In-Depth Assessment of an Outbreak of Nipah Encephalitis with Person-to-Person Transmission in Bangladesh: Implications for Prevention and Control Strategies

Lauren S. Blum,* Rasheda Khan, Nazmun Nahar, and Robert F. Breiman

International Centre for Diarrhoeal Disease Research, Bangladesh, Dhaka, Bangladesh

Abstract. Continued Nipah encephalitis outbreaks in Bangladesh highlight the need for preventative and control measures to reduce transmission from bats to humans and human-to-human spread. Qualitative research was conducted at the end of an encephalitis outbreak in Faridpur, Bangladesh in May 2004 and continued through December 2004. Methods included in-depth interviews with caretakers of cases, case survivors, neighbors of cases, and health providers. Results show contrasts between local and biomedical views on causal explanations and appropriate care. Social norms demanded that family members maintain physical contact with sick patients, potentially increasing the risk of human-to-human transmission. Initial treatment strategies by community members involved home remedies, and public health officials encouraged patient hospitalization. Over time, communities linked the outbreak to supernatural powers and sought care with spiritual healers. Differing popular and medical views of illness caused conflict and rejection of biomedical recommendations. Future investigators should consider local perceptions of disease and treatment when developing outbreak strategies.

INTRODUCTION

Eight outbreaks of Nipah encephalitis have been identified in Bangladesh from 2001 through 2008, with an average case-fatality ratio greater than 70% and devastating social consequences in the villages where they occurred.1–8 In 2001, an outbreak of Nipah encephalitis was also identified in Siliguri, India, which is located on the western border of Bangladesh.9 Although each outbreak has been associated with unique exposures, epidemiologic evidence suggests that person-to-person transmission occurs, increasing the potential for wider proliferation of this lethal pathogen and complicating prevention and control strategies.1–7 Because flying foxes (Pteropus species), the natural reservoir for the Nipah virus, are found all over Bangladesh, and no measures have been implemented to prevent transmission of the virus, it is likely that epidemics will continue.

The fourth recognized outbreak in Bangladesh, which occurred in 2004 in the Faridpur District with an estimated case fatality ratio of 75%, had several unique features.3 It had the longest duration, lasting more than two months, during which the outbreak spread to seven villages within a three-hour distance from the community of the index case. One person was likely responsible for transmitting the virus to 22 people, including 12 family members. Nipah virus can be found in respiratory secretions of infected persons,10 and in Faridpur the Nipah virus genome was detected in swabs of environmental surfaces, including the bed of a patient who died of Nipah encephalitis and the adjacent hospital wall,11 which highlight the potential risk associated with close exposure to infected respiratory secretions.

Nipah virus investigations in Bangladesh underscore the need for preventative and control measures to reduce transmission from bats to humans and decrease human-to-human spread during outbreaks. The current hypothesis is that Nipah virus spills over from bats to people when a person ingests bat secretions that contain virus, for example, by eating a piece of partially eaten fruit dropped by a bat or drinking date palm sap contaminated by a bat. Person-to-person transmission is likely related to the degree of close contact with a highly infectious case, perhaps amplified when the patient has co-existing respiratory symptoms, especially cough. Little is presently known about the local understanding of the disease or about caring practices provided to sick patients. Such information can guide the development of communication strategies aimed at decreasing human exposure and transmission of the virus during outbreaks.

Anthropologists have described the health system in Bangladesh.11,12 Pluralistic in nature, it is comprised of government, non-government, and private facilities offering biomedical care, allopathic practitioners selling medicines in community shops, homeopathic healers, and a range of magico-religious healers. Regardless of the illness, the first-line of treatment is frequently with unlicensed allopathic healers, who can offer a range of pharmaceuticals, or with homeopaths or spiritual healers.13 In this context, spiritual healers primarily include kobiraj (also herbalist) and fakir, whose care is sought when the illness is linked to supernatural powers.

