

## **Outbreak Ethnography The Anthropologist's Toolkit**

I thought your lecture was very insightful, but would it be possible to use an empathetic person in the village to collect these data?  
 –leading epidemiologist at Ebola seminar at Pasteur Institute, Paris 2004

The epidemiologist was asking the question because he was under the impression that most of my data were collected from simply “hanging out” with local folks. Why couldn't an empathetic listener do the same thing? The question startled me at first, but I realized that in public presentations I seldom describe my methods in any detail; instead, I focus primarily on the results of the study. Epidemiologists, by contrast, often spend half of their lectures on data collection and analysis. I politely responded, “But like epidemiologists, anthropologists have a diverse toolkit. And while it is very useful to be an empathetic listener and hang out with people in many different settings, we have specific tools to conduct the research.”

### **Field Conditions**

Field conditions during Ebola outbreaks are challenging and relatively unusual for most anthropologists; they challenged us even though we had years of field experience in rural central Africa and had worked around infectious and parasitic diseases. Specifically, Barry had worked on projects to control river blindness (onchocerciasis) and schistosomiasis, while Bonnie had worked with AIDS as a nurse.

Anthropologists usually spend months reading about the history, ecology, and ethnic groups in the area before actually going into the field. This preliminary preparation is not possible in outbreak ethnography. In both Uganda and Congo, the WHO called and wanted us in the field within days. We had to completely rearrange our personal and professional lives—finding people to care for our children and cover our university classes—in addition to making travel arrangements and packing. Our previous field experience in Africa clearly enhanced our abilities to do the Ebola work, but we went into the field with a limited background on the history and particular cultures of the impacted areas.

Once there, we found that the landmark field method in cultural anthropology, “participant-observation,” was difficult to implement. Anthropological fieldwork usually involves living intimately with local people and participating, observing, and talking with people in a variety of contexts while they perform daily activities. When Barry worked on projects to control river blindness and schistosomiasis, he lived in villages where the majority of the people had these diseases. Upon our arrival in Uganda, the WHO director of control efforts asked how Barry would like to conduct the anthropological study. He replied, “Take me to a village that has experienced several Ebola cases and leave me for a week.” The director proclaimed, “That's out of the question.” Rebels in the Lord's

Resistance Army<sup>1</sup> were fighting the government, attacking villages, killing people, and kidnapping children. Even travel within the government-controlled urban area of Gulu, the regional capital, was considered dangerous. International team members resided at the Catholic hospital where the outbreak was first identified; anyone traveling from the hospital into town had to be in constant radio contact with the security unit at Gulu's Ministry of Health. Travel outside of Gulu included a truck with both radio contact and six armed guards. Figure 2.1 shows Barry with the armed guards and Kaban

[Insert Figure 2.1 here]

Kabanyuke, a Ugandan medical anthropologist who joined the team at the end of the outbreak and rode along to Ebola-impacted villages outside of Gulu town.

Anthropologists also like to participate in a diversity of social activities, but during the outbreaks, the government banned or discouraged many normal activities. The police restricted all travel into or out of the area and closed borders. The government cancelled school and church services; told healers not to practice their trade; prohibited all large public events, including dances, soccer matches, and large funerals; and closed all nightclubs. Even traditional greetings by shaking hands were banned, although people developed an alternative greeting—bumping right elbows together. Similar restrictions were in place while we were in Congo, except that healers were able to continue their practice as long as they did not “vaccinate” or cut people with razor blades. (Here people greeted each other by snapping their fingers.)

Living intimately with the people in their village was not possible in Congo. The outbreak started shortly before we arrived. We were not sure who did or did not have Ebola or who was or was not a contact case, that is, someone who had contact with a confirmed case. A security issue also existed. Four schoolteachers were attacked with machetes and murdered the day before our arrival. The murderers believed that the teachers had special knowledge about Ebola obtained through secret and supernatural means (this will be explained in Chapter 4 and were using it to cause harm to others. Tensions were high, and violence against anyone associated with Ebola was possible. We stopped giving out our university business cards when we met people because they identified us as teachers.

In the early 1900s, Broinslaw Malinowski, the founder of the participant-observation method, said that anthropologists should “get off the veranda” of missionaries or other colonial administrators and start living with local people where they could learn the language and talk with people in a variety of informal contexts. This was not entirely possible in the two outbreaks described in this book. We got “off the veranda” during the day to talk with individuals, families and communities, but returned each night to a secure location. We realized that our lack of mobility could impact whom we were able to talk to and what they were able to say to us. However, while we were sensitive to this, it was never an issue. To the contrary, men, women, and children were warm, receptive, and interested in telling their stories.

