gender, population, etc.) noted on the back. A multidisciplinary research team that included the principal authors (BS, TT, GR, HR) sorted the cards into subthemes based on their similarity. This is a standard technique for identifying themes and subthemes that emerge from data.<sup>12,13</sup>

## RESULTS

### *Participant characteristics and adherence to official recommendations*

Thirty-nine participants were from BPF and 15 were from the HSOB. Brentwood postal workers were primarily African-American, slightly older, had less formal education, and were more likely to be female than HSOB participants (Table 1). As a result of our sampling strategy, rates of adherence were comparable across groups. Twenty-eight participants (52%) completed the full course of recommended antibiotics; 26 participants (48%) did not. Seventeen of 30 women (57%), but only 11 of 24 men (46%), adhered to the recommended course. There were no other significant sociodemographic differences in rates of adherence.

Patterns of nonadherence with medication were complex, varied, and comparable between groups (Table 1), with participants deviating from the recommended dura-

tion of medication (e.g., started late or stopped early) as well as from the recommended dosage (e.g., reduced dosage or took the antibiotics intermittently). Only one person did not start antibiotics.

### *Perceptions of the official response to the crisis*

One theme that emerged from discussion of the anthrax attacks and decisions about antibiotics was how the public health system, the U.S. Postal Service, and the Capitol's attending physician's office responded to the crisis. Initially, almost all participants had a positive or neutral opinion of public health officials and relied on them for information and guidance: One female postal worker expressed the common theme that "they [public health officials] are [here] trying to protect us." But as events unfolded, participants reported viewing the response as confused and disorganized (Table 2). Some were uncertain about who was responsible for providing information and advice; some believed that uniformed public health staff were military personnel; and they often referred to the Centers for Disease Control and Prevention and the District of Columbia Department of Health personnel as a collective "them." Many participants were concerned about agencies' levels of expertise/experience and thought much of the information was poor or inaccurate. As one female employee at the HSOB said, "This 'circus of specialists' came through and said that they had 'seen hundreds of cases of anthrax, and everything would be fine.' Hundreds of cases of anthrax? Where? In goats? It wasn't helpful or trustworthy when people were clearly bluffing." As a consequence, participants' trust in federal and local public health officials eroded, and several participants suggested that their health might not have been the primary concern of public health officials. One male employee at the HSOB represented the view of several of his colleagues when he described the response as being primarily "CYA for the Attending Physician's office and the CDC. . . . If anybody did contract and die from anthrax it would have been a huge embarrassment for the Attending Physician's office and the CDC." In contrast, Brentwood postal workers who held the view that their health was not the primary motivation of public health officials were more likely to believe that ". . . [public health officials'] main concern was wanting to experiment, not helping the employees."

For HSOB participants, the erosion of trust was partially compensated for by the response of the Capitol's attending physician's office, which quickly took over the medical care of the HSOB staff by organizing the flow of information about anthrax and advocating for better information for HSOB staff.<sup>14</sup> As described by one female employee at the HSOB, "I felt like somebody was working on this for us. . . . You [could] tell he was working 24

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS AND ANTIBIOTIC-TAKING BEHAVIOR OF PARTICIPANTS

Characteristic	<i>Hart Senate Office Building</i> (n = 15)		<i>Brentwood Post Facility</i> (n = 39)	
	%	n	%	n
Male	60	9	38	15
African American	0	0	97	38
Income, \$55K+	54	8	41	16
Education				
HS/some college	13	2	74	29
BA/grad school	80	12	10	4
Age, 35 years +	27	4	97	38
High-risk for anthrax exposure	100	15	100	39
Side effects from antibiotics	40	6	79	31
Patterns of nonadherence <sup>a</sup>				
Never started	0	0	3	1
Started late	7	1	5	2
Reduced dosage	20	3	23	9
Used intermittently	27	4	33	13
Stopped early	33	5	33	13
Discussion with private physician	33	5	82	32

<sup>a</sup>Totals under patterns of nonadherence are greater than the number of nonadherent participants since people may have been nonadherent in multiple ways.

hours a day on this for us. It made me feel I could relax because somebody else was worrying.”

