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ANTHROPOLOGY AND PUBLIC HEALTH: THE ROLE CULTURE PLAYS IN
EPIDEMICS

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ABSTRACT

During an epidemic, there are many factors that can inhibit or facilitate the spread of disease and the severity of the epidemic beyond biomedical responses, including structural and social considerations. This paper will be an interdisciplinary work between the areas of anthropology and public health and will explore the history of these two disciplines working together, including theoretical and methodological frameworks utilizing key concepts from both areas of study, as well as the development of the subfield of medical anthropology and the tools used to investigate disease like outbreak ethnography. In addition, the relationship between culture and epidemics will be analyzed, culminating in the examination of the use of anthropological techniques and their results throughout the history of Ebola virus disease outbreaks in central and western Africa. By utilizing Ebola outbreaks starting in 1976 up till the most recent outbreak of 2014, this paper will demonstrate how culture can play a crucial role in disease epidemiology and controlling infectious disease.

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Chapter 1

Anthropology and Public Health

The central concentration of the study of anthropology is community and culture. Often times, in the field of public health, populations or communities are described as being the “patient” rather than individuals (Parker and Harper 2006). This similar focus between these areas of study allows for connections between the two to be easily established. While anthropology has four widely recognized subfields – cultural anthropology, biological anthropology, archeology, and linguistics – in the past few decades, characteristics have been drawn from each of these subfields in order to create a new sub-discipline, which more directly applies to the field of public health, aptly named medical anthropology (American Anthropological Association 2016). Many of those in the medical and public health fields are unaware of the role anthropological study could play and how the results of those studies could lead to impacting health policy (Campbell 2011). Until recent years, anthropology has been underutilized in the field of public health, particularly when it comes to fast-moving epidemics where cultural constructs can play a large role in hindering or facilitating the spread of disease among populations and communities (Parker and Harper 2005). A more integrated approach between anthropology and public health can help to stem epidemics more efficiently and effectively.

Theoretical Frameworks

Utilizing the population-based perspective that is found in both areas of study, anthropology and public health have emphasized a medical-ecological approach that connects medicine and cultural anthropology in order to understand health through population and community, not individuals. Population health models like this one, explore a larger context of community health and systems over entire life spans, rather than focusing on one patient (Hahn 1999). The ecological model “emphasizes the importance of the social and physical environments that strongly shape patterns of disease and injury as well as our responses to them over the entire life cycle” (Institute of Medicine 2002:4). Developing in the mid-20th century, by psychologists and researchers in human development who recognized the impact of numerous interrelationships between individuals and their environments, public health professionals soon adopted the ecological model to be used in areas like epidemiology, maternal and child health, health promotion, etc. and further developed the model. Currently, the model is defined by The Institute of Medicine as “a model of health that emphasizes the linkages and relationship among multiple factors (or determinants) affecting health” (Institute of Medicine 2002:6). These factors can include: (1) individual factors like genetics or individual behavior, (2) interpersonal factors such as family dynamics and social networks, (3) community environments including the workplace, school, social services, etc., and (4) general social and economic factors that can consist of formal institutions like laws and regulations as well as social constructs like race and discrimination (McElroy and Townsend 2008). All of these factors are known as determinants of health and their interrelationships and impact on one another is part of the greater system and context considered in population health models. Though the determinants of health are often organized into a leveled hierarchy with individual factors acting as the most inner level and

expanding outward to interpersonal factors, community environments, and more general economic and social factors, there is a multidirectional flow between the levels in the hierarchy (Institute of Medicine 2002). This more simplistic ecological view of public health does overlap with earlier ideas of colonial anthropology that relied upon observation, rather than interaction to determine relationships, cultural constructs, and social and economic dynamics in a population (Geertz 1973). This basic anthropologic focus on population, rather than individual, patient-level, clinical care, like many biomedical approaches, is integral to the ecological public health approach (Campbell 2011).

Merrill Singer expanded upon the ecological model to further merge anthropological and public health ideas by suggesting a combination of two key concepts from population-based approaches – (1) health in a community is determined by a series of factors and (2) these factors are all components of a larger, complex system in which they interact with one other (Singer 1995). Singer described this interaction, particularly of the social factors included in these systems, as “syndemic” and used the inequalities resulting from social factors to define the characteristics, interrelationships, and changes of the AIDS pandemic (Singer 1994). This syndemic model offers a middle ground approach between broader, community level study and narrowly focused, individual level investigation. It incorporates both perspectives, not overlooking one in favor of the other, allowing for patient level behavior as well as more general procedural issues. By utilizing a dual approach, the syndemic model strives to identify the underlying structural issues that cause and affect community health in order to design interventions that better target the root problem of health disparities in larger, population systems. However, this syndemic approach is often overlooked and under-researched when it comes to disease interaction – most studies that examine the effects of disease on a person’s life

and physical ability choose to exclude people with more than one disease in their sample. This decision to exclude comorbidities has resulted in little research and data on disease interaction, though it is thought that patients with a greater number of diseases also have the greatest reduced quality of life. The lack of application of the syndemic model in a public health or biomedical context – Singer himself uses a lichen in a forest ecosystem as an example – has helped contribute to the lack of anthropological perspective and interactional thinking in public health and disease research (Singer 2009).

Interpretive anthropology, also known as symbolic anthropology, was first introduced by Clifford Geertz as a response to the traditional ethnographic writing methods being used in colonial anthropology (Geertz 1973). Rather than the anthropologist solely observing cultural symbols from afar and interpreting them, Geertz argued for active participation and incorporation into a culture, which would lead to understanding how members of a culture perceived each other and themselves, providing insights into how members interpreted cultural symbols (Panourgia 2012). This particular theoretical approach has proven integral in attempts to synthesize the fields of public health and anthropology – cultural interpretations can have great impact on community health. In 1990, Margaret Lock and Nancy Scheper-Hughes, both who self-identify as critically interpretive anthropologists, used the concept of the “sufferer experience” or the way a patient displays her disease and distress (physically, emotionally, psychologically, etc.) to develop their metaphorical framework “the mindful body” or “the three bodies” (Baer, Singer, and Susser 1997). These bodies are defined as: (1) the individual body including an person’s lived experiences while opposing dualism theories of mind-body, (2) the social body which refers to the way individuals receive information from their society and culture and how that information is then mirrored or reflected in the individual, and (3) the body

politic described as “the regulation, surveillance, and control of bodies (individual and collective) in reproduction and sexuality, work, leisure, and sickness” (Lock and Scheper-Hughes 1990:51) This framework seeks to include people’s varying perceptions of their own bodies (in health vs. sickness), as well as using these different bodies as a way to outline the relations in local communities and the globalized society as a whole in order to examine how these relations affect the bodies and individuals’ health (Lock and Scheper-Hughes 1990). “The three bodies” model is a more in-depth, complex evolution of the simplistic ecological model – each of the bodies vaguely echoes health determinants described in the ecological model, but more deeply integrates an anthropological perspective to a public health specific context (Campbell 2011).

Clinical anthropology, another theoretical framework resulting from the recent partnering of anthropology of public health, is unique in that it focuses on micro- and intermediate-level relationships including patient-physician relationships, individual experiences, and local health care systems, ignoring the “big picture”, population-based approach. Combining anthropology and public health on a clinical level may seem too narrowly focused to uncover useful insights to enact social change on a larger scale, but it can expose inequalities that may be more apparent at the individual level than at a community one (Konner 1993). It also examines the way medical professionals in different communities, countries, and cultures are trained and how these professionals distribute health services in clinics with a high level of need and how they interact with their patients. Paul Farmer, a leading medical anthropologist over the past few decades, established a hospital in one of the poorest regions of Haiti and using clinical anthropology has been able to discover the inequalities associated with various infections and diseases in the region including malaria, AIDS, tuberculosis, etc. as well as the community

perceptions and reactions to biomedical procedures like isolation/quarantine and local beliefs that characterize infectious diseases (i.e. sorcery). Farmer's work has led to closer examination of disease from suspected social factors in an area including political unrest and poverty. It has also increased critique of traditional biomedical models of disease that seem to simplify causal factors and ignore social determinants, minimizing the importance and effectiveness preventative health policies could have in areas similar to Farmer's region of Haiti – characterized by low socioeconomic status and poor health delivery systems. This theoretical framework has most accurately been able to integrate the key tenets of anthropological and biomedical perspectives by addressing individual patient needs through biomedical treatment at a hospital and through community initiatives that attempt to mitigate social, economic, and other inequalities to help curb common health problems like tuberculosis through a population-based approach (Farmer 1999)