A team of medical anthropologists was invited to explore the cultural or explanatory models of the Nipah virus during and after the Faridpur outbreak. Introduced by Kleinman,14 explanatory models are designed to elicit cultural perceptions of illness signs and symptoms and their progression, causal explanations, appropriate health resources and treatment, and the expected outcome of a specific illness event. Other study aims were to describe 1) caring practices for patients infected with the Nipah virus, 2) the perceptions and treatment of the disease among health providers, and 3) the level of understanding and acceptance of messages designed to control further spread of the virus during the Faridpur outbreak.

MATERIALS AND METHODS

Study site. The study was carried out in villages affected by the Nipah encephalitis outbreak in the Faridpur District, which is 145 km west of the capital of Dhaka. Data collection began towards the end of the outbreak in May 2004 and continued through December 2004. Typical of Bangladesh, Faridpur is an agrarian society where most of the population practices Islam.
Characteristic of life in rural villages, families reside within a *bari*, which is a homestead comprised of nuclear and/or extended families from the same patrilineal lineage. Women traditionally provide care for ill family members.

**Study design and sampling.** The research strategy was qualitative, consisting of key informants (4) and open-ended respondent interviews (32). Key informants provided information on cultural interpretations of the outbreak and included one case survivor, two caretakers of deceased cases, and one neighbor of the deceased. The sampling framework for the respondent interviews included households where at least one member had died from Nipah encephalitis (22), case survivors (5), and neighbors of households (5) that had been affected by the virus. The goal was to assess differences in perceptions and reactions to the disease according to the level of direct contact and human loss. Detailed narrative accounts of treatment and sequences of health seeking behaviors were collected from caretakers of confirmed Nipah encephalitis cases and case survivors. Perceptions of causal explanations were elicited from both households with cases and their neighbors.

Ten in-depth interviews were conducted with people involved with health care, including three nurses, two physicians, and one sanitary worker for the isolation ward in Faridpur Medical College Hospital, as well as two spiritual healers, one homeopath, and one unlicensed allopathic shopkeeper working in communities where the outbreak occurred. All of the health workers gave treatment to patients at different stages of the outbreak. These interviews focused on causal explanations of the disease, treatment provided, and advice given to caretakers.

**Data collection.** Two researchers with training in anthropology carried out the interviews in Bangla, the local language. All attempts were made to administer interviews in a private setting, either in the household or the workplace of a health provider. The researchers took detailed notes during the interview and expanded upon their notes shortly after the interview was completed. Efforts were made to collect descriptions of signs and symptoms and corresponding careseeking behaviors from the onset of illness to the time of recovery or death. All interviews were later translated into English by the researchers.

**Analysis.** Once data collection was complete, a coding system was developed, capturing the main research themes and concepts. Interviews were coded on Atlas.ti, a text-organizing software (http://www.atlasti.com/). Content analysis was used to identify trends of key concepts in the coded data. Data triangulation identified only those concepts that could be validated through a combination of data sources, such as multiple interviews and key informants.

**Ethical review.** Informed consent was obtained from all the human adult participants and from the parents or guardians of minors. The study was reviewed and approved by the International Centre for Diarrhoeal Disease Research, Bangladesh Ethical Review Committee, which uses international guidelines to ensure confidentiality, anonymity, and informed consent.

**RESULTS**

**Household respondents. Perceptions of Signs and Symptoms.** Particularly during the first days of illness, there was a wide range of illness conditions mentioned, totaling more than 20 different signs and symptoms. The initial sign most frequently cited was fever, which respondents explained fluctuated, sometimes reaching as high as 104°F. In addition, respondents consistently mentioned body ache and headache during the first days of illness. Generally, around day three or four, other signs associated with more severe illness, such as diarrhea, weakness, refusal to eat, nausea, vomiting, and lethargy, were evident. Just before death, the afflicted were described as talking incoherently, extremely restless, convulsing, and transgressing into a state of unconsciousness. Signs and symptoms such as cough, rapid and difficult breathing, chest in-drawing, and rattling in the chest, likely linked to acute respiratory distress, were also mentioned beginning on days three and four up to the time of death. Near death, many respondents noted that froth came from the nose and mouth, and the headache, which was severe at times, subsided.