Outbreak ethnography is most unlike other anthropological settings in that the risk of mortality is a daily concern. Sometimes anthropologists die in the field, usually in auto

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<sup>1</sup> The Lord's Resistance Army (LRA) is a rebel paramilitary group formed in 1987. The group operates primarily in northern Uganda and is engaged in an armed rebellion against the Ugandan government.

accidents (Howell 1988), but few field settings require daily vigilance, caution, and focused attention while interacting with others. It is essential to have training and background in the most up-to-date Ebola biomedical research to protect oneself from infection and to provide knowledgeable answers to villagers who ask detailed questions. Timely information and knowledge are at a premium during outbreaks because they can mean life or death.

### Images of the Field, Denial, and Distrust: Gabon 2002

In August of 2002, we had just finished our research in the Central African Republic where Bonnie had been working on research on death, loss, and grief among Aka forager adolescents (Hewlett 2005) <New reference added to References Cited>. We had two weeks left in Africa and decided to spend it in Gabon where the 2002 outbreak had been declared over in June. We thought we might look into the possibility of conducting research on Ebola among Bokola foragers. Having just completed a study of death and grief, we wondered how people experienced these emotions during and after a rapid killing epidemic. We made our way by plane from the Central African Republic (CAR) to Libreville, the capital of Gabon, and then by taxi to Makokou, the regional capital of northeastern Gabon (see map of Gabon in Figure 1.3). The residents of Makokou were busy dressing up their city for the much-anticipated arrival of the Gabonese president. Streets were paved, buildings painted, and banners erected, at least in the areas the president would pass through. Military personnel in great numbers were patrolling the streets in anticipation of the arrival of their commander in chief.

We had difficulty finding a place to stay as people came in for miles around to see their president. We were fortunately offered a room at an ecological reserve outside of town that was actually closed for the season. We ate our evening meal of canned peas, sardines, bread, and boxed wine outside while enjoying the view spread out before us—a great canopy of green, filled with chattering monkeys, hornbills, and grey parrots. Below us, a river wound its way through the green forest.

As we sat in the fading light, we met a man named Issa, out for an evening stroll. As it turned out, he was a newly elected parliament member who graciously offered to provide us with a ride in the direction we were headed—to Mékambo. Issa and other Gabonese officials we met repeatedly assured us that we had no need to worry, to limit our travel, to be careful to whom we spoke, or to be concerned about where we stayed; Ebola, they told us, was not present in the area nor had an outbreak taken place earlier in the year.

We were rather surprised by their assurances because the WHO had invited us (although we were unable to accept the invitation) to participate in efforts to control the very outbreak they were saying had not taken place. The WHO later reported to us that Gabonese villagers put up one of the most hostile resistances to date to the international team sent in to respond to the outbreak. Villagers and politicians were verbally abusive and angry at the team's presence. Small groups took up spears and machetes to block the team's entrance into villages, and village residents refused to take sick family members to the hospital. The international team had to be evacuated twice from the area.

Issa repeatedly reassured us, telling us the story of how a local politician had dealt with the international team. He went the morgue, unzipped the body bag of an Ebola

victim, kissed the corpse, and pronounced, “If this is Ebola as you (the international teams) say it is, I should die, but if I do not die you should leave.” The politician made his point; he did not become ill. This provocative story spread, reinforcing beliefs in the nonexistence of an outbreak and surely contributed to the reported resistance the international team members encountered in villages. Local officials had a lot at stake—knowledge of the recent occurrence of an Ebola outbreak would have put a stop to the visit by the president, his entourage, and the large amounts of money that traveled with him. Already enormous amounts of money had been poured into the region in preparation for his arrival and subsequent stay.

The next morning, our arranged ride fell through, so we flagged down a taxi (called a *traffique*) filled with an assortment of people and animals. On the roof of the bush taxi was a precarious tower of baggage piled up to 5 feet high, swaying ominously  
[Insert Figure 2.2 here]

around each turn (see Figure 2.2). *Traffiques* are unreliable, as the drivers might change their mind about traveling, or more commonly, the taxi breaks down. The drivers are ingenious mechanics, rebuilding and reusing old parts or manufacturing new ones out of an odd assortment of materials on the spot. Taxis are somewhat dangerous; accidents are not uncommon, either collisions with other cars, bicycles, and animals; slipping off muddy roads during the wet season; or more rarely, tipping over. Seatbelts are nonexistent, as (sometimes) are front and side windows. Back seats are often taken out and replaced with rows of wooden benches. Passengers jostle and pack themselves in until (we think) there cannot possibly be one additional person added, and then a family of five will appear and people will rearrange themselves and make room. *Traffiques* are hot, smelly, and dusty, especially during the dry season when dust blows in and coats everything and everyone with a thick layer of choking red dirt. We love riding in them. There is a sense, especially on the longer trips, of a shared adventure. No one is really sure if indeed today you will make it to your destination. Perhaps it is because you are sitting so uncommonly close to each other, but whatever the reason, stories, jokes, songs, and food are passed around. It is an in-your-face sort of encounter with humanity. This closeness only becomes problematic when you are wondering, as we did on our return trip, if the person sitting next to you has been exposed to Ebola.