Methodological Frameworks

Using traditional anthropological methodology in addition to biomedical techniques of information gathering has increased the insights into community health and allowed for a more accurate depiction health and health services as well as the disparities between various populations. This is due to the inclusion of descriptive and qualitative data gathering, which gives researchers a wider array of methodology to draw information from and can assist in uncovering community-specific trends that may influence health. The use of multiple techniques is known as triangulation and is often used to reduce bias in studies. Traditionally, anthropologists have used triangulation by utilizing observation, interviews (usually open-

ended), historical context, second-hand descriptions, and self-report surveys and data in order to gain a more accurate depiction of a specific community and their culture (Beebe 1995). In combining anthropology and public health, triangulation has been extrapolated and expanded to include all of these anthropological methods as well as more quantitative methodology typically used in epidemiology and other population sciences. Demographic research tools and community health mapping are just a couple of the additional research tools anthropologists can use in a public health setting. Also, because anthropologists are collecting data on-the-ground, in real time, they can aid biomedical research by acting as a proxy and collecting relevant data or biological samples needed for study (Trostle and Sommerfeld 1996). In addition to incorporating both types of methodological techniques, the development of rapid appraisal, which uses a multi-disciplinary team to rapidly produce and validate results, allowed researchers quick access to basic background information on communities needed to design contextually appropriate public health research and policies at a specific level (Utarini, Winkvist, and Pelto 2001) . Typically, biomedical research has disregarded interactions between internal and external health determinants, as well as conflicting internal health factors, as noted earlier in Singer's analysis of under-researched disease interactions due to the exclusion of patients with comorbidities in research studies (Singer 2009).

Combining anthropological and biomedical methodologies allows researchers to approach both social and cultural key issues, as well as those of biological health and disease with an emphasis on social organization, community vulnerabilities, cultural models of disease, and individual behavior. James Trostle and Johannes Sommerfeld, who reviewed the blended methodology and categorized a list of benefits, suggest the term “cultural epidemiology” to characterize this emerging subfield of research, believing it to describe “cross-cultural analyses

of the distribution and determinants of disease and illness and with unpacking variables (e.g. race, class, religion, time) to illustrate and specify their theoretical context and meaning” (Trostle and Sommerfeld 1996:266). The uncovered benefits include more effective communication of results, the identification of complex cultural and behavioral variables, increased efficiency and effectiveness of relaying results and insights back to the community, and utilizing anthropological knowledge of culture and community. “Cultural epidemiology” acts as a more holistic research approach, because of its ability to not only identify both individual and population health determinants, but also practically integrates anthropological and biomedical methodology, the results of which can then be used to inform any of the various integrated theoretical frameworks mentioned above (Trostle and Sommerfeld 1996).

Chapter 2

Medical Anthropology

Since its emergence in the 1960s, medical anthropology has become one of the most rapidly growing subfields of anthropology. The term “medical anthropology” was first coined in 1963 to describe empirical and theoretical research about social and cultural processes of health and illness, but the field has since evolved to study “human health and disease, health care systems, and bio-cultural adaption” viewing humans from an ecological and population-based perspective, much like the field of public health (McElroy 1996; Scotch 1963). Medical anthropologists utilize ethnography, the basic study methodology of cultural anthropology, in order to better understand and examine how the health of communities are impacted by interrelationships between the community and other communities, as well as the community and other species. Ethnography also brings to light cultural norms, social institutions, environmental factors, and political forces that may impact health. Often, medical anthropologists will also include the effects of increasing globalization may have on health situations, especially when their focus is on a local and/or remote community. These practitioners are meant to supplement a biomedical team, which addresses individual patient needs and medical treatment. Medical anthropologists’ goals are to identify the population determinants and inequalities, as well as the cultural beliefs and constructs that affect the health process in a community in order to leverage culture to help achieve positive health outcomes (Comelles 2000).

Background

Anthropology and medicine were originally linked since the development of both fields, but the two disciplines diverged as medicine became limited to clinical and hospital settings. Though earlier medical professions utilized ethnographic and demographic data commonly classified as anthropological methodology, most physicians abandoned this practice by the 20th century as it became more closely associated with the profession of social and cultural anthropology – though it was still used in rural medicine and international public health (Comelles 2000). Despite the move away from each other, anthropology and medicine still had an associative relationship until the 1960s and 1970s when medical anthropology began to be developed and defined. This early pioneers in medical anthropology were more likely to be medically trained either as physicians or in nursing, psychology, and other biomedical fields, but soon classically trained anthropologists and other social scientists began to join the discipline. Today, medical anthropologists are mostly formally trained as cultural anthropologists with additional education to specialize in the field of medical anthropology. More recently, a trend has emerged where those working in the field of medical anthropology will also obtain some type of health degree ranging from Master's degrees in public health to full medical degrees to allow practitioners to be educated in both the biomedical and anthropological perspectives (Saillant and Genest 2007).

One of the main motivations for the field developing was the desire to understand “folk medicine” or popular medicine – terms used to characterize health practices of native and small, rural populations. This mostly aimed to understand the stereotypical ritualistic and botanical elements of traditional medicine to, hopefully, be applied to modern pharmacology and to challenge the Western idea of religious ideals (Comelles 1996; Charuty 1997). Though this

topic was initially popularly researched by medical doctors, much like the early field of medical anthropology, social scientists began to take up the subject to define medicine, religion, and the importance of healers in these societies. These anthropologists were interested in discovering if every culture had their own medical system or if there were universals shared among cultures. Any aboriginal or native culture that presented a medical system unlike common 20th century European medicine was deemed “primitive” and made into an “other”, while classical cultures’ medical systems like that of Ancient Greece, was deemed “pre-technical”. This study of medicine among all cultures transformed medicine, both ancient and modern, into a cultural characteristic that anthropologists could study and compare between various societies and time periods. This helped facilitate the occupational shift in medical anthropology from healthcare professionals to trained cultural anthropologists and established the basic foundation for future medical anthropology to utilize cultural models in the explanation of medicine and disease (Leze 2014). Cultural models are specific communities’ perspectives and beliefs on disease and healthcare – often collected through ethnographic research. These cultural models can help international health teams interpret how communities view a particular disease and understand the communities’ responses to it, which will aid in the design of more culturally appropriate and effective health interventions (Hewlett and Hewlett 2008).

In North and South America, medical anthropology was initially concerned with the implementation of community health programs in minority and impoverished communities, using anthropological methodology to evaluate the current health infrastructure of the region. These ethnographies focused on social conflict, strife, and inequalities within the formal institutions of the community, finding that conflict between the different levels of medical professionals providing health services to the community, resulting in poor health care and a

reduced sense of ease and comfort in patients. This finding had a large impact in the decision to decentralize mental health and welfare facilities. Paul Farmer used medical anthropology to develop and implement his version of a holistic and integrative healthcare system in Haiti – the ethnographic data gathered by Farmer over his years of non-profit work in the region informed his administrative and biomedical decisions to find what Farmer viewed as the best possible healthcare system solution for the community (Farmer 1999; Comelles 2000). The initial research conducted in marginal communities in North and South America led to the expansion of medical anthropology into international health policy, particularly in community health in developing communities. It also furthered the scope of the field to include identifying and validating social and cultural variables in health and medicine, exploring a culture's receptiveness to innovation, technological advance, and biomedicine, and documenting and evaluating immigrant health in the western world and traditional medicine in the developing world (Baer, Singer, and Susser 1997).

Many of these areas are still salient in current medical anthropology research today. One of the principle concerns in modern medical anthropology is research into emerging disease that have the potential to become epidemics in certain regions. This has led medical anthropologists to study areas experiencing disease outbreaks in hopes of offering cultural insights that may help international health organizations work with local populations to curb disease transmission, expedite treatment, and overcome local misconceptions of the illness. However, often, international health agencies or national health agencies that are experiencing disease epidemics do not think to include medical anthropologists in the initial professional team selected to fight the epidemic. Many times, medical anthropologists are brought onto the team as an afterthought when the epidemic is already well under way or has even escalated in severity. Instead, medical

anthropologists should be included in the process at the very first sign of a possible epidemic so that they can collect relevant ethnographic data and identify cultural constructs that may be leveraged by health agencies to stop or slow the disease transmission before an escalation is reached in the epidemic (Hewlett and Hewlett 2008; Baer, Singer, and Susser 1997).

