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

Janice Blanchard, MD, PhD
Assistant Professor, Emergency Medicine
George Washington University
Bioterrorism Response: A National Priority

– Approximately $3.5 billion allocated in 2003 to strengthen the public health system and increase capacity to respond to bioterrorism

– Unfortunately, less attention has been given to improving communication between the medical system and the public
Overview

- Background
- Research questions
- Key findings
- Recommendations
- Discussion
The anthrax attack begins
<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>12</td>
<td>Letter to Sen. Daschle processed at Brentwood</td>
</tr>
<tr>
<td>15</td>
<td>Letter opened at Hart Senate Office Building</td>
</tr>
<tr>
<td>15</td>
<td>Nasal swab testing at Hart</td>
</tr>
<tr>
<td>17</td>
<td>Hart closed</td>
</tr>
<tr>
<td>19</td>
<td>Brentwood worker hospitalized</td>
</tr>
<tr>
<td>21-22</td>
<td>4 Brentwood workers with inhalational anthrax; 2 deaths</td>
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<tr>
<td></td>
<td>Brentwood closed; nasal swab testing and treatment begun</td>
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</tbody>
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Role of Communication

• Effective communication became critical during crisis

• Uncertainty during crisis led to changes in public health approach
  – Initial non-recognition that anthrax can “leak”
  – Risk to postal workers not appreciated
  – Treatment and nasal swab recommendations changed

• Poor communication made information appear inconsistent
Study Questions

• How did people exposed to anthrax get health information?

• What were their perceptions of the organizations responsible for delivering health information?
Populations Affected

• Capitol Hill (600 individuals)
  – Predominately white

• Brentwood (2,700 individuals)
  – 92% African American
Adherence Was Low

Antibiotic adherence

Capitol Hill

Brentwood

Percent of population
Adherence Was Low

Antibiotic adherence
- Capitol Hill
- Brentwood

Vaccine acceptance
- Capitol Hill
- Brentwood

Percent of population
Approach: Five 2-hour Focus Groups

• Brentwood: 4 groups, 36 participants
  – Predominantly African American
  – One group of people with hearing impairments

• Capitol Hill: 1 group, 7 participants
  – Predominantly white
Qualitative Study Methodology

• Open-ended questions used to assess key issues related to communication and trust

• All discussions recorded and transcribed

• Major themes and subthemes identified and coded
Examples of Themes Identified

I. Sources of information

II. Attitudes about those delivering information

III. Recommendations for improvement
I. Sources of Information

• Brentwood participants relied primarily on media
  – Post Office management was secondary

• Hill workers relied primarily on on-site medical groups
  – Capitol Physician’s Office
  – Navy physician

• Many thought physicians in local ERs and in the community were uninformed and some thought they were essentially “gagged”
I. Sources of Information: Hearing-Impaired Workers Faced Special Problems

“"I was talking with my friend on the internet and she let me know to watch the news ... So I turned on the TV and captioning was telling me ... to go and get checked out."

“I know the hearing people got more information than me...they could at least talk with the people sitting behind the desk, whereas I couldn't."
II. Attitudes About Those Delivering Information

Common subtheme: Mistrust

“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

“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.” Capitol Hill
II. Attitudes About Those Delivering Information

Subthemes associated with mistrust

• Hill staffers
  – Public health representatives lacked credibility

• Brentwood postal workers
  – Perceived bias and unequal attention due to race/class
  – Concern about experimentation
II. Attitudes About Those Delivering Information

Common subtheme: Perceived bias

“They tested the Capitol Hill dogs before they tested the postal workers.” Brentwood

“They should have treated us like we were Hart staff...treated us all equally.” Brentwood

“We’re just common black workers that don’t get anything.” Brentwood hearing impaired

“They gave [us] preferential treatment because [we] were in Congress.” Capitol Hill
II. Attitudes About Those Delivering Information

Brentwood subtheme: Specter of Tuskegee

“People kept saying they’re using us as guinea pigs...They’re very interested, but it was only for research.”

“I thought that it was a cover-up...Because the government’s done it before. They did it with syphilis.”

“We’re all being used. Everybody’s benefiting but us.”
III. Focus Group Recommendations

“[Have] a mediator. You get somebody from the CDC, the employee, top management [to form a] panel...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 the truth.” Brentwood

“One person...be the face of it and then that one person continue to give the information...if they don’t know, say I don’t know.” Capitol Hill

“Have a consultant liaison from the CDC accessible. Hot line 24/7...only for the anthrax people. I would give everybody that was exposed to anthrax...a PIN number.” Brentwood
What Did We Learn?

– People were unsure about risk and benefits
– Trust became critical
  • People needed and sought more information
  • Messages were not tailored to the diversity of the population
What Do We Need to Do?

• Make public health messages simple, consistent and clear; if you don’t know, say “I don’t know”

• Include members from the affected community in decision making
  – Establish community contacts
  – Should reflect community diversity

• Develop plans for specific special needs groups such as those with barriers based on language or disability
How Do We Get There?

- How do we improve communication during public health crises?
- How can we address disparities in information sharing and decision making?
- What steps can be taken at the federal, state, and local levels?