

Neo-Colonial Epidemiology: Public health practice and the right to health in Guatemala

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Abstract

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This is a study of the everyday practice of epidemiology in Guatemala and how it shapes and is shaped by the notion of the right to health. Much of the research on the relationship between public health and human rights adopts either a critical position towards public health as a potential human rights violator, or an uncritical assumption that what is good for public health is good for human rights, without an examination of how that relationship happens. With my research I show that the human rights impact of epidemiological practice is not unidirectional, and that it is influenced by the concrete configuration of transnational and local forces (political, economic, ideological, bureaucratic, scientific and symbolic) mediated by social relations in which the epidemiologist plays a key moderating role. I introduce the notion of “Neo-Colonial Epidemiology” to synthesize the ways in which these forces take shape in the Guatemalan context, where institutional chaos, disciplinary conformism, international health relations, and national social relations play key roles. To complete this research I spent a total of eighteen months doing fieldwork in Guatemala, over a period of three years.

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Dedication

For Meredith, with love and admiration.

Chapter 1. Introduction: Neo- Colonial Epidemiology and the Right to Health

“Why did I become an epidemiologist? Well, I think since one has a conception of helping humankind, perhaps since early in life, perhaps since one is five, six, seven years old, one comes with a call to serve and to help others. This materializes in me in a biological aspect and a spiritual aspect. I think when I was a teenager, I felt both calls and I seriously considered pursuing the religious path, but after two months in the seminar I realized I also had other ambitions I wanted to pursue, but without leaving my call to serve humankind. So the best way of doing it that I found was to become a physician. All through the years I wanted to help prevent or alleviate other people’s suffering, from every point of view, be it physical, psychological, or emotional. One of my goals back then was to help others without expecting anything in return, even if the medical profession could be turned into a very profitable one. But I realized there were so many people suffering and with little [economic] resources, so I never wanted to learn how to profit from other people’s suffering. So, in medical school one learns to become a general practitioner, with no specialty [...] so I decided to become a surgeon, which I did [...], and I realized that it was, like when you paint a wall, if you give a bad brushstroke, you can quickly fix it, right? So, surgery is the same, but I felt it was less than I wanted because it did not let me do what I wanted which was to help humankind [...] So I told myself I needed to do research because I wanted to get at the root causes of problems [in order to] find real solutions to those

problems, not just fix problems but find solutions. [...] so I went to get a masters in public health with an emphasis in epidemiology and then I was offered a job at the CNE, which, to me, was like a dream come true.“ (Epidemiologist at CNE)

Epidemiology and the right to health

When I graduated from Guatemala’s public university as a physician I knew I wanted to become an epidemiologist. It was the year 2000, and during the previous seven years I had moved from dreaming of becoming a good doctor to feeling committed to the transformation of Guatemala’s health system, and I genuinely believed that epidemiology would give me tools for speaking truth to the powers responsible for the country’s tremendous social exclusion. And I was not exactly naïve because during my years as a student, I was an active participant in the social and political processes that led my country from a 36-year civil war into a post-war period filled with hope and skepticism. In 2000 my country was trying to learn to live in democracy at the same time that it was learning that during the civil war the state had committed genocide against the indigenous peoples in the countryside. By 2000 I had also worked shoulder-to-shoulder with indigenous rights and feminist activists as well as with revolutionaries and shared their vision of our society. And yet, I wanted to become an epidemiologist. Six years later, I had worked with several epidemiologists and had earned a masters in public health with emphasis in epidemiology and still thought that epidemiologists had the potential of speaking truth to power, but at least in Guatemala they were just not doing it. And I saw that the more I did epidemiological work, the less I was paying attention to social inequalities and their transformation. I was living in a paradox: the more I sought the tools for understanding social inequalities in health, the farther away I was moving from

actually dealing with them. The more I delved into the epidemiological tools, the less I was aware of the human suffering that motivated my interest in epidemiology in the first place.

This dissertation aims at understanding how that paradox happens, in order to come up with ideas for preventing it from happening. Because after all these years, I still believe in the potential that epidemiological work has for addressing injustice. At the beginning of this research project back in 2009, I knew there were several people in Guatemala who had followed an epidemiology career because, just like me, they wanted to address the “real causes” of health problems but who were getting trapped in the same paradox I was. I had the sense that they were in many ways like me. I suspected that, just like me, they had gone through a lot of sacrifice through the country’s public school of medicine but decided to go against the current and not follow a clinical specialty or start a private practice. I imagined that in their heterogeneity, their social backgrounds were in many ways like mine: middle-class urban folks without the means to go to a private university, who had spent all or most of their lives in the country’s larger cities, and *ladinos* (that is non-indigenous, non-black, non-white, *mestizos*, very likely uncritically reproducing racism towards indigenous peoples). Some of them had been my teachers, some of them had been my classmates, some of them had been my co-workers, none of them were my friends, and all of them had jobs such as the one I would probably have if my life circumstances had not brought me to getting an anthropology degree in the United States. So when I decided to study “the tribe of Guatemalan epidemiologists”, as I found myself jokingly calling it, I was studying my own tribe, or more accurately, one of the tribes I am part of, or could be part of. And in that sense, when I point to

epidemiologists' mistakes, I think of them as mistakes I have made or I could make, just as I think about their achievements in the same way, because I am studying my own tribe, I am one of them. Or I almost am, because at the same time I am part of the tribe of anthropologists and it is because of that that I was able to conceive this project, and to gain the distance and detachment that made it possible. And after all I still believe in the transformative potential that may be gained through the practice of epidemiology, and I still want to be an epidemiologist, but of a different kind.

Epidemiology

Epidemiology is considered by its practitioners as "the key scientific underpinning of public health practice" (Brownson and Petitti 2006) and is broadly defined as the study of the origins and distribution of health-related events in specific populations and the application of such study to the control of health problems (Porta 2008). However, epidemiologists understand the origins of health problems and their solutions in contrasting ways that lead them to propose bold transformative actions or timid band-aid control measures. Contemporary epidemiology originated in the 18th century. It has been portrayed as an attempt to control the spread of disease among the poor, which were considered to be a threat to economic and political life in industrial cities. Others have explained epidemiology as a tool for controlling the poor through the control of disease. Epidemiology has also been described as a tool for the exploitation of European colonies, the American West and peripheral states, such as Peru or South Africa (Birn, Pillay and Holtz 2009). Today it is widely seen as an instrument for the protection of rich countries' national security and it has, from this perspective, been

linked to social control more often than to improving people's wellbeing (Brown, Cueto and Fee 2006).

And yet, epidemiology has also inspired social justice efforts and has sometimes been instrumental in uncovering the causes of suffering. Breilh (2003) sees in it the potential to become an "emancipatory science" if it addresses the political-economic causes of health problems and the triple inequality generated by sexism, racism and classism. Almeida-Filho (2000) characterizes it as a "timid science" for its lack of audacity, courage and determination to live up to the final consequences of its mission. He suggests epidemiologists should be more courageous.

The goal of epidemiology as a science practice is to study the origins and distribution of health problems in order to contribute to their solution. Although epidemiology's contemporary discourse and practice is largely defined through international institutions, global philanthropists and a handful of first world universities, its implementation needs to be studied as an ensemble assemblage of historically and geographically situated activities, symbols and tools to be found in the awkward space that is neither local nor global (Comaroff and Comaroff 2003). This kind of study would sort out the contradictory ways in which epidemiology's goal is understood as timid or emancipatory.

Few studies touch on these practices. Briggs and Mantini-Briggs (2003) show how public health workers' epidemiological knowledge combined with stereotypes reproduces racism disguised as technical knowledge. Kohrman (2005) explains the ways in which statistics were used to define the emerging field of disability for political and institutional purposes. Biehl (2007) describes how numbers that represent people's lives

get manipulated by public health workers, impacting those lives they represent. These works point to the need for understanding epidemiology as a situated practice because it has consequences for people's lives.

During 2009-2011, I conducted interviews and archival research focused on understanding the recent history of epidemiology in Guatemala and the work of epidemiologists. Through the interviews I quickly became aware that Guatemalan epidemiologists had their own views about the purpose of epidemiology and who should be considered an epidemiologist. According to their accounts, epidemiology is not an emancipatory science, and it was definitely not presented as timid. It was portrayed as quixotic.

If a Quixote is an idealist who pursues romantic goals through impractical actions we might at least ask where that image comes from and what it tells us about the practice of epidemiology in Guatemala. Is a quixotic epidemiology also emancipatory? Or is it one that becomes timid when faced with the social causes of health problems? If Guatemalan epidemiologists do not address the roots of epidemiological problems, are they timid Quixotes that pursue spurious ideals? And where does it leave the aim of addressing health inequalities prescribed by the notion of the right to health?

Public health goals and human rights priorities are often at odds. While the former tend to overlook individuals the latter have traditionally emphasized the rights of individuals. While public health is usually conceived in terms of public policy and programs expressed mostly in technical-administrative terms, the right to health is often thought of as a normative idea subjected to definition through national and international juridical-political instances. When a public health institution embraces the fulfillment of

the right to health as its mission, how does it handle these contradictions? Does it make a difference to people's health?

The right to health has been defined as the right to enjoy the "highest attainable standard of health", which is not equal to the "right to be healthy" (Riedel 2009). In practice, it considers the individual's biological and social conditions as well as the state's resources. In practice, it refers to access and availability to affordable health services and good living conditions for a specific population. An indicator of its achievement is the decrease in health inequalities (Hunt and Backman 2008).

Epidemiology and the right to health share some characteristics. First, although throughout their history they have been used as instruments of domination between countries and within countries, they have also served as instruments of humanitarian efforts and struggles for social justice. Second, they have developed simultaneously as part of national agendas and international systems. Third, the ways in which they are practiced is frequently controversial and contested. Finally, public health goals can be at odds with human rights goals, as has been illustrated through the case of female genital cutting (Shell-Duncan 2008).

Research project

In this dissertation research, I investigated epidemiology's contribution to the right to health through the ethnographic study of the Guatemalan Centro Nacional de Epidemiología (National Epidemiology Center). The Centro Nacional de Epidemiología (CNE) was created in Guatemala in 2004 within the Ministry of Health. Its creation was part of the changes facilitated by the Guatemalan Peace Accords, signed in 1996, marking the formal end of a thirty-six year war that killed about one quarter of a million

people. But there are other processes underlying its creation. On the one hand, the training of epidemiologists in Guatemala since 1997 by two universities receiving strong support independently from the Pan American Health Organization (PAHO) and the United States' Centers for Disease Control (CDC) marked a change. Before that, there were just a few epidemiologists in the country and they had all earned their degrees in foreign universities. The new model of training responded to foreign and international priorities and to the process of post-war "modernization" of Guatemalan institutions. On the other hand, the presence of Cuban epidemiologists after hurricane Mitch in 1998 brought their own views and experience to the practice of epidemiology in Guatemala. Their presence in the country is one of the Cuban government's tactics that are part of its post-Cold War international policy.

The CNE was created with the explicit mission of contributing to the orientation of public health policy aimed to achieve the right to health for Guatemalan inhabitants. Guatemala's human rights record is among the worst in the Western hemisphere, with civil, political and socioeconomic rights widely violated during the civil war (UNDP 1998) when state violence was so brutal that it was defined as genocide by a United Nations commission (CEH 1999). Although the general climate has changed since the war ended, human rights violations persist and, despite the strong available evidence, the country is divided about what to make of the history of genocide. In addition, the country has one of the highest indices of social exclusion and its health indicators show great disparities by race/ethnicity, sex/gender, class and place of residence (WHO 2012). In that context, the CNE stated mission demonstrates a pertinent commitment and a formidable challenge.

The objective of this research was to examine how the CNE envisions and projects itself in order to contribute to the achievement of the right to health. This research was framed by four sets of questions:

1. What is the history of the CNE? How did it emerge and change the practice of epidemiology in Guatemala? What were the personal, institutional, societal, disciplinary and international forces participating in its creation? What future do individuals who work within the CNE envision for it?
2. How does the CNE function? What is the nature of its everyday work? How do people who work there make decisions regarding health problems, their origins and solutions? How do personal, institutional, disciplinary and international forces participate in decision-making?
3. What are the interactions between the CNE and Guatemalan society? How do human rights activists see the CNE's work? What would they expect it to do to live up to its mission? What are the opinions about the CNE of people who interact with it? What are the social representations of Guatemalans that the CNE produces? How are those representations influencing the transformation or reproduction of social exclusion?
4. How is the right to health understood through these practices and discourses? What meanings and practices are attached to the notion of the right to health? What agreements, controversies or conflicts does it raise? Are health inequalities transformed through these practices?

The 2009 swine flu epidemic highlighted the interconnection between epidemiological practices in different parts of the world. This research looks at how a country like Guatemala – part of the periphery, the Global South, the Third World, the under-developed nations, or among the countries characterized as part of the “globalization non integrating gap” (Barnett and Gaffney 2005:18) - develops these practices and how it is inserted in the international public health system. At the same time, this research looks at how the universalistic idea of the right to health gets shaped in a Third World country and how it participates in the international human rights system.

Studying the social life of the right to health

There has been a renewed interest in the study of human rights from the perspectives of the social sciences in the last decade. Anthropologists have been particularly active in this academic turn (AAA 2006, Goodale and Merry 2007) and have highlighted the need for ethnographic investigations of the practices of human rights. “It is actually quite surprising how rarely studies of human rights take the time to explain how, in fact, ‘human rights’ is being used. Within the voluminous human rights literature it is much more common that the intended meaning of human rights is kept implicit” (Goodale 2007: 6, n.1). This observation is true of current understandings of the right to health, which has emerged in the last few decades to become part of the social discourse about health and health care in both the global North and South (Schuftan 2007).

Human rights can be understood as legal rights, moral claims, ideology, desire, strategy, and a topic in jurisprudence (Douzinas 2007). The different meanings of human rights “as a normative category” can be explored by imagining a spectrum with restrictive understandings on one end and increasingly more expansive ones as one moves towards

the other end (Goodale 2007). At the restrictive end of the spectrum, human rights refer to the body of international law derived from the Universal Declaration of Human Rights. A more open understanding focuses on the concept of human rights and how it operates and is brought to life in different ways by different actors. At the other end of the spectrum, human rights are understood to be just another discourse embedded in power driven transnational relations and the aim is to deconstruct it to show its flaws, gaps, and contradictions.

When I started graduate school in 2007, I was probably close to the middle of this spectrum, not interested in examining human rights as discourse but also not interested in their exclusively legal life. However, my multiple readings about the right to health from perspectives close to public health and medical anthropology made me realize the importance of thinking carefully about the discourses one is immersed in when talking about human rights, because important differences can arise from there.

Ideologies of human rights

One way to approach human rights without reifying them is to look at different understandings of human rights as ideological discourses. Although Goodale's suggestion is useful for me on a conceptual level, in order to move towards a more empirical level I find it useful to refer to Makau Mutua's typology of ideologies of human rights (Mutua 2002). His typology is less encompassing than that of Goodale, because it only includes believers in the idea that there are basic human rights and they should be promoted and protected by the state. Mutua distinguishes four types of human rights ideologies: conventional doctrinalists, constitutionalists or conceptualizers, cultural agnostics or multiculturalists, and political strategists or instrumentalists. Conventional doctrinalists

are, paraphrasing Mutua (2002: 39-44; 47-50), those who share a firm belief in the “redemptive quality and power” of international human rights legislation and see it in almost religious dimensions. Although there is variation in what they do, they tend to be “statisticians of violence” and see as their mission the denunciation of human rights violations. The majority of them work in the context of international non-governmental organizations based in the global North, although there are some academics that write from this standpoint. They stress the primacy of civil and political rights over all other classes of rights, and seek “immediate and blind application” of human rights law.

Constitutionalists or conceptualizers share with doctrinalists the belief in the “redemptive quality and power” of international human rights law and its application. Mutua calls the duet between doctrinalists and conceptualizers, the “human rights orchestra” because they are the composers and conductors of the human rights discourse. But they differ in several aspects. While doctrinalists were described as “statisticians of violence”, constitutionalists/conceptualizers are the main “systematizers of the human rights corpus” and they are strong believers in constitutionalism as a necessary step towards human rights achievement. Conceptualizers are more critical of the human rights corpus than doctrinalists and are usually academics. Another difference is that many constitutionalists/conceptualizers, although not all, recognize the supremacy of civil and political rights as “core” rights, but are willing to accept or even promote the expansion of that list to include at least some social, economic and cultural rights, but this expansion would need to recognize historical, political and cultural differences (Mutua 2002).

Cultural agnostics or multiculturalists are people who see the human rights movement and system from “outside” and find in the universalization of human rights norms some

convergence with non-Western social norms and therefore embrace the human rights corpus to a degree. However, they point to the limitations of the corpus for being “culturally exclusive” in some aspects, which makes them see parts of the human rights corpus as illegitimate or irrelevant. Some propose a multicultural approach to human rights, which would entail a reform of the human rights corpus. Scholars, activists and policy makers that are part of this group are often called “cultural relativists” by doctrinalists and constitutionalists/contextualizers (in a rather pejorative way that stigmatizes rather than illuminating their claims) (Mutua 2002). Finally, political strategists or instrumentalists are those governments and institutions that selectively and inconsistently “deploy human rights discourse for strategic and political ends”. Although he acknowledges that governments in the global South fall in to this category, his central focus is to show how governments and institutions from the global North and international institutions use the notion of human rights for advancing their political or economic agendas, while violating human rights themselves. From my perspective, this group also includes non-governmental organizations that use human rights discourses to advance their agendas. While there is an implied negative connotation of the political agendas promoted by the institutions and governments that Mutua describes in this typology (and I agree with him), my expanded use of his typology implies that the agendas are not necessarily negative. I found all four of these ideologies simultaneously at play in Guatemala.

Studying human rights practices

Studying the practices of human rights means, according to Wilson, “carefully documenting the social life of rights – that is, the social forms that coalesce in and around

formal rights practices and formulations, and which are usually hidden in the penumbra of the official political process” (Wilson 2006:78). One example of this kind of study is Merry’s research on women’s rights at the transnational and local levels (Merry 2006). In my research of human rights practices, I used the idea of the social life of human rights by applying concepts from the “anthropology of things” (Appadurai 1986, Kopytoff 1986) to health rights. By looking at the right to health as a “thing” I meant to interpret it as an “object in motion” which may or may not acquire the form of a commodity with an exchange value. This encompasses ideas, ideologies, people, goods, images, messages, technologies, and techniques, which characterize the current functioning of the world (Appadurai 1999:230).

Applying ideas from the anthropology of things to the right to health has the potential to offer productive perspectives and unique insights into human rights practices. First, the right to health becomes the subject of a series of strategies that attempt to define its value. This creation of value is politically mediated and shapes the “supply side” (Appadurai 1986:16-29) of the circulation of rights, i.e. how the right to health is fulfilled and by whom. Second, the circulation of the right to health becomes subject to social control and political redefinitions that shape the “desire and demand” (Appadurai 1986:29-41) for rights, i.e. who demands the right to health and how. Third, the value of things is closely connected to knowledge production, so that “the politics of value is in many contexts a politics of knowledge” (Appadurai 1986:6), which in the case of the right to health means that the way it gets defined influences its social value. Finally, one can construct the “biography of a right” by asking several types of questions. For example: What is its social status? Where does it come from? What has its career been

and what would its ideal career be? What are the periods of its life? What are its cultural markers? When does it get to the end of its productive life (Kopytoff 1986:66)? By using this detailed approach, I hope to look at the ways in which the right to health is practiced in daily life instead of looking at what it is supposed to mean. As I will show in the following chapters, this approach led me to pay very close attention to the technologies that shape epidemiological practice.

Studying epidemiological practices

This study is concerned with the role of the state in the production of health and suffering and the links between power and knowledge. My ultimate purpose is to contribute to the transformation of health inequalities. Thus, the general approach I follow is that of critical medical anthropology, or the "perspective which views health issues within the context of encompassing political and economic forces that pattern human relationships, shape social behaviors, condition collective experiences, re-order local ecologies, and situate cultural meanings, including forces of institutional, national, and global scale" (Baer, Singer and Susser 1997: 3-4). My emphasis in this work is on practices at the institutional level. By looking at epidemiological practices as a strategic site to study subjectivity, I am engaging in ongoing ethnographic explorations about the relation between structure and agency (Singer and Baer 1995:329-331; Biehl, Good and Kleinman 2007:1), active and passive subjectivities (Ortner 2005), disciplined and undisciplined subjects (Mbembe 1992:2, 5) and governmentality, understood as the "contact between the technologies of domination of others and those of the self" (Foucault 1988:18). The main focus of the study was at the intermediate social level, in which we study health institutions, and their decision-making processes, policies and

social interactions (Singer and Baer 1995:68-70). However, I also considered issues at the individual, micro-social, and macro-social levels, as they help understand epidemiological practices and their impact on people's lives. The study looked at epidemiological practices from three complementary points of view: the everyday, its context, and its products, which I explain in the following three paragraphs.

By approaching epidemiological practices in the everyday, I acknowledge the quotidian life of individuals as the site where social relations are reproduced, but also where they can be questioned, resisted and transformed. I approached this through the anthropology of everyday experience as developed by Kleinman (1999, 2006) to look at the ways in which epidemiologists make sense of their work at the level of action, cognition, affect and morality. The anthropology of experience has been critiqued (Singer and Baer 1995:268, Keesing 1987) for not paying enough attention to the larger social structures. Thus, I situated everyday practices in their material and symbolic context through an eclectic use of the concept of everyday life as proposed by Heller (1984), de Certeau (1984) and Smith (1987, 2005).

For understanding the context in which epidemiological practices occur, I used various perspectives. On the one hand, I looked separately at questions of how epidemiological knowledge is constituted, legitimated, tested, critiqued and transmitted (Janzen 2002:189). On the other hand, I examined the social organization of epidemiological practice, including questions of how it is controlled, professionalized, institutionalized and linked to social difference, the state and the private sector (Janzen 2002:212-236). My assumption, however, was that both knowledge and social organization are inseparable in epidemiological practices. I approached epidemiological

knowledge from a historical perspective, based on the interpretive analytics of discursive formations pioneered by Foucault, as presented by Dreyfus and Rabinow (1982:104-125). Foucault's approach has been used and expanded by social scientists studying medicine (Jones and Porter 1994) and other disciplines (Burchell, Gordon and Miller 1991). This kind of historical approach, based on tracing conceptual continuities, discontinuities and errors (Delaporte 2002), is based on the work of Canguilhem (1994), has informed Good's study of biomedicine (1994), and has been used to study the history of public health (Delaporte 1991). I used it to understand the disciplinary discursive assumptions that permeate epidemiological practice. I studied the social organization of epidemiological practice by looking at the process of its professionalization in the context of social relations in Guatemala. Although epidemiology meets Freidson's definition of a profession as the "fulltime pursuit by an individual of a specialized skill, usually for pay by customers or by an agency that buys the skills of the professional" (Freidson 1988:185), I did not assume what the level of professionalization of epidemiology in Guatemala was. Instead, I took as a reference the range of professionalization of health "organizations in the third world" identified by Last (1996:390-391): cultural societies, promotional groupings, unions, and professional organizations. As an analytic approach, I followed Janzen (2002:224-225) when he suggests adopting Smith's notion of "corporations" (Smith 1974:94-95) to study power and organization in medical professions. Using this approach, it is possible to address the formal, procedural and functional aspects of an organized group, as well as its internal and external relationships (Smith 1974:94). This ultimately allows understanding the relations of a profession to social stratification, the market and the state (Macdonald 1995). I approached

Guatemalan social relations based on Smith's analysis of the intersection between class, race and gender (1995), and further developments of her proposal (Hale 2007, Velasquez 2004).

Finally, I analyzed the products of the practice of epidemiology in two ways. On the one hand, most products were in written form: policy recommendations, reports about outbreaks, health situation analyses, and similar types of reports. I looked at them paying attention to the social and political processes that influence the production of such knowledge. On the other hand, the products have an impact on people's lives. The epidemiological interventions in an outbreak have a clear effect, but reporting on an outbreak also has an effect on the way future outbreaks are prevented, as I will show in the following chapters. Policy recommendations and health situation analyses have an impact on how problems are defined and how solutions can be achieved.

Research methods

I chose Guatemala for my study of right to health practices because, since 1996, the country has been in a post-war period in which it is redefining the role of the state. As a consequence, human rights practices are coming to life in the actions and motivations of different social actors. Part of that social life of human rights can be seen in the recent adoption of a discourse of the right to health by government institutions. My investigation used the National Epidemiology Center, which was created in 2004 with the mission of working "toward achieving the right to health for Guatemalan inhabitants" as its main research site, and traced the sources of the inclusion of the right to health in its work, and implications and consequences. Tracing these flows of the practices of epidemiology and the right to health also brought my research to other sites – both in Guatemala and in

transnational locations, “no-sites” or “global entities” – that are closely connected to the everyday life of the right to health in Guatemala. The Guatemalan National Epidemiology Center has between 20 and 35 epidemiologists (it varies each year) who work with other health workers distributed in 28 locations. They do not all meet together face-to-face very often, but function as a network of formal and informal connections.