The roads to Mékambo were surprisingly good though, lined with bamboo trees and small villages, and we could see mountains in the distance. Our *traffique* came to a stop outside the Catholic Mission, the only place in town with rooms to rent. We walked down to the center of the small village to buy our supper, more canned peas and sardines, and found the place deserted, save for a few shopkeepers. Everyone had gone to Makokou to see the president, visit family, and join in the festivities. The only priest at the mission told us that a few months earlier in that very area, several villages had lost fifteen people in six months—not to Ebola, the people had claimed, but to sorcery. The priest said that he did not think the cause was sorcery but added he did not believe it was Ebola either. Thus, once again, we received assurance that an outbreak of Ebola had not occurred. Everyone was emphatic that we had no reason to worry.

From Makokou, we took a *traffique* to the Bakola village of Etoumbi. It reminded us of the village in the CAR where we had often done fieldwork. The village was divided into two sections, an upper section for the “villagers” or farmers who had small fields in the area and a lower section where the foragers lived. We shook the hands of the forest

foragers (derogatorily known as pygmies) as they greeted us enthusiastically and invited us to sit under a shaded area in the center of the village. An older woman disappeared into a nearby house and came out wiping off two glasses on her T-shirt. A box of wine soon appeared. We sat together, watching as the wine was poured carefully and passed around. The Bokola spoke a little French, answering our many questions. We learned that they go in and out of the forest, hunting and gathering. The women fish, and farther south, the Bokola gather caterpillars as do the Aka of CAR. We were delighted to be in the company of these forest foragers.

As we sat sharing the box of wine and conversing with the Bokola, we noticed a fresh mound of red dirt near the house where we sat. It was a grave. The Bokola noticed our glances and explained that several people had recently died—of sorcery, not Ebola. They were hesitant to speak about what had happened, but as the hours passed and more wine was poured, they told us of their experiences. A mother took us to her baby's grave and told us that her baby had had a high fever, stopped nursing, and then died in her arms. She grabbed Bonnie's arm to show us how she had held the baby as it died. Two other adults had died, they told us, a Bokola man and a village man. The latter was buried on the side of the road just outside the village. His family had paid for a tombstone with his name and date of death carved into the grey stone. We stood beside his grave and began counting the number of days since his death. He had died and been buried twenty-one days before our arrival.

We eventually caught the same *traffique* on its return trip and, waving our goodbyes, left the village of Etoumbi. Back in Mékambo, we visited the office of the WHO representative. He seemed shocked to see us again and kept his distance, speaking to us from the far side of the room. We were painfully aware of his lack of customary greeting. He refused to shake our hands. As we moved toward him, he quickly backed away to avoid us. To him, we were now potentially "Ebola people," virus carriers and thus dangerous. In spite of his and other officials' earlier assurances before our visit to Etoumbi, he now informed us that the epidemic was not over. Two weeks earlier, someone had died of Ebola, only 40 miles from Etoumbi.

The next morning, we woke early, and the head gendarme found us not one but two potential rides back into town. It was a hot, dusty, and slow ride. The goats on top of the van released streams of urine at regular intervals, drenching the unlucky passengers sitting below. Newly purchased (and obviously dead) pangolins, gazelles, and porcupines slid around at our feet as we rode bumping over potholes, the driver honking at bicyclists, people walking, and other *traffiques*. In one village, we hit a baby pig too slow in getting out of our way, and our driver had to haggle with the owner over the compensation price of the piglet. In spite of the apparently ongoing outbreak of Ebola, in many ways, life seemed to continue as usual.

Red dust blew in the windows throughout the journey, and all passengers arrived in Mékambo red skinned and red haired. We were dropped off near the airport where not too many days before we had arrived. Now the airport looked like a military installation. A sea of green military vehicles and personnel in fatigues were spread out as far as we could see. The festival in honor of the president was over. Military personnel and guests of the president were all waiting for planes to take them back to the capital city. We saw our friend Issa, and he encouraged us to take a free plane back to Libreville. We were quickly hustled onboard a waiting plane and found ourselves sitting among officers and

their wives who wearing beautiful, brightly colored dresses. Soon the Secretary of Defense boarded the plane and sat in the seat in front of us. The door to the plane closed, and a stewardess came down the aisle offering champagne in crystal glasses for everyone. We sat there dusty red, sipping champagne, and smelling like goat urine and dirt. We were on our way back, feeling both sad to be leaving Africa and glad to be healthy and heading home.