**Providing care for the patient.** Female relatives were responsible for giving hands-on care, which entailed feeding the patient, cleaning the body including the nose and mouth, disposing of body fluids, and administering home remedies or medication. Extensive efforts were made to feed the patient liquids, either water or milk, in a glass, and most patients were fed solids either by the hand of a female relative or with a spoon. The caretaker also bathed and cleaned the patient, using a *gamcha*, a traditional rag, to wipe secretions such as vomit or froth coming from the nose or mouth, and she was also responsible for washing the patient after urination or defecation. Towards the end of fatal illnesses, most patients became incontinent, and the caretaker also cleaned clothes soiled by urine and feces.

Family members continued to share eating utensils and glasses, as well as to eat leftovers of sick patients. Typically, several people sleep in the same bed, and sharing a bed became even more important during the illness to ensure that the patient remained comfortable and proper support could be maintained. Respondents expressed a strong desire to have close physical contact directly before the death, involving hugging or feeding or whispering Koranic verses into the sick person’s ear. As a result, crowds of relatives and friends typically gathered to interact with the victim either through touch or verbally for a last time.

At the beginning of the outbreak, family and religious leaders followed the Muslim practice of preparing the corpse by cleansing the body, particularly the orifices, for burial. However, as more cases died, religious leaders refused to participate in the traditional burial and only immediate family members were willing to perform the rituals involved.

The following case study highlights caring practices for Afsar Monir,* the super spreader of the outbreak. Afsar Monir was the leader of an Islamic sect comprised of devout followers from his community. Those persons not in the sect viewed many of their activities as contrary to Islamic doctrine. For instance, members of the sect failed to pray five times a day or fast during Ramadan, and they were also involved in practices perceived as radical, such as holding all night praying sessions with men and women, smoking cigarettes, and singing.

**Case study: the super spreader.** The outbreak started in a village approximately 10 km from Monir’s home where the family of his daughter-in-law lived. His daughter-in-law’s mother was the third person in that village to die. While she

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*A pseudonym is used to protect the identity of the person.*
was dying. Monir was next to her, holding her hands, feeding her water, and reciting excerpts from the Koran into her ear. Subsequently, Monir came down with the illness and died 11 days later. Family members and worshippers elected to be near Monir the entire night before his death, providing direct, hands-on care, feeding him water, milk, and juice through a glass and solids by hand, and massaging his body with oil. They got close to his face to whisper blessings in his ear. Because Monir could not sit up, the disciples placed his head in their laps to comfort him. At the time, Monir had a violent cough, and he would frequently cough or spit liquids from his mouth.

After his death, eight members of his family died, and four other members became seriously ill. In addition, six of his followers died, and another got infected but survived. All of these victims had close contact with Monir before his death. In his honor, family and followers buried Monir in the household courtyard and made his tombstone a shrine.

**Home therapy.** Home remedies were provided at the onset of illness and measures were generally administered each day the patient remained in the household. Only in two cases did the patient not receive home remedies. Therapeutic treatment at home was primarily designed to reduce the fever, involving dousing the head or sponging the body with water. Family members also used mustard oil, which was believed to reduce muscle ache, to massage the body. Another common traditional therapy was to apply a paste made with vegetables to the head, which is believed to help the fever leave the body. The wife of a case explained,

> I made a paste of mustard seed and potato and put it on the top of his head. I thought that the headache was due to the heat he got from working in the field in the hot sun. We usually use this treatment of headaches caused by heat from the sun. If you put the paste on the top of the head, then the heat in the body comes out through the head. Along with that we rubbed mustard oil onto his feet and hands. We did this for four days. However, nothing worked to improve his condition.

Home therapy progressively diminished over time as patients either entered the hospital or died.

**Local allopathic practitioners.** In the first days of illness, many family members also administered a fever reducer, which they either had in their homes or obtained from a local village doctor or trained provider. On the basis of the description of the ill patient given by family members, health workers also provided other medications in the form of injections, pills, and syrups.

