

## Public Perceptions and Risk Communications for Botulism

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### ABSTRACT

**Formative research findings from 10 focus group interviews on botulism are described. Data were collected from a diverse sample of people throughout the United States in 2003, as part of a collaborative multisite initiative sponsored by the Centers for Disease Control and Prevention to improve communications materials on bioterrorism agents. Focus group guides included questions on knowledge, action, emotions, and information seeking in response to a series of scenarios on a hypothetical terrorist attack using *botulinum* toxin. Data were collected, transcribed, coded, and analyzed using content domains based on risk and health communications theories. Initial participant responses to scenarios were emotional, changing into immediate health and survival concerns conceptualized as information specific to the agent and event. Knowledge about botulism was low, and participants wanted clear, concise, and actionable messages. Broadcast media, the internet, and community-based sources were cited as sources of information. Findings have implications for botulism preparedness messages and for general public risk communications.**

**S**INCE THE EVENTS OF SEPTEMBER 11, 2001, and the ensuing anthrax attacks, public health and disaster experts have intensified preparations for future terrorist attacks in the United States, particularly in the realms of disaster response and communications systems. Although much progress has been made, work remains to be done in crafting, producing, and disseminating messages and materials that are appropriate for the general public before, during, and after a terrorist attack. This article describes formative research in collaboration with the Centers for Disease Control and Prevention (CDC) that was conducted with the general public to assess perceptions about the potential threat of botulism. Findings are being used to guide creation of messages that can be disseminated via the mass media during and after an event.

*Botulinum* toxin is the most poisonous substance known to man.<sup>1</sup> One gram of crystalline toxin has the capacity to kill more than 1 million people, and it can cause death in humans at doses as low as 0.05–0.1  $\mu\text{g}$ .<sup>2</sup> The

three forms of naturally occurring botulism (food-borne, wound, and infant or intestinal) are rare. However, recent events have indicated consideration of the toxin as a major bioweapon threat, not only because of its high levels of toxicity and lethality, but also because it is easily produced, easily transported, and creates a need for prolonged intensive care for those affected.<sup>3</sup>

Weaponization of the *botulinum* toxin has been ongoing for more than 50 years in many countries, including Japan, Iraq, and the former Soviet Union, and terrorists have already attempted to use the toxin in attacks. While use of the toxin in food and drink may prove to be the way terrorists deliver the agent, many experts believe that aerosol dispersion poses the greatest threat.<sup>5</sup> The Japanese cult Aum Shinrikō attempted to disperse aerosols of the toxin throughout Japan from 1990 to 1995. They obtained *Clostridium botulinum*, the bacteria that produce the toxin, from soil, because the bacteria exist in nature and are easy to obtain.

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The specter of a bioterrorist attack using *botulinum* toxin raises a significant and unique set of preparedness issues. Botulism is a health emergency, and prompt diagnosis and treatment are essential to minimize dire consequences.<sup>6</sup> Botulism poisoning causes paralysis, with symptoms starting at the head and moving down the body. Early symptoms include facial paralysis, droopy eyelids, slurred speech, and dry mouth, followed by respiratory failure if progression of paralysis is not halted by timely administration of the antitoxin. Therapy consists of long-term recuperation on a ventilator and supportive care. While antitoxin is available, supplies of hospital ventilators will be insufficient to meet demand should a large-scale botulism attack occur. The cost of an aerosolized *botulinum* toxin attack on a suburban population has been conservatively calculated to be about \$57,000 per person exposed and \$114,000 per person ill.<sup>7</sup> The occurrence of even a single case of botulism, especially if there is no obvious source of improperly preserved food, should raise the possibility of deliberate use.