This brief description provides images of one field setting and illustrates the pronounced distrust of international teams, how denial is a common feature of outbreaks, and the potential for medical anthropologists to contribute to control efforts. The strength of the people's denial surprised us. Villagers, priests, and top governmental officials supported the denial even though laboratory tests indicated the deadly agent was Ebola. The distrust of the international teams should not have been unexpected, given local peoples' experiences with French and American teams during an Ebola outbreak in 1996 described in the previous chapter. Six months later, the WHO invited us to help with control efforts (described in Chapter 4 in Mbomo, Congo, about 75 miles down the road and across the border from the Gabonese village of Etoumbi).

### **The Relationship between Theory and Methods**

The set of methods available to anthropologists is much larger than the one described in this chapter; it is but a small subset of anthropological methods (Bernard 2006). The selection of research methods was based upon the need to rapidly assess and provide answers to pressing questions from the national and international teams trying to control the epidemic and our own theoretical and conceptual frameworks. The next section of this chapter identifies our specific methods of data collection. We explore the links between theory and methods because the methods selected are often grounded in theoretical assumptions about what motivates and influences human behavior.

#### Cultural Models

Cultural models refer to people's knowledge and feelings about a particular domain. It is the "knowledge and schema" component of culture described in the first chapter. Suppose we were to ask, "What do the following have in common: fried eggs, hash browns, pancakes, cereal, bagels, coffee?" Most Americans would answer that they are all "breakfast foods." This is an American breakfast-food cultural model. The concept is derived from cognitive (D'Andrade 1995) and schema (Shore 1996) theories in anthropology. Both theories are based on the proposition that how people think and feel about something dramatically impacts their behavior. The models are socially transmitted and experienced and are the primary ways in which humans explain and make sense of their culturally defined world. Cultural models are particularly important for predicting and anticipating what will happen and how others will behave in particular settings. For instance, if one of our teenage children comes home at 1:00 a.m. after we asked her to come home at 10:00 p.m., she has a cultural model of what will happen—extra chores, grounding, limited TV or computer time. She then tries to develop a culturally appropriate reason to mitigate the outcome.

A cultural model for a particular disease refers to a local person's explanations and predictions regarding the disease. Some of the questions we ask when trying to

understand cultural models for Ebola include the following: How do you refer to the illness? How do you explain it (i.e., cause)? What are appropriate treatments? What do you do to prevent the illness? Kleinman (1980) calls these “explanatory” models and points out that patients, healthcare workers, children, and friends within a culture can have variant cultural models for the same illness. For instance, if you get a high fever and a sore throat and ask family and friends for advice, they usually ask you a few questions (e.g., Do you have a cough and runny nose? Do you have spots on your throat?) to try and determine what cultural model they are familiar with that may help to explain your high fever. You listen to all of their advice and eventually determine which model fits; the model you select influences the treatments you seek to treat the illness and what you expect to happen while you have the fever and sore throat.

Providing care and treatment for a particular disease is often based on negotiation between different cultural models. When you go to the doctor with a particular illness, the cultural model of your physician can be totally different from or a variant of your model; the treatment outcome, though sometimes imposed by the physician, is often negotiated between you, the patient, and the physician. For instance, once Barry had chest pains and thought it was a mild heart attack. At the clinic, the doctor asked many questions—How long have you had the pain? Where is the pain located? When does it come and go? The physician determined the pain was probably serious heartburn. Barry was relieved to hear this diagnosis but not entirely confident the physician was correct. The doctor acknowledged Barry’s concern and suggested a stress test of his heart to show nothing was wrong. In this case, patient and physician cultural models—causes, treatments, and prevention—were quite different. The physician could have imposed his model but was willing to negotiate the outcome and perform an additional test.

Anthropologists who use cultural models emphasize identifying and understanding concepts in the local language because local terms convey how people think and feel about the illness. Terms and concepts in indigenous languages can seldom be directly translated into English. This book introduces unfamiliar terms from a variety of cultures because they emphasize the importance and uniqueness of people’s views about Ebola. In anthropology, the perceptions gained from understanding local terminology are sometimes referred to as the emic, or insider’s, point of view. This contrasts with an etic point of view, which refers to how outsiders, such as physicians or anthropologists, use their own terms to describe a culture. We try to minimize the use of unfamiliar terms to make the book more readable, but our cultural models approach emphasizes the culturally specific meanings associated with local terms and concepts.

It is important to remember that cultural models can be both dynamic and conservative. They can change with the acquisition of new knowledge or different personal experiences, but they can also be remarkably resistant to change. Cultural models develop early in life: They are often based on lived experiences, shared with many others in the community, and have a strong emotional component. The costs and consequences of trying to change cultural models can be quite high.

The bottom line of this theoretical perspective is that to control Ebola outbreaks, you have to understand how local people think and feel about Ebola in particular and about biomedical care in general.