Data collection

I organized data collection and analysis in order to answer three interrelated operational questions. Question 1, “What are the flows of the right to health in Guatemala?” aimed at reconstructing the recent history of the right to health in Guatemala by identifying its sources, paths, actors and products. In order to answer this question I tried to map the recent history of the practice of the right to health in Guatemala, to map the recent history of epidemiological practice in Guatemala and its adoption of the right to health as part of its mission, and I studied the history of social difference in Guatemala, as the social context against which human rights practices need to be contrasted. Question 2, “What does the practice of epidemiology look like in Guatemala?” intended to describe and interpret the everyday life of epidemiological practice in the context of the right to health. I intended to describe epidemiological practice by looking at the formal aspects of its work, such as meetings, documents, schedules, fieldwork, and interactions with other institutions and people. I tried to interpret epidemiologists’ experiences while doing this work, and I traced the effect that epidemiological practice has on the achievement of the right to health. Question 3, “What are the transnational connections influencing epidemiological practice in Guatemala?” attempted to further explore the most relevant links between the practice of the right to

health and epidemiology in Guatemala with transnational practices such as trade agreements, international activism, multilateral institutions, and academic organizations.

Data collection involved the use of different research techniques at different stages in the development of the investigation. I collected most of the data between 2009 and 2011, and I used literature review, Internet searches, archival research, semi-structured interviews and participant observation, which I describe in the following paragraphs.

1. Literature review and Internet searches. First, literature review was focused on the identification of publications based on electronic searches of the following key words in Spanish, Portuguese, French and English: human rights and Guatemala and history; right to health and Guatemala; right to health and history; epidemiology and history; epidemiology and Guatemala; social difference and Guatemala. Second, academic journals centered on epidemiology and public health of the Americas were reviewed to reconstruct a conceptual history of epidemiology. Third, Internet searches were used primarily to read the websites of institutions that are relevant to the practice of epidemiology and the right to health in Guatemala. Fourth, I used these techniques to learn about institutions and people relevant to the practice of the right to health in Guatemala.

2. Archival research. I looked at the archives at Guatemalan institutions that are relevant to the practice of the right to health. These included the Ministry of Health, the Human Rights Procuraduría, and the Constitutional Court. In these archives I looked at definitions, examples and jurisprudence regarding the right to health and epidemiological practice.

3. Semi-structured interviews. Interviews were central to this research. I interviewed key informants who have been protagonists of the practice of epidemiology and human rights since 1996 in order to understand their interpretations of the recent history of epidemiology in Guatemala. I also interviewed epidemiologists at the National Epidemiology Center in order to understand how they organize their work. I interviewed people impacted by the work of the National Epidemiology Center, such as policymakers, activists, or people living in places where epidemiological outbreaks occurred during the years of my research. I also interviewed people at organizations and institutions that are connected with the practice of the right to health in Guatemala.

4. Participant observation. I conducted participant observation in one of the units of the National Epidemiology Center, situated in Guatemala City. My objective was to participate in their normal activities. This included attending weekly meetings (generally every Monday) at the CNE and other Ministry of Health offices, as well as spending days at the CNE building, just sitting there and taking notes and chatting with people and getting invited to join them in some of their tasks.

The following chart synthesizes the activities I carried out as a part of my data collection. In this chart, interviews include informal interviews and short, very concrete questions I asked informants to follow up with them, so these numbers represent the times I interviewed people and not how many people I interviewed. The same applies for the rest of categories because I did not go to 44 places looking for archival information, but instead went 44 times to a fewer number of places.

Table 1. Summary of data collection by technique and date

	Before	Jan-11	Feb-11	Mar-11	Apr-11	May-11	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Jan-12	After	Total
Interview	15	8	21	21	14	6	2	3	4	0	0	1	3	0	10	108
Life history	0	0	1	4	5	5	0	0	0	0	0	0	0	0	0	15
Observation	0	1	3	10	5	2	0	0	0	0	0	0	0	0	0	21
Participation	2	0	2	6	2	4	2	1	1	0	0	0	0	0	0	20
Archival	25	2	2	1	4	1	0	0	0	0	0	0	0	2	7	44

The following chart shows the data collection activities by type of subject, as I classified them for organizational purposes: “CNE” represents members of the National Epidemiology center, my participation in activities at the CNE, and searches for archival information at the CNE. “Protagonists” represent pioneers of the institutionalization of the CNE who no longer work there. “Institutions” represent people and places I accessed for their institutional affiliation, while “social actors” represent people who are part of social organizations or participating as individuals, and “other” represents people I accessed as experts in some topic.

Table 2. Summary of data collection by technique and type of human subjects category

	CNE	Protagonists	Institutions	Social actors	Other	TOTAL
Interview	23	6	35	25	19	108
Life history	11	4	0	0	0	15
Observation	8	0	8	5	0	21
Participation	11	0	6	3	0	20
Archival	3	0	39	2	0	44

Because the CNE has a presence all throughout Guatemala, I kept track of my data collection efforts, using the following chart, where numbers represent if I did (1= yes, and blank= no) some data gathering on that month in each department (equivalent to states or provinces; Guatemala is divided in 22 *departamentos* for political-administrative

purposes). It is evident that most of my work was concentrated in Guatemala and Sololá, and that I did no data gathering in 7 of the 22 departamentos.

Table 3. Summary of data collection by *departamento* (state) and date

Departamento	Before	Jan-11	Feb-11	Mar-11	Apr-11	May-11	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Jan-12	After	Total
Alta Verapaz																0
Baja Verapaz					1											1
Chimaltenango				1	1	1										3
Chiquimula	1			1							1	1	1	1	1	5
El Petén																0
El Progreso																0
El Quiché																0
Escuintla					1	1										2
Guatemala	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	13
Huehuetenango					1	1										2
Izabal																0
Jalapa																0
Jutiapa																0
Quetzaltenango	1				1	1						1			1	3
Retalhuleu						1										1
Sacatepéquez				1		1										2
San Marcos						1										1
Santa Rosa						1										1
Sololá	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	13
Suchitepéquez	1		1	1	1	1	1	1								6
Totonicapán					1	1		1								3
Zacapa					1											1

Data processing

All data was collected in notebooks, with the addition of digital voice recordings of life history interviews. I transcribed the interviews in addition to listening to each of them between 3 and 5 times while taking notes, searching for large themes and histories that respond to the research questions presented above. The dissertation you are about to read includes information and insights gained from this data collection and analysis techniques, but it also includes some of my own personal experiences of previous work I did in Guatemala as a rural physician.

Neo-colonial epidemiology

Contemporary Guatemalan epidemiology is a quintessentially neo-colonial endeavor. If neocolonialism can be broadly defined as “the economic and political policies by which a great power indirectly maintains or extends its influence over other areas or people” (Merriam-Webster), it is necessary to insist that, in the case of Guatemalan epidemiology, such influence is maintained and extended at various levels and through different means with distinct effects. I find the notion of neo-colonial epidemiology to be a compelling and illustrative way of synthesizing my research findings because they highlight the unequal relationships between Guatemalan epidemiologists and “international” epidemiologists (such as those at the Pan American Health Organization and the U.S. Centers for Disease Control and Prevention), but at the same time this notion highlights the role Guatemalan epidemiologists end up playing in maintaining the quasi-colonial social relations of exclusion on which the Guatemalan nation has been built. But to be honest, I had a hard time deciding which term to use, because at some point I considered equally compelling the following terms: “~~Post~~-Neo-colonial epidemiology”, “Post-colonial epidemiology”, “Third world epidemiology”, “Fourth world epidemiology”, and even “Magical realism epidemiology”. I wanted the term to highlight the features I present in the following paragraphs.

Guatemalan Neo-Colonial Epidemiology is post-colonially undisciplined, intellectually colonized, institutionally weak, norm obedient, fearful of the powerful, depreciatory of the powerless, marginal, egocentric, and ineffective. This is not to say that these are the characteristics of Guatemalan epidemiologists, but rather that these are the circumstances in which they operate. This is a key distinction, because the vast majority of epidemiologists I met were brought to epidemiology seduced by the idea of

dealing with the causes of health problems - even if that meant going against the tide – because it seemed the right thing to do. As a result, Guatemalan Neo-Colonial Epidemiology does not investigate the causes of health problems and does not contribute to addressing health inequalities. That is, the CNE does not fulfill the goals of epidemiology or its right to health aspirations.

Epidemiological protocols are a reflection of international consensus about prioritized health problems and their prioritized solutions. They also reflect the mainstream epidemiological approach to health problems, focusing mainly on the identification of infectious agents and their sources. There is nothing wrong with the existence of epidemiological protocols, but basing epidemiology's practice solely on those protocols does not allow for defining context-specific priorities and actions, and does not permit the analysis of health inequalities. The uncritical following of epidemiological protocols in detriment of epidemiological analysis is conditioned by the training received by epidemiologists, all of which is based on the priorities of the CDC and PAHO. Again, there is nothing wrong with the CDC and PAHO's priorities, but they do not necessarily respond to the health priorities of Guatemalans. There is an absence of locally produced knowledge and of critical approaches to epidemiology from other countries, more strikingly of Latin American Social Medicine, with a tradition of over 50 years in countries such as Mexico, Bolivia, Costa Rica, Venezuela, Ecuador, Brazil, Chile, and Argentina. More importantly, there is an absolute lack of interest in people's felt needs or in people's perspectives on the causes and solutions of their health problems, without which a right to health approach is unthinkable.

During my fieldwork it was evident that the CNE did not have enough resources to perform its job well. In weekly epidemiology meetings there was always some mention of the need to do specific research in order to better understand the trends that were identified for particular diseases, but I never knew of any initiative to actually do such research. Nobody was responsible for doing such research because the Ministry of Health's authorities had dismantled the CNE's research unit in the previous years. Epidemiologists in and outside the CNE questioned the authenticity of an epidemiological practice without epidemiological research and had coined the term "*brotólogos*" (which I will translate as "outbreakologists") to refer to such practice: epidemiologists whose only job is to respond to reported outbreaks without ever investigating their causes or analyzing the systemic conditions at their roots. But the CNE was not even doing good "*brotólogo*" work because the Ministry of Health's authorities had also dismantled the rapid response unit that had been created within the CNE to give an accurate and timely response to outbreaks without distracting the CNE's efforts to do research and analysis. In order to function, the rapid response unit needed two or three epidemiologists to be able to go to any part of the country where an outbreak was taking place in order to coordinate an accurate response. This meant having one car available for this purpose, laboratory tests ready to use, money to cover epidemiologist's expenses, especially when they would spend several days at the outbreak site. But those resources were not available to the CNE, creating frustration within and outside the CNE. In a couple of situations during my fieldwork, given the relevance of a particular outbreak, an epidemiologist was sent to help with the outbreak response, but the trip was made without institutional material resources. According to several epidemiologists I

interviewed, the CNE was working with about half of the people it needed to function and with virtually no resources in their budget other than for paying the salaries of their reduced staff.

But it is not only the insufficiency of resources that characterize the work of epidemiologists in Guatemala. I found through my research that basically nobody cares or respects or complies with their part of epidemiological work, as the following list should make clear. Virtually no private hospitals or private physicians comply with reporting the diseases of mandatory notification (*enfermedades de notificación obligatoria*, in Spanish). Public (Ministry of Health) hospitals often actively resist following national epidemiological protocols, do not notify the CNE in case of an outbreak, and do not send the weekly and monthly epidemiology reports they should send to the CNE. Public (Ministry of Health) health posts and health centers usually send their reports and notify the CNE in the case of an outbreak, but there is always a percentage of them (10-25%, from the data I got) who do not notify, which in turn makes it the CNE's job to spend time every week making phone calls requesting (often unsuccessfully) the reports. I witnessed several heated discussions between public hospital authorities and epidemiologists when the issue of mandatory reporting was raised. I know that when several nosocomial infection outbreaks took place in public hospitals, hospital authorities resisted (sometimes successfully) letting the CNE epidemiologists have access to study the outbreak. Similarly, there was a lot of conflict surrounding mining projects during my time in Guatemala, and there was a particular project that was rumored to have health impacts on people living near the mine. Rumors were common and there were even some videos on the Internet showing the negative health impacts of the mine. When I asked

epidemiologists if they had thought of investigating these rumors, they told me their Ministry of Health supervisor had advised them not to, because their lives could be in danger if they touched the interests of the powerful people involved in the mining project.

If an epidemiologist at the CNE does her job well from a professional and technical perspective, she has a high chance of getting directly or indirectly fired. Every single epidemiologist I interviewed gave me examples of this, without me explicitly asking. To be clear, there often are interpersonal problems (some of which may be motivated by political rivalry or inflated egos) in an institution such as the Ministry of Health and they may influence institutional decisions such as renewing someone's contract. But that is not what I am talking about here. Epidemiologists at the CNE often do not finish their investigations because what they may find could bring problems to the Ministry of Health authorities, as was the case in public hospital nosocomial infection outbreaks. More importantly, CNE's analysis and outbreak reports are not made publicly available through their website, and every time I asked if they had them filed in an organized way, they told me they did not. For instance, in August of 2012, the health situation analysis available on the CNE's website is from 2007. They have been producing such analyses every single year since then, but they do not make them available because – I was told more than once – making them available on the internet could be used against the Ministry of Health. Another example, when one of the most respected and experienced epidemiologists finished her report about a hospital infection outbreak that killed several newborns, she told me with a mix of frustration and normality that the report was presented to the Minister of Health and that nothing was going to happen with it, and that

it was most likely going to be managed with secrecy because she had found some wrongdoing by the hospital authorities.

All these situations reflect the institutional context of bureaucracies in the post-colonial setting. But epidemiological practice is not determined only by its institutional context. There is also the problem of what is epidemiology and what constitutes good epidemiological work. This is largely defined by epidemiology as an academic discipline and the way it is taught in Guatemala.

Guatemalan epidemiology as an academic discipline is relatively new and has been taught mainly through three academic programs. These programs are designed for training people who work in the Ministry of Health, although they are open to independent individuals or people working in other public institutions (Ministry of Agriculture, for instance), NGOs or the private sector. The three programs have been around for a little bit more than ten years and they all share a focus on “application” rather than on “theory”, the effect of which is that epidemiologists are trained in a few research techniques but are not trained in interpreting the context where health problems occur and they are only able to ask a small number of questions when faced with an outbreak or a health/disease pattern. The kind of questions they are able to ask using the techniques they learn leave out most social and economic aspects that could prove important in explaining and solving health problems. They also learn not to take into account “lay” or “folk” perspectives or to dismiss them as “beliefs”, “myths” or “superstitions”, and they do not learn how to promote social participation in what they do. Social participation is considered a key element to the construction of the right to health and it is impossible to understand and address the determinants of health inequalities

without social participation. And yet, Guatemalan epidemiologists are trained to not promote social participation. All this is a shame, especially since every single epidemiologist I interviewed told me that one of their motivations for becoming epidemiologists was precisely to escape the reductionist views of medicine or nursing or psychology, and to be able to address the real causes of health problems. In their desire to become epidemiologists were, of course, ideas of professional and economic promotion, but at the heart was also the intention of doing research that would be relevant for solving health problems. But they do not and will not do research as they imagined, not only because they are ill equipped to ask relevant research questions, but also because there are not institutional or professional incentives to do it and because of the lack the institutional infrastructure for developing research proposals.

The institutional and disciplinary shortcomings of Guatemalan epidemiology are enhanced by Guatemala's place in the international context of contemporary global health. Countries, institutions, business, science, and disease all play their role in mainstream understandings of global health and its priorities. And so do individuals: the philanthropist, the scientist, the victim, the bureaucrat, and the nurse. They all play their role in the global health concert. Such roles are not only imposed by the centers of power but are also created and recreated in the periphery. What, then, is the role of Guatemalan epidemiologists? If Guatemala and its people are seen as a potential source or pathway of pandemic threats or bioterrorist attacks, then the Guatemalan epidemiologist's role is to detect risks and potential threats and inform them in a timely manner. If Guatemala and its people are seen as the potential locus of tropical microbes and diseases to be controlled, then Guatemalan epidemiologists are the ones executing such control

measures. If Guatemala and its people are seen as a fertile site for conducting research on sick bodies or testing new drugs, then Guatemalan epidemiologists are those who can help researchers gain access to such bodies. If Guatemala and its people are seen as sources of sickness, beliefs, superstition, and myth, then Guatemalan epidemiologists are only able to help the real scientist in the metropolis and, because this is the case, Guatemalan epidemiologists do not need to learn how to ask research questions.

In addition to international relations, there is the issue of social relations within Guatemala. There are different ways of approaching it, but let me start by saying that most Guatemalan epidemiologists are *Ladinos* (that is non-indigenous mestizos, but also not white/European/American or black/African) from the lower-middle class, and they all come from urban settings. Although there is a tendency towards feminization in all the health professions in Guatemala (as in many other parts of the world), most epidemiology directors are and have been male. Every Guatemalan epidemiologist I have met graduated from Guatemala's public university, a fact that generally speaking situates them in the lower end of the physician's social structure, but also, acknowledging that they are among the less than 3% of Guatemalan's who make it to a university (making them an elite of some sort), they do not come from economically powerful families, which highly influences their position as social actors. Given that racism, sexism, classism and discrimination for coming from rural areas permeates Guatemalan society, one can at least ask how this plays out in the practice of epidemiology. At the same time, given that Guatemala is a formally independent nation but with a ruling elite and an international context that reproduces the social inequalities in which the Colonial period was built,

how do Guatemalan epidemiologists see themselves and their role in achieving social change?

It helps me think about all the features I have described as the four legs that hold the table where Neo-Colonial Epidemiology rests, and they are: institutional chaos, disciplinary conformism, global health international relations, and social relations at the national level. The four are linked and one cannot be understood without the other three. If one of them were to change substantially, the other three could not remain the same and the table would fall, that is, if one of Neo-Colonial Epidemiology's key features were to change substantially, epidemiological practice would change and probably stop being neo-colonial.

Neo-Colonial Epidemiology serves the purpose of the national and international powerful elites, and dismisses the interests of the excluded, marginalized people who receive the worst of health inequalities. Neo-Colonial Epidemiology is not set up for challenging health inequalities but to justify them. Neo-Colonial Epidemiology co-opts some of the most humanist-inclined health professionals and turns them into a semi-academic elite unable to live up to its dreams of explaining health problems, at the same time that becomes part of the maintenance of the status quo. Neo-Colonial Epidemiology, in a word, goes against the construction of the right to health.

Chapters

After this introduction that lays out my conceptual and methodological approach to the research project, and synthesizes my main conclusion in the notion of Neo-Colonial Epidemiology, chapter two presents a comprehensive sample of the uses I found of the right to health in relation to public health, and I offer a discussion around the notion of

who is “the human” in human rights. The chapter ends suggesting ways in which the latter discussion could suggest blind spots and alternative framings for the debate about the right to health in Guatemala.

The remaining substantive chapters offer a characterization and discussion of the practice of epidemiology in Guatemala as expertise, as bureaucracy and as technology. That is how Chapter 3 addresses epidemiological practice from the perspective of the anthropology of expertise, with an emphasis on epidemiologists’ role in knowledge production and the ideological aspects involved in it. I give some examples of epidemiological practices that highlight the role of knowledge and ideology, which cannot be completely separated from the institutional context where epidemiologists work. The institutional context is addressed more fully in chapter 4, from the perspective of the anthropology of bureaucracy, and I offer some historical and contextual information about epidemiology in Guatemala and some of its institutional conundrums. Finally, chapter five offers a discussion about epidemiology as technology, where I present the case of a mysterious outbreak that happened just before I first arrived to the field in 2009, but that illustrates the role of epidemiological protocols and technologies in the approach to the outbreak. The chapter discusses the implications for the notion of the right to health in the context of medical pluralism and social exclusion and discusses what “health” may mean in the right to health.

The final chapter offers some conclusions, insights and recommendations aimed at questioning and destabilizing the four features of Neo-Colonial Epidemiology presented in the introduction as the four legs of a table: institutional chaos, disciplinary conformism, global health international relations, and social relations at the national level.

Chapter 2. Uses of the Right to Health in Guatemala

“I would rather go to my grave than to the hospital,” replied Doña Manuela in response to a suggestion that I, a Mestizo physician from the capital city who made weekly visits to Manuela’s village, made to her. I did this as part of my job with the government’s new health care program that brought physicians trained in basic epidemiology to remote villages. Manuela had never left Seb’as, a small Q’eqchi’ village surrounded by forests and coffee and cardamom plantations. A skilled housewife and mother of eight children, she was eight months pregnant. I detected that the fetus was in a transverse position, which made it dangerous for Manuela to have a normal delivery, so I offered to make the arrangements for an ambulance to take her to the nearest hospital, about eight hours away, with the government covering the costs. I believed that the health care program I worked for helped guarantee the right to health in Guatemala; but Manuela rejected my proposals of what the program had to offer.

In 2001, I was the first physician working for the government to visit the village of Seb’as. The program I was working for began two years after the 1996 Guatemalan Peace Accords, which marked the formal end of a thirty-six year war that killed about a quarter of a million people. My presence in Seb’as, my ability to detect risk factors in Manuela’s pregnancy, and my offer of an ambulance were all part of a state effort to reduce maternal mortality, the country’s highest epidemiological priority. On the surface, the state’s priorities appeared to have changed from earlier times. During the war, it was the state that had been responsible for most of the massacres, some of which occurred in

villages surrounding Seb'as. Thus, the new health care program faced challenges that the program's designers had never imagined. Could people like Manuela now trust the government? Had things really changed by the simple signing of the Peace Accords? How could I see myself as an agent of the state, just as the military was? How did my detection of a risk factor and my adherence to the epidemiological protocols contribute to Manuela's right to health? How could Manuela and I each understand that our interactions were marked by a shared – but differently experienced – history of racism, sexism and social exclusion?

The right to health

“Right to health” is a term that has been increasingly used by politicians, academics, activists and journalists worldwide, as the chart below illustrates. Guatemala has been no exception. During my 2009-2011 fieldwork I saw the term used in unexpected places and by unexpected actors. However, when I scratched the surface, I found that most of the time the term was used as part of a wider agenda and without a clear notion of what the term came to mean. Such is the case of the CNE (the National Epidemiology Center) that includes the right to health as a central part of its mission statement, but without questioning what that meant for their epidemiological practice. Similarly – although in a different way – groups advocating for the rights of children, women, the disabled, the elderly, indigenous peoples, people living with particular chronic conditions (HIV, kidney disease, hemophilia, and others), and people in prison, would use the “right to health” as part of their claims, but would not have very specific contributions for me to understand what the right to health means and entails for different actors. I interviewed a few of these activists and found that to them the notion of the right

to health was commonsensical, and would be framed in terms of “if a child gets sick she should get the treatment she needs” or “people in prison should get the medical care they need”. This kind of statement, although profound in its implications, did not help me to understand the ways such claims are implemented.

Indigenous peoples’ rights activists I talked to framed the issue in a broader way, and did not have much interest in the specificity of my inquiry. Generally speaking, they are engaged in larger struggles over autonomy, self-determination, and right to land, and consider notions such as “health” to be overly reductionist, and have introduced the notion of “*Sumak Kawsay*” or “*Suma Qamaña*” (in the Qechua and Aymara languages spoken in South America), which has been translated as “*Buen Vivir*” (in Spanish) or “*Ri Utzilaj Kaslemalil*” (in the K’iche’ language spoken in parts of Guatemala) (Quizhpe 2010). The translations into Spanish as “Buen Vivir”, or into English as “Well being” have been criticized by indigenous rights activists as diluting the essence of the concept as one of “bio-pluralism” – that is, a respectful relationship with the nature of which humans are part of – in contraposition to “anthropocentrism”. Sumak Kawsay opens up a horizon of justice and social equality, dialogue between cultures, knowledges and lifeways (Albizu 2012). A wide range of indigenous intellectuals, environmentalists, politicians and grassroots organizations throughout Latin America have embraced the notion of Sumak Kawsay as a way of vindicating their shared indigenous roots, as well as the reciprocal relationships between humans and the environment, in a political alliance of resistance and counter-hegemony against capitalism (Albizu 2012). Sumak Kawsay stresses the multiple dimensions of life, and “buen vivir” or “well being” may not embrace such multiplicity (Fernández 2010).

Paraphrasing Ecuadorian Indigenous Activist and Politician Mónica Chuji (2009), the Sumak Kawsay has been emerging from the invisibility to which it was subjected for more than five centuries, and it is an alternative to progress, development and modernity. However, it should not be seen as a return to the past, nor to the Stone Age or cave lifestyle, and it does not deny either technology or modern knowledge, but it should be understood as an effort to recover the harmonious relation between human beings and their surroundings. In this sense, the Sumak Kawsay is part of the debate about our destiny as human beings, in which what is fundamental is humans, not markets nor economic growth. Therefore, we must enter a process of decrease in the production of things, and of measured human growth, not in terms of things, but in human terms. “In that context, we the indigenous nationalities and peoples need to reclaim our self-determination, to deepen and to extend the practices of living well into society” (Chuji 2009).

In this sense, Guatemalan indigenous rights activists are less interested in defining or applying the “right to health” and more interested in deconstructing the notion of “health”, as it has been pointed out by the Guatemalan organization that historically works with health and also with indigenous peoples rights organizations (ASECSA 2013). Moreover, indigenous rights activists are re-locating the problem into “a plane of immanence and historical ontology entangled with organized indigenous politics” (De la Cadena 2010:335), which is part of the political reconfiguration currently taking place in Latin America (De la Cadena 2010). This departure is so important and fundamental for understanding the politics of health and the right to health that, paradoxically, I was not able to address it in this dissertation and I am doing so elsewhere (Cerón, In preparation).