In contrast, Brentwood postal workers seldom mentioned any advocate, more commonly talking about relying on coworkers and the media for information about what to do. Many Brentwood postal workers also highlighted differences in the official response between BPF and the HSOB as examples of disparate treatment. A number expressed feelings similar to this female employee at the BPF, who described feeling neglected and upset that “they closed the Senate office building and didn’t close us down. We felt like the big house was more important than the field hands . . . . If the Senate got that letter, it had to come through us, we had to have contact with that letter. And they just seemed like they didn’t want to hear that.”

### *Perceptions of individuals’ risk to well-being*

All participants were within the defined “high-risk” category, based on their physical proximity to zones of contamination. Yet participants’ perception of their risk varied substantially, according to participants’ judgments about their level of anthrax exposure and their sense of vulnerability to becoming ill.

*Knowledge of personal exposure.* Nasal swab testing is an epidemiologic screening tool but not one used for disease diagnosis or treatment; its use strongly influenced

many participants’ perception of risk. People who were informed that their swab was positive concluded that they were at highest risk. In contrast, many participants mistakenly interpreted negative swab results as a signal that they were at low risk, as did a male employee at the HSOB who said, “Obviously, when I got the negative swab results, I felt pretty much in the clear.”

In addition, many Brentwood postal workers never received their swab results. This generated anger at public health officials, exemplified by the postal worker who described public health officials’ response to questions about the swabs as “no news is good news” and went on to say that “you don’t work that way when you’re talking about human beings. You [public health officials] took a test, the least you could do is call us back and say, ‘Well, your test came out negative,’ or ‘Your test came up with some signs of anthrax.’ But they didn’t do that.” A number of the postal workers also believed that if they weren’t given the swab results, then the results were positive. One worker said, “They never gave us the results. And the only thing I can make out of that was that they were getting a positive result.”

*Physical proximity and cues.* Those without positive swab results used a variety of visible and nonvisible cues to judge their level of anthrax exposure (Table 3). For example, perceived risk of exposure was highest in HSOB staffers who described having seen the powder after the envelope was opened or who handled the letter. As one

TABLE 2. PERCEPTIONS OF THE OFFICIAL RESPONSE TO THE CRISIS

<i>Worker type (Gender)</i>	<i>Interviewee Response</i>
Postal Worker (Female)	At first, yeah, I trusted them, because you figure, they [public health officials] are trying to protect us. But not after they wouldn't give us the results from those [nasal swab] tests. They were trying to protect themselves, I think. Not really us.
Capitol Hill (Female)	One day this "circus of specialists" come through and said that they "had seen hundreds of cases of anthrax and everything would be fine." Hundreds of cases of anthrax? Where? In goats? It wasn't helpful or trustworthy when people were clearly bluffing.
Capitol Hill (Male)	. . . it was just uncomfortable that they [public health officials] didn't know what they were doing. So, it wasn't that the anthrax was completely scary . . . but you got a little more worried once they kept changing information. Saying, these people should be tested, and then no, everyone needs to be tested, and then there was the Cipro . . . they were saying you should get the 60 days. Then a person who was literally 10 feet away would tell you something totally different . . . you threw up your hands. How can that make someone feel reassured that you are giving us good information?
Capitol Hill (Female)	We trusted his [the navy physician, working in conjunction with the Capitol Physician's Office] judgment. . . . I don't know why, but I did, I guess he never lied. If he didn't know, he said he didn't know. . . . Any recommendation he made medically, I went along with. . . . It made me feel like somebody was working on this for us, and he was working on it, you [could] tell he was working 24 hours a day on this for us. . . . It made me feel I could relax . . . because somebody else was worrying.
Postal Worker (Male)	We worked there that night [while they tested for anthrax]. He [a plant manager] told us that they had a biohazard problem in the building and that was it. Most of the information we received was through the news. And that's bad. Most of the information that came up the whole time came through the news on TV. Then it started coming from our family and friends. And we started networking and talking to each other.
Postal Worker (Female)	But I was really angry at the post office because they didn't close it down when the Senate was closed. They didn't close us down. I'm thinking that if they closed when the Senate [did], those two postal workers could have been on antibiotics. They wouldn't have died.
Postal Worker (Female)	. . . as soon as it went to the Hart Building, bam, they shut it down. And that was the 15th, and they didn't close us down until the 21st. What's that, eight days? Eight days later. And they knew the letter had to come through Brentwood. That's what bothered me. . . . They know it had to come through there. So what's the problem? That's what really bugged me. . . .
Postal Worker (Female)	What really upset us, too, was when they closed the Senate office building and didn't close us down. We felt like we were neglected. We felt like the big house was more important than the field hands. . . . If the Senate got that letter, it had to come through us. So we had to have contact with that letter. And they just seemed like they didn't want to hear that.
Capitol Hill (Male)	There was no evidence in any way, shape, or form, that we had come into contact with anthrax. It was CYA for the Attending Physician's office and for the CDC . . . if anybody did contract and die from anthrax it would have been a huge embarrassment for all the Attending Physician's Office and the CDC.
Postal Worker (Female)	Before [the Post Office] shut the building down . . . they had people in there with what I call spacesuits. . . . And they wouldn't respond to people's questions as to why those people were in there. . . . Personally, I feel like the Post Office knew what was going on. But their concern was more about getting the mail out than our health.
Postal Worker (Female)	They were just there giving out medication. And to me, that was their main concern, wanting to experiment, not helping the employees.