Critical Medical Anthropology

When medical anthropology was first coming onto the scene, its emphasis was on understanding and explaining health-related beliefs and behaviors in specific communities. While the insights into traditional and folk medicines were previously unknown and valuable to the field, initially, medical anthropology tended to ignore the larger processes and determinants of health associated with the ecological model and population-based approaches (Baer, Singer, and Susser 1997). Critical medical anthropology (CMA) uses the ethnographic methods common in anthropology and combines them with critical theory, recognizing the interactions between social structure and organization and individual experiences and health while focusing on the impact of political economy. Political economy includes the effects of government and economy on healthcare, as well as any structural inequalities that may exist in the society such as social class, gender, and ethnic biases. While inequalities may not seem to directly impact health, often they can cause services in communities to be disproportionately allocated among members depending on status, wealth, race, etc., which can cause significant indirect impacts on individuals' health (Singer 2014; Baer, Singer, and Susser 1997). CMA uses critical theory to discover hidden causes of poor health and poor delivery of health services in communities. This brings medical anthropological perspective closer to that of the field of public health by striving

to cultivate policy and health systems that address the underlying societal determinants that can directly or indirectly impact a community's health (Singer and Baer 1995).

Though introduced as a part of medical anthropology in the 1980s, the critical theory that is the basis for CMA dates back even further (Singer and Baer 1995). Unlike the traditional critical theory, CMA introduces anthropological views to avoid a uni-directional perspective and biases. Rather than a research team simply attempting to analyze the links connecting a social group to larger society, CMA's anthropological perspective focuses on examining structural inequalities and social origins of disease and how these underlying causes contribute to poor health. Though individuals and communities develop their own set of cultural beliefs and practices in response to disease, they perform this culture in a larger global context that is not always advantageous to them – the inequalities in their greater society significantly impact the options available to them (Singer 1995). Merrill Singer is among the notable medical anthropologists who advocate for the use of CMA as well as Nancy Scheper-Hughes (Singer 1995; Scheper-Hughes 1994). Singer proposes a “system-challenging praxis”, which utilizes actions to “challenge” structural institutions in attempt to enact social change, criticizing traditional medical anthropology for studying the larger structures that impede community health, but failing to attempt to address them. Singer argues that the theoretical framework of CMA offers the best approach to provoke these actions. This ties together methodological and theoretical frameworks of earlier medical anthropology to identify the community health determinants, as well as the practical application of public health interventions – attempting to address societal inequalities to improve population health (Singer 1995). Scheper-Hughes similarly believes traditional medical anthropology has some shortcomings like those of Michel Foucault's ideology of “biopower”, which states the body of the individual and the political state

are inseparable (Gutting 2013). Scheper-Hughes believes this view discredits and overlooks individual perspectives that CMA includes in its theoretical framework. CMA strives to understand individuals and how they utilize their own agency to react to the political state. Individuals are impacted by social structures and are not simply bystanders to them. While continuing to be a population-based approach, CMA combines research and exploration of societal structures and social inequalities with individual perspectives and experiences, so as not to ignore a large part of the equation of community health – balancing the individualistic perspective of biomedical approaches and the population-based perspective of anthropology (Scheper-Hughes 1994).

In terms of current CMA practitioners, the most well known example would be again that of Paul Farmer. Based out of Harvard University and classically trained as both an anthropologist and medical doctor, Farmer explores “structural violence” within communities – the institutions that prevent certain groups of people from obtaining medical care and health services or the societal structures that disproportionately allocate them among the population, focusing mostly on the poor individuals in a certain area. Farmer is a founding member of Partners in Health, an organization with the goal of “raising the standard of care for the poor everywhere”, that utilizes CMA to discover the instances of structural violence in communities and understand them in order to be able to enact health policy and programs to address them most efficiently. Partners in Health is a multi-national organization, but Farmer himself is best known for his work bringing quality health care and setting up an enduring health system in the poorest region of Haiti as well as discovering the obstacles that caused tuberculosis outbreaks to continue perpetuating in Russian prisons even after treatment. His successes in these regions act as a model, indicating that medical anthropologists should be included in health policy

development or emergency epidemic teams from the very beginning would produce the most positive outcomes (Farmer 1999).

Similar to Paul Farmer, his colleague at Harvard University, Arthur Kleinman has spent his career studying the intersections of culture, biomedicine, and social expression of disease . Kleinman is unusual in that his focus is on mental illness – an area of disease that is often overlooked and deprioritized by international health agencies in favor of more infectious diseases. A trained anthropologist, medical doctor, and psychiatrist, Kleinman is best known for his work studying mental illnesses like schizophrenia, depression, and suicide in Taiwan, China, and Hong-Kong, connecting how a person’s mental distress is often demonstrated physically (Kleinman 1986). Instead of attempting to address healthcare infrastructure in a poor community like Farmer, Kleinman’s work examines the doctor-patient relationship and its efficacy. Often doctors and patients are coming from vastly different backgrounds and perspectives, which can lead to misunderstandings and a negative impact on the patient’s care experience and the quality of care. In attempts to mitigate this underlying gap between doctor and patient that affected care, Kleinman promoted the use of an explanatory model designed to improve relations by helping doctors understand their patient’s disease perspectives through stories and narratives (Kleinman 1998). Though Kleinman’s work may seem less ground-breaking to Paul Farmer’s, he did utilize CMA to identify underlying causes of poor patient care of mental illness in Asia and designed an intervention in attempt to alleviate the cause, rather than treat the symptoms of the problem.

Chapter 3

Culture and Epidemics

The term “culture” is broadly defined and can refer to many different aspects of communal life. In the context of studying culture in epidemics, Barry and Bonnie Hewlett, who have conducted fieldwork during several outbreaks of Ebola during the early 2000s, define culture as “knowledge and behaviors transmitted and acquired through social learning” (Hewlett and Hewlett 2008:13). This definition encompasses many different aspect of community including institutions – political, social, educational, economic, etc. – shared knowledge, community practices, and local technology. In addition, Barry and Bonnie Hewlett utilize preexisting conceptions of culture, positing that it is both “in the mind” and “a provider of settings”, has both mental and physical representations, which includes cognitive constructs and artifacts (Hewlett and Hewlett 2008). A basic understanding of culture in general and what it may entitle is important in any anthropological study. However, culture’s specific impact on how people perceive their surroundings, particularly illness and healthcare, make it an especially salient variable to study during disease outbreaks. Local people’s perception of a disease specifically, as well as the general concept of disease, as well as their reaction to it, can be studied and expanded upon by international health teams during epidemics to construct culturally salient solutions. To do this effectively however, these various cultural beliefs must be identified early in the disease outbreak in order to make the largest impact possible (Singer 1994; Singer 2014).

Not only does culture influence people's perceptions, but it also impacts community members' emotions surrounding everyday routines and objects. This can include anything from meals, to clothing, to occupations, to medical care. "Culture patterns emotional reality" according to Barry and Bonnie Hewlett's findings from their outbreak ethnographies in Central and West Africa (Hewlett and Hewlett 2008:15). People attach emotions to cultural practices and foreign cultural practices will evoke particularly strong emotions – most likely negative. This emotional attachment to culture is one of the main causes of ethnocentrism around the world. Due to the sentiments and attachment people associate with their culture, they tend to believe their culture and their way of doing things is ultimately the best way or, more often, the only way to accomplish a certain task (Hewlett and Hewlett 2008; Singer 2014). In many local African cultures, this means turning to traditional or local healers that community members know and are comfortable with when it comes to healthcare and medical treatment. These healers have an established reputation in the surrounding areas and are trusted by communities. When disease outbreaks occur and international health agencies establish temporary clinics and isolation wards with biomedical procedures based on Western medical models, local community members are often fearful and skeptical of this method of healthcare since, from their ethnocentric perspective, the local healers are the only and/or best way to receive medical care (Hewlett and Hewlett 2008). The emotional attachments to the typical medicinal culture of the area will cause tensions and emotions to run high if international agencies attempt to impose their methods on communities rather than working in tandem with them. (Comelles 1996). For example, most health interventions include an educational component – it is important to educate a population in order to initiate behavioral changes on a larger scale and decrease disease incidence (ex: anti-smoking campaigns to prevent respiratory illness, safe sex practices

to prevent the spread of sexually-transmitted disease, etc.). These education initiatives must be tailored specifically for its target audience, a lot which includes cultural specificity. When working in a different culture, healthcare workers must take into account local language and dialects, power relations in the society that may affect healthcare, and the integration of local healthcare workers and community leaders into the education program. By including key community figures, international health agencies will be able to build a relationship of trust with the community. With relevant local champions promoting the educational program, as well as ensuring the material is easily understood from the local community's perspective, a health education initiative is more likely to succeed in its mission (Unite For Sight 2015).