Cultural models are applied to the real world in “clinical medical anthropology.” This approach emphasizes providing culturally sensitive and appropriate care in a hospital or clinic setting. Dr. Alain Epelboin, a physician, indigenous healer, and medical anthropologist with the National Center for Scientific Research (CNRS) in Paris and part of the WHO team for the Congo outbreak, introduced us to this approach. He conducts research on healers in Africa, and serves as a consultant for several Paris hospitals providing care to Africans. He helps hospital staff modify clinical settings and approaches so that they are sensitive to the cultural feelings and perceptions of African patients. The clinical medical anthropology approach emphasizes the technological and behavior aspects of culture. Amulets, cords, needles, gowns, and monitors are artifacts with meaning and feelings attached to them. Likewise, medical behaviors and treatments, such as enemas, taking vital signs, giving medications, and the gender of the person providing treatments, all have meaning and feelings attached to them. The clinical medical anthropology approach focuses on the physical and social settings of care.

Many clinical medical anthropologists are also physicians or nurses and understand the scientific rationale behind biomedical procedures and clinical environments. They are in an excellent position to integrate non-Western beliefs and practices into biomedical settings.

During the Congo outbreak, Dr. Epelboin assisted with the design of the isolation unit and suggested replacing the large plastic barrier placed around the isolation ward (see Figure 2.3) with a small fence. This adjustment enabled families to see and visit sick

[Insert Figure 2.3 here]

loved ones, albeit from a distance. The cultural models and clinical medical anthropology approaches both aim at providing more humanitarian care and intervention. Ideally, both approaches lead to more rapid and efficient control of Ebola. The control of Ebola epidemics is contingent upon providing humanitarian care to Ebola victims (living or dead)—from the isolation units to the special procedures necessary for burial.

### Structural Violence

The cultural models approach has been criticized because it focuses on “what is in the minds of community members rather than what is on their back” (Schepper-Hughes 1993). In other words, the cultural models approach assumes that people behave the way they do because of their “traditional” beliefs and practices rather than due to their particular political-economic circumstances. Researchers using the structural violence approach propose that Africans suffer from Ebola epidemics because of global and national political-economic inequalities, histories of exploitation, corruption, and poverty (Garrett 2003). Ebola spreads because hospitals lack protective gear, isolation wards, and basic medicines and infrastructures, such as paved roads, electricity, and clean water. Paul Farmer uses the term *structural violence* in his book *Pathologies of Power* (2005) to refer to how political-economic and other national and international structural forces lead to poverty, suffering, and inequality. Individuals make healthcare decisions, but they make these choices within the context of all of these oppressive structures. In many parts of world, these structures are implicated in contributing to profound levels of human suffering, from infectious and parasitic diseases such as AIDS, TB, malaria, and Ebola to rape, torture, genocide, and human rights abuses.

The same researchers are critical of the cultural model approach because it can create a distance between “us” and “them.” Descriptions of the exotic beliefs and



practices of “others” lead Euro-Americans to feel that the “others” and their suffering are far away; that is, their needs are distanced, and we become a “nation of bystanders.” Although we agree with Farmer and other critics that we must respond more actively to structural violence and be cautious in our use and descriptions of cultural models, we also know that structural change and reduction of violence take place through empathy, an emotional connection to the people who suffer. Humans are unique in their ability to put themselves in the shoes of peoples far away and unknown; Euro-Americans’ relatively generous aid in response to the 2005 Indonesia tsunami is just one example.

We discuss the structural violence approach because we thought about it frequently in the field as we observed the daily impact of political-economic structures and institutions on local peoples’ responses to Ebola. “Politics” is in the title of this book because of the importance of this aspect of human society. Our fieldwork focused on cultural models and clinical medical anthropology, while at the same time themes of the impact of political-economic structures, inequality and structural violence emerged from local peoples’ stories and experiences with Ebola. We refer back to our original discussion of culture—culture is “in the mind” as well as “out there.” Global and national political-economic structures are socially transmitted and therefore are cultural and part of a holistic anthropological perspective.

Controlling Ebola epidemics means changing not only the beliefs or behaviors of people on the scene but also the structures and institutions that contribute to inequality, lack of access to resources, and human suffering. Mobilizing communities to change the global system and fight for rights to equality and social justice is part of the solution. Nonetheless, our work did not focus on changing global structures of inequality. Instead, we have documented the importance of this global perspective with the voices of local people. We also use our Ebola research to advocate for policy changes within global political-economic structures (e.g., WHO and international healthcare organizations) involved in Ebola outbreaks.