**Hospital care.** Many patients were hospitalized on or after the third day of onset of symptoms. For some, this timing coincides with efforts by government officials who had gone house-to-house actively encouraging hospitalization of suspected cases once the high case-fatality rate was detected. Few patients remained in the hospital after the ninth day of illness because many patients died or were discharged by then. Care providers explained that hospitalized cases were dying, convincing them that treatment was not available; family members opted to return patients home where they could be close to loved ones and neighbors. Over time, the perception was that medicine administered in the hospital was aggravating the condition and that all hospitalized patients would die. When she returned to the hospital to see her son and stepson, this mother explained,

> I found that they were not talking like the previous day and they were making a ghor ghor sound in their throat. They had difficult breathing and they couldn’t recognize anybody. I decided to bring them home as their condition deteriorated after the hospital workers gave them medicine. They went to the hospital by foot, singing. How could their condition get so bad so quickly? No one left the hospital alive so I decided to bring them home. Hospital people didn’t say anything, they didn’t try to stop us. They knew that they couldn’t make them well. …If they had not been taken to the hospital they would have lived. They killed my son in the hospital. They pushed an injection and my son died.

Approximately halfway through the outbreak, a widespread rumor was that the health care providers were administering a medicine to kill patients and thus prevent the disease from spreading. People referred to a drug they called coramin that was apparently given by health workers in the past as a last resort to patients in a coma. This female caretaker said,

> After some time the nurse came and gave another injection. My sister’s husband said that they were giving my mother the last treatment. Then I cried loudly that they killed my mother by giving her coramin. Within a few minutes my mother died.

**Traditional healers.** Few patients visited a homeopath or hujur (religious healer) for treatment. Towards the end of the outbreak, treatment was sought with spiritual healers, including fakir or kobiraj. An elderly man who lost four family members explained why he took his grandson to the fakir.

> I don’t believe in fakirs, but when someone is in danger you have to try all options. I had to keep my grandson alive and I didn’t care whether that was through spiritual treatment or medicine from a village doctor. Whatever worked I was willing to try.

In general, at the end of the outbreak, there was an influx of community members claiming to have fever who visited spiritual healers for care.

**Causal explanations.** Caretakers initially associated the fever with hot weather or prolonged exposure to the sun. As the outbreak progressed, health outcomes raised skepticism and altered beliefs about the cause as indicated by this respondent.

> I thought this was fever, that people were dying from fever. However, I have never seen people die of fever. People can even survive with fever for six months.

Because home remedies and biomedical treatment proved to be ineffective, and people continued to die, the most common interpretation was *asmani bala* or *bala* described as a sudden supernatural force or curse inflicted by Allah. This respondent explained,

> Asmani bala is something in the air, a supernatural force that comes through the air. Maybe that supernatural force came to our village to kill people.
Another caretaker informant said,

Not only me but all the villagers are saying that this is asmani bala. If it were not asmani bala the medicines would have worked. ...We considered it as bala after a lot of people died and we saw the medicines were not working.

People explained that Allah wanted to punish the family of Afsar Monir and his disciples for being involved in such anti-Islamic activities as worshiping a religious leader of a small sect or not subscribing to the pillars of Islam, as well as committing sinful acts. Respondents also cited the burial of Monir, which opposed Islamic custom that states that the burial should be far from the home of the deceased. We were told that Allah had decided to penalize the entire community for these sins. This caretaker respondent explained,

Allah was angry and wanted to punish people by killing them. Doctors working in the hospital were saying that the disease is called Nipah and it comes from bats. However, doctors don't know how to treat the illness. Therefore, it must be asmani bala. If doctors could treat the illness I would not call it asmani bala. Four or five people from the same household would not die unless it was asmani bala. Earlier people had died of cholera and pox. Now people are dying of fever. People are not saying their prayers and they are telling lies and Allah is angry. So Allah showed his anger by taking lives. It's not only the sinners who were punished. Any one can be punished for these acts.

This interpretation was confirmed by the sudden onset of the outbreak, the high case fatality rate, particularly among the religious sect, the fact that it affected healthy persons and the primary symptom was a simple fever, that it had never been experienced before, and that there was no known treatment. Community members became highly concerned and responded by arranging a congregation to pray to Allah and recite the Koran. Rice was collected and offered as a sacrifice to the supernatural forces. People also reacted by attending the mosque regularly and appealing to Allah for forgiveness. After the outbreak, members stated that Allah forgave them and the curse was lifted because they returned to the path of God.