This ethnocentrism runs both ways from the local communities and international organizations. Not only will communities be suspicious of Western medical care and the motivations behind the newly established healthcare facilities, but international agencies, with science and factual evidence to back up their biomedical culture, will often dismiss the already established cultural pathways of healthcare in communities in attempts to implement the most effective medical care as quickly as possible during an outbreak (Konner 1993). This one-sided view that does not take into account communities' preexisting culture and their emotional attachment to it and will likely exacerbate tension and conflict between the two groups. The constant clash between local communities and international health teams due to attachment to their respective cultures and ethnocentric views creates numerous obstacles that hinder the effort to curb an epidemic. Often times, these delays could possibly have been avoided with the help of anthropologists and the use of tools like outbreak ethnography to learn how the culture perceives the disease and healthcare, which can inform international health agencies on the best ways to

introduce contextually-appropriate healthcare in the communities more efficiently, circumventing misperceptions and misunderstandings (Singer 2014).

Culture, surrounding particular topics like disease, can be affected by extrinsic variables as well. Political, economic, and biological institutions will all play a role in how a community reacts and perceives disease and healthcare (Institute of Medicine 2002). For instance, poor nationwide healthcare infrastructure coupled with inability to access financial resources for payment and policies that restrict travel during epidemics could all be major factors contributing to a community strengthening its trust and faith in traditional healers, rather than biomedical care (Comelles 1996). The existing structures that may affect healthcare in communities during epidemics can be identified through medical anthropology methodology (Hewlett and Hewlett 2008). In terms of biology, human beings are wired to protect offspring to allow for their genetic lineage to continue (Neuberg, Kenrick, and Schaller 2011). This simple and universal imperative reveals commonalities worldwide among cultures' outbreak protocols – the majority will have a procedure for protecting children, usually keeping them isolated and far away from infected individuals, even if those individuals are immediate family members (Hewlett and Hewlett 2008).

To be able to paint that picture, anthropologists first need to know how community members think, feel, and explain disease and epidemics. This is true for both general illness and for the particular disease causing the epidemic. Also important, is to establish whether communities had previous knowledge and experience with this illness and whether or not there is a delineation in the culture between general sickness and disease epidemics, so that outbreaks may be locally recognized (Hewlett and Hewlett 2008). If the outbreak has been underway for some time already, gauging the communities' local response and the traditional epidemic

procedures in their culture should also be considered, as well as how the international health response is perceived. Above all, local communities should be made to feel comfortable about the introduced healthcare and policies. By utilizing medical anthropologist from the start, international healthcare agencies can prevent health policy missteps in a particular culture – common in the early stages of an epidemic – and design culturally appropriate interventions from the start (Hahn 1999).

All of these factors make up what is known as cultural models – the way communities or a culture perceives and explains a disease (Hewlett and Hewlett 2008). The primary study focus of a medical anthropologist during an epidemic is to establish and define these cultural models, in the hopes that international health agencies can incorporate at least parts of them into their health policy and implementation methods – aligning the healthcare interventions and cultural models to prevent as much conflict between the two as possible (Baer et. al. 1997). By taking the communities' preexisting cultural beliefs into account, many of the issues mentioned previously can be circumvented and a relationship of mutual respect can be established to facilitate future partnerships between the communities and the international health agencies for general healthcare initiatives outside of disease epidemics.

Chapter 4

Outbreak Ethnography

In terms of utilizing medical anthropological methods during a disease outbreak in attempts to learn cultural models of infectious disease and to halt the spread of disease, the most effective “tool” in an anthropologist’s toolkit is the method of outbreak ethnography (Hewlett and Hewlett 2008). Usually, cultural anthropologists will spend exorbitant lengths of time reading and learning about the local culture of an area – the religion, the customs, the rituals, the traditions, the language, etc. – before even thinking of conducting fieldwork and an ethnography of the area (Campbell 2011). However, in outbreak ethnography, this extensive period of groundwork and investigation to establish a solid foundation of knowledge about a culture, its people, and the surrounding areas, is not possible. Anthropologists who practice outbreak ethnography are usually called in as consultants by an international health organization in order to evaluate the on-the-ground situation of an epidemic. This means the anthropologists are often called only after the disease epidemic has begun and is already thoroughly underway in an area, causing them to have to pack and leave quickly – often within a day’s notice. These conditions make any background research on an area and its culture difficult, so that anthropologists conducting outbreak ethnography often have little or no familiarity with the culture they are attempting to study (Hewlett and Hewlett 2008).

The traditional ethnographic methodology calls for anthropologists to live among the culture they are attempting to research, which allows them to gather data from participant observation. In other words, anthropologists are able to collect information on the community and its culture by actively participating in it with native members (McElroy 1996). Again, this characteristic of ethnographic methodology is impractical when conducting outbreak

ethnography. The communities being studied are in the midst of an outbreak of a, sometimes deadly, disease. In attempts to mitigate the already high risks of being in the field, international health organizations will not allow their researchers to live in the community among the people where the risk of disease transmission is constant. While this is formally opposed by the international health agencies, the anthropologists themselves also recognize the risks of trying to collect data through participant observation despite the typical anthropological perspective that emphasizes the negative impact a boundary between the community and the researcher's residence can have (Singer 1994). Depending on how long an outbreak has already been occurring before the anthropologist gets on the ground, how long the incubation period for the particular disease last, and any other combination of situational factors, the researchers are often unaware of which community members have already been infected (Hewlett and Hewlett 2008). Living in the community, among undiagnosed cases would greatly increase their personal risk, though the risk of injury and even death is high throughout fieldwork due to the political unrest, poor infrastructure which cause automobile accidents, the inaccessibility to quality healthcare if injured, and other characteristics that often appear in areas unable to contain disease outbreaks (Singer 1994). Though anthropologists may have little background information about the area and surrounding communities, it is imperative that they are up to date on the research and information pertaining to the particular disease in the outbreak (Hewlett and Hewlett 2008). Being knowledgeable about modes of transmission, possible symptoms, and other disease characteristics can make a difference when it comes to anthropologists and other researchers protecting their health.

Though anthropologists are able to “get off the veranda” during the day to speak to community members, as suggested by the founder of participant observation Bronislaw

Malinowski, it is often impossible for them to leave the veranda entirely since they are unable to live among local people and must return to a secure location every night (Ogden 2008). Due to this separation of researcher and the target of their research, anthropologists must act as and gather data as a third-party observer, which only exacerbates the already obvious differences between researcher and participant community. The separation may impede the collection of accurate and truthful information and could influence what areas anthropologists conduct research in, as well as the people they come into contact with since their time frame is much more limited than it would normally be during an ethnographic study (Hewlett and Hewlett 2008). There are limitations to the scope of outbreak ethnography and what anthropologists can learn about a community's cultural perspective of disease. Data is generally gathered through systematic one-on-one interviews and though these may provide valuable insights into a community's beliefs, there is no guarantee that the interviewees are a representation sample of the population and the beliefs that they express may not be shared by the majority of community, causing a skew in data (Hewlett and Hewlett 2008). These restrictions mean that the ethnography methodology practiced during outbreaks more closely follows older version of colonial anthropology than modern, more favorable anthropology practices. However, due to all the extenuating circumstances, this is still the best possible methodology available to gain valuable insight into cultural modes.

The ethnography methodology is already hindered by the reasons mentioned above, but the government will often obstruct research even more by banning certain social and "everyday" activities during an outbreak due to the state of emergency (Singer 1994). Travel may be restricted making it difficult for anthropologists to reach their area of study, functions like school and church may be cancelled in the interim, and public events like large gatherings,

sports games, and cultural ceremonies may be discouraged or even temporarily banned. All of these events and occurrences are normally a useful place for anthropologists to observe community interactions and shared culture among its members. Without these opportunities for observation, the anthropologist is limited to individual interviews and narratives when gathering their data (Hewlett and Hewlett 2008). This is obviously not ideal as cultural and community beliefs are defined by the fact that they are shared among multiple members of a society. The inability to observe the community as a whole will at least slightly skew the collective findings of the ethnography.