### Dunn’s Framework

Fred Dunn, a physician and anthropologist, developed a simple framework for integrating anthropological research into disease-control efforts (Dunn 1985). He suggested that anthropological research on the control of a particular disease should pay attention to the following four areas: (1) factors in the community that are health enhancing, (2) factors in the community that are health lowering, (3) factors outside of the community that are health enhancing, and (4) factors outside the community that are health lowering. “In the community” refers to local cultural practices and beliefs, while “outside the community” refers to national and international programs, teams, and structures. Dunn’s model is a bit dated and has some limitations, which will be discussed in Chapter 7, but we like it because it is simple and easy to remember in the field, integrates cultural models and structural violence approaches described previously, and draws attention to the possibility that local peoples’ beliefs and practices may be useful in efforts to contain an epidemic. Most biomedical teams and social science approaches in public health often view local culture as “problematic” and a barrier to overcome, not build upon.

The following news story and comments from an Angolan ministry of health official from the 2005 outbreak of Marburg, the cousin virus of Ebola, exemplifies this view:

But convincing some communities to change their traditions in order to protect themselves from the communicable disease remained a serious challenge. We're working hard on social mobilization in communities in Uige, trying to motivate a change in behavior. . . .

We have some cultural problems. People think if they don't bathe the dead body then they are not properly putting them to rest.

Culture is a "problem." Although some aspects of culture may contribute to the spread of Ebola, for example, washing or touching the body of a deceased Ebola victim before burial, such commentary gives little consideration to the possibility that actions of local people could be useful and incorporated into public health control and prevention strategies. Dunn's framework suggests that social mobilization teams, health educators, and clinicians can incorporate aspects of local cultural perceptions and practices into control efforts. The framework does not romanticize indigenous cultures because it concedes that some beliefs and practices may also be detrimental to health.

Dunn's framework also pays attention to structural violence because it considers how forces outside of the community may amplify an outbreak. The framework suggests anthropologists consider the positive contributions of national and international teams, such as providing the technology and expertise to diagnose Ebola in the field, and also how the international teams' activities may amplify or complicate control efforts, such as the competition between American and French researchers in Gabon that led to multiple blood draws from local people and served to amplify distrust of the international teams and control efforts.

Dunn's framework is useful to us because it reminds us to pay attention to both the positive and negative components of both local and global communities. The framework is not a "model" because it does not make specific theoretical assumptions and predictions about what motivates or shapes human behavior, but it is a useful tool for guiding the collection of field data and providing a framework to analyze results.

### Evolutionary Biocultural Theory

We refer to evolutionary biocultural theory in some of our previously published work (Hewlett and Lamb 2002; Hewlett and Hewlett, in press). This theory influenced how we conducted field research as well as our ability to explain human responses to Ebola. Evolutionary biocultural theory refers to the use of relatively recent theoretical contributions to Darwin's theories of natural and sexual selection. A few elements of this theory are presented here to illustrate how they influenced what we did in the field. This theoretical orientation is described in greater detail in Chapter 8, where it is used to explain the cross-cultural uniformity and diversity in human responses to rapid killing epidemics.

Evolutionary approaches focus on individuals because they are the unit of selection in Darwinian theory. Individuals weigh the costs and benefits of particular actions according to the impact on their reproductive fitness. Methodologically, it means paying attention to individuals or at least subgroups of individuals within a culture because their interests and contexts may vary. This theoretical orientation explains in part

why we wanted to talk to as many of the “stakeholders” associated with the outbreaks as possible. Men, women, children, healthcare workers, and Ebola survivors may have very different interests and factors to consider in responding to an outbreak. From a Darwinian perspective, all are active agents trying to do the best they can to survive in our particular political, economic, or natural settings. For instance, your response to someone sick with Ebola will likely depend on whether the infected person is your mother, your child, a stranger, or a patient as well as on what information you have about Ebola, what resources you have available to help you respond, and your political-economic position in the community. The theory impacted what we did in the field by reminding us to pay attention to the contexts of a broad range of individuals. We tried to talk with as many different people and as many stakeholders as possible.

Recent evolutionary theoretical contributions also point out that evolutionary processes have shaped emotions. Love, lust, fear, anger, and empathy are universal human emotions that evolved in the context of human and primate history to solve reoccurring problems and are evoked in particular contexts that impact fitness. This aspect of Darwinian theory reminded us that we are all part of the human family and share common feelings in particular settings—the loss of a loved one or fear of the unknown or rapid death. It influenced us in the field because it made us think and ask questions in open-ended interviews about universal human emotions that emerge during outbreaks and the contexts in which they are evoked.

Evolutionary theory is a relatively new and controversial theoretical orientation in anthropology, in part because of the previous misuses of “evolutionary” concepts in the history of anthropology (LaLande and Brown 2002), but it influenced what we did in the field, and we hope to demonstrate in Chapter 8 how recent theoretical developments in this area enable us to understand the interactions of biology, culture, and ecology in human responses to Ebola outbreaks.