A less frequent explanation for the deaths related to fate. In Islam, it is believed that before birth Allah decides when a person will die; respondents explained that Allah had sent the illness to take the lives of community members destined to die. Another interpretation was that by witnessing so many deaths, victims were struck by fright, causing shaking and convulsions. Other less common explanations included evil spirits, bird flu or germs.

Views on contagion. Person-to-person contact and contagiousness was rarely mentioned as a cause of the disease. Rather, the fact that many care providers did not contract the disease, despite having close contact with patients, confirmed that the disease was not contagious. This woman who lost her husband and son said,

The reason I do not think it is contagious “choache” is because I did not separate anything while they were sick. We took the rice and water from the same plate and glass while they were sick. My younger son and my daughter ate their leftovers. We touched them a lot but we did not get the disease. If it were contagious then it would infect me first. I cleaned the vomit, stool, and clothes. I fed them with my hand, I rubbed their bodies, but I did not get the disease.

The daughter-in-law of a death case said,

If it was contagious, then why did the people who had very close contact caring for the patient, washing their face and nose from coming from the mouth, leaning their face near to the deceased person’s face, not get infected? When we didn’t get infected, we realized that it wasn’t contagious.

Caretakers also indicated that advice given by hospital workers regarding contagion opposed cultural norms. This wife of a case explained,

They alerted me by saying that I should be more careful while nursing my husband. They said that it is contagious and I should cover my mouth while going to him. I did not do this since I am his wife. Would I cover my mouth with my hands or take care of him? Apa “sister,” he did not smell badly, then why would I put the cloth to my nose and mouth? No matter what, he was my husband. He would get so upset if he saw me covering my mouth.

Health care providers. Hospital workers. The epidemiologic team investigating the outbreak informed hospital clinicians about the etiology and transmission of the disease, providing instructions on the care of patients and appropriate protective measures. Doctors and nurses were told that the reservoir of the virus is bats, likely contracted to humans consuming fruit partially eaten by bats and that the disease is contagious and likely being transmitted person-to-person. During in-depth interviews, doctors and nurses expressed skepticism about the role of bats, suggesting that consumption of bat-eaten fruit is common, and if bats carried the virus, epidemics would occur annually. Doubts about the infectious nature of the disease were also raised on the basis of the close contact of the caretakers and clinicians with patients. Doctors and nurses insisted that an infectious disease is transmitted through touch and is not air-borne. Nurses admitted that they frequently failed to wear personal protective equipment (masks and gloves) distributed during the outbreak. One doctor stated,

It cannot be contagious. The reason is we touched the patients on many occasions without knowing what the patient had, and we did not get infected.

This nurse working on the isolation ward said,

I don’t think that the disease is contagious. If the illness were contagious, then I would not have survived. I touched a lot of patients, took the temperature, and administered medicine. If anyone touches the patient and gets the disease that means it is contagious, like scabies. But if it is spread by sneezing and coughing or spitting, that doesn’t mean it is contagious.

Another nurse said,

If it was contagious then the first affected person would be the family attendant who cleaned the saliva and slept
and ate with patients. For this reason, I don't think the disease is contagious.

At the same time, we found that messages regarding contagion and protective strategies instilled fear among clinicians, particularly nurses, who admitted to avoiding touching and providing care to patients. Their primary concern was that they would contract the disease and subsequently infect family members. One nurse and cleaner stationed on the isolation ward refused to work for several days. As the death toll in the hospital increased, doctors described a feeling of panic, influencing decisions not to accept or to discharge patients or, at the outset of the outbreak, send cases to the capital Dhaka. Those working on the isolation ward indicated that they were shunned by other clinicians in the hospital. Nurses also expressed difficulty convincing patient attendants to follow precautionary measures, such as washing their hands after touching patients, and avoiding eating with, and maintaining close contact and sleeping with patients.