In terms of standard biomedical response to possible epidemics, the WHO has a list of guiding principles in case of international outbreak. These principles, not surprisingly, do not mention the inclusion of the social sciences in the response. After a potential outbreak is verified and shared with the Global Outbreak Alert and Response Network, a rapid response team of the “most appropriate experts” (no mention of their disciplines) is assembled and sent to affected state(s) to carry out coordinated outbreak control activities. While this team is supposed to recognize the role of national and international non-governmental health organizations and the government’s health infrastructure and leverage their networks to reach isolated populations, the response team seems to be in charge of any outbreak control efforts. The emphasis of these principles is on time sensitivity – containing an outbreak as fast as possible. The very last principle listed does call for all responses to be respectful of “ethical standards, human rights, national and local laws, cultural sensitivities and traditions” (World Health Organization 2017) . However, being respectful is not exactly the same as abiding by them. Culture is mentioned once, in passing, throughout this list of eleven guiding principles to outbreak response. As a key social factor that can affect health perspectives and community response to epidemics,

addressing “cultural sensitivities and traditions” may need to be closer to the forefront of international health agencies’ guiding principles to outbreak response.

Chapter 5

The Role of Culture in Ebola Epidemics: A Case Study

The Ebola virus disease (EVD) was first documented in 1976 when two simultaneous outbreaks occurred in central Africa, one of which began in the village of Yambuku in the Democratic Republic of Congo located near the Ebola River, for which the disease is named. The virus is zoonotic and originally transmitted from wild animals, thought to be from the contaminated bushmeat of chimpanzees, gorillas, fruit bats, monkeys, etc. found dead in the rainforest. Ebola is then easily propagated throughout human populations through direct contact with blood, semen, and other bodily fluids of the infected or surfaces contaminated with these fluids. The virus is highly infectious – healthcare workers and caregivers are often infected while treating patients with EVD. A high fatality rate, ranging from 25% - 90% in past outbreaks, (on average the fatality rate for EVD is about 50%) combined with the high level of infectivity makes the disease a deadly one. Though healthcare tools like rehydration and symptomatic treatment can help improve chances of survival, as of now, there is no medical treatment proven to cure the disease. Ebola virus disease first presents itself in a patient through fatigue, weakness, fever and abdominal pain – symptoms almost indistinguishable from other common infectious diseases like typhoid fever and malaria, making an initial Ebola diagnosis difficult. Soon after, patients become dehydrated as a result of extended periods of fever, vomiting, and diarrhea, often becoming delirious. As a hemorrhagic disease, in some cases of EVD, the patient will experience both internal and external bleeding, hemorrhaging from their gums, nose, vagina, eyes, etc. (World Health Organization 2016). These extreme symptoms combined with the mode

of transmission and the disease's high levels of infectivity and fatality have resulted in great difficulty containing outbreaks in the past.

The First Ebola Outbreaks: 1976

The very first outbreaks of EVD occurred simultaneously in 1976 in the central African countries of Sudan and Zaire – what are now South Sudan and the Democratic Republic of Congo (World Health Organization 2016). These two initial outbreaks lead to the identification of two distinct and common strains of Ebola, aptly named the Sudan and Zaire strains. In Zaire, the outbreak is thought to have begun on September 1, 1976 and ran over a month, finally concluding on October 24, 1976. During this time 318 documented cases of EVD occurred in the region around the village of Yambuku. By the end of the outbreak there had been 280 deaths (a 88% fatality rate) and only 38 confirmed survivors. The first cases sought treatment at the nearby Yambuku Mission Hospital where they were initially treated for malaria with an injection of chloroquine. All subsequent cases were thought to have resulted from exposure at the hospital over the next few weeks, after which, Yambuku Mission Hospital had closed as 11 of its 17 staff members had died of the disease (World Health Organization 1976b). The EVD outbreak in Sudan lasted longer, (from June till November 1976) but was less fatal. With a total of 284 confirmed cases in the surrounding areas of the town of Nzara and 151 recorded deaths, the fatality rate was 53% overall. It appeared that the outbreak began among workers in a cotton factory where their relatively isolated homesteads kept transmission to a minimum, but the

outbreak was later amplified by transmission in a larger, nearby hospital when a related case was admitted (World Health Organization 1976a).

In each of these outbreaks, the disease was still unknown and therefore international health agencies, particularly the World Health Organization (WHO) were called in to consult. In Sudan, WHO officials worked alongside Sudanese colleagues to determine the mode of transmission, identify active cases, collect samples of the new virus, and perform laboratory tests for antibody studies (World Health Organization 1976a). The focus of their investigation was very narrowly based on biomedical topics like epidemiology, pathology, and virology. Almost no research was conducted on local people's perceptions of the outbreak and the origin of the cotton factory workers was only discovered by tracing connected cases back through the initial patient admitted to the hospital. Only local volunteers were sent into the surrounding communities to identify currently active cases of EVD – these teams were only accompanied by one Sudanese health official and equipped with minimum protective clothing in the form of disposable gowns, gloves, and masks (World Health Organization 1976a). In Zaire, the emphasis of the international health agency's investigation was even further from including cultural constructs in attempts to curb the outbreak. Instead, two teams were airlifted to Zaire from their current position in Sudan with the mission of seeking and identifying a link between the two epidemics. The teams did advise medical personnel in Zaire of the epidemic and basic information on EVD, including best practices for protecting oneself against infection. Little effort was made to investigate the communities and their relevant coping mechanisms for the outbreak (World Health Organization 1976b). Since many Ebola patients are never even admitted to a hospital, instead choosing to be treated by family and friends in the comfort of their own home, the advice of the WHO may not have reached the necessary audience. Instead

epidemiological investigations and Western biomedical research was prioritized. This type of prioritization may have been necessary in these particular outbreaks, as the disease was yet unknown to the world and the biomedical research was immediately necessary to determine the inner workings of EVD, such as clinical manifestations, incubation times, and modes of transmission. However, if ethnographic research endorsed by international health agencies was conducted in the regions affected by these outbreaks, even after their conclusion, a protocol for including cultural constructs and perceptions in future Ebola epidemics could have been established. Unfortunately, medical anthropology was just developing as a field and the clear benefits of including anthropological research in public health issues, particularly in highly infectious disease outbreaks, were not yet seen by the field of international health.

Gabon: 1997

It was not until the mid-1990s and early 2000s when subsequent Ebola outbreaks of note occurred once again in central Africa. Gabon, the Democratic Republic of Congo, and the Republic of Congo (the latter two of which were formerly known as Zaire) all experienced a series of outbreaks over the next decade or so. Uganda and Sudan also experienced outbreaks during this time (Center for Disease Control 2016b). Some of these outbreaks were also the first times anthropologists were consulted to collect data about cultural perceptions and beliefs on EVD, the epidemic, and the international response teams that suddenly appeared at the communities' doorsteps. Barry and Bonnie Hewlett, a married pair of anthropologists, were asked to consult by the WHO in several of these epidemics due to their interest in medical anthropology and their past research background in relevant geographical regions. This pair was

one of the first to document their use of outbreak ethnography, the cultural models they uncovered during their work, and recommendations to use these insights in order to more effectively address the outbreak.

During the 1990s, Gabon experienced three separate outbreaks of Ebola. In 1997, Barry Hewlett received a university grant to conduct preliminary research in communities that experienced Ebola about their response to the epidemic. This was one of the first times anthropological research would be applied to an EVD epidemic, and it was being done independently after the outbreaks had subsided. When interviewing local people, Dr. Hewlett discovered that they identified EVD as *ezanga*, which was a local word describing “bad human-like spirits that cause illness in people who accumulate [things] and do not share.” The rough translation of the word is “vampire” (Hewlett and Hewlett 2008). The utilization of this word by local people uncovered two cultural beliefs about the epidemic: (1) the origin of the illness was believed to be supernatural by local people and (2) people with accumulated wealth (gold miners and lumber-company workers) were at the greatest risk for the disease due to the jealousy of others. *Ezanga* is also associated with chimpanzees and other apes – the fact that the first Ebola cases in the area were linked to eating contaminated chimpanzee bushmeat further validated the communities’ belief that this disease was the result of *ezanga*. Dr. Hewlett also uncovered that the Gabonese communities had their own versions of outbreak control and were already doing what they could to contain the spread of disease using their limited resources before the international health teams arrived (Hewlett and Hewlett 2008).