I explain my inability to address the Sumak Kawsay in this dissertation as follows: this project takes the notion of the right to health to question and criticizes the practice of epidemiology. Since the Sumak Kawsay so radically questions the notion of “health”, then the idea of the right to health needs to be radically questioned as well. I have no problem questioning the notion of health and of the right to health, but I just was not able to figure out a way of including in the same dissertation such questioning at the same time that I was using the right to health to question epidemiology. This difficulty may also have to do with the “social-intermediate level” where I situated the dissertation project from the beginning, which has allowed me to engage with institutional and disciplinary practices, but probably brings limitations to my ability to engage with the broader social level.

However, there were systematic efforts I identified of organizations or institutional networks trying to define what the right to health is – either from a conceptual perspective or building its meaning through practice – and how it would be implemented in Guatemala. I offer in this chapter a description of all such efforts as I found them, and try to draw lessons from them to characterize the uses of the right to health in Guatemala.

The right to health in Guatemala’s Human Rights Procuraduría

In 2008, the Guatemalan Human Rights *Procuraduría* (henceforth Procuraduría) counted an unprecedented number of reported violations of the right to health: 288 investigations, a six-fold increase since 1999. Although everybody would agree that these numbers only represent a fraction of the violations of the right to health that happen in Guatemala, what is more relevant is that the stories behind those numbers show a

significant diversification in the type of incident considered to be a violation of the right to health.

Before moving forward, let me give some background about Guatemala and the Procuraduría, since I think the institutional setting is important for my argument. In 1996, the Guatemalan Peace Accords were signed, marking the formal end of a thirty-six year war that killed over 200,000 people (CEH 1999). During the war, it was the state that had been responsible for most of the massacres, but after the accords were signed, the state had formally accepted the responsibility of protecting human rights. The Peace Process began twelve years before, and one of its first milestones was the creation in 1987 of the Human Rights Procuraduría.

The Procuraduría is a public institution directed by the *Procurador de los Derechos Humanos*, or the Attorney for Human Rights. The Attorney is elected by and responsible to the legislature for the defense of human rights guaranteed by the Constitution. He also monitors the public administration of the executive branch of government. The Procuraduría has the power to investigate human rights violation complaints, make recommendations, issue public censures for unconstitutional acts, promote judicial or administrative actions or appeals, and report annually to the legislature. As you can see, the Procuraduría is sunk in one of the fundamental paradoxes of human rights: while human rights are meant to protect individuals from the abuses by state forces, they can only be guaranteed by the state. But the Procuraduría is also immersed in the bureaucratic logic of public institutions and the ways in which they define and are defined by public projects, programs and policies. Despite the signing of the Peace Accords, the creation of the Procuraduría, the support of the international

community, international NGOs, the effort of dozens of human rights advocates and the work of many grassroots organizations, the Guatemalan human rights situation has not significantly improved. So, what follows is meant to illustrate some steps in the right direction in relation to the right to health that unfortunately are insufficient.

Now, let us go back to the Procuraduría's statistics. In 1999, there were 45 investigations on violations to the right to health, while there were 288 in 2008. More importantly, complaints in 1999 were typically about poor quality of health care services delivered by public hospitals and clinics. The investigations always began with an individual's complaint and were usually focused on insufficient resources, malpractice or mistreatment. Here is an excerpt from the Procuraduría's 1999 (PDH 1999) report corresponding to the Totonicapán province:

People are suffering a series of problems due to the scarce resources in the different public health centers and the lack of control by the corresponding authorities, as well as the notable insensitivity of human resources in charge of providing services. (p. 118)

The province of Santa Rosa reported that "health services are not in all communities and where they do exist they face difficulties and limitations in offering efficient care to patients" (p. 143). The province of Zacapa recounts:

The regional hospital emergency room offers terrible services. This is similar for the Social Security Institutes health care services and administrative area where dozens of charts are waiting to be dealt with. (p. 152)

The investigations by the Procuraduría tended to focus on the follow-up to each individual complaint and according to research conducted in 2001 (Cerón and Ramírez 2003) they were not successful in changing the conditions that generated the complaints.

In contrast, one fifth of the violations the Procuraduría has reported each year since 2008 were related to environmental contamination, water sanitation and epidemics. More importantly, the investigations were not necessarily started with an individual's complaint, but the Procuraduría's active monitoring. The follow-up was now oriented toward understanding the institutional causes of the problem and working with the institutions implicated in the violation of the right to health to solve the institutional causes. Look at this example from the province of Chiquimula:

In August 2008, the regional public health workers' union expressed their concern because the Dengue fever season was advancing and there were not enough public health activities to control the mosquitoes that transmit the disease. They were already seeing people with Dengue and were worried about an uncontrollable outbreak. The Procuraduría started an investigation without receiving a complaint and asked public health officials about the reasons for the lack of preventive actions. As it turned out, there had been changes in some administrative procedures, which were causing a delay in the purchase of the supplies required to visit the affected communities and develop actions to detect and control sources of mosquitoes. Through the joint intervention of the Procuraduría and the Ministry of Health, the administrative bottleneck was overcome and the mosquito control activities were resumed.

In a similar case, in May 2008 there was a complaint against the mayor of San Jacinto because the municipal water service was deficient: there was not enough water for all the neighborhoods. When the Procuraduría investigated, it found a series of problems, including that the water was not safe for human consumption because it was contaminated with microbes. So they teamed up with provincial public health officials to test water quality at the eleven municipalities under their jurisdiction. They found that the tanks in eight of the municipalities were not being treated so they investigated the reasons. They discovered that lack of water sanitation had to do with scarce resources and with the mayors' preference for recapping roads and building basketball courts instead of investing in equipment to treat water. After the Procuraduría's intervention, and the monthly monitoring by public health officials only 5 out of 23 water tanks in the province were having quality problems in July 2009, and they were due to major infrastructure deficiencies that needed amounts of money unavailable through the regular budget.

These interventions certainly do not change the fundamental causes of health inequalities in Guatemala, as prescriptive definitions of the right to health would suggest the goal should be. My account may also sound as if the Procuraduría is some kind of heroic institution. That is not the case. In fact, many people criticize the Procuraduría and the work they do. However, this change of focus touches on one of the fundamental dilemmas of human rights today. How can human rights practice avoid the classic individualistic approach to human rights when it is addressing social and economic rights, like the right to health? In the case of the Guatemalan Procuraduría, the answer lies in the ideologies of public health used to reframe their practice.

In 2003, a new Attorney for Human Rights was appointed by the legislature. He and his team brought a new approach to the practice of the Procuraduría. Although they do not make it explicit, I think their approach is based on the Basic Needs Approach to development and poverty eradication. This approach has also been used in public health, particularly by people interested in promoting social justice. Therefore, we can call it a public health ideology. This is how a member of the Procuraduría's team explained their approach to me:

We begin with the assertion that human rights are not based on human nature, but on human needs and their satisfaction. Human rights are the means to guaranteeing the satisfaction of human needs. In practice, from a societal perspective, human needs are satisfied through political constitutions, public policies and institutional programs.

This statement not only goes against the fundamental philosophy of human rights that takes for granted that human rights are universal because they originate in human nature, but also explicitly claims that the practice of human rights only becomes concrete through public policy. From a philosophical and theoretical perspective, these affirmations are even more interesting if we consider that precisely in 2003 UNICEF launched a publication proposing that a “human rights approach to development” could overcome the limitations of the “basic needs approach to development” (Jonsson 2003). Prominent public health advocates of social justice have adopted these views and highlight the power of presenting the right to health as inherent to human nature (Schuftan 2007). From a practical perspective, however, the Procuraduría's approach is

groundbreaking because it allowed an expansion of the scope of their own practice while providing clear actions to address the right to health. The Procuraduría's approach is an example of what Sally Engle Merry calls "the vernacularization of human rights" (2006) or the translation of norms meant to be universal into local discourses and practices.

Among the actions that this approach brought to the Procuraduría's work are: they began monitoring unmet needs, and when they identified them tried to understand what the underlying institutional mechanisms were and tried to change them. When solutions could not be found in the institutional mechanisms, the Procuraduría followed judicial and criminal procedures on the one hand, or political and legislative advocacy, on the other. In this way, the Procuraduría aims to influence the conditions that generate the human rights violations.

Now, it is clear to me that these actions do not transform the fundamental inequalities that generate social exclusion and reproduce health disparities. So, my point is not to advocate for the Procuraduría's approach as the correct way to go about the right to health. But I think we can learn at least two lessons from their experience. On the one hand, every day practice can and should question the limits of our theories and ideologies, and on the other hand, ideologies can be at the same time limiting and liberating. The difference between the limiting and liberating potential lies in being aware of the ideologies within which one is operating and challenge them. The limited approach adopted by the Guatemalan Procuraduría made a difference for thousands of people who are now getting uncontaminated water and for dozens of communities where there were less Dengue-transmitting mosquitoes. I have no reservations in judging these as steps in the right direction that changed the Procuraduría's practice in three ways: addressing the

collective nature of the right to health, identifying concrete needs, and working with the bureaucracy to address them.

Steps in the right direction, perhaps, but, as one of the Procuraduría's members told me, "we still have not been successful in changing Guatemala's fundamental problems: racism and wealth inequality".

The challenges of implementing the idea of the right to health, if we pay attention to the Procuraduría's work can be summarized as follows: the vast majority of the cases they deal with have to do with scarcity of resources at Ministry of Health health care facilities, and at the same time, the Procuraduría usually receives complaints from at least relatively marginalized people, who are the ones usually utilizing those health care facilities. Despite the Procuraduría's efforts to address issues of health policy or of collective health, those remain marginal in their work, and their achievements in these two areas are practically inexistent. Therefore, if my effort in this chapter is to try to understand the ways in which the notion of the right to health gets implemented, I identify the following sets of dichotomies here: individual versus collective rights; curative versus preventative health interventions; and public versus private health care facilities. At the same time, I identify the questions of who is the subject of the right to health, or who uses the right to health, or for whom the right to health is doing something. Let me explore these questions in the discussions that happened in two conferences that took place in Guatemala during my fieldwork.

The right to health in two 2009 National Conferences

Two National Conferences addressing the right to health as their central concern took place in Guatemala in 2009. The National Public Health Conference was held in

August and the National Conference on the Human Right to Health took place in December. The first one was organized by a group of international NGOs, local experts and Ministry of Health officials, while the Human Rights Procuraduría organized the second one with support of the Guatemalan Medical Society and the Pan American Health Organization. The difference between talking about the “right to health” and “the human right to health” was an important conceptual difference pointed out by the Procuraduría’s organizer, highlighting that the “human right to health” stresses the indivisibility of human rights and goes against addressing the right to health isolated from other human rights. In the remaining of the section I present each of the conference’s highlights.

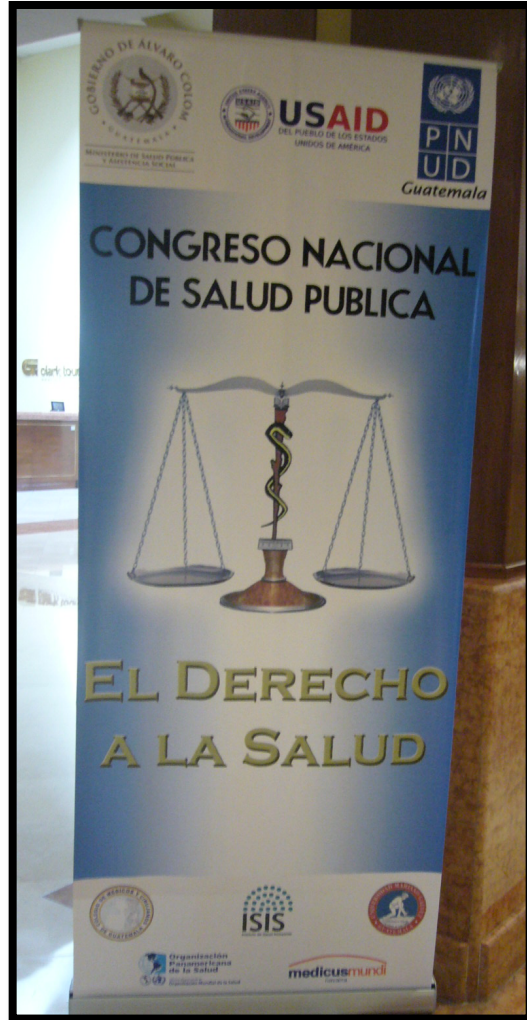


Figure 1. “Right to Health” – 2009 Guatemalan National Public Health Conference Official Logo

A public health conference on the right to health

The Guatemalan National Public Health Conference took place on August 11-13 of 2009. Many years had passed since the last time such an event was organized in the country, where there is no formally functioning public health association, although there have been attempts to organize one. The uniqueness of the event is highlighted by the fact that no other national public health conference was organized in the following three years. The central topic the organizers chose was the right to health and the goal of the three-day meeting was to generate a space for dialogue about Guatemala’s public health,

reorienting it through the examination of the implications that the right to health perspective may have on public health practice. Over 400 people participated in the event, which was organized by international agencies (U.S. Agency for International Development, Pan American Health Organization, Medicus Mundi Navarra) Guatemalan private (Guatemalan Medical Association, Mariano Galvez University) and public institutions (Ministry of Health).

The meeting attempted to examine the political, juridical, financial, managerial, and environmental dimensions of the challenges posed by the right to health focus. It included an introductory key note by a representative of the United Nations High Commissioner for Human Rights (UNCHR) office, followed by a panel and then by a presentation by a former Pan American Health Organization representative for Guatemala, focused on the relationship between demography and epidemiology. The UNCHR representative offered a conceptual framework based on United Nations regulations. He highlighted that the right to health has to be implemented gradually and progressively, and that it includes four interrelated components: availability, accessibility, acceptability and quality of health care, health conditions and their determinants. He pointed to six challenges Guatemala needs to address in order to advance in the fulfillment of the right to health: a small health budget, taxes as sources of income for the state to function properly, the inclusion of a human rights focus throughout the life cycle, addressing discrimination against indigenous people, producing reliable information, and creating mechanisms of justiciability for the right to health (i.e. making it easy, accessible and fast to report violations).

In addition, four panels with invited speakers offered a more detailed perspective on four topics. The main message I got after listening to the three presenters and the commentator in the first panel is along these lines: Guatemala's health system marginalizes women, indigenous people and people in rural areas, causing health inequalities, which should be addressed through a health care system organized with integrality (i.e. horizontal rather than vertical programs, a classic public health debate) and some form of universal public insurance, which is the ethically sound thing to do and therefore is coherent with the right to health. The second panel was meant to address the "health care delivery model", that is the way in which health care is offered to its users. In reality, it was a series of presentations of what is good or bad about a Ministry of Health program designed to bring a "basic package" of health care interventions to people living in rural marginalized communities. There were two opposing views on the issue: those who said it was better to do something than nothing and those who said this program offered health care for some sort of "second-class citizen". An interesting point made by one of the presenters was that there needed to be an epistemological shift to be able to work in an inclusive way with different ways of understanding health problems. The third panel was about the public health impacts that contemporary environmental challenges were bringing to the table, but in reality it was a couple of presentations about how global warming is a reality and not a myth, without making very explicit links with either public health or the right to health. The message was that if we do not take care of our environment there will be bad consequences for public health, which is bad for the right to health. The last panel was about the current situation of Guatemala's health system financing, which offers almost no insurance programs, relies mainly on private

out-of-pocket spending, and tends to increase the inequalities in the health system. There were presentations about the alternatives for creating a more efficient and less inequitable financing sub-system, with basically two positions: a public health insurance with universal coverage or a mix of private and public health insurance. The general idea was that the current system is inequitable and needed to change, but that would mean that the economically affluent would have to help fund the system.

One of the panel commentators asked: “we have been talking about inequity, distribution, gaps, violence... are there epidemiologists addressing them?” and later he made a call for an “epidemiology of human suffering”. There was no discussion about these suggestions. I later asked him about those ideas, and he told me he could not understand what a Guatemalan epidemiologist does if it is not addressing the problem of inequality. The reasons why epidemiologists do not address what they should are related to the disappearance of the “human” in what health care workers do. This is a point he makes in an essay he wrote several years ago (García Noval 2001), where he argues that health workers in Guatemala seem to forget the shared human nature between themselves and the people they serve.

A human rights conference on the right to health

Just as the public health specialists were facing the difficulties of figuring out what the right to health should look like, the National Conference organized by the Human Rights Procuraduría – “The Human Right to Health” also took place in Guatemala City and it lasted 3 days (December 7-9). It was not only longer than the other one, but also had a much fuller schedule, with over 50 presenters, panelists and discussants, so I will not go into too much detail as I present it, but rather I will show the

general patterns I identified in their treatment of the right to health. The conference opened with a presentation by the Pan American Health Organization's representative for Guatemala, Pier Paolo Balladelli, who gave a very compelling presentation focusing mainly in the different health inequalities that characterize Guatemala and he was exhaustive about it: indigenous peoples, rural/urban, women, and people with disabilities. He highlighted that the Guatemalan constitution already warrants the right to health, social participation and the coordination of the national health system, but that very few people are conscious about that. He recommended increasing health expenditures in an efficient way, and tackling the determinants of social and health inequalities. The remaining presentations and panels can be classified in three general types, which correspond to the three institutional organizers of the event. The first one (and the most widely represented in number of presenters) was what I will call the Procuraduría's approach, which included topics such as the place of the right to health in the Guatemalan legislation, and the right to health of specific groups (women, indigenous peoples, children, people in prison, people with disabilities, and the elderly). The second general type, was the Pan American Health Organization's approach, which included topics relating health and development, the health system, and health and the environment. The final approach, and the least numerous, was the Medical Society's approach, including topics related to bioethics in the clinical encounter. The first two approaches pointed to lack of resources, lack of access to health care, and social exclusion. The last approach pointed to the need to re-humanize clinical practice.

The last half-day of the conference was devoted to a workshop type of effort organized in five workgroups addressing the five dimensions the organizers identified as

those to be addressed in terms of protecting the right to health: social protection of health, the state's guarantee of the right to health, health promotion, the potential of non-government human resources, and strengthening of the health system.

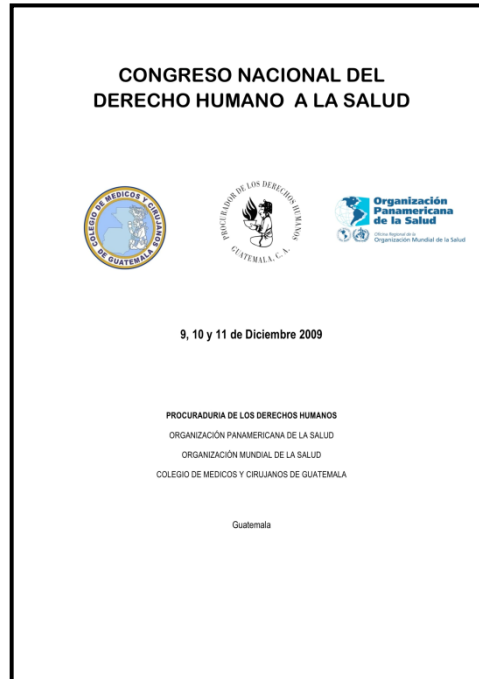


Figure 2. 2009 Guatemalan 1st National Human Rights Conference on “The Human Right to Health” - official program front page

The two conferences I described highlight the importance given to the notion of the right to health, but also the profound institutional differences on what to make out of the notion. What struck me the most, was the sense I got that in both conferences there was very little analysis or debate about the notion and its implications, but rather an instrumental use of the concept which was used to fit each institution's, discipline's, or individual presenter's work priorities. The same kind of instrumental use seemed to permeate the writing of two separate pieces of legislation, as the following section shows.

The right to health in two National Health Law initiatives

During the last decade, different groups in Guatemala have launched or supported initiatives to create a national agenda for the health system. The general idea is that health outcomes need to improve, which in turn requires significant changes in the health system, during a period that transcends the four years of an individual government cycle. The initiatives have shared a discourse that privileges dialogue and at some point in the year 2006 there were at least three of such dialogues simultaneously going on in the country. By 2012, these processes materialized – so to speak – in two distinct law initiatives: the General Health Framework Law (Ley Marco de Salud, initiative 3609-2007) and the Universal Coverage Law (Ley de Cobertura Universal y Financiamiento de la Atención Integral en Salud, initiative 4216-2010). These two initiatives of law are going through the legislative process, and it remains to be seen if they both get approved or not. Each of them emphasizes different aspects of the Guatemalan health system, and each of them has distinct supporters. The Ley Marco was strongly supported by the business chambers, while public health experts and activists were behind the creation of the Universal Coverage Law. Both initiatives have been repudiated by left-leaning human rights activists. Finally, both laws start by recognizing that health is a human right and try to justify the need to change the current laws that regulate health and health care. Before examining each of the laws, let me summarize the status of the right to health in the current Guatemalan legislation.

Health in the Guatemalan Constitution

The notion of health in the Guatemalan Constitution has changed over time as can be seen through an examination of the constitutions that have been in effect during the last two centuries. The first element to be found in the constitutions relates to what the

state's responsibility is towards health, and the second relates to whose health is talked about in the constitution. A third element has to do with the regulation of private interests as they relate to health and health care. The three elements can be integrated in the three notions one can identify in the constitutions: charity, salubrity, and right. All the constitution's mention of health up to 1927 is in terms of charity with a null or limited role of the state. Health was conceived as a private matter and charities (mostly religious labor with private funding) were the ones offering health care to those who could not deal with it on their own. Starting in 1927, the notion that the state has to deal with salubrity appeared in the constitution, initially making sure that private people would not spread dirtiness (garbage and human waste) and progressively changing to assign the state the role of keeping public spaces clean. Charities were still dealing with health care but the state began to take on some of the expenses, initially of the one large hospital (San Juan de Dios, in Guatemala City) and progressively created the institutions, infrastructure and human resource allocation to offer health care and tackle the spread of epidemic diseases through the creation of the Ministry of Health in the 1940s. Public health care services were still conceived as a form of charity, offered to all, but in reality were only meant for those who could not fend for themselves. The notion of the right to health does not explicitly appear until the constitution of 1985 and the health sector has been slowly taking on the notion. In today's Guatemala, the notions of charity, salubrity and right to health permeate the discussions on the role of the state towards health and the right to health agenda has not advanced, partly because the idea of charity is more suitable to the reality of social exclusion and a weak state that characterize Guatemalan society.

Table 4. Approaches to right to health in the Guatemalan Constitutions (1812-2012)

Constitution (Year)	Right to health approach
Cadiz Constitution (1812)	It is limited to the notion of charity under responsibility of the municipalities.
Independence act (1821)	No mention of health.
Federal Constitution (1824)	No mention of health.
Constitution of the State of Guatemala (1825)	Affirms the right to life, with no mention of charity or salubrity.
Constitutive Laws and Declaration of the Rights of the State and its Inhabitants (1839)	President must protect charity institutions. Affirms the right to life and privileges common welfare.
Liberal Constitution (1879)	No mention of health, charity or salubrity.
Reform (1921)	Stresses the state's duty towards workers salubrity. Keeps the notion of charity.
Reform (1927)	Strengthens executive branch's relation to salubrity and moves away from notion of charity.
Constitution (1945)	Notion of health and hygiene in a social sense and as a state function.
Political Statute (1954)	No mention of health.
Constitution (1956)	Keeps the notion of health and hygiene in a social sense, but explicitly makes reference to the possibility of it being in charge of the private initiative.
Government Fundamental Letter (1963)	No mention of health.
Constitution (1965)	Similar to the 1956 constitution.
Government Fundamental Statute (1982)	No mention of health.
Constitution (1985)	Broad concept of health. Health as a fundamental individual right, as public good, and as a third order human right.

Recent efforts to create a Ley Marco de Salud, or a Universal Coverage law are embedded in this history of legal understandings about the public and private aspects of health. In addition to the national constitutions, the legal framework as it relates to health and health care is complemented with the Código de Salud (Health Code), approved in

1997, just after the peace accords were signed. The Código de Salud acknowledges in its introduction that health is a human right, but in its substantive articles, it does not mention it again. The main criticism of the Código de Salud are that it only set up the stage for privatization of anything that has to do with health, and it weakened the public institutions dealing with health regulation or health care. Let us move now to examining what the two current initiatives - Ley Marco and the Universal Coverage law – add to the debate.

Ley Marco de Salud

A group of congressmen known for coming from the traditional business sector (some would call it the oligarchy) presented the Ley Marco de Salud to the National Assembly in February of 2007 and, although it has not been approved as a national law, the different congressional commissions that have studied it have recommended its approval. The Ley Marco was conceived as part of the Plan Visión de País, a private sector driven effort to set up an agenda for the main sectors and aspects of the Guatemalan society and economy: education, economic development, health, agriculture and foreign investment. Although the promoters of the Plan Visión de País invited other organized groups to participate in the construction of the plan, most of them were skeptical of its purpose and its contents. At the same time that the Plan Vision de País was being conceived, the Ministry of Health was conducting a parallel effort to set up an Agenda Nacional de Salud (National Health Agenda), inviting a wide range of organized groups, but also receiving skepticism from them. Both the Plan Visión de País and the Ministry of Health's Agenda Nacional de Salud were publicly presented in 2006, and they were both taken into account when the Ley Marco de Salud was written.