TABLE 3. PERCEPTIONS OF INDIVIDUALS' RISK TO WELL-BEING

<i>Worker type (Gender)</i>	<i>Interviewee Response</i>
Capitol Hill (Female)	I was exposed as soon [as] when the letter was opened. It was October 15th at 9:45 am.
Postal Worker (Female)	They didn't tell use why they were swabbing, they just said they were going to do everyone here. And I thought that they were going to be able to tell something to help the employees . . . [but] that wasn't the case because employees were saying they were swabbing to see what location each employee might be in.
Postal Worker (Female)	And it made all of us nervous that we never got our test results back to know exactly what amount of anthrax you could have inhaled in your body.
Postal Worker (Female)	[after the nasal swab test] they were supposed to get back to you and let you know if you were at risk, right? Which they never did. And then when you called, they'd say, "Well, if you don't have—no news is good news." You don't work that way when you're talking about human beings. You took a test, the least you could do is call us back and say, "Well, your test came out negative." Or "Your test came up with some signs of anthrax." But they didn't do that. Like I said, the whole thing in a nutshell, was just experiment.
Postal Worker (Male)	What got my attention is when we went in there and they initially wanted to swab everyone's nostrils and they were putting them in little sealed packages, little zip lock bags . . . they never gave us the results. I never got it. And the only thing I can make out of that was that they were getting a positive result.
Capitol Hill (Female)	I saw it and smelled it [the anthrax spores]
Capitol Hill (Male)	. . . when I saw the envelope [on TV] that I had recognized from the Friday before, I knew that my hands had been all over it. I'd say it was as stressful a time as I've ever had in my life. I don't know if I've ever been that scared ever. I was absolutely freaking out. But obviously, when I got the negative swab results, I felt pretty much in the clear.
Capitol Hill (Male)	I was [in] proximity. I was on the same floor with everyone with exposure. Same floor. A period of almost 24 hours had gone by when they had located it. And people could walk right by it. The offices shared ventilation systems.
Postal Worker (Female)	They were testing the letter cases and they left, so I didn't think anything. And I figured that if the building wasn't safe, they should have closed it [like] when the letter was found in the Senate Building. But because they did not close the building and let us continue working, I thought we were safe.
Postal Worker (Female)	I felt at heightened risk, because I didn't believe even the officials knew [who was at risk]. . . And the other reason was because I had found, in my own research, the path that official mail took. And found that I crossed that path often.
Postal Worker (Female)	I saw those men everyday. . . . everyone knew that when they clean the machine it blows dust everywhere, so we were all at risk, not just the guys on the machines.

male employee at the HSOB related, "When I saw the envelope [on TV] that I had recognized from the Friday before, I knew that my hands had been all over it. . . . I don't know that I've ever been that scared ever. I was absolutely freaking out." Those who did not have these experiences, and who were not physically close to known danger areas such as Senator Daschle's office, the freight elevator where spores were found, and the office ventilation system, felt themselves to be much less at risk.