One element of successful disaster management is timely, accurate, and understandable messages for the general public. Research shows that for people to be able to respond appropriately to warning messages, they must get the information in a timely manner, understand it, decide on a feasible plan of action, and be able to act.<sup>8,9</sup> Message development needs to take into account people's capacities to process information, particularly in high-stress situations, as well as to define the types of information that enable or stimulate action.<sup>9,10</sup> Moreover, warnings are heeded more readily if messages are accurate, clear, specific, consistent, and definite and if the sources of the messages are credible and familiar.<sup>11-13</sup>

Converting individual knowledge and perceptions into action, long a concern of health promotion and health communication experts, relies on numerous interrelated theories of individual behavior change, two of which are most relevant here. The Health Belief Model suggests that people must perceive that a situation poses a threat before action is taken.<sup>14,15</sup> Social Cognitive Theory posits that people's likelihood of carrying out recommended actions depends on their level of skill, their attitudes about their own capacity to perform the behavior (self-efficacy), and their belief that behavioral performance will lead to some desirable outcome (outcome expectations).<sup>16,17</sup> Theories from the risk communication field suggest that people adopt heuristic methods to process information, which can bias interpretation,<sup>18,19</sup> and that emotional responses to information also are important.<sup>12</sup>

Based on these theories and models, formative research with audiences of interest was conducted on botulism to elicit insights into their informational needs, preferences, and capacities to inform message development.<sup>20</sup> Formative research can identify specific pre-

disposing and enabling conditions unique to the topic, and these can then be translated into the content, format, and delivery system for those messages.<sup>21,22</sup> Research findings presented here suggest potential content and sequencing of messages that are geared to crisis communications for the general public should a bioterrorist attack using *botulinum* toxin occur.

## METHODS

From May through August 2003, a total of 10 botulism focus group interviews were conducted with 93 individuals of various ethnic/racial backgrounds from across the United States. Among the general public, there were eight groups, one group each for the following ethnic/racial categories: Urban African American, Urban Asian, Urban Hispanic, Native American, Urban Caucasian, and English as a second language, and two groups comprised of first responders (EMT) and frontline public health workers (hospital staff). Focus group interview participants were drawn from convenience samples of people fitting criteria outlined, and they were recruited at participating community-based organizations. Each of four collaborating university teams conducted 2-3 botulism focus group interviews in their region. Focus group interviews were led by moderators trained to elicit responses from all participants in a nonjudgmental manner. Total duration for each focus group was approximately 1½-2 hours. All participants read an informed consent document and verbally consented to the study prior to their interview, in accordance with university Institutional Review Board standards.

To stimulate discussion and assure that information on topics of interest was elicited, open-ended interview guides were created. Questions on interview guides reflected constructs from the health communications theories cited and included knowledge and beliefs, perceived risk, emotional response to threat, intended actions, and information-seeking behaviors. The discussion guide was structured to gain insight into the sequence of responses to unfolding events during a hypothetical terrorist attack using *botulinum* toxin. This was done by reading a series of three consecutive hypothetical scenarios involving a botulism outbreak. Following the reading of each of these scenarios, moderators asked the same series of questions to elicit information about the major content domains defined. An assumption of the scenarios and ensuing focus group interviews was that while people portrayed in scenarios were at risk of exposure to the agent, they were not themselves the first cases or in the epicenter of the event.

The first scenario presented the possibility of a biological attack with a nonspecific agent; the second became

more specific, providing information on symptoms; and the third scenario gave confirmation of the agent as botulism and a description of institutional response. Following are the scenarios used for this study.

*Scenario, Part 1:*

You wake up about 7 am on a Tuesday and turn on the local news to hear that President Bush has raised the Homeland Security Advisory System threat level to severe (red). The president and his advisors report that this change in the national threat level is based on knowledge of a credible threat that a terrorist group may be planning a biological attack in [Los Angeles]. Officials suspect that the attack may involve a biological weapon.

*Scenario, Part 2:*

A week later, early on a Monday afternoon, you turn on the radio and hear that 15 people in [Los Angeles] have presented at local emergency rooms and doctors' offices with blurry vision, heavy eyelids, difficulty speaking and swallowing, weakness, and facial paralysis. Although the cause has not been confirmed, these symptoms are consistent with botulism. Botulism is a toxin that affects the central nervous system and is spread through food and water.