### Theory and Methods in the Book

The four theoretical and methodological approaches appear in different chapters in this book. We present cultural models for Ebola in Uganda and Congo in Chapters 3 and 4. Clinical medical anthropology was implemented during the Congo outbreak and is discussed in Chapter 4. The impact of history and political-economic structural violence emerge in the origin stories for Ebola in Chapters 1, 3, 4 and 6. We describe the nature of structural violence during the outbreaks in greater detail in Chapter 5, where survivors and nurses tell their stories, and in Chapter 7, where we discuss the activities of international interventions. The Dunn model provides the framework for analyses of all Ebola outbreaks analyzed in Chapter 7, while the biocultural evolutionary theory is used in Chapter 8 to explain crosscultural patterns of human responses to rapid killing epidemics.

### **What Did We Do in the Field?**

We went into the field with practical questions from WHO and our particular theoretical biases and frameworks—cultural models, clinical medical anthropology, Dunn’s framework, and biocultural evolutionary theory. One reason we like these models and frameworks is that they are relatively easy to remember. If we sit down in a pub to have a

beer or go down to the river to wash our clothes and run into people to talk to, the models are simple enough so that we do not have to take out our notebook to look up a set of predetermined questions to ask. This approach allowed us flexibility in adapting our methods and questions to different locations and situations in the field.

### Uganda 2000–2001

The field conditions in Gulu, Uganda, enabled Barry to use a wide range of methods. The outbreak was well underway; several research and response teams were already in place and willing to assist a medical anthropologist. It was an urban outbreak—community and government services were nearby and centralized; Ugandan infrastructure (electricity, paved roads, functioning schools, and high literacy rates) was relatively well developed by comparison to other parts of Africa, and consequently, basic supplies and the use of a computer and other technology were possible. One ethnic group, the Acholi, predominated in the impacted area, making communication and the study design less complex; and, Uganda has one of the world’s best health education programs for AIDS. In short, many resources existed in Gulu to help conduct the study. Richard Amola, an Acholi health officer with Ministry of Health, was hired as a research assistant to help in communicating and negotiating the local social terrain.

Our first few weeks of research emphasized open-ended, semi-structured, and focus group interviews as well as document review (e.g., health education materials, reports). A “focus-group” is a nonrandom sample of a small group of individuals asked to informally discuss a particular topic. An open-ended interview includes general questions such as these: “Do you know Ebola?” “Do you have a local name for it?” “Do you have any idea as to how to treat it?” Once we had an idea about general cultural models and other topics, we turned to semi-structured interviews with more detailed questions, based on what we had already learned. We conducted open-ended and semi-structured interviews with the following: (1) ten individuals and four focus groups in villages or neighborhoods with large numbers of early cases of Ebola, (2) eight individuals and one focus group with survivors of Ebola (both healthcare workers and community members), (3) four focus groups with male and female elders (two meetings with each gender), (4) three individuals and two focus groups with children, (5) four individuals and two focus groups with healthcare workers responsible for the isolation unit and counseling survivors, and (6) four individuals and one focus group with healers. Focus group meetings usually had five to eight participants. We also conducted group interviews with survivors and health educators. Group interviews are different from focus group interviews in that they take place when the group is having their regular meeting (e.g., survivors association meeting), and the size of the group is often larger than a focus group (e.g., more than fifty at the survivors meeting and fifteen at the health educator meeting).

Part of the applied anthropologist’s approach to research is to talk to as many of the “stakeholders” as possible. A stakeholder, as noted earlier, is an individual or group with a vested interest in Ebola control efforts—the men, women, and children who suffer from or at risk of getting the disease, those who survive the disease, and the nurses, healthcare workers, epidemiologists, and indigenous healers who are trying to control or cure the disease. We made special efforts to talk to women, children, and nurses because their experiences are seldom represented in reports on disease outbreaks. The views of men and physicians tend to dominate such reports. We also made an effort to talk with

individuals privately, not in focus groups, because some of the topics, especially for individuals who experienced the disease or suffered the loss of a loved one, were sensitive, emotional, and could potentially lead to family or political conflict. Talking to individuals also enabled us to get a sense of intracultural variability in cultural models and decision-making processes involved with how to treat infected family members.

Our last few weeks in the field emphasized the development of questionnaires to try and determine whether or not the cultural models that emerged from the open-ended and semi-structured interviews were representative of the general population. We administered precoded questionnaires (i.e., a set of questions with a limited number of choices) to forty-nine adults in Gulu, including twenty-five women and twenty-four men. We selected one adult from every third house from two randomly selected Gulu neighborhoods (one neighborhood with many Ebola deaths and one neighborhood with no Ebola deaths) and sixty Ebola survivors, including twenty-two men, and thirty-eight women. All survivors were located through a survivors' organization (in this outbreak about 50 percent of victims survived). The questionnaires incorporated local Acholi terms and reflect the knowledge obtained from the in-depth interviews with individuals and focus groups. From an anthropologist's point of view, questionnaires are worthless unless one asks questions that are meaningful within the community. Staff members from the Ministry of Health assisted us in the administration of some of the questionnaires. We administered a short open-ended questionnaire to eighty-five Gulu high school students, 15–21 years of age, and all members of the three senior classes, altogether thirty-three men and fifty-two women. Finally, we examined existing documents, such as field reports and health education materials used in the outbreak (e.g., posters, brochures, music cassettes, and a WHO video).