Brentwood postal workers were unable to use physical

proximity to judge their level of risk. Spores were found throughout the BPF, and illnesses and deaths of coworkers were not centralized by location or job type. For these reasons, there was little variation in perceived risk of exposure among Brentwood postal workers; all believed their risk was quite high. As one female postal worker remarked, "I saw those men everyday . . . everyone knew that when they clean the machine it blows dust everywhere, so we were all at risk, not just the guys on the machines."

*Susceptibility and symptoms.* Perceptions of risk were often influenced by participants' perceptions of how susceptible they were to becoming ill with anthrax if exposed, with many older individuals believing they were at greater risk than younger colleagues. Conversely, other participants mentioned other medications they were taking or their hardier constitution as protecting them. Feelings of susceptibility were also heightened in people who had a cough or a cold. In contrast, several participants who prematurely discontinued antibiotics cited the absence of any symptoms of anthrax after a few weeks as an indication that they had not been exposed. As one postal worker said, "I wasn't sick; why did I need medicine?"

#### *Sources and types of information used to make adherence decisions*

To make decisions about taking antibiotics, participants used many sources of information about anthrax infection, risks of exposure and susceptibility, and benefits and risks of treatment options (Table 4). Announcements, meetings, and notifications from public officials figured prominently, particularly in the first days of the crisis. But so did conversations with family members, friends, and coworkers and information from the news media and the Internet. One postal worker described how "most of the information that came up the whole time came through the news and on TV. Then it started coming from our family and friends. And we started networking and talking to each other."

Coworkers, friends, and family not only encouraged participants to begin the antibiotics, but urged them to continue taking them. One postal worker described how her decision was influenced most by her daughter: "Because she [her daughter] knows that I don't like to be taking different things. And she was like, 'You take it, Mama, because you were there.' So that influenced me [and] I took the Cipro." Participants were also influenced by coworkers' decisions to take or not to take antibiotics. As one HSOB staffer said, "My coworkers and colleagues are smart people . . . and I guess if they're going to take it, I might as well, too."

Personal physicians, and family friends or relatives who were physicians, also figured prominently in decisions about taking the medications. More than two-thirds of our participants got specific advice about taking the medication from a private physician. Slightly fewer than half of these participants reported that their physician strongly supported the recommendations made by public health officials: One postal worker described "finding a medical professional I could trust and sticking with what he said and my coworkers said. I picked the people I trusted and blocked out everything else." However, other participants reported that their physicians did not sup-

port, or actively disagreed with, the recommendations of public health officials: A postal worker described how her doctor "listened to my complaints, about my body irks and twirks, and I told her about what we went through, and she told me that she wouldn't take it, so I stopped taking the medication."

#### *Perceptions of public health recommendations*

Deciding to continue to adhere to the antibiotics involved weighing the benefits of continued prophylaxis against concerns about the long-term consequences of antibiotic use, such as the side effects and symptoms participants attributed to the medication (e.g., skin problems, fungal infections, joint problems, neurological effects, etc.). Most participants experienced side effects that they believed to be related to the antibiotics, and some participants had severe side effects.

Decisions about preventive measures, such as wearing gloves and masks or being vaccinated, involved similar weighing of pros and cons. For example, wearing gloves and masks was a minor inconvenience (in fact, many postal workers were already routinely wearing gloves while handling mail), but few participants viewed wearing gloves and masks as a real preventive measure for anthrax, believing that such measures would not protect them from inhaling spores. As one postal worker said about the masks, "The anthrax particles are so small and fine that they'd pass through it regardless. If you didn't have a breathing apparatus, it wasn't going to do you any good anyway."