*Scenario, Part 3:*

Later that same day, you turn on your TV to find that a local government official has issued a statement. She confirms that there has been a deliberate release of a biological toxin in [Los Angeles], and the agent has been confirmed to be botulism. It was believed to have been released through a food source still under investigation. So far, there are 30 presumed cases; however, more persons in [Los Angeles] are potentially poisoned. Local health workers and emergency personnel are working to contain the problem by continuing the investigation outbreak, administering antitoxin, and providing supportive therapy for those infected.

All focus group discussions were tape recorded and transcribed, and transcripts were finalized by incorporating note-takers' comments. Transcripts in their entirety were then transferred into ATLAS.ti® (Version 4.2, Scientific Software Development, Berlin, Germany), a computer software program designed to assist with the coding, organizing, annotating, and comparing of text segments.<sup>23</sup> The first-level analysis was undertaken to conceptually organize and reduce the data into major domains or categories based on specific constructs outlined above. Emergent constructs of trust in government and the media also were incorporated. At this level of the

analysis, each transcript, which had been coded by two persons, was compared; when codes for the same segment of text differed, concordance coding techniques were used to reconcile the differences. The second level of analysis consisted of sorting and grouping of coded text segments from all transcripts by major domain/category. Within each content domain, analysis consisted of identifying and organizing the full range of responses that were found across all focus groups, the basis for findings reported here.

## FINDINGS

In this sample ( $N = 93$ ), ages ranged from 19 to 91 years, with a mean age of approximately 48 years (see Table 1). Sixty-two percent of participants were female, and slightly more than half (52%) were married or living with a partner. A majority of the sample (78%) reported having children, and 67% spoke English in their homes. Seventy-six percent of participants had a high school education or better, with 38% reporting having completed a college or graduate degree. Sixty percent of the sample reported being currently employed. Approximately half of the sample reported a family income of less than \$30,000 for 2002. The demographic profile for botulism groups was similar to the groups for the overall project.

### *Emotional response*

A large range of emotional responses were voiced after the first scenario was described. The most common emotions were fear, anxiety, distress, nervousness, and helplessness. A commonly voiced theme was the fear that the stress of not knowing much about the situation would cause either the participants themselves or others around them to panic. Other concerns that surfaced were the safety of children and, among ESL and Hispanic groups, the ability to understand English. A number of people also said that they would feel a need for prayer in these circumstances.

As the second part of the scenario rolled out, fear among participants seemed to intensify, and there was sadness and empathy for the victims. While participants were grateful for the information they had gotten, not knowing everything about the event made them edgy and concerned. As one participant noted:

You need more information. . . . You need to know the connecting elements between them. If there is no connecting element then that's when you are going to start being a little bit more concerned. (Rural Caucasian)

Others noted that this type of announcement had an impact on everyone in the community, and the onus of pro-

TABLE 1. CHARACTERISTICS OF PARTICIPANTS

<i>Characteristic</i>	<i>Category</i>	<i>Botulism groups (N = 93)</i>
Age	Range	19–91 years
	Mean/SD	47.52/16.62
	Missing	7%
Sex	Male	38%
	Female	62%
Education	Less than high school	8%
	Some high school	16%
	High school diploma or GED	15%
	Some college	22%
	College degree	25%
	Graduate degree	13%
	Missing	1%
Ethnicity/race	African American/Black	21%
	American Indian/Alaskan Native	10%
	Asian/Pacific Islander	23%
	Caucasian/White	27%
	Latino/Hispanic	17%
	Other	2%
	Missing	—
Language in home	English	67%
	Spanish	15%
	Bilingual/English & Other	6%
	Other	12%
	Missing	—
Marital status	Single	18%
	Married or living with partner	52%
	Divorced or separated	12%
	Widowed	17%
	Missing	1%
Children	Yes	78%
	No	20%
	Missing	2%
Currently employed	Yes	60%
	No	36%
	Missing	4%
Family income	Less than \$10,000	22%
	\$10,000–\$19,999	19%
	\$20,000–\$29,999	12%
	\$30,000–\$39,999	8%
	\$40,000–\$49,999	9%
	\$50,000–\$59,999	6%
	\$60,000–\$69,999	1%
	\$70,000–\$79,999	3%
	\$80,000–\$89,999	—
	\$90,000–\$99,999	—
	\$100,000 or more	3%
	Missing	17%

tection shifted to individuals. That is, as it became clear that the agent was carried by food or water, individuals had to change their consumption patterns to protect themselves.