In its introduction, the Ley Marco de Salud acknowledges the constitutional mandate to protect the right to health but denounces the co-existence of two levels of health citizenship (*ciudadanía diferenciada en salud*) –those with access to health and health care and those without it, according to their individual and family economic means- and calls for an agenda of modernization, decentralization, and diversification of funding sources. Although it does not define how it understands the notion of the right to health, it offers definitions for eight guiding principles for the law (see Table and Figure below).

Universal Health Coverage Law

The Universal Coverage Law was presented to the National Assembly in September of 2010, after a two-year long process led by public health experts in different institutions: the Ministry of Health, at least two universities, the Pan American Health Organization, and some NGOs. According to some participants, it was not a smooth process because, although they quickly reached consensus about the aim of the law (setting the principles for a health system able to guarantee the right to health), they had very different ideas of what such a health system should look like. Although the process of designing the law was not closed to other actors, it was not a participatory process per se. The leaders of the initiative reached out to different groups and experts to talk about the law, and then incorporated their inputs. Some of the same public health leaders organized a series of highly participatory meetings in Guatemala City in August and September of 2011, which were directly linked to the law they had presented to the National Assembly a year before, and under the motto of building a “dialogue for the universalization of health”. According to some of its promoters, the Universal Coverage

Law was in part conceived as a reaction to the Ley Marco (although for some of its promoters it was literally a decades-long effort), so it stresses particular points that its authors wanted to highlight.

In its introductory part, the Universal Coverage Law does not show fundamental differences with the Ley Marco, but in its third article it defines the right to health as the “faculty of all inhabitants of the nation to access and utilize the set of benefits, programs and services of promotion, prevention, recuperation and rehabilitation of health, that the State must guarantee with the aim of procuring the highest level of quality of life and health”. The same article goes on to state that the rights included in this law “are universal, therefore all inhabitants of the nation of Guatemala have the right to the social protection of health”.

In addition to defining the right to health as the right to the social protection of health, the law also defines a set of fourteen guiding principles (see figure and table below). The rest of the law is concerned with defining the health system and its organization, as well as with providing guidelines to define the benefits, programs and services the state must guarantee access to.

Comparing some aspects of the two laws sheds light on the discussions around the right to health as they relate to public health in Guatemala. First, six of the guiding principles are the same in the two laws, although their definition may be significantly different. Of the remaining principles, it seems to me that the notion of “subsidiarity” included in the Ley Marco, and the notion of “social protection” included in the Universal Coverage Law are key to understanding how the right to health is supposed to be implemented.

The principle of subsidiarity is defined in the Ley Marco as the “action or responsibility of the State in the matter of health, that supplements or strengthens another more important [action], of each individual, who is helped or supported by [the State], in the measure that his or her economic condition requires it”. This understanding of the role of the state regarding health is closer to the notion of charity included in most Guatemalan constitutions.

By contrast, the Universal Coverage Law defines the principle of “social protection” as “the set of public measures (or private [measures] but organized and regulated by the [state]) directed to reducing the social stress and economic loss (lost productivity, inability to work, decreased income or payment for treatment) produced by sickness”.

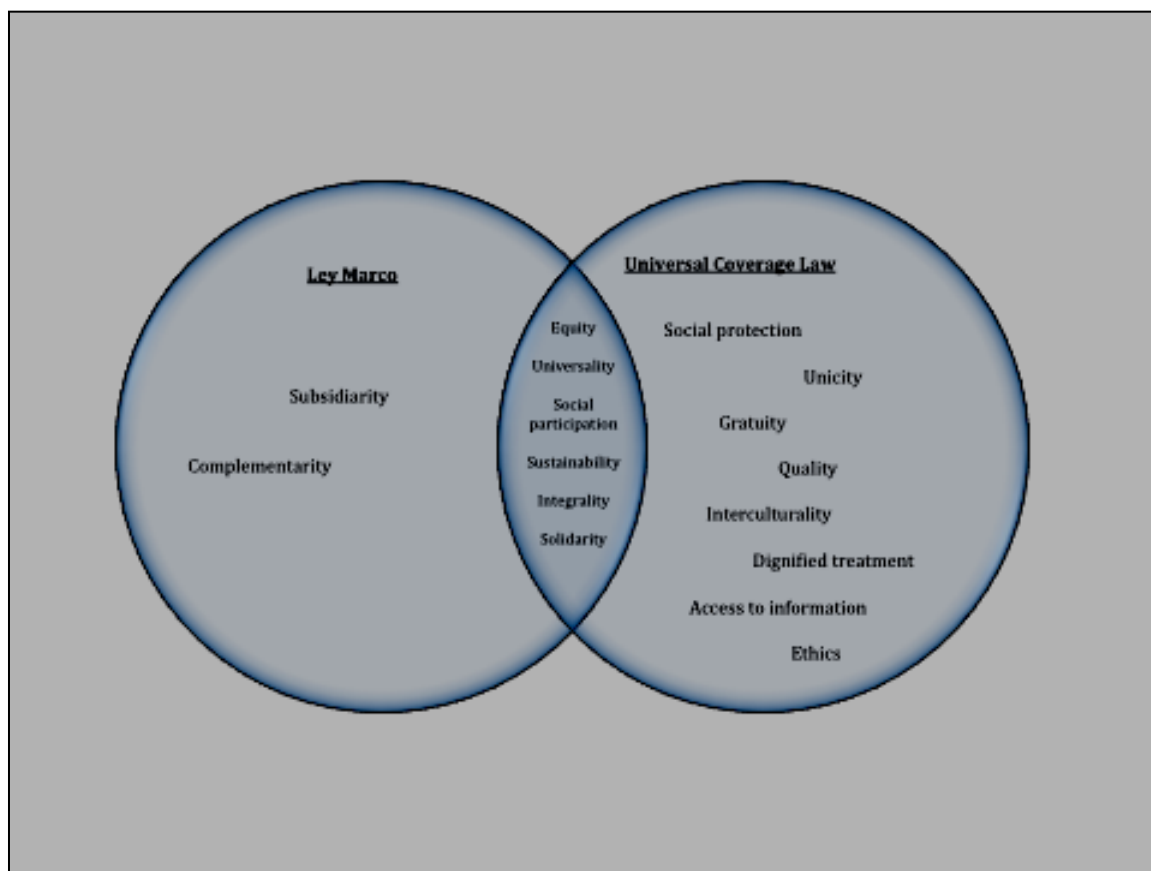


Figure 3. “Guiding principles” in the Ley Marco and the Universal Coverage Law

Similarly, the six principles the two laws have in common, may be defined in distinct ways, as the table below shows. Principles such as equity, social participation, solidarity and universality are defined in such a distinct way in both laws that they end up having opposite meanings; in each law there are competing ideas of financing of the public health services and the role of the private sector in health care. On a deeper level, they imply different views of human agency and social difference that lead to different conclusions on how to tackle health inequalities in Guatemala.

Table 5. Guiding principles in two laws

Ley Marco de Salud	Principles	Universal Coverage Law
Enjoyment of health as a right of all inhabitants, who can access and receive health care, with no discrimination of any kind.	Universality	All citizens have access to public health care, integral, equitable, continuous, permanent, of quality, in the whole national territory, regardless of social, economic, or cultural condition.
Access to comprehensive health care, including prevention, promotion, recovery, rehabilitation and complementary to achieve physical, mental, and social wellbeing.	Integrity	Promotes coordination of all national health system resources in terms of actions, policies and structures.
Opportunity to access health care and nutrition facilities, privileging vulnerable sectors.	Equity	Elimination of unjust, unnecessary, and evitable social differences in health protection.
Acknowledgment that public health care services must privilege the most disadvantaged groups.	Solidarity	Society as a whole contributes to the financing and development of the health system, with the aim of assuring that anyone who needs it, receives its benefits and services in a timely and effective way.
People's participation in the processes of planning, execution and evaluation of health and nutrition programs as a means for promoting community's capacities towards their development.	Social participation	People's right to participate in all decision making levels regarding design of public policy, its implementation, control and follow-up.
Actions included in this law should not be affected by political, cultural, social, financial, organizational or other factors, taking into account the limitations of available resources.	Sustainability	Processes aimed at health promotion, protection and preservation must be permanent and uninterrupted, so they cannot be negatively affected by political, economic, cultural, social, administrative, financial, or other factors.

A last comparison I want to present to make the same point (the differences in how the right to health is understood in relation to human agency and health inequalities) regards the conceptualization of the health system that each law proposes. Both the Ley Marco and the Universal Coverage Law devote about two thirds of their articles to define the health system and how it should be organized and directed. It is hard to find differences between the two laws in this regard, other than the stress the Universal Coverage Law makes on warranting the right to health and the one the Ley Marco makes on coordinating and decentralizing the health system.

The comparison of the two laws makes it clear that there are competing interests at stake when principles, values and regulations are presented. That should come as no surprise. But a more careful analysis also helps us lay out who the involved actors are and what their roles are in the health system, as well as the implications to the notion of the right to health. Aside from the actual proponents of the legislation pieces, it is evident (although not explicit) that there are private and public institutions and individuals who shape the health system and who have concrete interests at stake, such as politicians, pharmaceutical industry representatives, private health care providers, and public health regulators, to name a few. But also implicit, there emerges the abstract image of those whose right to health needs to be protected, an image that I think emerges is of an impoverished single mother living in the city's outskirts, or of an indigenous child living in rural Guatemala, or of someone like Manuela, the woman I introduced at the beginning of this chapter. Interestingly to me, despite the differences in both law initiatives, I perceived the presence of the kind of human whose rights need to be protected, and who is not the same kind of human as the one crafting the law. And because both laws seem to give life to that kind of abstract "other", I see the notion of the right to health emerging as closer to the charity model permeating the history of Guatemalan constitutions than to the entitlement one introduced in the latest constitution. But the image of "the human" in the right to health that emerges from analyzing these two laws is not the same we get when we analyze the Constitutional Court's jurisprudence, as I do in the following section.

The right to health in the Guatemalan Constitutional Court

The Guatemalan Constitutional Court is the national entity responsible for protecting the National Constitution. It works as a supreme court when the matter in

discussion is if an act (a decision, a law, an action) violates the constitution. Since the right to health is explicitly included in the Guatemalan Constitution, the Constitutional Court is a good source (and the one with the last word) of jurisprudence regarding the right to health. It is possible that other lower ranked courts have dealt with important cases touching on the right to health, but it is very likely that any case brought to the judiciary system where the right to health was at stake, would have ended up in the Constitutional Court. Therefore, the Constitutional Court is a good place to look at in search for jurisprudence about the right to health, giving us the chance to both characterize what kinds of cases are brought to the court and also review the interpretation that the court has made of the right to health.

As it has been noted in a previous section, Guatemala's 1985 Constitution explicitly states that "the enjoyment of health is a fundamental human right, without any discrimination" (art. 93), and that "the State will keep vigil for health and social assistance of all inhabitants [...] with the aim of achieving the highest physical, mental, and social wellbeing" (art. 94). It also specifies "health of all inhabitants is a public good [and therefore] all people are obliged to keep vigil for its conservation and recuperation" (art. 95). The constitution goes on and states that the State will control the quality of all products that may affect health (art. 96), it aims at reaching a balance between environmental protection and human health (art. 97), promotes community participation in health programs planning, execution and evaluation (art. 98), and considers the right to food and nutrition (art. 99) and the right to social security (art. 100).

The Constitutional Court explained how these rights should be interpreted in an often-cited judgment from 1993, which I quote here:

“with great amplitude, the Constitution guarantees the right to health and to health protection, by which every human being can enjoy a biological and social balance that constitutes a state of wellness in relation to the surrounding environment; it implies the ability to access services that allow the maintenance or restitution of physical, mental, and social wellness. This right, as others warranted by the [Constitution], pertains to all inhabitants, to whom it warrants equality in basic conditions to exercise it. It is people’s prerogative to enjoy opportunities and facilities to achieve their physical, mental and social wellbeing; and it is State’s responsibility to warrant its full exercise with the [appropriate] modalities [to the country], which implies that the State must take adequate measures for the protection of individual and collective health, and provide, within the reach of everyone, the services needed for fulfilling basic needs. It also implies the adoption of the providences needed to guarantee that inhabitants can exercise this right and collaborate in the solution of general health problems.”
(CC 1993)

The Constitutional Court has also stated, in a different judgement, that the state is obliged to adopt all pertinent measures through its institutions to warrant the right to health. (CC 2004)

According to a search of the Constitutional Court’s database (www.cc.gob.gt/siged2009), I found 82 Constitutional Court judgments where “right to health” had been invoked, which I synthesize in the table below. Types and subtypes of

cases came from my own analysis and do not reflect the Constitutional Court’s thinking. I classified them according to the main purpose for which the case was initially filed.

Table 6. Constitutional Court cases where the right to health was invoked

Type of case	Sub-type	Frequency	Total
Medicine or treatment			72
	IGSS denying medicine or treatment to individuals	49	
	IGSS not offering enough medicines or treatments in general	20	
	Public hospitals not having enough resources	3	
Environmental contamination	Clandestine garbage dump, bus terminal, lake contamination		3
Opposition to a new law	Private business opposing law prohibiting smoking in public places		3
Commercial battles	Private business fighting for the right to commercialize a generic drug; or requesting that HIV drugs not pay taxes		3
Avoid prison	A man wanting to stay in a public hospital instead of going back to prison		1
Total			82

The main pattern I identified here is that an overwhelming majority (69 out of 82) of the cases that have made it to the Constitutional Court have been filed against the Instituto Guatemalteco de Seguridad Social (IGSS), the social security institute, a semi-autonomous entity that covers 15% of the economically active population, and is a “solidarity-based” (money goes to a common pool, not to individual accounts) health insurance which is also a health care provider. Its funding is based on contributions by workers, employers and taxpayers and, although it has a lot of problems, it is the wealthiest health care and health insurance institution in the country. All the cases were requesting that IGSS pay for expensive treatments for chronic diseases such as kidney failure, various cancers, diabetes, multiple sclerosis, HIV, Turner syndrome, lupus, vitiligo, or multiple mieloma. Some of the cases were presented with support of the Procuraduría de Derechos Humanos and are a follow-up of processes started at the

Procuraduría, but private citizens present the majority, with private lawyers acting on their behalf. When I asked a lawyer what explains this pattern, she replied:

“Isn’t it obvious? IGSS has the money to pay for expensive treatments, so people in need of those treatments will do anything to get them. They don’t do the same at the public hospitals because in the end they don’t have the money to pay for expensive treatments. For most people not having their treatment covered by IGSS equals a death sentence.”

Although the 1993 Constitutional Court judgment offers an interpretation of the right to health that pays attention to individual and collective rights, as well as curative and preventative measures, and that is meant for all the country’s inhabitants, this overview of the actual cases that the court has been involved in tells a different story about what the right to health is and who it is for. And the image that emerges is that the right to health is used in individual cases when patients need very expensive medical technologies (mostly pharmaceuticals) and they could be covered by the social security system. This image of the right to health is very different from each of the ones I documented in previous sections of this chapter. The right to health emerging from the Procuraduría’s reports and actions was largely pointing to the scarce resources in public institutions that the poor attend, and the response was moral condemnation or attempts at working out solutions with the Ministry of Health. The right to health emerging from the two 2009 conferences was fragmented but for the most part in line with the reality of an “other” who is the subject of the right to health and that is represented by the most marginalized groups in the Guatemalan society, which was similar to the image of the

right to health coming out from the two law initiatives. All those images of the right to health were closer to the charity model than to the entitlement one. In contrast, the Constitutional Court jurisprudence shows a discourse and a practice closer to the entitlement model of the right to health, but that applies only for individuals who can afford a lawyer and who are covered by the IGSS (less than 25% of the economically active population, PAHO 2011, MSPAS 2012). Manuela, the woman I introduced at the beginning of this chapter, does not meet the profile of those seeking right to health protections through the Constitutional Court. Let me now show how these images of the right to health in Guatemala contrast with the one shaped by and through the visit of the UN special rapporteur in 2010.

The right to health in the visit of the UN Rapporteur on the Right to Health

In May of 2010, Anand Grover, United Nations “Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”, visited Guatemala and met with government and civil society representatives, health professional leaders, and indigenous communities’ representatives. Mr. Grover presented his findings in a report to the United Nations General Assembly in 2011 (Grover 2011). The report characterizes Guatemala’s health sector as seriously lacking resources and as being highly inequitable, with a higher concentration of resources in urban areas. He identified the barriers to health and health care for indigenous people and women as the main health inequalities. In addition, he expressed his concern for the public policies towards medicine purchases that tend to present barriers for generic drugs.

As he stated at the end of his 7-day long visit to Guatemala, ““while some progress is being made, there remains a long way to go.” (OHCHR 2010)

The report provides the historical context that partly explains the social exclusion towards women and indigenous peoples. Mr. Grover identified deeply-rooted forms of discrimination against indigenous peoples, and locates urban concentration of resources and linguistic barriers among the mechanisms that perpetuate health inequalities, but sees the lack of a health policy aimed at indigenous peoples as a concrete way in which discrimination has been reproduced. His overall perspective on the health of indigenous peoples in Guatemala is summarized here:

Due to a confluence of factors, including historical repression and prejudice, and the civil war, indigenous peoples have faced significant barriers in realizing the right to health. Indigenous peoples have the right to specific measures to improve their access to health - care facilities, goods and services that are culturally appropriate. The Committee on Economic, Social and Cultural Rights has noted that States should provide resources for indigenous peoples to design, deliver and control such services. Unfortunately, the indigenous peoples in Guatemala have been systematically excluded from health-related decision-making, which has contributed to major gaps between indigenous and non-indigenous health outcomes. (Grover 2011:9)

The report's focus on women's health mainly addresses sexual and reproductive health and points to barriers and inequalities in access and utilization of contraceptives and obstetric care. It also highlights the high rate of abortions despite their being illegal

under Guatemalan law. It finally expresses concern for the high rates of different forms of violence against women. Mr. Grover's report synthesizes the situation of women's sexual and reproductive rights as follows:

Maternal mortality rates dropped to 136 deaths per 100,000 live births in 2010, from a previous rate of 153 deaths per 100,000 live births in 2000. Nevertheless, the rate is not decreasing quickly enough to achieve the Millennium Development Goal of 55 deaths per 100,000 births set for 2015. Moreover, these gains disguise the failure to make progress in certain populations. In 2006, eight departments in Guatemala had rates higher than the national average; in each of these departments, the majority of the population was of indigenous descent and recorded low levels of educational attainment. Indeed, maternal mortality has been recorded as up to three times higher amongst indigenous than amongst non-indigenous women. The Government informed the Special Rapporteur of its efforts to strengthen local service networks in order to reduce maternal mortality in heavily affected areas. In that context, the Multisectoral Committee for Safe Motherhood (Comisión Multisectorial para la Maternidad Saludable) was created on 7 December with a view to monitoring and evaluating a strategy to reduce maternal mortality. (Grover 2011:14-15)

Mr. Grover's analysis of the situation of the right to health is closer to the international discourse of Mutua's doctrinalists and constitutionalists and, as such is shaped by the entitlement model of the right to health, which differentiates it from most of the approaches presented in the preceding sections. At the same time, in its emphasis

on addressing health inequalities, it ends up identifying and characterizing the health of particular groups, which in this particular report are indigenous peoples, women (particularly if they are indigenous), and people living with HIV and other chronic diseases (in the section on access to medicines). Again, as it has happened in the examples I gave in the preceding sections, the right to health seems to be used as a means for addressing the suffering of some kind of “marginalized other” getting the short end of the stick. I am not saying there is anything wrong about this, but I think that the way “the human” in the right to health is understood has deep implications in the ways the right to health is implemented. Let me now switch to a discussion about the issue of “the human” in human rights, from philosophical and theoretical perspectives.

Biopolitics and the “Human” in Human Rights

The notion of biopolitics offers a fertile perspective for the analysis of human rights and for how “the human” is understood in their context. However, the ambiguity of the term leads to different interpretations that give different weights and meanings to its two components: life and politics. For some, the emphasis is on the biological aspects of life and the technologies that allow their manipulation. For others, it is necessary to understand life in a more comprehensive way that should be central to the concept. The different meanings of life get interwoven with different meanings of politics. At one pole, are interpretations of politics as the stage of struggle and negotiation of collective resources, and at the opposite pole, politics is understood as ubiquitous power. As I will discuss in this section, those different meanings of politics are one of the keys to unpacking what the “human” means in human rights. I am interested here in better

understanding the right to health by focusing on the “human” in human rights. This “human” can be found in the multitude, the people, the refugee, the citizen, the passive subject, or the political subject. The ways the right to health deals with a different kind of “human” is influenced by the concept of biopolitics implicitly or explicitly adopted. That is why my search for the “human” in human rights is tightly intertwined with the search for the “political” in biopolitics.

The idea of Human Rights has been at the center of modern Western debates about the social and the political. Its importance has been manifested either by the centrality it has received in the writings of some political philosophers and social scientists – from Rousseau to Rancière – or by the way in which important authors have kept it at the periphery of their work – such as Weber and Foucault. The importance of human rights for the modern nation-state should be evident if we analyze some of the essential presumptions of the latter’s existence, such as territoriality, government and property, which rely on the definition of humanity and citizenship. That is, the very existence of the nation-state depends on the corroboration and denial of privileges and obligations in favor of its inhabitants.

Given the centrality of the idea of human rights to modern nation-state, students of society have integrated their view of the interactions between the social and the political to their positions respecting human rights. This is visible in the writings of the ‘fathers’ of Western modern sociology, none of whom made human rights a central part of their work. Marx, for example, understood human rights “in their authentic form” (the way they were defined following the American and French revolutions) as *droits de l’homme* in opposition to *droits du citoyen*, and considered them as “nothing but the

rights of a member of civil society – i.e., the rights of egoistic man, of man separated from other men and from the community” (Marx 1844: 16). After Marx’s time, the importance of human rights as a social and political phenomenon has increased, particularly since the period “between wars” and played a key role during the Cold War, after which their importance is even greater in the context of neoliberal globalization, the ‘war on terror’ and the rise of humanitarianism (Douzinas 2007: 15-33).

The emergence of human rights during this period has made some contemporary students of society pay closer attention to them as central to the understanding of the contemporary world, oftentimes reflecting in their analysis their positions towards those of the “classic” sociologists. For example, when Jacques Rancière says that human rights do not separate the citizen from the human, but they “separate the whole of the community from itself” (Rancière 2004: 305; see also Žižek 2005: 131), he is clearly making reference to Marx’s 1844 critique of human rights cited above. Agamben’s homo sacer as the subject of human rights also seems to be part of this conversation, because Agamben is pointing out with that concept that the difference that Marx makes between *homme* and *citoyen* is essentially mistaken.

Nevertheless, the ever-increasing importance of human rights talk is filled with paradoxes. Costas Douzinas (2007), in an attempt to contribute to the development of a politics of dissent given the connection he sees between human rights and “empire”, affirms that the paradox of human rights is their organizing principle: “the ‘human’ in [human] rights is a ‘floating signifier’, ‘human rights’ is a thin, underdetermined concept” (p. 8) which, in consequence, carries with it a diverse range of conceptual and semantic connotations. Human rights can be understood as legal rights, moral claims, ideology,

desire, strategy, and a topic in jurisprudence (p. 9-12). Similarly, the right to health has been portrayed as a legal instrument, a policy framework, a moral imperative, a floating assertion, or a catchy slogan (Willen 2011:308). In my view, it is in those paradoxes precisely where one can explore the limits and possibilities of the idea of human rights, as well as their presumptions and implications for political systems, institutions and individuals.

One of human rights' paradoxes, perhaps the most fundamental or at least the most commented by contemporary philosophers and social scientists, is the one pointed out by Hannah Arendt (1966) as part of her analysis of the refugees at the rise of totalitarian states in the dawn of World War II. Arendt argues that the origin of the idea of human rights is not human nature (as it is often argued by scholars and activists) but 'human artifice'. By human artifice, Arendt means that the root of the rights of man is not to be found in men's shared divine origin (we are all created in God's image) nor in their common human nature; it is to be found in the creations of modern society, particularly in the materialization of the nation-state because it is through its institutions that the rights of man are established, understood and implemented. If all men share the same human nature and human rights are based on that, Arendt argues, the implicit consequence of the idea of human rights is a collective aspiration for equality. Such equality can be understood in diverse ways, but the apparatus of the state tends to equate it to homogeneity, therefore developing assimilationist policies that end up being the root of structures of violence against groups that are outside the definitions of such homogeneity because of their ethnic identity, nation of origin or political aspirations.