#### *Differences between adherent and nonadherent individuals*

All of the major themes were prominent in participants' descriptions of their decisions, and adherent and nonadherent individuals had many thoughts, feelings, and experiences in common. For example, both adherent and nonadherent participants had similar perceptions of the public health response. There was also no significant difference between adherent and nonadherent individuals with respect to their experiences with medication side effects. Many individuals with side effects remained on the medication, as did one postal worker who noted, "I just had to stay on it as a precaution, even though it made me feel sick." However, others with side effects chose to reduce their dosage.

In addition, with the exception of the few participants who had positive nasal swab results (all of whom completed the course of antibiotics and were vaccinated), adherent and nonadherent individuals gave similar descriptions of their own initial reactions upon learning about the anthrax and their decision to start antibiotics. They spoke of being afraid, uncertain about their level of risk,

TABLE 4. SOURCES AND TYPES OF INFORMATION USED TO MAKE ADHERENCE DECISIONS

<i>Worker type (Gender)</i>	<i>Interviewee Response</i>
Capitol Hill (Male)	I did some web-based information searches . . . but then the emails started flowing around . . . about Cipro and anthrax. There was like an informal network of people sharing information. . . .
Postal Worker (Female)	First I didn't take the medication because I was afraid of it—the first two or three days. But my family insisted that I do, and I just took it.
Postal Worker (Female)	. . . I was more influenced by my daughter than [concerns] about me, really. Because she knows I don't like to be taking different things. And she was like, "You take it, Mama, because you were there." So that influenced me . . . I took the Cipro.
Capitol Hill (Female)	I think at the end when I stopped taking the medicine a lot of [my coworkers'] decisions to not take it weeks before I stopped. That influenced me to say, "I'm probably going to be fine." And I stopped taking it.
Postal Worker (Female)	CDC was helpful to a certain point. Then I started relying mostly on my primary care physician.
Postal Worker (Male)	I talked to my personal physician's wife, who is also a doctor. I asked her opinion over the telephone. She told me, being a doctor, that she felt I should take it.
Capitol Hill (Male)	I did turn to a family doctor to get his opinion on the situation, because he was removed from it. . . . I viewed it as a kind of third party verification of what the [official response] medical personnel are telling me here. [The family doctor] said, "Yeah, you should take it."
Postal Worker (Male)	My doctor . . . informed me, "Take it when you want to take it." If it was making you feel uncomfortable, then don't take it. Go back to it. Long as you get the full amount in your system is all that matters. They didn't have to be consecutive as far as she was concerned.
Postal Worker (Male)	Your own physician is the reality expert. If you're not exposed to [anthrax], then you're exposing yourself to other things by taking the antibiotics.
Postal Worker (Female)	She [my doctor] listened to my complaints, about my body irks and twirks, and I told her about what we went through, and she told me she wouldn't take it, so I stopped taking the medication. So evidently I trusted her enough to stop taking that medication.
Postal Worker (Female)	I think it was finding a medical professional I could trust and sticking with what he said and my coworkers said. I picked the people I trusted, and I blocked out everything else.
Postal Worker (Female)	They told me that I had an upper respiratory infection, and I told them I worked at Brentwood and that I was exposed to anthrax, so they asked me what I was taking, and I told them "They put me on amoxicillin because I was allergic to the other two [antibiotics]." And the doctors told me that I was in God's hands because amoxicillin does not protect you against anthrax. So when you heard that, I really fell apart. Because I knew that I was just taking the antibiotics for nothing. And it would have no effect on saving my life, if I had really been exposed to anthrax.

and concerned about the risk to their own health; many also expressed concern about their families' health. The initial uncertainty and fear, which for postal workers increased significantly upon learning of the deaths of their coworkers, was often related to beginning the antibiotics. One postal worker echoed the sentiments of everyone: "I did not really want to take the drugs, but, again, out of fear and [a] kind of uncertainty and the unknown . . . I did do it [take the drugs]."