After the third scenario, respondents noted that some of their fears were allayed. This was mainly due to the fact that the agent was confirmed and that authorities were working to resolve the issue. Others said they would still be anxious and would need to know more, such as where the cases were clustered, where the toxin was, how they could protect themselves, and that an outbreak investigation was continuing, before they could relax.

### *Knowledge and beliefs*

Overall, participant knowledge about botulism was limited. After the first scenario was read, some participants speculated that increased surveillance since 9/11 has made the United States safer. Some participants worried about the veracity of information transmitted by the news media, and others were concerned about the release of contaminants or chemicals into the environment. Specifically, lack of information gave rise to speculative thinking in regards to who was responsible for the attack and what was being done.

By the second stage of the scenario, concurrent with increased emotional arousal, a number of beliefs about the general event were expressed. A few people made the connection between a number of people becoming ill, eating contaminated food or breathing in the toxin, and an outbreak investigation. There was some confusion over communicability. Some thought that botulism could be spread through the air or through deliberate actions on canned goods. There was a general recognition that some consumption behaviors needed to change, although it was not clear what could be done until the investigation had been completed. Participants were not clear about symptoms, what treatment entails, or treatment availability and accessibility.

By the third stage of the scenario, when botulism was confirmed, respondents started to discuss not only their own personal safety but the safety of the public more generally. Clearly, the fact that the threat had been named and to some extent localized relieved the people who were not immediately affected and allowed for discussion of the "bigger picture." The general consensus was that there is currently a high level of threat in the United States and that security is insufficient to stop such an event. One area in which all concurred was the need for general preparedness prior to event occurrences.

Although participants were not familiar with botulism per se, many were familiar with food outbreaks, and many related the scenario event to what they knew about

other food contamination issues, such as salmonella, poisoned Tylenol, or bad lots of food from processing plants. However, these perceptions were overlaid with a lack of understanding about botulism symptoms, transmission, whether botulism was contagious, treatment, and treatment availability and accessibility. There was little recognition of the possibility that botulism could be delivered through an airborne modality.

Some participants assumed that presenting at the hospital would be helpful to the investigation. Others took a very dim view of going to the hospital and believed that risk of contamination would be higher; this belief attests to the lack of knowledge about contagiousness and transmission. Finally, many people believed that they would not necessarily be in the line of fire, especially those who lived in rural areas, as they claimed that terrorist events were most likely to happen in the center of large cities.

### *Behavioral intent*

Initial actions that participants would take in response to the first scenario may be categorized into the following types of responses. The majority said they would "stock up" on supplies, including food, water, first aid supplies, batteries, and gas. The implication was that they were prepared to stay in their homes. A second group said that they would seek a way to leave town. A third group said they would "wait and see" what the experts told them to do before taking action. A number of people said they would call family members or make sure their children were safe. Many mentioned seeking up-to-date information. A few people said they would also pray. Finally, there were a few people who believed that nothing could be done once an attack had occurred. Other strategies mentioned included listening to the media, staying home if instructed, and avoiding getting caught up in a hypothetical panic situation. As one person said in this regard: "I mean, why get wrapped up in it, get in a panic, and get out there with 1000 other people that are driving 100 miles an hours, and get killed?" (American Indian)

By the second scenario, some participants still believed they should pack up and leave town. However, as suspicion now was directed toward a food-borne illness, fear of panic seemed to subside, and participants' attention was focused more specifically on food and consumption patterns. There was a major reversal of thinking about actions related to food and drink. Instead of ritualistically rushing out to stock up on food and supplies, participants said they would reconsider what to do.