In this sense, she affirms, “equality [...] is not given to us, but is the result of human organization insofar as it is guided by the principle of justice. We are not born equal; we become equal as members of a group on the strength of our decision to guarantee ourselves mutually equal rights” (p. 301). This is the paradox of human rights: that they should protect humans from the abuses of the state but the state is their only guarantor. As a counterpart of such social construction of human rights, Arendt shows the way in which human rights are lost. “The paradox involved in the loss of human rights is that such loss coincides with the instant when a person becomes a human being in general [...] and different in general, representing nothing but his own absolutely unique individuality which, deprived of expression within and action upon a common world, loses all significance” (302). It is in the intersection of these two paradoxical relations – individual/state and equality/homogeneity – that I will explore the relationship between biopolitics and the subject of human rights, as a way for better understanding the subtleties of how the right to health gets implemented.

In order to explore this relationship, I begin by presenting Giorgio Agamben’s influential biopolitical critique of human rights. Then, I select Agamben’s idea of biopolitics and contrast it with alternative uses of the concept and their implications for the study of the subject of human rights.

Agamben’s biopolitical critique of human rights

In 1993, Giorgio Agamben published *Beyond Human Rights*, where he analyzes the paradox of human rights pointed out by Arendt, and takes it further. He states that “[such] paradox is precisely the figure that should have embodied human rights more than any other”, but instead, it marked “the radical crisis of the concept [of human rights]”

(1996: 18.9). He bases his argument in his assumption that the refugee should be considered as a “limit-concept” – that is, a concept that encapsulates the essential attributes and therefore touches the foundations of the nation-state. He developed these ideas in the essay titled Biopolitics and the Rights of Man (Agamben 1998: 126-135), where he aims to analyze the historical function of human rights in the modern nation state.

Agamben revisits the difference signaled by Marx between *homme* and *citoyen* in the French Declaration of the Rights of Man and Citizen but makes an analogy of the relation between *homme* and *citoyen* with the one between the Greek concepts of *zoē* (naked life) and *bio* (political life). He affirms that *homme* (i.e. *zoē*, naked life) is the foundation of the French Declaration, representing “the originary figure of the inscription of [naked] life in the juridico-political order of the nation-state” (1998: 127). But at the same time, Agamben identifies the absorption of *homme* by *citoyen*, which eliminates the independence between naked life and political life. In this way, Agamben takes the paradox of human rights even further than Arendt, identifying that rights originate in man (*homme*, naked life) only to the extent that man is the “immediately vanishing ground” of the citizen (*citoyen*, political life). In other words, the ‘human’ in human rights is not a free and conscious political subject, but man’s naked life (1998: 127-128; see also 1996: 20.1). Therefore, the modern nation-state needs to constantly redefine the limits between political and social life, between citizen and man, between life and death. And it is in the exploration of this constant need that Agamben makes use of the concept of biopolitics, a term he borrows from Foucault, but to which he gives new meanings that I will present in the following section.

Biopolitics in Agamben and Foucault

Agamben attributes to the modern nation-state the need to constantly redefine the threshold between man and citizen. In other words, the limits of the 'human' in human rights are continuously being redefined. To explain this, Agamben refers to Foucault's idea of biopolitics. Let me present a comparison of some of the assumptions underlying Agamben's and Foucault's concepts of biopolitics in order to find some of the intersections, parallelisms and contradictions between each author's uses of the term. I will start introducing each author's definition of biopolitics in the context of their larger work. Then I compare their assumptions about sovereignty and the relation between the political and the social.

Foucault's concept of government developed throughout his career, as a product of his interest in the technologies that humans use to know themselves, of which he identifies four types: technologies of production, of sign systems, of power, and of the self. The contact between the technologies of power and the technologies of the self is what he calls governmentality (Foucault 1988: 18). By governmentality, he explains later (Foucault 1991), he means three things: the ensemble of institutions and practices that allow the exercise of government, the tendency which leans toward the pre-eminence of government, and the result of the process through which the state changed from one based on justice, to one based on administration, to one that "becomes governmentalized". Nevertheless, in his conception of contemporary society there are traces of three types of power that function simultaneously and interdependently: sovereignty, discipline and government (p. 102-103).

It is in the context of these ideas that Foucault traces the ancient sovereign's "power over death" – in which the juridical existence of sovereignty was in question -

and sees it shift in the seventeenth century into a “power over life” – in which what is at stake is the biological existence of a population. This power over life has evolved into two complementary forms: on one pole, the anatomo-politics of the human body, subjecting individuals to disciplines centered on the body, and on the other pole, the biopolitics of the population, subjecting the species to regulatory controls (1978: 137-139). I want to highlight three key elements of Foucault’s concept of biopolitics for the aims of this discussion. First, Foucault emphasizes a change in the purpose of the sovereign’s power from protecting its own legitimacy to managing the life of the population. Second, he conceives sovereignty as a type of power, which in contemporary societies works together with the other types of power: discipline and government. Third, the three types of power coexist and interact to generate a variety of discourses and practices in which power relations are produced and reproduced.

These key elements of Foucault’s concept of biopolitics are essential to contrast it with Agamben’s use of the term. In *State of Exception* (Agamben 2005), the author presents his book as an investigation of the ambiguous interface “between public law and political fact, and between the juridical order and life” in order to understand the “supposed difference between the political and the juridical” (p. 1-2). Previously, he had stated that Foucault’s thesis needed to be corrected or completed “in the sense that what characterizes modern politics is [...] that, together with the process by which the exception everywhere becomes the rule, the realm of bare life [...] gradually begins to coincide with the political realm, and exclusion and inclusion, outside and inside, bios and zoē, right and fact, enter into a zone of irreducible indistinction” (1998: 8). In this

zone of indistinction, the social and the political are no longer distinct, as the “human” of human rights becomes simultaneously and indivisibly *homme* and *citoyen*.

Agamben identifies two processes happening parallel to the rise of modern democracies: on the one hand, state power makes man into its own specific object, and on the other hand, man presents himself no longer as an object but as the subject of political power. “These processes – which in many ways oppose [...] each other – nevertheless converge insofar as both concern the bare life of the citizen, the new biopolitical body of humanity” (1998: 9). Agamben’s main point here, in what is relevant for our discussion, is that sovereign power has existed in the first place to make decisions about life and death (1998: 12). In contemporary society, however, biopolitics acquires new forms, one of which is the constant expansion of the aspects in which the state of exception applies to decisions in bare life, and at the same time, the limits between decisions on life and decisions on death are blurred, turning biopolitics into “thanatopolitics”. As a consequence, “in modern biopolitics, sovereign is he who decides on the value or the nonvalue of life as such” (1998: 128-132).

I want to point out some elements Agamben is introducing. First, he underlines the gradual inclusion of bare life into politics as one important aspect of modernity. Second, he conceives sovereignty as a function of the state of exception. Third, he presents the state of exception as a technique of government, the technique that defines the relation between the political and social realms.

Agamben and Foucault are both interested in the subtleties of the operations of power in society, focusing on different aspects of the ambiguous space between the social and the political. When I compare their use of the term sovereignty, I see them giving a

different weight to it in their analysis of power. They also use it for different purposes. Foucault uses sovereignty to show the changes in the types of power that have been prevalent since medieval times, and then focuses little on its contemporary operations. Agamben uses it to underscore the continuous presence of sovereign forms of power since classic Greece and Rome to our times. They both say that sovereignty has suffered important qualitative changes but also preserves its essence. Agamben is interested in the ways in which sovereignty has become biopolitical, while Foucault is more interested in the governmental and disciplinary ways in which biopolitics is implemented. I see both uses as complementary.

In terms of their ideas of government, Foucault is taking the concept all the way from the subjective government of oneself to the ways in which the state governs the population. Agamben is closer to classical political theory in analyzing the political and the juridical as a continuum, although he innovates the way to understand it through the use he makes of the idea of the state of exception. I also see both authors as complementary here. They are both following their different analytical goals of understanding the microphysics of power and the ambiguity between law (and no-law) and life (and death). Each analytical approach has implications for the kind of questions and inquiries they allow in terms of the study of biopolitics.

Both uses of the term biopolitics have implications for understanding the “human” in human rights. On the one hand, the ambiguous limit between the social and the political allows for analytical approaches that have the potential to pay closer attention to the operations of power, at the same time that they seem to leave little space for political action. On the other hand, Agamben’s reexamination of Arendt’s paradox by the

introduction of the concept of the state of exception and the indistinction between homme and citoyen, leave open the question of how and who constantly redefines those distinctions. If the “human” in human rights is the homo sacer, and the sovereign is constantly redefining who lives and who dies, then human rights are an illusion. Are they a form of “false consciousness”, as most Marxist interpretations would put it? How far does this concept of biopolitics take us, when we are searching for the “human” in human rights, from Marx’s distinctions between man and citizen? If we agree for now with Agamben that biopolitics is one key way in which the limits and definitions of the ‘human’ in human rights are redefined in contemporary nation-states, it is worth it to take a look at some critiques of Agamben’s use of the concept, which I present in the following section.

Criticisms of Agamben’s understanding of biopolitics

The idea of biopolitics has been used by an increasing number of philosophers, social scientists and humanists. A search in AnthroSource turns back 118 entries in a variety of anthropological fields. The topics to which it has been applied vary, but the more consistent have to do with human rights, biomedicine, medical humanitarianism and bio-technologies. From 1989 to 2002 there is an average of 1 entry per year, but after that they increase, reaching the highest point in 2006, with 49 entries. The first entry is from 1977, and illustrates the multiple directions in which the concept has been used. It corresponds to the Book Notes (American Anthropological Association 1977: 742-743) for Albert Somit’s edited volume “Biology and Politics: Recent Explorations”, which is introduced as “the first comprehensive treatment of the decade-old discipline of biopolitics” and presents conference papers, commentaries and reviews dealing with bio-

behavioral analytical frameworks (behavioral genetics, ethology, and psycho-biology), biological techniques (electrophysiological measurement of skin conductivity, blood pressure, and cerebral stimulation) and biosocial measures (crowding, drug use, and the frequency of left-handedness [sic]).

The description of Somit's book might seem at first sight totally unrelated to Foucault's or Agamben's notion of biopolitics, but to me it illustrates the different ideas that can be associated with the combination of the concepts of biology and politics, which can result in two related ideas, that of "the politics of life" or that of "the politics of the study of life". This is relevant because behind the current use of the word, different authors pay different amounts of attention to each of the terms and their interaction. For instance, Nichter (2008) understands the term biopolitics in two senses. In a first sense, he explains it as the "regulation of populations through the exercise of power over health and life" which involves the "governing of ways of living through normative practice", and sees biopolitics in public health practice when it is extending its administrative and regulatory control (Nichter 2008: 152). In a second sense, he sees biopolitics as the "politics of health and medical citizenship" and as the "politics of emerging assemblages" (people, institutions, technologies, ideas, charities, corporations) "in a globalized world and a new information-technology environment" (Nichter 2008: 152). As we will see in the following section, some authors - like Rancière or Žižek - pay attention practically just to the "-politics" part of the concept, while others – notably Rabinow and Rose – emphasize the "bio-" part of it. The authors' different emphases open different windows to look at the "human" in human rights. Let me now present often cited theoretical positions that use Foucault or Agamben as a starting point.

Biopolitics as a Mechanism of Control

Michael Hardt and Antonio Negri (2000) use the term biopolitics as one of the building blocks of their “theory of Empire”. They understand biopower as “a form of power that regulates social life from its interior, following it, interpreting it, absorbing it, and rearticulating it”, and the term makes reference to “a situation in which what is directly at stake in power is the production and reproduction of life itself” (p. 23-24). They affirm that we are living in a society of control, which is the only one able to adopt the mechanisms needed for the implementation of biopolitics, expressing power as “a control that extends throughout the depths of consciousness and bodies of the population and at the same time, extends to the whole of social relations” (p. 24). Until this point, they imply the need to differentiate production and reproduction of biopower, which is essential in their thesis. They insist on using the Marxist concepts of production and reproduction when looking at “life” that is the object of control in a biopolitical society and, although they affirm they are not giving preeminence to the material over non-material production, they focus their analysis on the material production of life.

When I look further for ideas that help in my search for the “human” in human rights, I find that for Hardt and Negri, the concepts of society of control and biopower are essential to the operations of contemporary empire, in which “the new notion of right emerges in the context of globalization and presents itself as capable of treating the universal, planetary sphere as a single, systemic set” in which the rule of law continues to play a central role, right remains effective and (by means of the state of exception and police technique) becomes procedure, revealing the unmediated relationship between power and subjectivities (p. 26). Here, Hardt and Negri seem to give a vital function to the notion of human rights, which seems to be an ideological one, some sort of “false

consciousness” that ties subjectivities to the operations of power. Those subjectivities are those of the subjects of human rights, and it is biopolitics that presents power with alternatives to the dichotomies obedience/disobedience, participation/refusal, life/death, wealth/poverty, and production/reproduction. In other words, it is through the control over the (material and ideological) production and reproduction of life itself, that globalization uses human rights as technologies to create and control subjects. That is to say, law and human rights are just partial representations of the power of empire.

Therefore, in their view it is not as important to focus attention on the concept of rights – as Agamben does – because it obscures the understanding of the mechanisms that set in motion the power of empire. Instead of focusing on the concept of rights, they make a call for paying attention to the “productive dimension” of biopower (p. 27), which has not been built by theorists interested in biopolitics. They attempt to understand the production of life itself, which they find in social production and juridical legitimation, which in empire tend to coincide (p. 41), and they find that the political, the social, the economic, and the vital (life itself) are entirely interrelated and interchangeable, and it is there where the biopolitical fabric opens to the constitutive, constituent power (p. 406). In the context of prevailing discussions about biopolitics, this call has its merit, and points to interesting directions of inquiry, such as looking at the political economy behind the construction of new forms of citizenship based on the administration of life and death. However, Hardt and Negri do not give explicit elements for the conception of the “human” in human rights. Their main contribution in this sense is the difference they make between people and multitude as the social body (p. 103).

Biopolitics as a Tool for Understanding Emergent Mechanisms of Power.

Paul Rabinow and Nikolas Rose (2006) criticize and distance their view of biopolitics from those of Agamben and Hardt-Negri. They make a call for transcending “celebration and denunciation as analytical approaches” (p. 215) and present their interest in developing Foucault’s concepts of biopower and biopolitics as analytical tools. They propose some elements that the concept of biopower should include (p. 197). First, analysis based on the concept of biopower needs to account for the discourses about the true ‘vital’ character of living human beings and the authorities considered competent to define that truth. Second, biopower should allow the study of “strategies for intervention upon collective existence in the name of life and health”. One of the important tasks here is the definition and redefinition of those collectivities, which may be in terms of territory, race, gender, religion, or emerging forms of citizenship (such as genetic or biological citizenship). Rabinow has used the term “biosociality” to examine the emergence of these collectivities. Finally, the “modes of subjectification” and their relation to technologies of the self aimed to improve life or health, as well as the mechanisms through which they are shaped, such as forms of authority and their relation to discourses of truth. Rose has examined these modes of subjectification through the concept of “somatic individuality”.

It is important to note that the essential elements they suggest - discourses of truth, strategies of intervention upon collectivities, and modes of subjectification – do not explicitly approach the political as the “problematic of negotiating the powers and values of enduring collectivities” (Brown 2005: 76). In fact, Rabinow sees in the development of biopolitical forms of government the progressive elimination of the limits between the social and the political (Rabinow 1999: 186), although for different reasons than the ones

that made Agamben come to a similar conclusion. Although I consider the lack of an explicit inclusion of the political in Rabinow and Rose, I acknowledge that their emphasis in understanding the complexities of the new forms of control over life, and how they interact with new forms of intervention upon collectivities and new forms of subjectification gives useful insights for the understanding of the subject of human rights. For example, they consider that we are witnessing the emergence of the “political economy of vitality”, in which:

“transnational flows of knowledge, cells, tissues and intellectual property are coupled with local intensifications and regulated by supranational institutions. Mobilizations of persons, tissues, organs, pathogens and therapeutics operate at different speeds and encounter local obstacles and incitements. Individualizing and collectivizing subjectifications are also mobile and transnational” (p. 215)

In order to address such “political economy of vitality”, they go on, we need to use the concept of biopower in a precise way to develop empirical investigations that account for the complexities of these emerging phenomena. The understanding of such complexities can be helpful in understanding the emergence of new forms of citizenship that are linked to the new forms of intervention over individual and collective lives. Those new forms of citizenship can be key in the analysis of contemporary human rights, since these forms of citizen will probably challenge the limits of human rights in the discourses and practices of citizens, governments and other social actors. If the “human” in human rights is going to be defined and redefined by new forms of biological

citizenship (to use Adriana Petryna's term), then understanding the complex mechanisms that create such new forms will be a fundamental task of biopolitics as an analytical tool.

Biopolitics as the Subversive Counterpart of Biopower

After Rabinow's and Rose's emphasis on the new ways in which we understand life, we will look at writings of some authors that emphasize the political aspect of biopolitics in their analysis. Maurizio Lazzarato, for instance makes a distinction between "biopower dispositifs" and "biopolitical forms-of-life" (Lazzarato 2005). He points out that Agamben reduces the multiplicity of power dispositifs (discipline, sovereignty, and biopolitics) to the relation between the power and the naked life. For Negri, he affirms, it seems that the concept of biopolitics means there is no distinction between economy and politics and erases the specific relations of micro-powers and government. In Lazzarato's interpretation, Foucault's perspective was not that after World War II the biological regulation of the species (biopolitics) was deepened, but that the new technologies of power, those directed to the control of "the milieu" took preeminence. These technologies have as their objects the modulation of differences and the regulation of minorities. "It is not life as biology, but life as virtuality that is at the center of the new power dispositifs". In the society of control, the interventions are not targeted to the players, but to the rules of the game, to 'the milieu'. The new dispositifs will define economic, technological, social, juridical, communication and vital conditions in which individuals will exercise their "free will" in already determined conditions. Power is now exercised over the possible actions and not over executed actions.

As can be seen, Lazzarato distances his understanding of biopolitics from that of Agamben and Hardt-Negri. Moreover, he affirms that it is not the biological aspects of

life at stake in biopolitics, but the opportunities for life in a more general sense. In this way, he also distances himself from interpretations such as that of Rabinow and Rose (although not explicitly making reference to these authors), which give centrality in the concept of biopolitics to the biological manipulation that new technologies make possible. In his view there is something else that makes the notion of biopolitics useful.

Fundamental to biopolitics in Lazzarato's view is the multiplicity of forces involved in power relations. The fundamental political problem in modernity is not the source of sovereign power, but the multiplicity of forces that act and react between each other in relationships of obedience and command. Biopolitics is "the strategic coordination of those power relations in order to allow the living ones to produce more power. Biopolitics is a strategic relation and not a power to dictate the law or to found sovereignty" (Lazzarato 2000). The functions of biopolitics are to coordinate and to give purpose. The relationship between sovereign power and biopower can only be understood taking into account the multiple and heterogeneous action of the forces involved.

For Lazzarato, biopower is "the art of government", which can be transformed into the "production and government of new forms of life", which he terms biopolitics, through the introduction of resistance and creativity. In this way, Lazzarato differentiates biopower from biopolitics, including in the latter the possibility for political struggle. This view is, doubtlessly less refined on its approach to the "bio-" in biopolitics, but takes back to the center the "-politics" in it. For a definition of the "human" in human rights, Lazzarato's contribution can be seen as one that distances itself from understandings that reduce humanity to biology, but for a more concrete contribution that attempts to put

politics at the center of biopolitics in search of the “human” in human rights, we will turn into two additional authors in the following section.

The paradox in Agamben’s biopolitical critique of human rights

Jacques Rancière (2004) phrases Arendt’s paradox of human rights in that “either the rights of the citizen are the rights of man [...] or the rights of man are the rights of the citizen [...] or in other words, human rights are] either the rights of those who have no rights or the rights of those who have rights”, which he finds either void or tautological. He presents an alternative interpretation when he says that human rights “are the rights of those who have not the rights that they have and have the rights that they have not” (p. 302). In other words, we talk about human rights when they are violated or when someone perceives that his or her rights were violated. For him, the ontological question of who is the subject of human rights can only be answered by acknowledging that the subject of rights is also the subject of politics, because the “subject of rights is the subject [...] that bridges the interval between two forms of the existence of [human rights]”: the written rights and the enacted rights (p. 303). This way of looking at it differs importantly from that of Arendt’s.

For Arendt, the ambit of implementation of human rights is that of citizenship, or the realm of political life as different from that of private life. For Rancière, it is precisely the definition of the limits of those two realms that politics is about (p. 303), and therefore, “the very difference between man and citizen is not a sign of disjunction proving that the rights are either void or tautological. It is the opening of an interval for political subjectivization” (p. 304). In other words, the distance between man and citizen gives the opportunity for political action when that distance is perceived. “A political

subject is a capacity for staging [...] scenes of dissensus [in which] two worlds are put in one and the same world” (p. 304) and the “generic name of the subjects who stage such cases of verification is the name of the demos”, [...] which is not the lower classes or bare life, but “the power of those who have no qualification for exercising power” (p. 304). That is, when those who are not exercising power perceive the difference between the rights they actually enjoy and the rights they should enjoy, they have the potential to bridge that gap and it is then when they become the subject of human rights, or the political subject.

Therefore, for Rancière “these rights are theirs when they can do something with them to construct a dissensus against the denial of rights they suffer. And there are always people among them who do it” (p. 305). The problem with Arendt’s conception is that she presupposes that the rights belong to fixed citizens, denying all the struggles that happen outside of the formal framework of the nation-state, which leads to a dead end in which those who are not citizens will not enjoy the rights of those who are citizens, which narrows the political alternatives and seems to empty human rights of their essence. But human rights are “political names” and therefore “can never become merely void” because “the void will be filled by somebody or something else” (p. 307). What we see here is Rancière’s rejection of a fixed or essentialized concept of human rights and its subject. But moreover, we see him reclaim the inclusion of political possibility as essential in the definition and redefinition of the “human” in human rights. This is even more obvious in Žižek.

For Žižek (2005), what happens to human rights when they are, as Arendt and Agamben have shown, the rights of the excluded, of those who have no rights and are

treated as inhuman is that the “human rights of Third World suffering victims” are the “right of Western powers to intervene in their Third World countries in the name of defending human rights” (p. 128). Conceiving human rights as the new cosmopolitan and universal ethics “relies on a violent gesture of depoliticization, depriving the victimized other of any political subjectivization”, and this depoliticization of human rights is “unexpectedly” close to the one implied in Agamben’s application of the notion of biopolitics to human rights, which puts us all in some sort of “biopolitical trap” that erases the differences between democracy and totalitarianism (p. 128).

Agamben’s biopolitical critique of human rights is not far from the Marxist notion that the legal is an ideological manifestation that hides the real interests that maintain it (p. 129). But that notion, as that of Hardt and Negri, is insufficient in that it only allows seeing human rights as a “symptom” of the concrete social reality of exploitation, overlooking the alternative, “more subversive” way to look at the “appearance of égaliberté” (a term he borrows from Etienne Balibar) as a source for the perception of tension that contains some sort of “symbolic efficiency” of its own, allowing “to set in motion the rearticulation of actual socio-economic relations by way of their progressive politicization” (p. 131). For Žižek, the consequence of Rancière’s analysis is the identification of a symmetrical paradox to the one identified by Arendt and subscribed by Agamben:

“At the very moment when we try to conceive the political rights of citizens without reference to a universal ‘meta-political’ human rights, we lose politics itself; that is to say, we reduce politics to a ‘post-political’ play of negotiation of particular interests” (Žižek 2005: 131).

The ‘Politics’ in Biopolitics and the ‘Human’ in Human Rights

Agamben’s contribution to the critique of human rights is essential for the understanding of human rights today. His use of Arendt’s paradox and Foucault’s biopolitics prepares the conversation for a critical view of the discourses and practices of human rights in the real world, and it allows for getting rid of romantic or essentialist views of cosmopolitan human rights as a universal value and as a global ethical standard. However, his use of biopolitics seems totalizing and ambiguous, therefore not leaving space for analytical refinements that explore the complexities of today’s management of life and death. More importantly, his use of Arendt’s paradox leaves no opportunity for political action around human rights, which does not correspond with the reality of such actions in the real world. Nevertheless, his contribution of bringing biopolitics to the analysis of human rights is important, and has the potential to develop in many different directions. From the exposition presented so far, I can clearly see three interesting implications for understanding the right to health.

First, Rabinow and Rose are developing the understanding of the mechanisms in which the microphysics of power is implemented. In particular, they focus on emergent ways of understanding life derived from recent advances in biotechnology. Although they do not study human rights as such, their research helps understand the ways in which new conceptions of humanity are being developed and interiorized by individuals. Second, Hardt and Negri’s recuperation of political economy can be of interest. I could imagine productive ways to combine this approach with that of Rabinow and Rose in order to better look at the ways in which power is actually exercised, and the connections to different aspects of social life. Finally, Lazzarato, Rancière and Žižek

bring back the political to the equation. As Wendy Brown eloquently shows, the delimitation of the political has important implications for the conception of actions that can actually influence social change:

If the political is signaled by the presence of any human relations organized by power, then it is inevitable that we would find the political everywhere today, but if the political is alternatively signaled by the distinct problematic of negotiating the powers and values of enduring collectivities, then the political cannot simply be indicated by the presence of power. The first renders almost everything political; the second radically delimits the scope of the political. (Brown 2005)

As I have discussed in this section, the limits and definitions of the “human” in human rights are explicitly or implicitly the object of political definition which I would argue happen in both of the senses Brown delineates above. I hope to exemplify this in the following section with the case of how epidemiologists at the CNE took on the task of reducing maternal mortality.