Our living conditions in Uganda were relatively comfortable by comparison to those experienced on previous trips to the field in central Africa. We were used to living with foragers in the middle of the forest, sleeping on log beds, and walking long distances every day. In addition to the relative physical comforts, the people were incredibly warm, hospitable, and open in their interviews and informal conversations. As in Barry's initial trip to Gabon, people in Uganda wanted to talk about their experiences and losses and do whatever possible to help control the outbreak.

### Congo 2003

Field conditions were quite different in Congo. In Uganda, it was possible to fly directly from Kampala, the capital, to Gulu. In Congo, it took two and a half days driving over some of the worst roads in Africa (Figure 2.4) to get from Brazzaville, the capital, to the

[Insert Figure 2.4 here]

Mbomo-Kéllé area of the outbreak. Since we were part of the initial team to evaluate the outbreak, we had to be particularly attuned to who and what we were touching as we conducted our research. Few government services and poor infrastructure (e.g., inadequate roads, few physicians, no electricity, and lack of regular health education services) existed in the rural area. It was more difficult to conduct the research because several ethnic groups lived in the area (compared to Uganda, where the Acholi predominated), and it was more difficult to visit affected villages due to the lack of roads.

Outbreaks were occurring in two Congo health districts—Kéllé and Mbomo. We were among three medical anthropologists invited to participate in control efforts. The other was Alain Epelboin, mentioned in the previous discussion of clinical medical

anthropology. We traveled to Mbomo while Epelboin and Pierre Formenty, WHO Ebola specialist, traveled to Kéllé. Mbomo and Kéllé towns are only about 100 km apart, but it took one full day to drive the distance. We focused on understanding local cultural models of Ebola and identifying beliefs and practices that may amplify or help curtail the outbreak, while Epelboin focused on cultural sensitivity of clinical and intervention strategies, i.e. clinical medical anthropology. He interviewed Ebola patients and their families at the hospital and attended and participated in several funeral ceremonies. He also helped establish the isolation ward at the Kéllé hospital.

In studying the outbreak response, we did not accomplish as much as we would have liked due to field circumstances—lack of roads and concerns about violence against team members. We conducted open-ended and semi-structured interviews with men, women, and children in Mbomo and outlying villages. We conducted informal focus group meetings with the following: five groups of women, four groups of children, three groups of Red Cross volunteers, one group of nurses, one group of teachers, and three village chiefs and councils of elders in three neighborhoods in Mbomo. We attended community meetings in four rural villages and arranged separate meetings with Kola, Mboko, and Mongome ethnic groups in two of the four villages. We conducted interviews with the following individuals in Mbomo: the physician at the national park, Ministry of Health medical chief, two healers, and the director of Lossi Reserve<sup>2</sup>. We also attended daily morning meetings with health personnel and the regional Ebola crisis committee meetings chaired by the Sub-District Chief two times a week.

### Limitations and Concluding Remarks

The ethnographic data presented in this book are limited by time constraints. The data are based on four months of research in three different countries. We had to be cautious in interpreting the results, but we were fortunate in that we were able to place our results within the context of our previous 30 years of living and conducting research in Africa. Although confident about what we can say, we still know relatively little about human responses to Ebola. Long-term research on Ebola and other epidemic diseases is desperately needed.

This chapter describes the special conditions of conducting ethnographic research in outbreak situations, identifies how anthropological theory influences decisions to use particular methods in the field, and describes some of the specific anthropological methods used during the Uganda and Congo outbreaks. These first two chapters provide a foundation for understanding Ebola, culture, and a few basic anthropological theories and methods. The next four chapters provide the stories, experiences, and feelings of Congolese and Ugandans who encountered and, in some cases, survived one of the deadliest diseases known to humans.

### Figures

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<sup>2</sup> A protected reserve located near and part of the 13,456 square kilometer (5,200 square mile) Odzala Park, under the protection of the Forest Ecosystems of Central Africa (ECOFAC, a conservation project financed by the European Union).

Figure 2.1 It was necessary to have armed guards while conducting ethnographic research in villages outside of Gulu.

Figure 2.2 Bush taxis are a common form of transportation in rural central Africa.

Figure 2.3 Plastic tarp around isolation unit in Uganda

Figure 2.4 Roads in northern Congo