When the final scenario rolled out, actions continued to echo prior responses. A small group continued to suggest they would leave town, but the tone of the responses had softened considerably to being more of a joke than a serious consideration. The biggest concern continued to be

knowledge about whether food and water were safe. A number of people said they would search for more information about the outbreak and the people who were victimized, in order to try to understand possible sources of the outbreak. There was still a great deal of concern about panics and a mass exodus, but a number of participants suggested that it was important to remain calm and listen for information.

*Information seeking: What participants want to know*

What participants wanted to know also varied according to the phase of the scenario. After the first scenario, questions were very basic and can be summarized as comprising the content domain of protecting self and family. Questions asked and implied were: What can one do? How does one prepare? What should one do about one's children? Which places are safe? Where is the threat? Where do you go to be safe? What is the treatment? Where do you go to get treatment?

Following the second part of the scenario, participants' information-seeking needs became specific to botulism. Questions centered on understanding the illness and symptoms, transmission, and what could be done to prevent the illness, a content domain we characterize as trying to understand the seriousness of the threat. Questions included: What happened? What is the agent? Who is affected? How is the illness transmitted? Is it contagious? Where is the threat? Where is it centered? How wide-spread is the threat? What could be done to prevent the illness? How can one assure safety from exposure?

After the third scenario, the nature of information sought shifted once again. Here the issues were not so much about personal survival as after the first scenario, or of epidemiology as after the second scenario. The issues and questions at this point reflect perceptions of the meaning and context of the event and included who is doing what, the source of information, and system readiness. Some questions were: Where did the disease come from? Why did it get here? Who is responsible for the attack? How does the emergency broadcast system work? In what languages is emergency information available? What are the specific roles of government and health agencies as well as community organizations and schools?

*Information seeking: Where participants want to get information*

Following the first scenario, participants reported that they would seek out information from local television stations, local radio stations, national television and radio stations, and the internet. Local stations were seen as the first type of media to turn to if the story was local. Once the story got onto national news, television networks

such as CNN, ABC, NPR, and CBS were cited, as was the BBC. Responses were similar with regards to radio, with people giving preference to local stations due to speediness of response. There was some mention of the Emergency Broadcast System, but many more people mentioned that they would turn to the internet. Internet sites mentioned were CDC, Homeland Security, and local or state health department websites. Other main sources of information were community-based health, religious, and first responder organizations. There was little mention of elected politicians or physicians. A few people mentioned that they would seek information from multiple sources, including mass media and interpersonal networks.

After the second scenario, media choices expanded somewhat as well as individuals' rationales for using them. Participants said they would go to newspapers and the internet for more in-depth information. Types of internet sites mentioned were government and university sites that deal with bioterrorism.

By the third scenario, participants continued to seek information from sources already mentioned, but they were also interested in briefing sessions, town hall meetings, or community-based forums. The types of spokespersons mentioned as credible were health or emergency response experts, national leaders, or familiar news reporters. Local politicians and elected officials were not specifically mentioned as reliable sources of information.

In sum, throughout all of the focus groups interviews, participants expressed a high degree of need for as much information as possible through a variety of sources, a normal response in the context of a disaster or event affecting a large segment of the population. However, they wanted to feel as though information was valid and came from trustworthy sources. Both media and government evoked mixed feelings in regards to trust, especially among ethnic minorities. Moreover, while space does not permit analysis of participants' responses to CDC materials on botulism that were also a part of this exercise, in general receiving information on botulism was seen to allay participants' fears, as the condition was perceived to be noncontagious, reasonable to contain, possible to prevent, and curable.