“We need to count every single death, because every death counts”

Reducing maternal mortality has been one of the top three priorities for Guatemala’s Ministry of Health in the past twenty years, so it was a priority in my job as a rural physician back in 2001, as I presented at the beginning of this chapter. One recurrent topic in the efforts for reducing maternal mortality is the accuracy of the statistics that account for the number of deaths that are, could, and should be classified as maternal deaths (for an anthropological account on maternal mortality in Guatemala, see

Berry 2006, Berry 2008, and Berry 2010). For instance, in 2009 the then-Minister of Health was cited to the National Congress in part to explain what his administration was doing regarding maternal mortality reduction, and his inability to give accurate numbers was one of the reasons that justified a vote of “lack of confidence” by the legislators, as well as his eventual resignation. There has also been a very active social coalition around the issue of maternal mortality that gave life to OSAR (Observatorio de Salud Reproductiva, Reproductive Health Observatory), a coalition of universities, politicians, and activists, supported by the international community, to secure an accurate follow-up to the efforts to reduce maternal mortality. OSAR used the phrase “we need to count every single death, because every death counts” (“*contar cada muerte porque cada muerte cuenta*”) in their efforts to improve accountability as it related to improving reproductive and sexual health. OSAR is one of the leading efforts in making the issue of maternal mortality one of human rights and, in fact, during my pilot research in 2009 many informants mentioned OSAR as the example of civil society efforts bringing together epidemiology and the right to health. During the time of my fieldwork (2009-2011) there were revived efforts for improving the accuracy of maternal mortality estimates as well as improving the interventions for preventing maternal deaths from happening.

One of these efforts was the research that led to the publication of the recent National Maternal Mortality Study (MSPAS 2011). It involved a lot of financial and technical support from international organizations such as USAID, CDC, PAHO, UNFPA, and UNICEF, as well as the leadership of Guatemalan government officials. The issue is very delicate because in the end, the numbers are easily interpreted as the

responsibility of health authorities, so if the numbers showed an increase in maternal mortality, some Ministry of Health officials risked being removed. The issue is also highly technical and each step in the process involves technical decisions with statistical implications that influence final interpretation of the results. The study was conducted primarily in 2009 but it took the better part of the following two years to come up with a report that satisfied all the technical requirements.

The other effort was the revision and publication of the updated epidemiological protocol aimed at reducing maternal mortality. The protocol is interestingly titled “Surveillance of the pregnant [woman] and of the death of women in childbearing age (10 to 54 years old) for the identification of maternal deaths” (MSPAS 2010). The protocol involves two measures: prevention of maternal deaths and identification/analysis of maternal deaths. Prevention of maternal deaths involved early detection of pregnant women at the local level (involving a national network of public health care facilities including 30+ hospitals, 400+ health centers, 1200+ health posts, and nobody-knows-how-many-thousands of community units, just within the Ministry of Health), risk classification for each pregnant woman, and follow up through prenatal care, as well as delivery and post-partum care. Every day, pregnant women detected to be at risk had to be reported to the immediate supervising unit of the Ministry of Health, so that the CNE in Guatemala City would know, “as close as possible to real time” as one epidemiologist explained it to me, how many pregnant women were at risk of complications that could lead to their death. Identification and analysis of maternal deaths involved a very thorough investigation of every death that happened among women between the ages of 10 and 54, to rule out if there were maternal deaths. When they were identified as

maternal deaths, the protocol prescribes an analytical process aimed at identifying the critical events that led to the death with the purpose of addressing them in order to prevent future deaths. The justification of all this effort was the well-known fact that at least one out of three maternal deaths were not classified as such in the official civil registry.

During my fieldwork I participated in a number of monthly meetings at the health center level, where they did their part of the surveillance, and I saw the tremendous amount of effort devoted to identifying pregnant women, having lists with their names and addresses, and producing maps locating their homes with green, yellow and red flags according to their low, middle or high level of risk. I also saw nurse aides being congratulated or reprimanded according to the percentage of pregnant women they had identified and classified, as well as for efforts they were making to ensure all women were getting prenatal care, including going to their houses whenever they failed to come to their appointment. I also heard of cases where health care workers made great efforts (such as going on a weekend to look for the woman's husband to convince him to let his wife deliver in the hospital, as well as health care workers facilitating the arrangements with neighbors to make sure the pregnant woman's children could remain at home while she was not present) for making sure a pregnant woman in risk would deliver at the hospital. I once asked Dr. R., the physician in charge of one of the health centers I visited (whom I learned to admire for her commitment and energy), about these efforts, and she replied:

“Well, this is a national priority and we have to make our best effort. There is no excuse for letting one of those women die, even if we have to move the heaven and

the earth [...] It is our responsibility to control our population, we have to know them, we have to let them know us, and we have to let them know what our priorities are and what we can offer them. [...] We have to be very respectful, but above all we have to prevent maternal deaths from happening, even if we have to insist with them some times.” (Physician in charge of a Health Center)

This kind of intervention seemed to me similar to the kind of intervention that, as the history of public health goes, happened primarily in Germany and France before public health, a period of interventions usually referred to as “medical police” (for more on medical police see Rosen 1958, Carroll 2002). When I learned about medical police, it was taught as a period that pre-dated “modern public health”, but this kind of “surveillance of pregnant women” as the protocol calls it, made me think that it is still part of the public health repertoire.

Conclusion

When the right to health is talked about in Guatemala, and when it is implemented, the kind of interventions and who they are targeting shows not only the ways in which human rights get contextualized, but also the ways in which a specific society is organized. The case of the “surveillance of pregnant women” shows how for a particular case the “human” of human rights gets defined as a political issue in both of the senses Wendy Brown pointed to. On the one hand, the priority given to maternal mortality is a win for sexual and reproductive rights activists and it has to be celebrated as such, but on the other hand, the way the issue gets conceived involves an implicit identification of a certain kind of “marginalized other” who is at risk of maternal death. Interventions on

these “marginalized other” are an example of power being everywhere, because the kind of control exercised over women and their families can only be conceived in the presence of unequal power relations.

Chapter 3. Epidemiology as expertise

In March and April of 2011, there was an outbreak of nosocomial infection in the Pediatric Intensive Care Unit at Roosevelt Hospital, one of the country's two public reference hospitals. The outbreak received ample coverage by news media and there was a lot of speculation about its magnitude and causes. Roosevelt Hospital is part of the Ministry of Health, so as soon as the outbreak was reported, one of CNE's most experienced epidemiologists was sent to investigate the outbreak. I asked her to describe her work documenting the outbreak.

“So as soon as the outbreak started, they told me to go and I went. And the news media is giving some numbers [of victims], and [hospital] directors are giving other numbers, and the [hospital's committee for the prevention of] nosocomial [infections] seems to disagree... and there is lack of coordination and lack of teamwork. But the data I have got will surprise them, but my data come from a thorough revision of each and everyone of the medical records. That's why I always say [...] because people think when they are sent out to investigate an outbreak they just go and ask for the numbers [...] and that's it. But that is not investigating an outbreak. Investigating an outbreak is getting involved and supporting the efforts to make things better. Because people at Roosevelt's nosocomial committee did not even know what a [statistical] rate is, so I had to explain to them what it is and why it is important and how to get the data needed to calculate it. They did not even have the trends for the Acinetobacter [the bacteria responsible for the outbreak], and in fact we don't have those trends yet

because the person responsible for the [hospital's] lab doesn't care at all. They told me she said "that is nonsense, those epidemiologists don't even know what they want [...] it is well known where the bacteria is to be found." But she, they don't understand the importance of finding out what the source [of the outbreak] is in order to remove the source, right? But clinicians don't understand that kind of thing. That is why I think clinicians should receive at least one year of epidemiology in the university to open up their minds to understanding the importance of epidemiology. So in this case we did not have to discover the responsible bacteria because we already knew it was Acinetobacter, with the only difference that we weren't able to determine what the source was, because they did not allow us to take samples. It's unbelievable! But when [one] doesn't let samples be taken it is because there must be something to hide. They did not take samples from hands, or from other surfaces... nothing. They still have not sent me the microbiology database, because [some people] say last year there were five Acinetobacter outbreaks, but none of them has been documented or reported. Everybody says there is Acinetobacter all over the hospital, but they did not give us [the database]. I even offered that if they gave me [the raw data] I could organize it and give them [the trends], but up until now they have only given me some monthly figures... at least that! But for this kind of bacteria, so lethal, it is necessary to have daily or at least weekly data. And this is... I was given this task with direct approval by the Minister... with his authorization to look through the clinical records and everything [...] but even with that approval I had a hard time getting the information, or to take samples. [...] It is amazing how little things

have changed, because in the Roosevelt hospital, children are dying, but they don't care to take a culture. They don't care. They don't bother to take a sample from a stethoscope to see if there is... because the Acinetobacter does not fly, it has to be carried from one patient to the next. So things have not changed but are just called by a different name. It is just because there have always been nosocomial infections in hospitals, so it is normal when they happen; but it should not be that way. They can be prevented from happening. They do not know that doing surveillance is in order to prevent outbreaks and ultimately to prevent people from dying. [...] There are three epidemiologists at Roosevelt hospital. When I got there, they said they would not deal with the outbreak because it is the responsibility of the nosocomial committee. The infectious disease doctor in charge of the committee [...] and the two nurses who are part of the committee said they were in a meeting and could not receive me. Receive me! Can you imagine? And it was the same, the following day, and they told me to come back next week. Unbelievable! I felt as if I was a door-to-door seller or something! So I decided to go to the epidemiologists and they did not want to get involved. Incredible! Because they are well-trained epidemiologists [...] and they did not want to get involved! [...] So I ended up sending a list of requests to the hospital's director to ask for access to the information, and that is what let me get some of the information. [...] Now I am writing the final report because I have to turn it in tomorrow. Unfortunately... I will be honest with you. I will prepare the report because it goes directly to the Minister. There are a lot more deaths than what they are saying. More than three times what they are saying. The number of

infected people is more than double what they are saying [...] So I would like to keep it confidential for now because I do not know how are they going to react. And I do not know what my supervisor will say, because if he tells me to send it out, then I will just – poom! – send it out to everybody. But we have to wait and see what the Minister says and what the Vice-Minister says, because it could turn into a problem. I think it will go to the X files [chuckles].” (Epidemiologist at CNE)

Anthropology of expertise

Studies of expertise have been included in what some call the “third generation” of the social studies of science and society. Although it may be tempting to take the task of defining what an expert is, such effort would prove sterile because expertise is something people do rather than something people “have” or “hold” or “are” (Carr 2010). In this sense, I am more interested in looking at what epidemiologists do than to what they say they are, or the titles they hold, or their job description. Expertise is then, defined by practices that tend to be routinized and organized in institutional boundaries that are defined by the different ways in which different professions, crafts or disciplines go about getting to know their objects (Carr 2010). Expertise is always ideological and always interactional (Carr 2010) and it reflects and reproduces power relations that may be repressive or productive (Foucault 1991). In this chapter, I present some elements for understanding the ideological and interactional features of epidemiological practices in Guatemala.

Epidemiologies as ideologies

Epidemiology is not a monolithic discipline. There are debates within the discipline, which can be synthesized in some modifiers that get added to the term epidemiology: field-, applied-, social-, among others. “Field” epidemiology is linked to the U.S. Centers for Disease Control and Prevention’s Field Epidemiology Training Program (CDC-FETP), which I explain in a following section, and it is concerned with producing epidemiologists able to perform the essential tasks of epidemiological surveillance and disease control. Field epidemiologists are trained in basic statistical analysis that allows them to identify simple statistical associations and risk factors. What they learn to do is to deal with the daily epidemiological concerns faced by public health officials at the national, regional and local levels (López and Cáceres 2008). “Applied” epidemiology, on the other hand, stresses the need to link epidemiology as a discipline to the more general practice of public health. The justification of an applied epidemiology is that if epidemiology loses its link to public health it loses its relevance. The difference between field and applied epidemiology appears to center on the link to public health decision-making. This divergence is reflected in the different kinds of training they receive; applied epidemiologists are trained in public health management in addition to epidemiological methods, while field epidemiologists have a more thorough training in epidemiological methods in practice (Thacker and Buffington 2001, Brownson and Petitti 2006).

This rather theoretical distinction seems to play out in generating some tensions at the CNE. Most epidemiologists I interviewed had a clear opinion about which kind of training was best – usually the one they received. FETP trained epidemiologists had a tendency to disregard broader public health training as something for administrators,

while epidemiologists with a Master in Public Health (MPH) were inclined to emphasize the difficulties for field epidemiologists in understanding the broader context in which epidemiologic events happened. Most epidemiologists I interviewed explicitly said that field epidemiologists were the real epidemiologists, while MPH-trained epidemiologists lacked the fundamental skills to perform epidemiological work. These tensions seemed to become more important when I noticed that all the heads of unit at the CNE in 2011 were not FETP trained but had MPH training. This was not the case before 2009.

Applied versus Academic Epidemiology

However, “field” and “applied” epidemiology are very similar as compared to “academic” epidemiology. There is a history to the debate between “applied” epidemiology and what has been called “academic” epidemiology. Let’s take a look at some of its recent highlights in order to become more familiar with the kinds of differences epidemiologists see in what they do and how they address different situations.

In 1988, The Acheson Report, a report about public health in England, concluded that academic epidemiology has limited relevance to the everyday practice of public health in that country. It recommended that training in epidemiology should remain in academia, but should be expanded to involve projects in applied public health. In particular, the authors argued that, the major contribution of epidemiology should include a way of thinking which focuses on the many aspects of life that might influence health (Bruce 1991).

In 1996, a series of articles in the American Journal of Public Health (Winkelstein 1996, Koopman 1996) focused on Mervin Susser's critique of epidemiology’s current focus on risk factors, or what he termed ‘the black box paradigm’. Susser and Susser

(1996a and 1996b) emphasized the need to attach epidemiologists to public health and called for a practical program to ensure that during their training epidemiologists would be socialized to keep the improvement of the public's health as a primary value. They emphasized the need to include faculty with experience in public health that embody “public health values”. Commenting on Susser's paper, Pearce (1996) argued that epidemiology must reintegrate itself into the practice of public health.

The American Journal of Epidemiology published another series of articles in 1997 and also discussed the failure of academic epidemiology to prepare students in public health by assuming that risk factors for disease in individuals could be summed to understand the causes of diseases in populations (Shy 1997). Another series of articles that appeared in the Journal of Epidemiology and Community Health in 1998 argued that epidemiology has historically found its equilibrium in the tension between the investigation for causal relations and the advancement of public health; emphasis on either perspective puts epidemiology at risk of losing its value (Porta and Alvarez-Dardet 1998). In 1999, a final series of articles which was published in the International Journal of Epidemiology focused on epidemiology's tensions: between methods and population health; between the biological and the societal; between integration and specialization; and between investigator-initiated research and research driven by population needs. It was argued that modern epidemiology is based on methods that are inadequate for studying population health and that the loss of the population perspective risks limiting epidemiology to a measurement tool for testing hypotheses developed by other researchers (Pearce 1999, Susser 1999).

In all these discussions, critics argue that epidemiologists often seem more concerned with modeling complex relationships among risk factors than understanding their origins and their implications for public health and doing something about health problems. These critics also argue that graduate students in epidemiology learn study design and methods for data analysis rather than how to generate hypotheses regarding the social dynamics of health and disease.

Of course, it seems hard to be against these arguments for an applied epidemiology and one can easily see the importance of an “applied” approach to epidemiological training. I would argue that there is nothing wrong with the “applied” approach, unless you focus on what it leaves out. The debate between applied and academic epidemiology overlooks one important aspect. There are alternative views among academic epidemiologists that address some of its limitations. Among them, we can identify the perspectives from Latin American Social Medicine, and more generally, what is known as “social epidemiology”.

Social epidemiology

Social epidemiology studies the social distribution and determinants of health status. It aims to provide information relevant to understand the impact of public policies on health inequalities (Krieger 2001; O’Campo and Dunn 2012). Its research focuses on social inequalities through the search for statistical associations between health status indicators (mortality rates, life expectancy, and cancer prevalence) and social structural variables (such as socioeconomic status, type of public policies, sex/gender, race/ethnicity). There are important similarities and differences between social epidemiology and its field- and applied- counterparts (Alvarez 2008).

According to Segura (2006), field epidemiology promotes action without reflection, restricting the opportunities for epidemiologists to ask questions about the problems they face. Social epidemiology, on the other hand, tends to emphasize reflection about the need to change, but it rarely translates into concrete action. They also are different in the level of intervention they tend to privilege. Field epidemiology intervenes at the microsocial level, controlling specific epidemiological outbreaks, while social epidemiology aims to intervene at the macrosocial level, influencing social inequality. Finally, they differ in the vehicles they use to communicate their findings. In general, social epidemiology does not communicate to wide audiences and its methods and findings are often hard to understand even for other epidemiologists. Field epidemiology is more often in contact with mass media and part of its daily practice includes communicating with the community.

Of equal interest are the similarities between field epidemiology and social epidemiology. Practitioners of both approaches are concerned with methodological rigor from a positivist epistemology, assuming there is an objective reality that can be measured and analyzed in ways that minimize the subjectivity of the epidemiologist. Moreover, both disciplinary communities base their knowledge on building statistical associations, although of different levels of complexity. Social epidemiology, for example, takes into account the individual, community and national level and does not rely on simplistic notions of risk factors, but in the end is based on more complex methods that look for statistical associations (Alvarez 2008). It is fair to say, however, that both field epidemiology and social epidemiology are in a process of epistemological opening (Segura 2006). Another similarity is their original interest in observation as the

source of their knowledge, although their analysis depends more directly from databases, sometimes alienating the analyst and the reality they study (Segura 2006, Alvarez 2008).

Finally, social epidemiology differs from what we could call the mainstream academic epidemiology in the purpose of its work and the level in which each imagines interventions. Mainstream academic epidemiologists portray the discipline as a scientific endeavor, and questions social epidemiology's lack of neutrality. It uses and develops complex statistical methods to study risk factors, usually at the individual level, and sees society as the addition of individuals. According to its critics, at least in the United States, it tends to be situated in academic institutions sometimes associated with biomedical hospitals, but not so much with public health departments. It has given rise to the term "clinical" epidemiology, to emphasize that it aims to contribute to research relevant to clinical practice.

It is also important to acknowledge the existence of "folk epidemiologies" (Nichter 2008), given that subaltern groups also develop their own ways of understanding health problems and their solutions. I will not address those epidemiologies in this chapter (refer to chapter 2), because my focus here is on epidemiology as a professional and academic discipline. However, I consider that any epidemiology that aims to be truly transformational needs to take into account the different subaltern epidemiologies present in its geographical area of work, because folk knowledge is usually generalistic in nature, which allows it to consider problems from more comprehensive perspectives that include the experiences of those who live with those problems.

In summary, we have identified different epidemiologies: field, applied, social, mainstream and clinical. This typology does not reflect that some epidemiologists and

institutions might use combinations of the different approaches. However, the typology allows us to analyze the situation of epidemiological practice in Guatemala, and helps us advance towards my goal in this chapter of identifying the ideologies of epidemiology as a means for understanding epidemiological practices in emergency and normal times.

Epidemiology as cultural practice

Epidemiology can be analyzed as a cultural practice. It gives a common meaning to epidemiologists' everyday work and, at the same time, they re-create it in diverse ways through their practice. Epidemiology is constantly influencing and being influenced by social life beyond its own disciplinary and professional boundaries. Power relations at the micro- and macro-social levels shape the flow of cultural discourses and practices within epidemiology. From our overview of the recent history of epidemiology in Guatemala and how it is linked to broader discussions within the discipline of epidemiology, we can identify "field" and "applied" epidemiology as part of the competing discourses that shape the discipline of epidemiology. I propose to look at epidemiology using the relationship between culture, hegemony and ideology as presented by Jean and John Comaroff's understanding of Antonio Gramsci and Raymond Williams. In this way, we will be able to look at ideological and hegemonic discourses that shape the culture of epidemiology in Guatemala.

Gramsci sees culture as "the shared repertoire of practices, symbols, and meanings from which hegemonic forms are cast – and, by extension, resisted" (Gramsci 1971). In this sense, he characterizes "culture as totality". Applying this notion to our study of epidemiology, we would see epidemiology as a subset of practices, symbols and meanings that deal with health, disease and its distribution. So, when I propose to look at

the culture of epidemiology, I am not suggesting to look at it as a coherent and closed system of ideas, behaviors and tools, but rather, to look at it as part of that totality suggested by Gramsci. It is within “culture as totality” where the dialectics of domination and resistance take place, between competing and historically situated discourses and practices. Hegemony and ideology are the ways in which those discourses and practices compete. Hegemony and ideology are “the two dominant forms in which power [...] is entailed in culture”. (Comaroff and Comaroff 2002: 209)

Hegemony refers to the practices, meanings, symbols and epistemologies that have come to be understood as a given, as the way things naturally are. If we go back to the different epidemiological approaches presented above, we can identify several hegemonic features shared by all those epidemiologies. The positivistic epistemology and the dependence on statistical associations, for example, is taken as a given in epidemiology. If we situate our analysis in Guatemala, we see that field and applied epidemiology are hegemonic there. Their underlying assumptions and implications are seen as shared and are not normally questioned. If they became questioned, they would stop being hegemonic and would start being one of the competing ideologies.

Ideology, on the other hand, is a relatively coherent system of “meanings, values, and beliefs of a kind that can be abstracted as [the] world view of [a] social group” (Comaroff and Comaroff 2002: 210). This world view, although relatively coherent, is in reality heterogeneous because different social groups have the capacity of perceiving and ascribing different meanings, values and beliefs to the social world. Subaltern groups also create and recreate ideologies. Ideologies are susceptible to being perceived as an issue of adverse opinion – an opinion against something – and of particular interests and are

therefore open to contestation. Hegemony is naturalized, but when it is questioned, it opens up the opportunity for a reconfiguration of the discourses and practices of interest. In the case of Guatemalan epidemiology, attempts to incorporate the discourses and practices of academic or social epidemiology would likely be seen as ideological, while the practices and discourses of field and applied epidemiology would be seen as the natural way to go about epidemiology.

Given that field epidemiology is the hegemonic form of epidemiology practiced in Guatemala, it has the ability to shape the subjectivities of those who practice it. It also shapes the debates around the origins and distribution of health and disease, and therefore, the solutions that can be envisioned. The practices, meanings and symbols associated with field epidemiology become associated with epidemiology as a social practice. They also influence the ways in which epidemiologists think about their own work and what differentiates it from other forms of work related to public health.

Identity Boundaries

In 2003, the Department of Epidemiology of the Guatemalan Ministry of Health published the revised version of the Epidemiological Surveillance Protocols for Guatemala. It was a significant achievement given that the latest version was from 1988 and in reality there was no national unified criteria on the actions to detect and control epidemiological outbreaks in the earlier versions. The publication of the protocols reflected the growing technical capacity of Guatemalan epidemiologists and the priorities of the Ministry of Health and international agencies supporting its work, such as the Pan American Health Organization and the Centers for Disease Control and Prevention.

The 275-page document devotes most of its content to detailed information about the definition of 29 health problems considered national priorities and the actions to prevent and control them. Of particular significance is the “editorial” presented on page 3 of the document. It is a reproduction from “Los Ecólogos de la Salud” (The Ecologists of Health), an epidemiology book by Rodolfo Carcavallo and Ana Rosa Plencovich, published in Venezuela in 1975.

The book is not widely known in Guatemala and the diffusion of the excerpt that was reproduced in the Protocols began in 1998, when Cuban epidemiologists arrived as part of the humanitarian aid by the Cuban government to respond to the disaster caused by Hurricane Mitch. The excerpt does not talk about the approach to health by the Cuban revolution. Instead it portrays epidemiologists as Quixotic figures whose importance is hardly acknowledged by anyone else. The appearance of this excerpt in arguably the most important publication by Guatemalan epidemiologists in the past 25 years, talks about the identification they felt with the portrait presented by the text.

Figure 4. The Ecologists of Health

“We once defined the epidemiologist as the ecologist of health. Also as a Quixote with a jeep as a hack and a syringe as a lance. Charged with curing the afterpains that nature (or more frequently man) causes to human health. It is he who must know the multiple circumstances which result in the loss of the level of health, and also propose, supervise, normalize, execute or evaluate solutions to sanitary problems. [It is he] who must be attentive and vigilant to ecologic realities, changes and tendencies that influence endemic or epidemic disease modalities. Always with the technical response to the authorities’ consultation, [he] will witness how often responses are different from those suggested by him, knowing that sooner or later they will again request his knowledge to correct what went wrong; but it will be too late and he will more likely be made responsible for the failure. And regardless of [his] ability and the [profession’s] prestige, [he] will have to endure the injustice without complaining, because [he] depends on [his] salary, doesn’t have a private practice that allows [him] to face with disdain the undeserved criticism. When [he] carries on [his] studies at [his] office, physicians from other specialties call him, with scorn, “paper-doctor” [médico papelero]; when [he] works at the lab, everybody asks him what he is doing there if [he] is not a bio-analyst; when

[he] carries out [his] field investigations he is accused of going as a tourist; when he presents geographic, climatic, sociologic, cultural or political projections, he is criticized for using those disciplines without being a specialist in any of them.