Traditional healers. Spiritual healers associated the outbreak with supernatural powers, suggesting either that asmani bula in the form of kharap batash (bad air) or bod jin (a genie or demon) was sent to punish people for their sins. Treatment involved incantations, massaging the body with blessed oil, applying herbal paste to the head, praying to Allah, and wearing amulets as treatment and protection to family members.

Allopaths and homeopaths. The medical shopkeeper treated patients for fever and headache at the initial stage of the outbreak, and if the fever persisted, referred them to a trained physician. Once he learned about Nipah encephalitis, he sent patients with fever directly to the hospital. When treating patients, he diagnosed fever, associated with seasonal change, and advised care involving fever reducers and antibiotics. He too rejected the idea that it was contagious, arguing that all the inhabitants would have died. The homeopathic doctor indicated that the epidemic had been inflicted by God.

Overview of messages. Investigations into the understanding and acceptability of messages developed by the scientists and conveyed to residents of communities touched by the outbreak and patient attendants and health care providers in the hospital setting show striking contrasts. Table 1 presents some of the messages transmitted and the reaction of respondents.

**DISCUSSION**

Social norms in Bangladesh demand that family members and loved ones maintain close physical contact with sick patients. As the severity of disease increases, so does the perceived need for hands-on care and body contact. Those persons who fail to engage in direct contact are sending a signal that the ill person is not important. In the case of Nipah encephalitis, the progression to a severe form of the disease also translates into higher secretion of body fluids. The combination of the social need to have greater contact with sicker patients, and the excretion of fluids probably at the height of contagiousness, is likely to raise the risk of human-to-human transmission of the virus. In particular, the social status of the super spreader demanded a demonstration of affection involving physical contact by his followers, leading to 22 subsequent infections. Evidence suggests that close body contact with infected cases by friends and family paying their last respects perpetuated spread of the virus within the outbreak community and to other villages. Cultural burial norms involving cleansing of the orifices immediately after death were also potentially dangerous.

The most common first sign of illness onset was fever, which was associated with over-exposure to the sun. The failure to comprehend that the symptom could be dire influenced the ethno-diagnosis, guiding subsequent home management involving the use of counteracting cooling substances to reduce the fever. In contrast, the public health strategy involved getting patients to a hospital environment with the hope that supportive care involving fluid management and respiratory care could be provided and further transmission of the disease prevented. However, families had reservations about taking infected patients to the hospital. First, the primary symptoms of fever and headache suggested to residents that the illness was harmless and would quickly pass. In explanatory systems, there was no reason to believe that more serious illness signs such as vomiting, convulsions, and unconsciousness constituted the same illness domain. Only when symptoms perceived to be serious more conclusively identified the disease over time did villagers consider hospital care.

Researchers have described the abysmal conditions of many Bangladeshi government hospitals where clinicians are commonly absent, supplies are inadequate, unofficial fees are collected, and the quality of care, including willingness to provide hands-on care, is poor. As a result, the hospital setting is viewed as a last resort only to be used when the condition is extremely serious. During the Faridpur outbreak, hospital health workers were reluctant to provide hands-on care to infected patients, and as more patients died, community members lost confidence in their care. Ironically, the distance maintained by health workers may have served to protect these and other hospital workers involved in previous outbreaks from exposure to the virus. In contrast, in India where patient care practices appear to involve greater contact, health care workers contracted the disease from hospitalized patients. Subsequent rumors regarding hospital workers, who were said to inject cases with a lethal substance, underline the general fear and suspicion of hospital care, which served as rationale to reject biomedical treatment.
Over the course of the Faridpur outbreak, people developed causal explanations linking the outbreak to supernatural powers. The fact that the disease predominantly affected followers of an orthodox religious sect engaged in practices perceived to be offensive to the majority of residents served to confirm beliefs that the outbreak was invoked by the wrath of divine forces. Local understandings of contagion and the fact that many caretakers of patients did not contract the disease strengthened these interpretations. The symbolic significance of fever, including its perceived lack of lethal power and linkages to exposure to the sun, seems to have further undermined biomedical explanations related to the infection, adding credibility to the association with mystical powers and over time influencing an increase in the proportion of people seeking treatment with spiritual healers.