Over time, however, participants' decisions about continuing antibiotics were influenced by other factors. Participants who took the full recommended course of antibiotics were more likely to mention ongoing support and encouragement from family and friends. Such comments were far less common among participants who did not follow the recommended regimen.

Private physicians' advice also appeared to strongly influence participants' decisions to adhere. Of participants



who reported that their physician told them to take the medication as directed by public health officials, all but one did so. In contrast, of participants who reported that a private physician didn't clearly advise them to adhere to public health recommendations—either by being vague about the public health recommendations regarding antibiotics or contradicting the recommendations—fewer than one in five took the antibiotics as recommended.

## DISCUSSION

This study is the first to examine individual decision-making during an emergent public health crisis. People had to decide whether or not to follow public health recommendations in an environment characterized by uncertainty. Despite the fact that the nature of the exposure and the official responses to the event were quite different across the two sites directly affected in the Washington, DC, area, the decision-making processes of HSOB and BPF participants were similar. Participants used information and support from a variety of sources, as they weighed the risk from anthrax resulting from their level of exposure and their susceptibility against their perceptions of the advantages and disadvantages of treatment.

Challenges faced by public health officials in communicating the risk from anthrax and recommended actions with the public during the anthrax attacks have been described elsewhere.<sup>1,8,15</sup> One particularly challenging area of communication concerns recommended changes in protocols for screening or treating at-risk individuals; changes in protocol can greatly increase confusion or be perceived as inequitable when not communicated appropriately.

Despite these communication problems, however, fear and uncertainty about anthrax led almost all participants to begin antibiotics as recommended. But over time, information and support provided by family, friends, coworkers, and private physicians became increasingly important as participants reconsidered their decisions. Public health officials should anticipate that people will turn to other sources of information and support in a crisis, including family, friends, coworkers, private physicians, and the media. Efforts at federal, state, and local levels to provide risk communication guidelines and training to public health officials may improve their ability to communicate in an initial crisis response.<sup>16,17</sup> However, our findings suggest that officials should seek to give people reliable information throughout the entire period of risk, not just during the initial crisis response.

In making decisions, participants used not only what public health officials told them but also were influenced by officials' actions or inaction. The most prominent example was the nasal swab test. Despite announcements

that the nasal swab test is an epidemiologic screening tool and should not be used for disease diagnosis or treatment, participants inaccurately believed that nasal swab testing could confirm whether they "had anthrax." Despite the fact that one of the postal workers who died had a negative swab test, many of those with negative results believed it meant that they had not been exposed and didn't need to take the antibiotics. In contrast, participants with positive swab results acted as if it confirmed infection, taking all antibiotics as recommended as well as the anthrax vaccination. And participants who did not receive their results were uniformly concerned or angered by that lack of information.

Diagnostic tests and treatment are familiar to most people; epidemiologic tests and prophylactic medications are not. Public health officials should be aware that even with better education and personal guidance regarding epidemiologic surveillance and prophylaxis, many people may still have difficulty grasping these concepts. Our data suggest that the nasal swab tests became an important tool for participants in judging personal exposure. Empirical studies are needed to examine whether people falsely reassured by negative epidemiologic tests are less likely to follow public health recommendations.

Even with superb communication, a public health crisis involving an emergent infectious disease will be characterized by insufficient information and conflicting opinions. Changing recommendations are likely as more is learned during outbreak investigations.<sup>18</sup> Our participants described how these changing recommendations were often perceived as conflicting information and advice, making it difficult to determine the appropriate course of action regarding antibiotics. The role of private physicians in individual health care decision-making must also not be underestimated; the overwhelming majority of our participants followed their physician's advice. Unfortunately, the difficulty in determining the best course of action may not be limited to at-risk individuals. Many participants reported that physicians contradicted public health recommendations regarding antibiotic prophylaxis, often providing vague or uncertain information about the risks of anthrax and the benefits of prophylactic antibiotics. As one postal worker related, "I told [the doctors] 'they put me on amoxicillin because I was allergic to the other two [antibiotics].' And the doctors told me that I was in God's hands because amoxicillin does not protect you against anthrax."