That's how we see them in institutions, labs, jungles and deserts, with test tubes, serums, calculator, containers with insects, syringes, vaccines and forms [planillas]. Wandering. No one remembers him, unless [there is an] emergency. Nevertheless, [he] provides the foundations to the totality of existing sanitary programs. Every once in a while, a Minister or director will tell [him] how important his job is, but nobody, not the unions or the professional associations that forget he is a colleague, will be concerned about [his] working conditions, the time [he] spends away from family, [his] low and insufficient salary, the archi- exclusive commitment [he] has to devote to [his] task. That is mainly what explains why there are so few "serious" epidemiologists. In return for the habitual unpleasantness, [he] will know the world and its people, environment and human conditions that others read in books or watch in movies. But evidently, the Ecology of Health, or Epidemiology, has to have something so that there [still] are professionals who after spending twenty years between primary and secondary school and university studies, commit to it.

Giving up many comfort goods, [to] the economic sufficiency that private practice can give, to the "thank you doctor" that comes with a champagne box or a Chinese jade statue, attached to the check with which the healing of a relative is paid. Yes, the ecology of health has something. It is the most exciting of medical specialties. Also, we cannot deny it, the most pedantic. Because its mission is explaining everything, preventing everything, well, knowing everything. The epidemiologist – ecologist of health – is a Quixote, what we have said is not to arouse pity for him. On the contrary: he is the happiest of paranoid doctors, he is the most paranoid of happy doctors, he is the most doctor of the paranoid happy. [He] is happy in the middle of anguish, among limitations and frustrations. Because discovery is [his] routine, the epidemiologist who does not discover anything cannot be one, [his] life is investigation and everything else is secondary. That is why [he] is pedantic, sometimes unbearably [pedantic]. Now, let's try to approach this exciting erudite, totalitarian and quixotic discipline. Let's try to understand it, comprehend it and forgive it. Forgive it for that pedantry that, as we said before, attempts to sum up the infinite.

Translated from CNE 2003:3

There are five characteristics that emerge from this portrait of epidemiologists: commitment to the search for truth, the scientific-technical character of their work, fieldwork as a key component, differences with other health professionals, and the lack of recognition for their contributions. It portrays, in other words, the epidemiologist as a Quixote.

In this self-portrait, epidemiologists present themselves as idealists on a quest for the truth, for which they will get no recognition. In order to carry out this quest, the self-portrait goes, they renounce economic retribution and social status while they embrace scientific-technical knowledge and methods regardless of their consequences, and they go to remote places to carry out important investigations. Such is the payoff for understanding better than anyone else the nature of health problems. Epidemiologists' work is presented as truly quixotic. This portrait is compatible with field epidemiology. I can see a relation between the epidemiologist-Quixote and the worn-out shoe sole, the symbol in Guatemala's epidemiology logo, a logo explained in the next chapter. The shoe sole would be a result of the unlimited dedication to seeking truth with no social and economic recognition, the kind of dedication that the different epidemiologists portrayed in this dissertation showed when we were implementing the protocols and guidelines to respond to the different outbreaks. If the protocols were aimed at unveiling the causes of the outbreaks, they would truly have been on a quixotic quest. But rather than explaining what causes the outbreaks, the protocols are guidelines to document the outbreak and record some of its characteristics.

The portrait also draws some professional boundaries. First, it identifies the epidemiologist as a physician, but as an awkward one, who is tangentially interested in the social sciences and who will never enjoy the rewards – economic, humanistic and social - of clinical work. Second, it presents epidemiologists as powerless quasi-scientists who are always subjected to the decisions of those making the political and administrative decisions, that is, politicians and other public health specialists.

The definition of professional boundaries is unclear in the case of Guatemalan epidemiologists, given that they are not that many and it has been a little over a decade since the first programs started to train considerable numbers of them. As a result, the definition of those boundaries is not yet legitimized by institutional or national laws, or by any professional society. Epidemiologists' boundaries are in the making in Guatemala, and this process can be analyzed through the lenses of identity and boundary formation, as a means for understanding epidemiologists as experts.

Epidemiology as profession

Epidemiology can be understood as a profession, which is the “fulltime pursuit by an individual of a specialized skill, usually for pay by customers or by an agency that buys the skills of the professional” (Freidson 1988:185). Professionalization is a process in which certain social mechanisms are set up to ensure the place of a particular group of experts in a social practice. Those mechanisms are aimed at defining the distinctive subject matter of the emerging profession, securing its place in specific institutions and legitimizing certain professions while de-legitimizing its competitors. Examples of these mechanisms are found in the rise of medicine in the United States (Starr 1982, Loustaunau and Sobo 1997), the process of a distinction between physicians and “paraprofessionals” (Freidson 1988), the emergence of dietitians (DeVault 1994), genetic counselors (Rapp 1999) and sonographers (Taylor 2008).

The process of professionalization is still incipient for Guatemalan epidemiologists. The formal mechanisms – professional associations, legislation, institutional regulations and so forth - that will define epidemiology as a profession are not yet set up, and epidemiologists have not yet defined what those mechanisms will be.

Epidemiologists are not yet recognized in the institutional definitions of the Ministry of Health and it is unclear if the emphasis on epidemiology that some public health Master's programs have, count as epidemiological training. On the other hand, epidemiologists trained through the FETP are trained in the operational aspects of their fieldwork, but do not pay attention to notions of public health and its broader issues. This explains in part why they do not yet have a professional association.

Given the incipience of the process of Guatemalan epidemiologists' professional definition, I propose to use the analytical concept of boundaries, just as Fredrik Barth used it to study Norwegian private firms. Barth (1969) argued that identity was chiefly a social and political, rather than a cultural phenomenon. "It is the boundary that defines the group, not the cultural stuff that it encloses" (1969:15), that is, group identities and boundaries are defined based on the relationship between groups, not the culture of groups. Those relationships are what give meaning to the boundaries. Given that there are differences within groups and similarities between groups, what matters when one is studying them, is that they perceive themselves as different and interact on that assumption. As with epidemiologists, the symbols used to define ethnic identity and ethnic boundaries have a dual character; they are at the same time emotional and political.

Here, we can see that some of the differences between field epidemiology and applied epidemiology become important in Guatemala. Given that the presence of academic epidemiologists, or social epidemiologists is marginal in the country, differences between non-academic approaches seem more important. Applied epidemiologists are thought to see themselves as part of the public health system and their work as providing input for public health decisionmakers. This translates to

curricula that studies public health principles, including public health management. It also translates to more hours spent in a classroom (MSP 2000, MSP 2007). Field epidemiologists, on the other hand, spend less time in a classroom and focus on data collection and analysis, as well as epidemic outbreak control. They become very fluent in the intricacies of data collection and analysis but learn less about broader public health issues and management (CNE 2007). While those who study at universities get a master degree in public health with emphasis in epidemiology, the FETP is a pyramidal program in which most of its alumni do not have the master level, however skillful they are in collecting and analyzing epidemiological data. Field and applied epidemiology are still very similar, and the worn-out shoe sole still represents their orientation to work in the field, solving real-life problems. They share their epistemological perspective and statistical methods, as well as the general purpose of their work, focused on solving short-term problems. However, when it comes to defining the profession, tensions arise, perhaps because the professional characterization will define the legitimacy of each approach and its usefulness to gain access to institutional resources.

As Anthony Cohen (2000) points out, the definition or ascription of a group's identity may be the subject and outcome of a cross-boundary struggle for control. It is in cross-boundary relations that identity becomes explicitly contingent, when people on either side of a boundary see different issues as being at stake. Although I am not sure that there is an ongoing struggle between field and applied epidemiologists, informants I spoke with pointed to tensions when it comes to define who should get the important institutional positions. These processes, together with the symbolism of having been trained by the CDC's FETP versus the symbolism of having earned a master degree in a

Guatemalan university play out in the ways epidemiologists conceive themselves as a collectivity. Practitioners of both applied and field epidemiology share a lot and are different only in very specific aspects of their training. I speculate that if there were an outspoken group of social epidemiologists or academic epidemiologists, the similarities between field and applied epidemiologist would bring them together. However, because such a group does not exist, their differences become important in situations in which control over resources is at stake. Therefore, it is useful to understand the qualitative character of social boundaries, and to show how they are implicated in the formation, articulation, management and valorization of collective identities.

But it is equally important to remember that marking a distinction does not necessarily involve drawing a boundary (Barth 2000). Distinctions and boundaries are often assumed to separate the entities they distinguish, but they also connect them. The ways in which Guatemalan epidemiologists define their identity also highlights how they are connected to those from which they want to differentiate themselves. Let us take a look now at other groups with which epidemiologists relate when defining the boundaries of their discipline and profession.

Blurry boundaries

Epidemiology has blurry boundaries. These boundaries change depending on the perspective of who defines them. First, epidemiology is often seen as equal to medicine or part of it. This makes sense, since epidemiology is one of the disciplines that feed medical practice and in most of the world the majority of epidemiologists are physicians by training. Moreover, from a historical point of view, epidemiology is a discipline derived from medicine in many ways. Most medical descriptions of diseases begin with

an epidemiological description and most physicians are trained to take into account epidemiological considerations when facing a clinical problem. However, most epidemiologists I know distance themselves from physicians and explicitly mention that epidemiology tries to look more broadly at health problems instead of the reductionist view offered by biomedicine.

Second, epidemiology is equated to or part of public health. The reasons are similar to those presented for medicine: epidemiology and public health share a common origin as disciplines and often epidemiology and public health academic programs are part of the same department or school. However, there are some classic distinctions public health practitioners make between those devoted to epidemiology and those devoted to health services. Moreover, in some places there are more subdivisions among public health practitioners, such as environmental health and occupational health. Traditionally, epidemiologists are portrayed as those who go to the field and then immerse themselves in paperwork, statistics and numbers, while health services specialists deal with programmatic decisions, budgets and the general administration of public health services (Buck et al 1988).

Third, epidemiology and social sciences have been interested in the social aspects of health problems at least since the 19th century. Most contemporary epidemiologists would not consider themselves to be social scientists and most social scientists working on health related issues would not consider themselves epidemiologists. However, physicians sometimes refer to epidemiology as closer to the social sciences because its practice is generally concerned with the social world more explicitly than physicians'

practice (Buck et al 1988). In addition, there are academics that bridge the gap between social sciences and epidemiology because they have been trained in both.

Finally, institutional affiliations and work assignments also play a role in epidemiologists' identities and boundaries. Epidemiologists working at public health institutions in Guatemala see themselves as different from those who work for NGOs or universities. Moreover, people who do epidemiological work without having epidemiological training, like Tomás and me in the Rotavirus outbreak described in the following chapter, are in an ambiguous position. For example, in Seattle-King County Public Health, the positions of epidemiologist 1 and 2 are filled by people with no formal training in epidemiology, public health, nursing or medicine (perhaps something equivalent to Tomás). Their job – after a certain amount of on-the-job training - consists for the most part of performing surveillance and disease control activities.

I have argued so far that in order to understand epidemic emergencies, anthropologists need to study the work of epidemiologists in normal times and specific contexts. I also have argued that in order to understand normal epidemiological work, it is necessary to look at epidemiology as the product of constantly competing discourses and practices situated in space and time, rather than looking at it as a monolithic discipline. Only in this way, one can begin to understand what shapes the responses to epidemiologic emergencies. In Guatemala's case, current epidemiological practices, such as Dr. Zecena's response to the swine flu outbreak, or as the visit Tomás and I made to Chuisacabaj are framed by the hegemonic status of field and applied epidemiology and the marginality of academic or social epidemiological approaches to health problems.

The consequences of the resulting configuration of epidemiology in Guatemala are illustrated in the following section.

Epidemiological knowledge in Guatemala

If we go back to our definition of epidemiology as the study of the origins and distribution of health-related events in specific populations and the application of such study to the control of health problems (Porta 2008), we can examine how this study is made by epidemiologists in Guatemala. I will start by presenting two recent examples of the products of Guatemalan epidemiologists' work. By using these examples, I want to illustrate the shortcomings of applied and field epidemiology when it comes to analyzing health problems or Guatemala's health situation. In my view, these shortcomings originate in the lack of attention to statistical associations as academic epidemiology would suggest, and to the total omission of health inequalities, as social epidemiology would urge.

Example 1. Analysis of maternal mortality

Maternal mortality is one of the most important problems in Guatemala. In 2001, there was an investigation to try to understand the magnitude of the problem and its main characteristics. Assuming there could be underregistration of maternal deaths, every woman between 15 and 49 years old who had died in 2000 was identified as a possible maternal death, and their families were visited. It was a tremendous effort to carry out this research and in the following years, there were different analyses of the data collected. In an article by a group of epidemiologists (Tzul et al 2006) they found that:

“Although some characteristics of intra- and extra-hospital [maternal mortality] cases are similar, a greater proportion of deaths were extra-hospital. This could be

related to the high percentage of the population that lives in rural or marginalized areas, which in addition to certain cultural aspects (related to the fact that most of the population is indigenous) may impede access to health services. The results of this study can be useful for determining intervention strategies to prevent maternal mortality in intra- and extra-hospital contexts in Guatemala.”

This text makes implicit assumptions about indigenous people having cultural aspects that constrain access to facilities. Given the inaccuracy of that assertion, very close to a racist statement, I looked for the supporting evidence in the article. I could not find such evidence. But I did find in the discussion section a paragraph that shows clearly the logic behind that conclusion. I quote:

“Among the findings it stands out the fact that indigenous women are – both for hospital and non-hospital deaths – the most vulnerable group. In Guatemala, the Indigenous population is 48% of the total population, and it lives in rural areas or marginal areas of the important cities; it predominantly presents extreme poverty and low education levels, which are factors that, in combination with other disadvantageous cultural aspects of indigenous people, are limitations for access to health care facilities, all of which makes them a high risk group. Regardless of the actions undertaken to improve those women’s health, this group remains behaving as the one with the highest risk. Reducing maternal mortality in this group is a goal with a high level of difficulty in countries like Guatemala, where cultural aspects usually are important barriers to overcome”.

This paragraph presents a stereotypical characterization of Guatemala's indigenous people, so often assigned as taken for granted that they are not even explored in public health or medical analyses. In addition, it states that indigenous women "remain behaving" as a high risk group "regardless of the implementation of actions" because they are poor, uneducated and bearers of "other cultural aspects". The article cites three references to support these assertions, but they do not touch the topic of culture. Furthermore, the methods used in the work presented in this article did not approach culture at any time, which makes the prominence of culture in the discussion and conclusions even more surprising. One would expect that the positivistic epistemologies privileged in this publication and the discipline of public health it represents require showing data to support assertions. That is not the case in this article. The lack of evidence in which its conclusions are based has a double effect: it hides its own results and it reproduces racist stereotypes.

What I see at play here is a combination of lack of epidemiological concern for understanding health inequalities, combined with racial stereotypes prevalent in Guatemalan society. I would argue that, if epidemiologists involved in this analysis had some exposure to the tenets of social epidemiology, they would have at least not used racist stereotypes to explain their statistical findings. The lack of theories did not allow them to explain their findings.

Example 2. Health situation analysis

In 2007 the Guatemalan Centro Nacional de Epidemiología published its guidelines for health situation analysis (CNE 2007a). The publication of the guidelines is justified because it is necessary to know more accurately the health situation of

Guatemala in order to make informed decisions that will impact the health situation of Guatemalan inhabitants. The 109-page document does not say a single word about health inequalities, or about the triple axis that explains most of them: sexism, racism and classism. The 23 cited references address specific issues about indicators and evaluation of health care programs and public health programs. They do not address societal health and its origins. They do not talk about interethnic relations or gender inequality, which have been the central focus of most social research produced in Guatemala in the last 15 years, reflecting some of the more prominent concerns in post-war Guatemala. They do not even cite the Pan American Health Organization's documents about the social reproduction of health, which were prominent during the 1990s.

They do explain in very specific detail about the process of transforming "data" into "information", so that it becomes "knowledge" that will inform "decisions" that will translate into "actions". Apparently, the process involves, for the most part, some number tweaking and registration on the proper forms. There are not published reports using these guidelines, to be able to assess the kind of health situation they end up portraying, but there is a report produced by the same institution that created the guidelines (CNE 2007b), that analyzes the health situation in Guatemala in 2007.

The 90-page report is a collection of statistics, maps and graphs of several of the main epidemiological problems in Guatemala, as defined by national and international epidemiologists, including groups of symptoms such as diarrhea and pneumonia, specific diagnoses such as cholera or influenza, problems prevented by specific interventions such as diseases preventable through vaccination, and specific policy priorities such as maternal and child mortality. Again, there is no mention of health inequalities or the

social and economic origins of health problems. It is a good piece of work, but limited by the scope of the frames of reference and the kind of information allowed to be included in it. I have heard talks by some of its authors and I can attest to their being conscious of the social aspects of health problems in Guatemala. However, their report not only does not address health inequalities as social epidemiology would suggest, but it does not analyze statistical associations as academic epidemiology would. So, the risk factor model is not even presented.

Finally, the United Nations Development Program in Guatemala published in 2008 a collection of studies about the Guatemalan health system. One of the books included in the collection was about the epidemiological situation and two renowned epidemiologists authored it (Moscoso and Flores 2008). The 75-page document includes interesting and appealing graphs, charts and statistics and it reflects a high degree of dedication and professionalism. However, it has the same general characteristics I pointed out for the 2007 health situation analysis report. The social aspects are absent and there are not even statistical associations linked to risk factors.

Summing up, the examples presented in this section point to the problematic role of epidemiologists when it comes to defining and explaining Guatemala's health problems. Having an opportunity to explain the complexities of maternal mortality (Tzul et al 2006), they choose to blame it on indigenous women's culture. When they have the chance to analyze Guatemala's health situation (CNE 2007a, CNE 2007b) they decide not to talk about who are suffering poor health and who are not. When they are faced with the challenge of presenting the key epidemiological aspects of Guatemala's reality (Moscoso and Flores 2008), they do not make any connections between the social,

economic and political spheres and that of health and health care. Is there anything quixotic about these choices? Do they only reflect the timidity of a discipline unwilling to assume its emancipatory potential?

If Guatemalan epidemiologists' work during normal times does not pay attention to the social differences that lay beneath health problems, and they do not address the social aspects of these problems, I would argue that the same shortcomings are present in their approach to epidemic emergencies, as illustrated by my own experience with the rotavirus outbreak in Chuisacabaj. Are Guatemalan epidemiologists quixotic as the 2003 protocol editorial suggests? Or are they just timid with a worn-out shoe sole?

Timidity as a survival strategy

During the time of my fieldwork one of the most contentious issues in the country was, (and it persists to the time of this writing) the opposition by people living in rural communities where the Guatemalan government has authorized mining exploitation projects of transnational companies, with the Government always taking the side of the companies and dismissing community consultations rejecting the projects as well as ignoring community concerns for the health impacts of mining. Several of such projects – and the corresponding community opposition – were (and still are) in the departamentos of Huehuetenango and San Marcos. When I interviewed one of the epidemiologists in that region, we had the following exchange:

ALEJANDRO: How do you compare what you learned when you study epidemiology and what you do as an epidemiologist?

EPIDEMIOLOGIST: Well, the main difference is that, for instance when there is an outbreak and we go to the community, we sometimes are not allowed to get blood samples. And when people say no, it's no, you know. Maybe it's the culture, at least here...and we have personnel [whose first] language is the same [as the people in the community]. Yeah, that's the main difference. We can't just go to the community and start applying the steps of an epidemiological investigation or outbreak control. Sometimes the communities will not let us do our work, and if we would insist it could even be dangerous [for us].

A: Does the same kind of thing happen elsewhere? I mean, you are telling me sometimes the communities don't let you do epidemiological work, but does it happen also. For instance, if there is an outbreak in a restaurant, can you just go...

E: I can't remember a case with a restaurant, but I remember one at a private hospital, during the times of H1N1, and the hospital owner would not let us go take samples, until he finally accepted because of all the media talk about H1N1 and all that.

A: And how about the mining projects? You know, there is a lot of talk about the health effects...

E: Yes, there has been a lot of talk and people talk to us as well. So a few months ago some of us at the [local Ministry of Health office] started talking about going and collecting some samples and everything... but our supervisor told us not to even think about it because, as he put it, we would be touching very powerful people's interests and our lives could be in danger...

A: In danger? Meaning...

E: Yes, there are a lot of *narcos* in the region, and *ganaderos* (cattle owners), and others that may use violence... I mean, that's the kind of thing everyone knows about but nobody wants to talk about.

This conversation made me realize that any analysis about the emancipatory potential of epidemiology, or about its timidity, plays out very differently in a post-colonial context of weak institutions and weak rule of law, where people do get killed every day and in more than 90% of cases, the crimes will never get solved.

Chapter 4: Epidemiology as Bureaucracy

It was in 2006, when the rapid response unit was created, and the CNE did not even really exist [it was in the process of being created], I think it was the next day after me and my colleague were appointed to the unit – the unit was the two of us – and we received a direct order from the director of health care programs, our boss, to go check out a hepatitis outbreak in the Ministry of International Relations building. So we rushed to get there and we were all excited and we only found one case! The outbreak was of just one single case, can you imagine? And there we were rushing to get there and reviewing the protocols and everything. [But what had happened] was that six co-workers of the guy with hepatitis started to think they might also have hepatitis, and wondering if things they were feeling were actual symptoms, but they did not even have any real symptoms! But also what had happened was that the Minister of International Relations was informed about the supposedly ongoing outbreak, and he called directly to the Minister of Health, and he called my boss who sent my colleague and me. That was my first case of “political outbreak”, and there were many to come [together with real outbreaks, of course]. [...]

I remember another one, and I went on my own to this one. It was near Puerto Barrios [...] in a [relatively isolated] village, with people who only spoke Q'eqchi'. Well, there was a guy there, who claimed to be a teacher and also acted as the village doctor. This guy traveled frequently to Puerto Barrios [the

department's capital city], for his business, and he also had other kinds of interests [maybe political or who knows what]. So this guy talked there to a [local T.V. news station] and said that in his village, there was an outbreak of hemorrhagic conjunctivitis, and that there were kids dying of it. So because it was on the news, I received a call that night at ten saying "tomorrow very early in the morning you are going to Puerto Barrios." Luckily I had an institutional car designated for that kind of purpose, so I left at 4:30 to Puerto Barrios and picked up [a local ministry of health worker] and we went to the village. Luckily, there was nothing. It was just made up by this guy, and before coming back I even had to talk with the press to tell them the truth, and at five, I started back because I had things to do the next day. And that's how it was. Of course there were also real outbreaks, so we were very busy, so busy that we were able to hire a third epidemiologist. [...] But then, without an explanation, because of political pressures I don't want to talk about, one of my colleagues was moved to a different unit, and the other colleague did not get her contract renewed, so all of the sudden, the unit was just me. And a few months later, I was moved to where I am now [epidemiologic surveillance] and nobody was appointed to the rapid response unit. So you can see there [he points to a nearby door], there is the sign "Control de Brotes" [outbreak control] it says, but nobody does that work anymore. And it is a huge loss, because there was always one or two of us traveling investigating outbreaks, and sometimes the three of us were in different outbreaks. [...] And I think people all throughout the country resent that now they don't get this kind of support from the CNE. . (Epidemiologists at CNE)

A recent history of epidemiology in Guatemala

Epidemiological practice has been an organic part of the Guatemalan Ministry of Health for a long time. The Ministry of Health was created in 1945 and it included an Epidemiology Section, which was upgraded in 1980 to become the Disease Surveillance and Control Division. Ministry of Health officials with job training but no academic specialization carried out epidemiological work. They worked under the supervision of physicians with no academic training in epidemiology. There were some exceptions, cases of epidemiologists with degrees earned in foreign universities, but as a general rule they did not work for the Ministry of Health.

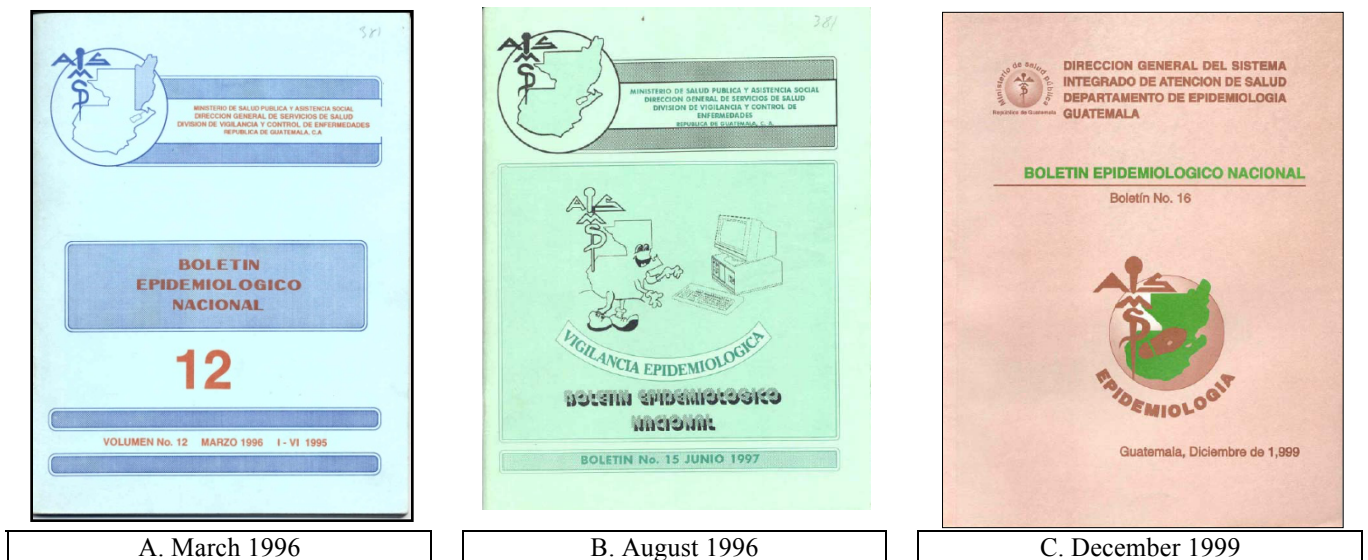
The turning point towards the practice of a “modern” epidemiology was 1990, when eight Ministry of Health officials were part of a Master Program in Public Health and Epidemiology, sponsored by the Pan American Health Organization and carried out by its Instituto de Nutrición de Centro América y Panamá (INCAP). In 1996, the Sistema de Información Gerencial en Salud (SIGSA) brought up-to-date computerized technology to the Ministry’s information system.