These interviews were the first time the local people had their feelings taken into account when it came to EVD and they were eager to share their thoughts with Dr. Hewlett. Many reported that the international health teams that came in response to the epidemic (French and

American teams) only collected test samples of blood and fecal matter. The teams never returned after retrieving the samples and the patients never received the results of their tests. Some of the patients that gave samples died afterwards not knowing if their tests were positive for EVD (Hewlett and Hewlett 2008). The Gabonese people were still feeling the effects from the colonial era and very wary of Euro-American outsiders and these practices bred suspicion, animosity, and general mistrust toward the international health teams. The exploitative history of colonialism affected how communities responded to the epidemic, a problem that was only exacerbated when the international health teams disregarded the communities and viewed them as samples instead of people. Finally, this research discovered the potential uses for medical anthropologists during epidemics – Dr. Hewlett was able to identify the index cases for one of the outbreaks that was previously unknown, his interviews also uncovered a possible new outbreak and its modes of transmission that the international health community did not yet know about, as well as provide humanitarian care to community members who used the interviews as an outlet to express their grief, anxiety, and anger.

Uganda: 2000-2001

From 2000-2001 Uganda experienced one of the largest recorded Ebola outbreaks. This time, the Hewletts were formally asked to help by the WHO and the CDC after Barry Hewlett called both agencies and learned that an anthropologist had not been included on the “multidisciplinary team” that had been assembled to control the outbreak. After being added to the team, the WHO gave the Hewletts express instructions to find the answers to several questions they had regarding local people’s behavioral responses to the epidemic: (1) Why were

the potentially sick running away from the ambulances sent to help them? (2) Were traditional healers amplifying transmission? (3) Were burial practices amplifying transmission? To answer these questions, the local people, an ethnic group called the Acholi, were interviewed in order to identify their cultural models of EVD. Two different cultural explanations, a supernatural poison and an epidemic illness, were identified (Hewlett and Hewlett 2008).

Once these models were identified and analyzed, it was easier to understand communities' perceptions of Ebola, which in turn helped to explain their behavior in response to the epidemic. It also uncovered a pre-existing local protocol for epidemic containment that predates European arrival in the area. The community recognizes the danger of an epidemic, even if they do not understand the biological inner workings of the disease – the Acholi call an epidemic illness *gemo*, a mysterious cause of illness that “catches” you and is spread through many modes of transmission. To protect themselves, communities had pre-established protocols to control the spread of *gemo*, including “(1) isolating patients and identifying their residences and the village with external markers to indicate illness (2) using survivors as caregivers to current patients and as a burial team if a patient should die (3) limiting normal social behaviors like travel between villages, sexual relations, dancing, and eating rotten or smoked meat (4) taking extra care to protect vulnerable people like pregnant women and children from sickness (5) banning outside food and (6) burying a patient’s body at the edge of the village” (Hewlett and Hewlett 2008:44-45). When international health agencies first arrived in Uganda, they wrongly assumed that local people had no understanding of Ebola or ways of preventing its transmission and attempted to implement their own prevention protocols based on Western biomedical culture. Unlike Euro-American healthcare professionals who believed that local people could only follow either the Western protocol or their traditional cultural beliefs, the Acholi people do not believe that their

cultural models are contradictory to the international health agencies models of EVD – disease is viewed as having spiritual, social, and biomedical components.

The major areas of concern for agencies like WHO, were able to be evaluated as a result of these ethnographic interviews and the discovery of the cultural model of *gemo*. The cultural practices for each area of concern, both the traditional and modified practices, were identified and helped determine whether or not a particular concern was propagating the epidemic.

Traditionally, a close female relative washes and prepares a body for a funeral – a major cultural event that can last for days. Family and friends make contact with the body one last time before burials (called a “love tap”) and the deceased is buried next to the family home. The practice of washing the body and the “love tap” was proven to be a believed mode of transmission among a small percentage of those infected – probably occurring at the beginning of the outbreak before Ebola had been identified as *gemo* by communities. As soon as a disease is classified as *gemo*, communities modify burial practices so that only survivors or elderly women come in contact with the body, which is then buried away from the town (Hewlett and Hewlett 2008). These modifications, which were implemented before interventions by the international health agencies most likely prevented even further outbreak. This finding was in complete contradiction with the health agencies hypotheses that traditional burial practices were one of the main modes of transmission during the epidemic.

The international health agencies assumptions about traditional healers in the region were also inaccurate and baseless – no evidence was found that healers help perpetuate the spread of EVD. This hypothesis was formed after WHO healthcare workers had heard a story about a traditional healer who had become infected through her work and then continued to treat community members for other afflictions and spread Ebola as a result. In reality, the Hewletts

tracked down the healer from this story and while it was true that she was infected after treating another Ebola patient, the only people she went on to infect were those that had volunteered to care for her during her illness (Hewlett and Hewlett 2008). The warped vision of traditional healers by international health agencies lead to a ban on all traditional healing, which created a rift between communities and the health teams. Community members trust their traditional healers and often find solace and guidance in their words. If the international health agencies had chosen to partner with traditional healers, educating them so that they could, in turn, educate their community, instead of dismissing them as a result of an untrue story, perhaps an even greater impact in stemming the spread of Ebola could have been made.

The ethnographic data collected by the Hewletts uncovered why potentially infected people were running away from the ambulances sent to help them. The WHO inaccurately assumed that community members were avoiding ambulances and treatment at the hospital because those who died at the hospital were buried in a mass grave to avoid the body spreading infection after death – a stark difference to the region’s meaningful traditional burial practices. After simply asking during their interviewees, however, the Hewletts discovered that community members actually appreciated the mass grave burials because it protected the living from infection. By taking dirt from the mass grave site home and performing simple rituals to honor the dead, local people even found a way to merge the necessary mass burial with their traditional practices. Instead, the interviews revealed that people had stopped seeking treatment because (1) they could not see in or out of the isolation unit (2) family members were not present at a patient’s time of death and (3) corpses were immediately removed in body bags. While these biomedical practices seemed innocuous to the international healthcare workers, they bred rumors among local people that the Euro-Americans were selling organs and body parts of the deceased

(Hewlett and Hewlett 2008). Without this insight, the international health agencies would not have been able to make accommodations in order to placate the public's fears and to begin to build a relationship of trust between the two parties. By replacing the walls of the isolation unit with chain-link fences and inviting the family to observe the patient near time of death, the local communities' fears could be allayed and infected Ebola patients may have begun to seek the treatment they needed to increase their chances of survival.

Before the Hewlett's involvement in the healthcare team attempting to address the Ebola epidemic in Uganda, international health agencies had incorrect, misguided hypotheses about the major modes of transmission among communities. Without the use of outbreak ethnography, the international health agencies would have based their public health interventions on inaccuracies, which would have resulted in policies that were in direct contradiction to cultural beliefs. This would have made implementation extremely difficult and may have caused backlash from local communities. Instead, insights gained through interviews helped international health agencies understand what the communities real concerns were and how to effectively stem the epidemic. In addition, the cultural models outlined through the research, identified practices already being used in communities to contain EVD – practices that international health agencies could build off of, instead of attempting to implement foreign biomedical protocols.

West African Epidemic: 2013-2014

The most recent EVD outbreak located in West Africa, lasted almost an entire year and affected several different countries simultaneously. This devastating outbreak was the largest and most complex one to date with 28,616 cases identified (suspected, probable, and confirmed) and

11,310 deaths recorded as a result – more cases and deaths than in all other Ebola outbreaks combined (Center for Disease Control and Prevention 2016a). While Ebola was spread to outlying countries like Nigeria and Senegal through travel, the most severely affected countries were Guinea, Liberia, and Sierra Leone – all of which have weak healthcare infrastructure, lack extensive resources, and have pasts embedded in long periods of instability and conflict (World Health Organization 2016). The focus of extensive media coverage, the media painted the areas of outbreak as “helpless and hopeless”, full of local communities that hold unscientific, irrational beliefs about the disease and perpetuate troubling cultural practices that only add to the spread of EVD. Unlike the Uganda outbreak, anthropologists were not utilized effectively during this particular epidemic. The sheer scale of the outbreak caused panic among the international health community, which attempted to implement the ideology the science trumps cultural beliefs in times of dire need (Maxmen 2015). This disregard for cultural practices ultimately lead to a relationship of distrust between communities and international health agencies that often caused significant conflict over burial practices and other key cultural beliefs – to the point that the conflict between the parties may have lead to an escalation in the epidemic.