## DISCUSSION

Focus group interviews revealed that general public audiences are primed and concerned about bioterrorist events. There is little awareness, however, of the nature of specific agents, in this case *botulinum* toxin. Although awareness about botulism was low, it is important to note that participants had some knowledge about food-borne illnesses and thus were able to make connections and draw inferences from previous similar experiences. In

fact, there was a general trend among the more health-literate participants in their ability to be able to understand key concepts of exposure and transmission, a finding that is supported by similar research underscoring the importance of basic health principles for understanding bioterrorist communication messages.<sup>25,26</sup>

As the scenarios rolled out, the first categories of responses fit what we know about responses to risk and threats. When the threat or risk level is uncertain, out of one's control, and manmade, risk perception theory tells us that people are much more upset than in a certain, controllable, natural situation.<sup>18,19</sup> Not only are people in a heightened state of anxiety, but there is also a great need for obtaining more information.<sup>12</sup> There was little knowledge of what actions to take in the situations described in the scenarios. Participants' statements initially conformed to what we know about disasters more generally. When individuals are confronted with disasters, a typical response is to go out and stock up on food and water, even though the household may have sufficient supplies. As with other research studying information-seeking behaviors after actual or fictional biological events,<sup>27,28</sup> information seeking among our participants also followed predictable pathways, with most turning to broadcast/local news first; as the event continued, they also used different media such as the internet or the newspaper to obtain more news and information.

The primary implication of these findings is that given the dearth of basic health and safety information in the news media,<sup>29</sup> communication messages need to incorporate these basic principles, ideally at the time the event is being announced. As well, our findings suggest that the organization of content for messages should be based on human response patterns that occur as a result of unfolding terrorist events. It is important that people's primary concerns for survival, for medical care if exposed or infected, and for prevention be addressed before more general information needs such as the epidemiology are explained. This finding is supported by the CDC national surveys conducted after the 2001 anthrax outbreak, which revealed that individuals believe that information about transmission, minimization of exposure, and recommendations for treatment are the three most important in the case of a biological terrorist event.<sup>27</sup> Once people are assured of their own survival, then the more technical information may be discussed. This "frontloading" of content does not follow scientific norms, where rationale and theory for actions typically precede the recommendations made. However, when people are under stress, the most important messages to transmit are the actions necessary to see the situation through, the justifications for such actions, and sources where more information can be obtained. Descriptions of emergency response systems are also important to reassure people.

Our recommendations for organizing or sequencing content for the general public, whether for a deliberate release of botulism toxin or another similar noncommunicable bioterrorist event, are:

1. *Survival messages*—Messages should include information about what to do if an outbreak occurs, including:
  - the seriousness and "location" of the threat;
  - symptom recognition of botulism toxicity for adults, children, and infants;
  - potential means of exposure; and
  - what to do if exposed or if symptoms of toxicity are present.
2. *Treatment and outcomes*—Messages should be available about treatment efficacy and outcomes and should include:
  - diagnostic procedures,
  - treatment goals and means,
  - treatment availability, and
  - recovery.
3. *Prevention of spread*—This set of messages has to do with more general actions that people can take to prevent exposure or the spread of the illness, such as:
  - food preparation,
  - household decontamination, or
  - sheltering in place.
4. *Epidemiology of botulism*—This set of messages follows the action steps and can include messages about:
  - the nature of botulism,
  - transmission,
  - potential methods of dissemination,
  - routes of exposure,
  - dose response, and
  - incubation.
5. *Response system*—Finally, there should be messages providing information on system-level responses, credible sources of information, and ways to access these resources (i.e., website addresses and toll-free numbers).

Our findings also suggest that to reach the widest audience possible, messages should be in multiple formats, keeping in mind that key messages need to be kept consistent across the different media used. Given how people use the media and how current broadcast media is organized, messages could take the form of television video news releases, radio news releases, live reads or scripts for newscasters or health officials, websites, and printable fact sheets. For some of these formats, it may be appropriate to use a journalistic or documentary style. Use of simple, nontechnical language whenever possible, as well as inclusion of graphics and pictures, is also recommended, as it was clear that many people in our sample had low to moderate literacy levels.<sup>25</sup>

In summary, the research carried out suggests that audiences are lacking agent-specific knowledge at present; however, people would be swift to seek out information should an event occur. Such information should be readily accessible, as it can allay fears and stimulate potentially life-saving actions. In the words of one African American participant: "So if someone would have had the information when we were panicking, everybody wouldn't have panicked."

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