Trained health workers maintained many of the same cultural belief systems as the local community. Nurses held misconceptions about contagion, and both nurses and doctors insisted that infection is transmitted through touch and is not air-borne. These beliefs may have led to unwillingness to subscribe to personal protective measures in the hospital setting.

Sharp contrasts between the local and biomedical causal explanations and views on appropriate caring practices caused an incongruence that compromised communication between the scientific investigators and biomedical health care providers and the local community. For instance, local beliefs about contagion undermined messages transmitted on disease transmission. In the future, public health officials will need to explain that attack rates for infectious diseases never affect entire populations in a manner that does not cause them to lose credibility with the people to whom they are providing risk reduction messages. Differences in beliefs and knowledge seem to have contributed to the fact that over time the population opted to seek care with local spiritual healers who, in their view, shared the same explanatory disease model, offering treatment that coincided with their understanding of the illness.

Historical accounts have shown that differing medical and popular views of illness can cause suspicion and conflict, leading to the rejection of biomedical recommendations. A prime example comes from colonial India when the promotion of smallpox vaccination by medical experts interfered with indigenous causal explanations and religious beliefs. Although scientists treated smallpox only as a disease, most of the population firmly linked smallpox to the wrath of the goddess Sitala, the deity believed responsible for smallpox, thus causing them to reject the vaccination. In the case of Nipah encephalitis, doubts about biomedical explanations regarding contagion and treatment strategies encouraged people to seek alternative solutions.

While this study identified dangerous practices, it also raises many questions about human-to-human transmission of Nipah virus. Although evidence suggests that close contact with Nipah encephalitis cases increases the risk of infection, many caretakers had physical contact throughout the illness episode and yet did not contract the disease. Important next steps involve understanding 1) what risk factors are associated with person-to-person transmission, 2) what constitutes the height of contagiousness when exposure to cases is more likely to transmit disease, and 3) what level of contact is needed for transmission. Given continuing outbreaks in Bangladesh, it is imperative that these questions be answered and communication messages developed in the future be based on narrower evidence.

CONCLUSIONS

Social scientists are rarely involved in disease outbreak investigations. Our results highlight the importance of carrying out in-depth studies to gain valuable insights into local perceptions of disease and views on appropriate care and treatment. A major challenge is that beliefs and behaviors are fluid, evolving as new information is shared and processed within social networks and the disease affects members of the population. Particularly in the case of an emerging infectious disease, the situation is dynamic because changing scientific evidence requires the development of new research questions and a refocusing of the public health response.

Theories regarding how disease attributes influence the development of cultural models of explanation and management have been developed by anthropologists. One theory is that if the symptoms are clear-cut, the disease is common, the length of time between exposure to the causal agent and manifestation of disease is short, and effective treatment is available, these factors will determine the rationality of cause and effect problem-solving. In the case of this emerging, sporadically occurring disease, Nipah encephalitis, the time between exposure and development of serious illness symptoms was long (4–7 days) and curative treatment was unavailable, leading to the construction of causal explanations and care-seeking focused on religious and spiritual solutions. In Bangladesh, evil spirits or bad air continue to play a prominent role in cultural models of illness. With an emerging disease such as Nipah encephalitis, explanatory models are likely to draw on common illness concepts and broader indigenous beliefs available in communities.

Communication specialists developing preventative and control messages for Nipah encephalitis need to make use of the information collected to devise infection control approaches that take into account health ideology and social customs while at the same time supporting sound public health strategies. Important considerations include illness belief systems, caring practices for sick patients, and prevailing perceptions of hospital care. An exploration of health providers’ understandings of infectious disease and treatment provided is also imperative. Finally, unless hospitals can offer services to improve survival, they will continue to be avoided and fail to play an important role in controlling outbreaks. This has implications not only for Nipah encephalitis, but for other emerging and epidemic-prone infectious diseases.

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Authors’ addresses: Lauren S. Blum, American Embassy Kinshasa, Unit 2220, Box 178, DPO, AE 09828-0178, E-mail: laurensblum@yahoo.com. Rasheda Khan and Nazmun Nahar, International Centre for
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