In all three West African countries greatly affected by the Ebola outbreak, burial practices are extremely important in local culture. Like in Uganda, preparations of the body are normally carried out by close family and friends with bare hands, which only amplified transmission of EVD (Richards and Mokuwa 2014). Unlike Uganda, no pre-existing epidemic cultural protocols had been established. This lead health authorities to attempt to implement strict, biomedical protocols to avoid spreading infection after death – a monumental difference from traditional rituals causing locals to be unwilling to give up their cultural practices easily. Community members were suddenly expected to allow loved ones’ bodies to be taken away in

faceless body bags with little to no goodbye – a difficult thing to ask of a population that is used to washing and dressing corpses by hand and holding extravagant funerals. To Euro-American health teams with the sole mission of containing the epidemic, the choice to change burial practices to protect the living from infection seemed like an obvious one, but local communities did not share this belief (Maxmen 2015). This conflict often became physical as the outbreak continued. Often as health authorities attempted to separate those afflicted with EVD or the corpses of the dead from the communities, the designated ambulance drivers and burial teams were pelted with stones thrown by community members. In a confrontation in Guinea, eight people distributing educational material about EVD were killed. Families stole away into the forest with their sick relatives rather than allowing them to be treated by the international health teams, which only increased the prevalence of transmission. Julienne Anoko, an anthropologist originally from Cameroon, ultimately recognized the rift between the healthcare teams and local communities as the underlying cause for the ongoing conflict – “The problem was that the people handling the intervention only looked at this as a health issue; they did not try to understand the cultural aspects of the epidemic” (Maxmen 2015:1). Anoko was originally contacted to find a compromise to satisfy both a health team insisting a pregnant woman be buried as is and mourners who, following centuries of tradition, demanded the fetus be removed before burial to ensure her spirit would reach the village of the dead. Eventually, Anoko discovered an elder who knew of an acceptable reparations ritual that would take place while the health team hygienically buried the woman (Maxmen 2015). While this compromise is exactly what the Hewletts would have advocated for and executed during their research in Uganda, utilizing an anthropologist as a mediator between culture and the community and the international health agencies had not yet occurred in the West African outbreak. The

fundamental disconnect between biomedical-minded health teams whose ethnocentric perspective disregarded the significance of local culture and local communities entrenched in hundreds of years of tradition, created unnecessary conflict that only intensified the severe epidemic already under way. It was not until much later that anthropologists began consulting for the international health agencies in attempts to soothe the outright distrust of local communities. If incorporated earlier, like the Hewletts in Uganda, much of the ideological conflict that led to Ebola patients hiding from health teams and increasing risks of transmission, as well as the physical conflict may have been circumvented.

Overburdened healthcare systems and overworked hospital staff also added to the distrust created between communities and health agencies in the West African epidemic. Long periods of civil and political unrest left Guinea, Sierra Leone, and Liberia with weak healthcare systems. Healthcare resources were scarce to begin with and after the advent of the outbreak there were often not enough beds or staff to care for Ebola patients. As a result, patients were shuttled between various hospitals with little record of their movements. Families often did not know where their loved ones were being treated or even if they were alive or dead, as deceased patients were quickly whisked off to be buried in unmarked graves to minimize the risk of infection to others (Ferme 2014). The lack of communication and the disappearances of loved ones fueled a conspiracy among communities that Ebola was a hoax. Similar to Uganda, the belief that healthcare professionals were selling organs and body parts manifested among local people. As the conspiracies gained momentum, people were less and less likely to bring infected family members to healthcare facilities for proper treatment (Maxmen 2015).

Rather than attempt to be transparent with the community about healthcare practices, many health agencies complained about the stubborn nature of local communities.

Anthropologists, who understand the beliefs of culture and people and can find the optimal way to change those attitudes, pressed international health agencies to understand as well, but were largely ignored until later in the epidemic. Eventually, those familiar with local culture and customs helped educate healthcare teams and the biomedical perspective slowly changed to realize that accommodating these deeply held beliefs was the only way to effectively contain the outbreak. Health workers and designated burial teams altered their protocols with the help of anthropologists, while community leaders worked to change communities' perspectives and adapt traditional ceremonies to help slow the spread of EVD (Maxmen 2015). Finally, multidisciplinary teams of anthropologists, culturally significant community leaders, and healthcare professionals worked together to create meaningful public health messages and awareness campaigns (Thompson 2015). This collaboration, though much later than preferred, did end up building trust with local communities and stemming the spread of Ebola. These instances of conflict and distrust between health agencies and communities only emphasizes the important role anthropology, particularly ethnography, can play in the area of public health and epidemic containment. Incorporating these tools as early as possible during an outbreak may prevent complications and cultural obstacles that can affect the spread of disease and helps to foster a partnership between international health agencies and local communities from the beginning.

Chapter 6

Moving Forward: Anthropology in Epidemics

Including anthropologists on emergency response teams is the first step toward more effective outbreak containment and better integration of anthropological and biomedical perspectives. Beyond inclusion, more anthropological tools, like collaborative networks, are being developed and implemented in hopes of increasing efficiency, so that culturally appropriate health policy solutions can be designed and implemented more quickly during emergency epidemic situations. International health teams are looking to anticipate future outbreaks of disease, rather than simply react, as they did in the case of Ebola. While outbreak ethnography is a viable tool in an epidemic setting, especially if little information or research has been conducted in an area in the past, it is a reactionary measure – making the need for updated anthropological tools that can be used in the midst of emergency epidemic crises apparent.

Though anthropology is finally starting to receive recognition of its importance, often its involvement in international health situations is delayed and only implemented in small scale. Even larger international health players in the most recent West African Ebola epidemic were slow to utilize anthropologists and their use was extremely limited – the CDC did establish anthropology desks internally, but they were used sparingly considering the amount of United States resources committed to curbing the epidemic (Abramowitz et. al. 2015). As the international health community moves forward, a greater integration of anthropology and public health will hopefully allow agencies and governments to get a better handle on disease epidemics in a timelier manner, preventing infections from occurring and preserving life.

Ebola Response Anthropology Platform

The Ebola Response Anthropology Platform (ERAP) is one such collaborative tool that has been developed and launched as a result of lessons learned from the most recent Ebola outbreak in 2013-2014. During the outbreak, agencies like the WHO and Médecins sans Frontières, as well as the governments of France, Sweden and the United Kingdom eventually sought the consultation of local and international anthropologists and called for the support of anthropological research. A collaborative platform like the ERAP pools information from experts across disciplines located all over the world to act as a database of relevant and pre-existing knowledge in case of another outbreak occurring, but also prevents redundancy in research during emergency medical and humanitarian situations where time is of the essence (Abramowitz et. al. 2015). Headed by the London School of Hygiene & Tropical Medicine, in conjunction with several other organizations and schools, the ERAP hopes to gather relevant research and information to advise both international health agencies and local community health workers to accurately and effectively diagnose cases of Ebola, treat patients, and hygienically dispose of the dead in a way that prevents further infection. In addition, the platform, which was created by medical anthropologists with an expertise in West Africa, the site of the most devastating EVD outbreak to date, ensures all the interventions and recommendations of the platform are designed for local contexts and are culturally appropriate to increase participation in local communities (Grant and Benson 2014).

Since its launch during what was at the time, an ongoing outbreak, the ERAP received a heightened demand for its services and anthropological consultation. In addition, the platform continued to regularly update and manage an online research portal, as well as launch research initiatives, which included disseminating relevant literature on West African cultural context and behaviors that affected disease transmission, identifying the key anthropologists that have expertise in these areas, providing real-time advice service to health agencies, developing training materials to education the West African healthcare sector on epidemic response, and executing research and producing both research literature and policy recommendations to increase the wealth of knowledge on Ebola and emergency epidemic response (Enhancing Learning & Research for Humanitarian Assistance 2015).