Our findings are consistent with a survey of emergency physicians conducted in the months following the anthrax attacks that found that many were uncertain about who should receive antibiotic prophylaxis and the utility of nasal swabs in diagnosing anthrax.<sup>19</sup> More recent findings indicate that only 24% of private physicians believe they are personally prepared to respond to bioterrorism.<sup>20</sup>

Physicians must have accurate, up-to-date information regarding any emergent infectious disease so that they can appropriately advise patients about compliance in the face of invisible and potentially dormant health risks. During the anthrax crises, efforts were made to send fax communications to area hospitals and physician offices; however, at the time of our analyses these communications were no longer available. Future studies should examine what information public health officials provide to private health care physicians, how physicians assimilate this information during a public health crisis, how the information affects physician behavior during public health crises, and how physicians communicate this information to patients.

The challenges inherent in integrating private physicians and the public health system to respond to a public health crisis extend beyond those related to more effective communications. The primary responsibility of private physicians and other clinicians is their patients' health; the primary responsibility of public health officials will be to craft a population response that balances overall risks of illness with other factors—for example, how best to distribute a limited supply of antibiotics or vaccines, or how to minimize the risk of infection to uninfected individuals. In some situations, there may be fundamental tensions between appropriate advice on a broad public level and the needs of at-risk individuals for expert advocates for their own health. Clinicians may also be appropriately concerned about potential liability for “poor” clinical decisions based on public health recommendations. A thorough examination of these issues and proactive steps to address some of the fundamental tensions that may arise during a public health crisis are likely to enhance the effectiveness of a public health response during a crisis.

Perceived disparities in the response between HSOB and BPF have been discussed elsewhere.<sup>1,7</sup> A number of our participants mentioned how these perceptions may have resulted from the racial and socioeconomic differences between HSOB and BPF personnel. We found no substantial differences in the frequency of such statements between adherent and nonadherent individuals. However, it should be noted that perceived disparities in public health actions as a result of racial and socioeconomic factors have the potential to affect many components of a public health response to a bioterrorism event, including the sources that individuals turn to for advice and whether they follow instructions from officials.<sup>8,21</sup> Additional studies are needed to provide a more comprehensive picture of this important issue.<sup>22,23</sup>

Limitations to our study include the interim period of 18 months (on average) between the initial exposure and the interviews, during which time other events and experiences may have influenced participants' recall of events

and factors affecting their decisions. We have only the participants' descriptions of the discussions with private physicians; without interviewing private physicians, we are unable to verify the information that physicians actually provided to their patients. Biases about the process may have made people more likely to volunteer for the interviews, and our convenience sample is not intended to be statistically representative of a larger group of exposed people. Rather, the interviews seek to capture the range of peoples' experiences, thereby deepening our understanding of how people make decisions in an emergent public health crisis.

## CONCLUSION

As public health agencies continue to prepare for a future bioterrorism event, the interviews with victims of the anthrax attacks highlight several important limitations to public health actions. The credibility of information provided by public health officials will be enhanced if the information communicated during the initial crisis response is clear, consistent, and appropriate. Yet, officials must anticipate that even with optimal communication efforts, a substantial number of people may remain uncertain about the best course of action, or may misunderstand or misinterpret the reasons for public health actions (e.g., nasal swab testing) or recommendations (e.g., continuing prophylactic medications in the absence of symptoms). In any event with an uncertain and persistent threat, effective communication with the public must become an ongoing effort, because people will revisit decisions about their behavior many times as the crisis evolves.

Our interviews confirmed the critical role played by trusted individuals, such as family, friends, and coworkers, as people make important decisions. Our study identified advice provided by private physicians as one of the most critical factors influencing long-term adherence. That advice often contradicted the larger public health message, undermining its potential effectiveness. Increased effort and attention are urgently needed to ensure that private physicians are equipped for their key role in aiding personal decision-making during a public health crisis. Unless private physicians are actively involved in shaping and communicating the public health response, our nation's ability to thwart an emerging infection may be seriously hampered.

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