This collaborative network allowed for easy communication across all international health agencies and countries, acting as a central hub for the latest culturally relevant information on the Ebola epidemic. The amount of information collated and shared speaks to its efficacy, while the fact that the platform was launched in the midst of an ongoing epidemic validates that this type of collaborative anthropological tool can be used to help contain future epidemics. Though the platform is specific to EVD and its latest West African context, the design and idea behind the platform is easily adaptable to be applied to other diseases that may cause emergency epidemic situations in other geographic regions. Unlike outbreak ethnography that may send anthropologists unfamiliar with either the disease or the location into the field, this platform takes advantage of a pre-existing knowledge base that can be updated and accessed internationally, allowing the most qualified professionals to add their expertise. While only tested in the most recent EVD outbreak, using collaborative networks mirrored on the ERAP may prove to be a valuable anthropological tool in future disease epidemics.

Lessons Learned: Preparing for Future Epidemics

Though the 2013-2014 Ebola crises that affected numerous countries in West Africa was both devastating and tragic, the thousands of deaths it caused did act as a much needed forewarning about the dangers and destruction a disease epidemic can cause, not only to communities, but to entire countries and continents. Until this most recent outbreak, the world has been lulled into a sense of security, believing large-scale, deadly epidemics were a thing of a past. From the Black Plague of the Middle Ages, to the outbreaks of smallpox common in up until the late 1800s, to the massive Spanish influenza epidemic of 1918 that claimed millions of lives, modern medicine has made deadly infectious diseases a thing of the past. Even the ongoing global HIV/AIDS epidemic has begun to fade from public view as medical advancements have increased the life expectancy to the point that the disease is now chronic and no longer considered a life sentence. So far, humanity has gotten lucky – Ebola is far from the most infectious disease known to man. Though the epidemic was able to be eventually contained despite sluggish response time and a lack of preparation and basic understanding, even if the Ebola response had worked at peak efficiency it may have still failed to contain an a more infectious disease (Gates 2015). With increasing urbanization, climate change, and other modern influences, the world is more vulnerable than ever to a possible pandemic. Combined with cuts in funding to the biggest international health agencies like the WHO and the United Nations, as well as to scientific research grants and a host of newly adapted and mutated pathogens, the

world must utilize the horrifying 2013-2014 West Africa Ebola outbreak as a warning sign to begin preparing for a much worse scenario (Dhillon, Srikrishna, and Bieier 2017).

After the media craze about Ebola began to fade, the world turned its attention to another virus making headlines for jumping international borders – the Zika virus. Though far less deadly than Ebola, Zika has been linked to several birth complications. Transmitted through mosquitoes and sexual contact, many of those infected are unaware because Zika causes mild symptoms or, sometimes, none at all, causing it to be deemed a silent epidemic. Due to its relatively mild nature compared to Ebola, the response to Zika by international health agencies has been on a much smaller scale, despite the threat it poses. Though agencies like the WHO and the CDC originally dispatched emergency response teams, the funding and concern has been minor (Frieden 2016). If the Ebola epidemic was a warning to the international health community about their lack of preparedness, health agencies seem to be repeating some of their mistakes when it comes to the Zika epidemic. Analyzing and criticizing the response to the West African Ebola epidemic can provide insights into how the global health community should prepare and plan for future epidemics including Zika.

Anthropologists are part of that solution. In terms of the newly emerged Zika epidemic, with a lack of treatment or vaccine and a vector-borne method of transmission, mosquitoes, most of the epidemic containment work is in prevention. This mode of transmission also creates a strong social gradient – meaning some populations have a much higher chance of exposure to Zika virus than others. This includes high density neighborhoods where there is often a higher frequency of open water sources, possible mosquito breeding sites, and poor waste disposal. These characteristics typically correspond with poorer populations. People who work outdoors or areas that experience disease clustering are also at a higher risk for exposure – again,

characteristics that correlate to areas with low socioeconomic status. Preventing the spread of Zika will be most effective by addressing these social and economic factors (Zika Temporary Interest Group 2016). In situations like these, utilizing critical medical anthropology (CMA), which identifies underlying structural inequalities that may affect health directly or indirectly would be beneficial (Singer 2014). In this case, community resources are disproportionately allocated as a result of socioeconomic inequality, which in turn, causes uneven and disparate levels of risk to the disease. Utilizing CMA would allow health agencies to uncover hidden causes of these inequalities, allowing them to create more impactful public policies in attempt to alleviate them.

Anthropologists familiar with the area and the highest risk populations will be advantageous in developing appropriate public policy to help mitigate these structural inequalities – much like how anthropologists were able to understand populations’ perspectives on Ebola and the international health agencies’ responses to it to correct ineffective health interventions. For example, in America Samoa it is believe by Dr. Michaela Howells that the Zika problem is not only complicated by poverty, but by the island’s widespread conservative Christian values. Sex, condom use, and family planning are rarely publicly discussed – sex education is not taught in public schools. Since Zika can also be spread through sexual contact, this cultural belief has been detrimental to some of the health interventions intending to prevent the spread of the disease. Early interventions by the Department of Health included distributed condoms and educational materials. However these educational material did not depict people of Samoan descent, were not translated in local languages, and discussed sexual contact very explicitly causing villages to reject the prevention program outright. Eventually, at the behest or medical anthropologists like Howells, the Department of Health worked in conjunction with the

Department of Samoan Affairs to produce culturally appropriate materials (Kraft 2016). Failed prevention programs like this one may be avoided in the future with the help of anthropologists who are able to observe, interpret, and explain local communities cultural beliefs and perspectives that have the potential to impact the success of a particular intervention.

Anthropologists are often seen as a source of expertise about local, “exotic” cultures by international health agencies, anthropologists should also observe and examine the agencies they are consulting for. By acting as an intermediary, anthropologists can not only inform healthcare teams about local cultural beliefs that may impede care or could possibly be leveraged to help, but can also help work in conjunction with the agencies to reevaluate the organization’s practices to be as effective as possible in a specific cultural context. This means that anthropologists must be incorporated into the emergency response team early – in West Africa, few anthropologists were actually deployed to teams “on-the-ground” and those who were arrived much later in the epidemic, meaning they had no chance to influence the health intervention designs or their implementation plans (Menzel and Schroven 2016). Early inclusion in epidemic response means that anthropologists can also utilize the resources at their disposal – often university-based multidisciplinary teams, including students and faculty – that can track cultural, political, economic, and other social aspects of an outbreak and can act as home-bases for advocacy, fundraising, and education globally. In addition, anthropologists who are familiar with a particular geographic area from past research can share their local contacts with international health agencies. Over extended periods of research, anthropologists establish deep personal and professional relationships with key community members that may be advantageous in an epidemic containment effort like community and local non-profit organization leaders, as well as research assistants and interpreters. Though anthropologists must be included early in response

efforts to contribute effectively and have the highest possible impact, they may also be useful near the end of an outbreak or in its aftermath. Epidemics often destabilize an area after overwhelming its healthcare infrastructure and devastating its local populations – this can lead to the same area becoming vulnerable to other diseases and health concerns. As a result of ethnographic approaches and established community connections, anthropologists would be able to detect these public health threats before the international health community (Abramowitz 2014).

In conclusion, anthropologists have a host of tools available to them to make an impactful contribution to the public health sector during times of disease outbreak. The importance of culture is often underestimated in the international health community. Sometimes many iterations of a health intervention are attempted before one is finally successful – in emergency epidemic situations, time is of great importance and the longer an intervention takes to implement, the longer a population is at risk for infection and disease. Leveraging anthropological knowledge and local networks would allow these health interventions to circumvent a lot the cultural obstacles that often derail their effectiveness. Incorporating anthropologists as early as possible in outbreak control and considering their critique of health policies in development would produce culturally appropriate, impactful interventions more efficiently and help create powerful, collaborative partnerships between the international health agencies and local communities.

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Developed recruiting materials and handled public relations for the Humanitarian Engineering and Social Entrepreneurship Program. Edited research manuscripts. Mentored student teams through the research and manuscript writing process

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Coordinated lecture, film, and other events, as well as the promotional campaigns for them. Interviewed relevant visiting lecturers. Maintained blog and newsletter for the office. Planned and executed an international education program for children at the local public library.

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International Education (including service-learning abroad):

Humanitarian Engineering and Social Entrepreneurship, Zambia (Summer 2015) – Piloted an affordable greenhouse venture in rural Zambia. Conducted an IRB-approved research study that interviewed local consumers' on their

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