The influence of these institutional changes on epidemiological practice can be traced through epidemiologists’ self-representations in the design on the covers of the National Epidemiologic Bulletin. The Bulletin has been around for decades, but the earliest available cover dates from 1989. All covers prior to 1996 have the same design showing the Ministry of Health’s logo, the institutional identification and the bulletin’s volume and number (Figure A).

Starting in 1996, there is an addition to the covers: a drawing that was different on each issue but that invariably represented computers or statistical graphs or both (Figure B). The content of the bulletin also reflects changes, showing relatively sophisticated

analysis and the use of personal computers to present charts and graphs. These changes show the beginnings of epidemiologists differentiating themselves from other Ministry of Health officials. But there was a more relevant change in 1999 (Figure C). The cover now has as a central motif the new epidemiology logo, which consists of the old Ministry of Health logo with a single addition: a worn-out sole footprint on Guatemala's map. This logo is still used today by epidemiologists in Guatemala and it adorns the pages of every report, bulletin or guidelines document they have produced since then. It also shows up on shirts, mugs, baseball hats, shoulder bags, educational campaign materials and so forth. But what does that footprint add to the definition of epidemiology in Guatemala?

Figure 5. Covers of the Guatemalan's Ministry of Health's National Epidemiologic Bulletins of March 1996, August 1996, and December 1999

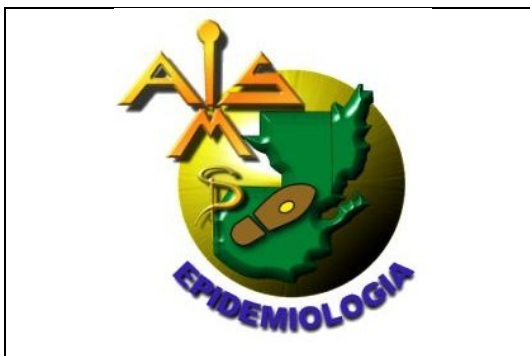


The worn-out sole footprint on Guatemala's map in the logo was introduced in 2000. This footprint is internationally recognized as the icon of the Epidemic Intelligence Service / Field Epidemiology Training Program (EIS/FETP). A milestone in the development of epidemiology in Guatemala was the devastation produced by Hurricane

Mitch in 1998 and the response that followed. Part of that response was the support of the EIS/FETP of the United States' Centers for Disease Control and Prevention (CDC).

The Epidemic Intelligence Service (EIS) of the CDC is a training program with origins in the 1940s as an effort to control and prevent malaria among the United States' armed forces located in South East Asia. In the post World War II period, the menace of biological warfare was recognized by U.S. officials who considered that the best defense against this danger would be the availability of applied epidemiologists who could investigate potential threats. This turned into the beginning in 1951 of an EIS training program in applied epidemiology that has developed throughout the years. The idea is that "epidemiology is best learned by working on epidemics in communities as they occur, initially with close supervision from an experienced epidemiologist" (CDC 2009).

Figure 6. Logos with the worn-out sole footprint.



Logo of the Epidemiology Department at the Guatemalan Ministry of Health (CNE 2003)



Logo of the CDC's Epidemic Intelligence Service (CDC 2009)

The success of this program and the need for trained epidemiologists in other countries led to the creation of the Field Epidemiology Training Program (FETP) in 1979, with strong support from the World Health Organization's South East Asia Regional office in India. The first FETP was started in Thailand and by 2000 there were twenty programs located throughout the world, one of them in Central America.

The Central American FETP started in 2000 as an element of the response to the damage produced by Hurricane Mitch in 1998. Its goal is to build public health epidemiological capacity through training personnel to become leading field epidemiologists and by strengthening disease surveillance (López and Cáceres 2008). It currently has a presence in Costa Rica, the Dominican Republic, El Salvador, Guatemala, Honduras and Panama.

Table 7. Students graduated from the FETP in Guatemala (2001-2010)

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
Advanced	3	2	2	4	0	0	5	0	6	0	22
Intermediate	19	19	19	16	29	25	0	25	18	0	170
Basic	148	146	120	100	140	120	0	172	0	20	966
Total	170	167	141	120	169	145	5	197	24	20	1158

In other words, the inclusion of the worn-out sole footprint on Guatemala’s map in the Department of Epidemiology’s logo links it to the practice of “field” epidemiology. More than one thousand Guatemalan epidemiologists (Table 7) have been trained through the Field Epidemiology Training Program (FETP). In fact, every single epidemiologist I interviewed mentioned the FETP, and the CDC’s Central American Program (CDC-CAP) as one of the most positive hallmarks in Guatemala’s recent epidemiological history because it has brought a massive professionalization of epidemiological practice, access to CDC’s technology, as well as a network with epidemiologists from other CDC programs. On the flip side, the CDC-CAP has made more visible some of the handicaps of Guatemalan epidemiology and the public health system in different ways. First, there has been some tension around who defines the agenda and the priorities in terms of training, funding and programs. The CDC-CAP responds to the CDC’s priorities, which do not necessarily match the Ministry of Health’s priorities. Although the people at both

institutions make efforts to coordinate and collaborate, those efforts are constrained by the institutional agendas. Second, although the CDC-CAP and the FETP are meant to help strengthen Guatemala's epidemiology, there has been "internal brain drain" from the Ministry of Health to the CDC-CAP. Several factors have influenced this tendency; the main one seems to be that the volatility of the political environment at the Ministry of Health has interfered with the research, training and programmatic agendas of the CDC-CAP and, in fact, of the CNE. Some of the most renowned epidemiologists have left the CNE for the CDC-CAP and, to be fair, other international organizations. Finally, the priorities of epidemiological work have been shaped by this institutional duality, as one of the historic epidemiologists put it:

"In Guatemala we do not have epidemiologists. What we have are "brotólogos" (which I would translate as "outbreakologists"). They only focus on responding to outbreaks and not on analyzing the health situation or defining a research agenda to improve our understanding of our health problems." – And why is that, I asked. – "It all started with the CDC... they train us to study outbreaks and they do the research according to their priorities... but it is not their fault. We are to blame because we do not prioritize creating our own epidemiological knowledge..."

But not all epidemiological training in Guatemala is through the FETP. As I mentioned before, eight epidemiologists were trained in the 1990s through a Pan American Health Organization (PAHO) sponsored program. Also, around the turn of the century two universities started offering public health master's degrees with an emphasis in epidemiology. These programs were also supported by PAHO, were catered to train

Ministry of Health officials who would undertake epidemiological tasks and they all have an emphasis in “applied” epidemiology. An epidemiologist at CNE, with a Masters in Public Health (rather than one of the FETP certificates) told me in reference to the FETP-trained epidemiologists: “They are like epidemiology *maquilas*. They are data *maquilas*. In public health, we see more, we look at the context, we offer a stronger analysis.”

However, this is not to say that PAHO’s influence is free of contradictions with the strengthening of Guatemala’s epidemiology. For instance, in May 2011 the annual epidemiology meeting organized by the CNE had as one of its speakers a PAHO official whose talk was directed to push the CNE and regional epidemiologists to prioritize the implementation of the International Health Regulations (IHR), the international legal framework that prescribes required actions from all World Health Organization member states to prevent and respond to pandemic emergencies and bioterrorism threats. It was evident to me that this was not a priority felt by most of the epidemiologists in the room, who had been talking about maternal mortality, response to disasters, hospital infections in newborns, dengue, as well as about problems with their information system and access to laboratory tests. The PAHO official was, of course, doing his job and even helping the Guatemalan government fulfil its international commitments, and the IHR are not a bad thing to promote. But what was striking to me was the tension between institutional priorities and epidemiologists’ priorities, and how they both were essentially removed from what I would think as a right to health agenda.

It can be seen, therefore, that epidemiology-training programs in Guatemala do not have more than ten years in place, and their approach is either “field” epidemiology

or “applied” epidemiology. But, what does that mean and what other forms of epidemiology does it leave out?

The National Epidemiology Center (CNE)

Dr. Celso Cerezo, then-Minister of Health, in a press conference on May 5th 2009, announced the first confirmed case of swine flu in Guatemala. The government declared a state of emergency and public debate centered on the kind of measures that needed to be taken to control the spread of the virus. Churches, sports events and businesses worried about the potential impact that radical measures such as those taken by the Mexican government during the previous week could have on attendance and earnings. The public media was filled with news about the spread of the pandemic worldwide and its impact on Guatemalan health services.

Away from the microphones, reporters’ notebooks and flashing cameras, there was a different debate going on. Since the beginning of the pandemic in Mexico and until two days prior to the Minister’s announcement, the person providing most of the information at the daily press conferences was Dr. Walesska Zeceña, the first female director of the National Epidemiology Center, which is part of the Ministry of Health. Two weeks later she would be removed from her position as director. Everybody I spoke with in July and August that same year agreed that she was one of the best qualified epidemiologists to direct the pandemic response because she had taken part in the discussions that resulted in the 2005 version of the International Health Regulations (IHR).

The IHR is the international legal instrument that outlines the actions required of all World Health Organization member states to prevent and respond to pandemic

emergencies. It went into effect in 2007 requiring countries to report directly to the World Health Organization. Everybody I spoke with also agreed that she was removed from press conferences and then from her position as director of the National Epidemiology Center because she was following the IHR requirements whereas the Minister of Health wanted to control the flow of information in order to control its potential political impact.

Cerezo's decision to remove Zeceña was hardly a matter of personal hatred. Judging from his actions when faced with a hemorrhagic dengue outbreak and with a child malnutrition "outbreak" (widespread hunger) later that year, he had a negative attitude towards the free flow of epidemiologic information. He was also suspicious of international agencies, such as PAHO and the CDC, having too much influence over the Ministry of Health. Earlier that year he got in trouble when, in a Congressional briefing, he minimized the magnitude of maternal mortality. Later in September, he was removed from his ministerial office after being questioned by Congress and the National Human Rights Office for his neglect of all these health problems. An opinion column published in June 2009 accused him of dismantling the National Epidemiology Center and of "turning his back on science" as a means to face health problems. The article goes on to accuse him of "lack of transparency in counting influenza's cases followed by absolutist centralization of information needed to fight the outbreak." (Asturias 2009)

This situation shows one of the essential features of epidemiology at work I found at the CNE. If we take to heart that part of the mission of the CNE is to contribute to the achievement of the right to health, we need to keep in mind that this kind of social mandate for epidemiology – regardless of its legitimacy – is subjected to a complex "set

of linked interdependencies inseparable from personal troubles, public issues and social change agendas” (Star 1995b). Looking at epidemiology as work, we acknowledge that epidemiologic knowledge and epidemiologic work co-construct each other (Forsythe and Hess 2001) and these social, psychological, political and economic interdependencies are intrinsic to epidemiological work and not an anomaly. When the CNE was created, it was placed in the Ministry of Health’s organizational chart as a direct adviser to the Minister of Health. This organizational placement has impacted the CNE in several ways, making its priorities gravitate around those of the Minister, and, in turn, relegating priorities considered to be more technical in nature by epidemiologists. This status as adviser has also created ambiguity about its actual place in the Ministry of Health’s structure and has enhanced conflicting relationships with almost every unit in the organization. More importantly, as the conflict around the Swine flu shows, the CNE gets caught between its technical goals as an epidemiological center, and its political commitments derived from its status as staff adviser for the Minister. This tension between the technical and the political came up with every single epidemiologist I interviewed, and most of that tension was personified in the CNE’s director. Epidemiologists would refer to present and past directors in terms of their ability to navigate the political waters of the Ministry of Health while remaining faithful to the technical and scientific nature of epidemiology. Although I noted a general frustration with the prominence of the political aspects getting in the way of technical processes, I sensed some ambivalence when I asked if it would be better for the CNE to have a more academic structure, as is illustrated by this CNE epidemiologist’s remarks:

“The problem here is that everything is political. Ministers know nothing [about public health priorities] but if under nutrition becomes a sensitive political topic, they prioritize it and there you have the CNE focusing on getting data about under nutrition, which is important but is not our work... Then there is a news story about newborns dying of infections in hospitals, so it becomes a sensitive political topic to the Minister, and there you have the CNE focusing on newborn hospital infections and forgetting about under nutrition... until the next time...” – Should the CNE’s place as staff adviser change then? I asked. *“No, because it was worse before, when we were just a part of SIAS (the health care services unit) and nobody listened to us...”*

This work organization configuration allows us to look at some ways in which anthropology can contribute to the study of epidemics. Shirley Lindenbaum argues for the need for an anthropology of epidemics. She points to the usefulness of epidemics in investigating the "relationships among cultural assumptions, institutional forms, and states of mind" (Lindenbaum 2001). Three recent journal editorials highlight the primary contributions of anthropology to our understanding of epidemics. Briggs and Nichter (2009) emphasize the dynamics of knowledge production as political and ideological and showcase the notion of biocommunicability (Briggs 2005). Singer (2009) suggests an agenda for the development of an anthropology of epidemics by studying its biosocial aspects. Atlani-Duault and Kendall (2009) call for anthropology's involvement in understanding the social effects of epidemics. A collection of essays that presents the contributions of anthropology to the study of epidemics, “from the science of modeling

epidemics to the social science of understanding them” supports my argument (Herring and Swedlund 2010).

Although I agree with these authors, concentrating only on epidemiologic emergencies overlooks an important fact: the emergency is defined through epidemiology’s knowledge and practices developed during non-emergency times. In her approach to pandemic flu, Dr. Zeceña was following guidelines and regulations defined by epidemiologists at the international level. Epidemiologists draw lessons from epidemics and adapt their knowledge and practices to those lessons during non-emergency times. When emergencies arise again, they use the revised forms of knowledge and practices to define and control the new outbreak. They draw lessons from this new epidemic and adapt their knowledge and practice and so on (CNE 2007c).

In this way, the life of epidemics is not limited to the critical moments of growing numbers of sick bodies, the increased presence of disease in the popular media, government’s declaration of a state of emergency, experts’ advice on how to avoid getting sick, and conspiracy theories about the outbreak’s origins. Epidemics’ lives begin before the crisis and outlive it. During the inter-crisis periods, epidemiologists work on defining what will count as an epidemiological emergency in the future and how it will be addressed. Thus, the anthropology of epidemics needs to study epidemiology’s practices in both moments, and in fact understand them as a continuum, paying attention to those who embody the epidemiological work.

The case about the relationship between the Minister of Health and the National Epidemiology Center demonstrates aspects of the practice of epidemiology at the highest national level. It portrays Dr. Zeceña as a truly quixotic figure, being the first female

director of the National Epidemiology Center and following the dictates of her technical expertise in spite of the consequences for her professional stability. Her commitment to epidemiology's highest scientific goals is what prevented her professional ascension. Her mission to document and understand the outbreak was aborted by the political interests and power embodied in the Minister of Health.

What are epidemiologists for?

On Monday, March 15th 2011 I attended one of the weekly meetings of the Technical Council of SIAS, one of the four departments that integrate the Ministry of Health. SIAS – *Sistema Integral de Atención en Salud*, or Comprehensive Health Care System – is the department in charge of directing, coordinating, managing and supervising everything that has to do with Ministry of Health service provision. Health care service provision is carried out by health care workers in a network of facilities that include all the different types of facilities shown in the following chart

Table 8. Ministry of Health facilities by level of resolution

Level of health care	Types of health care facilities	Quantity
First level	TOTAL	1,101
	Health posts	777
	Health posts, strengthened weekends	245
	Health posts, strengthened	64
	Minimal units	15
Second level	TOTAL	346
	Permanent care centers	180
	Health centers	110
	Ambulatory care centers	40
	Maternal and child comprehensive care centers	5
	Cantonal maternity wards	4
	Medical urgencies centers	3
	Peripheral clinics	2
	Specialized centers	2
Tertiary level	TOTAL	45
	District hospitals	13
	Departmental hospitals	10
	Regional hospitals	13
	National reference hospitals	9
Grand total, MSPAS, health care facilities		1,492

Source: MSPAS 2012.

The SIAS Department oversees the health care provided in all these facilities, and the SIAS Technical Council made up of all the heads of the SIAS divisions, including: environmental health, human health care, and health education, as well as the administrators, and technical advisers. The Technical Council is presided by the SIAS director, and the SIAS sub-director follows-up on the Council's decisions. I attended several of the Council's weekly meetings, and the one I describe here was mainly focused on Dengue control, because the incidence of new Dengue cases during the previous weeks had been on the rise, and there was the perception that health care workers were not doing enough to control the spread of the disease. Dengue is transmitted through mosquitoes that reproduce in stagnant water within homes or other places where people gather, particularly early in the morning and at dawn. The Council had invited a representative of CNE and a representative of the Ministry of Health's Program for the Control of Diseases Transmitted through Vectors (in which Dengue is included).

The exchange I am about to reproduce from my fieldnotes exemplifies some of the tensions epidemiologists face within the Ministry of Health. But let me make some points that will add some context, because some of the lines in the discussion below are better understood in the light of other public health institutional tensions. First, there is the historic and international tension between public health vertical programs (such as the Vectors Program invited to the meeting) and public health horizontal programs (such as SIAS). The debate here has historically been to decide to what extent should public health programs be organized according to diseases that are prioritized (Dengue, HIV, Malaria, Diarrhea, to name a few), and to what extent should health programs be organized in units that pay attention to all the priorities. The implications for vertical vs.

horizontal organization are many, but let me just name three: in vertical programs, there are rural health workers that only focus on the control of Dengue without paying attention to other problems, Dengue control would have its own budget and resources, and Dengue experts would be highly appreciated. In a comprehensive or horizontal program, health care workers include Dengue as one of their priorities, Dengue control does not get its own budget and Dengue experts are important advisers but have no control over operational decisions. Vertical programs have historically been praised by international philanthropists and international aid for being more efficient (with more and clearer results for each dollar invested), but it is acknowledged that there cannot be vertical programs for every health priority because then what you have is a lot of redundancy and inefficiency. Moreover, horizontal programs are potentially more sensitive to people's health rather than focusing on specific disease indicators.

The second tension I want to point out is the tension between SIAS and hospitals in the Guatemalan Ministry of Health. Hospitals have historically rebelled against any attempt by the Ministry of Health to regulate or supervise their practices. As the story goes, physicians in hospitals despise the rest of the physicians in the Ministry of Health for not having a clinical specialty and, at the same time, more public health oriented physicians despise hospital physicians for being arrogant and not academically rigorous.

However, the main tension in this conversation implicates epidemiologists, who were not present in the meeting, given that they just came at the beginning, gave their presentation and then left (because, as the epidemiologist who gave the presentation told me later, they considered that the Council needed to have its own discussion and there was no place there for epidemiologists).

SIAS HEAD 1: We need to have an alert-response system, so we should not be too worried about epidemiological surveillance, but about entomologic surveillance [mosquito counts in houses and communities, and determining if they are infected].

SIAS HEAD 2: But then what does the epidemiologist do? Isn't that the kind of analysis they should do?

SIAS HEAD 3: The big question is if the epidemiologist is doing his job! I have two hypotheses. First, the epidemiologist has not been doing his job. Second, the Health Area technical teams have not been doing their job [the Ministry of Health is organized nationally in 29 health areas].

SIAS HEAD 2: The correct level for initial analysis is the Health Area, not just the epidemiologist, but also with the rest.

SIAS HEAD 3: Has the Health Area Director been doing his job as well as each of the technical team members?

SIAS DIRECTOR 1: We would need to have a strategic alliance with the CNE, to put together an operational manual, because in some Health Areas we don't have epidemiologists. But the manual needs to focus on management commitments to make sure it is operational.

VECTOR PROGRAM 1: I noticed we have not been able to have anyone from hospitals take part in these meetings.

INTERNATIONAL ADVISER 1: There will be a vaccine against Dengue in two years, according to Pasteur Institute in France. The vaccine will get rid of all these problems.

VECTOR PROGRAM 1: There is a problem in recognizing the problem at the different facility levels. For instance, the first level of care is implementing an indicator of elimination of mosquito hatcheries.

SIAS HEAD 2: Coordination has to be through the Health Area, not through the Vectors Program.

VECTOR PROGRAM 2: According to Article #40 of the [Decree] 85-89, the Vectors Program becomes normative and operational...

VECTOR PROGRAM 1: What is lacking is more leadership from SIAS in each Health Area, and a master plan. In the case of Dengue, people's living conditions have deteriorated [he gives several copies of a Dengue control manual his program put together many years ago], but we know exactly what needs to be done. We also need to involve the municipalities.

SIAS DIRECTOR 1: The normative part of the surveillance is done by the CNE.

SIAS DIRECTOR 2: Yes, but we need to act. [CNE] gave us four suggestions: multidisciplinary teams, increase control measures, evaluate the implementation of control measures, and supervise the teams. That is just conceptual, and what is important is what is operational!

SIAS HEAD 3: In the Health Areas we are doing surveillance, health care provision, and training.

SIAS HEAD 4: We have data by municipality, and we have a report on deschatarrización [process of getting rid of all the junk that may facilitate mosquito reproduction]. So we only need to request from the Health Area epidemiologists a characterization of the outbreaks.

VECTOR PROGRAM 1: The problem of Dengue will continue every year, what we need to do is to guarantee good clinical management of the cases and to study everyone with a fever.[...] There is a National Commission on Dengue, and also a National Technical Group on Dengue, and there are Department-level Dengue commissions as well. All that is in the Ministerial Agreement 9-2010.

VECTOR PROGRAM 2: We have taken the leadership and we are coordinating with the CNE, the National Laboratory, the hospitals and the Ministry's social communications unit.

INTERNATIONAL ADVISER: We won't stop the epidemic, but we can minimize its effects and aim at zero deaths. References to hospitals have been bad, and classification and clinical management has been very bad.

VECTOR PROGRAM 1: Yesterday, there was a press release from the CNE with a lot of incorrect information. All the Dengue information should come out of the Vectors Department.

SIAS HEAD 2: The CNE is always walking alone.

SIAS DIRECTOR 1: Yeah, they are always just by themselves.

SIAS HEAD 1: Yeah, that's the problem. That's why I told the epidemiologists the other day that they needed to come down with the operational teams, and not just keep all the knowledge in a small group.

SIAS DIRECTOR 2: The problem is that we need to act, while epidemiologists stay in the Olympus.

As this exchange went on, I often found myself listening to criticisms of epidemiologists that questioned the usefulness of what they do, and interestingly enough, many epidemiologists dealt with the same kind of contradiction themselves, when they were trying to explain their vision of what epidemiology should look like. They often ended up explaining what epidemiology is by stating who should be an epidemiologist. Let me address this question in the next section.

Who is an epidemiologist?

On January 14th 2005, Tomás and I arrived to Chuisacabaj. We were greeted by dogs and then by children. As soon as they recognized Tomás, adults started to come out of their homes and we asked them to gather at the school. The one-classroom school was made out of unevenly matched wood boards and metal siding. We met with about ten adults and 25 children. Our purpose: to control a rotavirus outbreak reported the day before.

Rotavirus is believed to have caused the majority of the almost 500 diarrhea-related infant deaths in Guatemala in 2004. Most rotavirus infections occur between November and February and the season in 2005 seemed tougher than usual. Newspapers had reported hospitals working at full capacity and outbreaks with high fatality rates.

Chuisacabaj is in the province that was reporting the highest prevalence by January 2005. Nationwide, diarrhea would kill 700 infants that year, becoming the second cause of mortality among that age group, with a mortality rate of 23 for every 1000 infants. The public health system was in a state of emergency.



Photos: Alejandro Cerón

Figure 7. Tomás talking to participants at the meeting in Chuisacabaj's school

The response to the emergency included Tomás and me, as part of a health care team working closely with the Ministry of Health in Sololá's Boca Costa. Tomás was a health promoter from that region and he had a lot of knowledge about traditional healing. He was in charge of the health post closest to Chuisacabaj, about a two-hour walk. I had come from Guatemala City two years earlier to be a physician in charge of coordinating the work of 35 health workers in 27 small rural communities. This was my fourth visit to Chuisacabaj. It took us two hours of driving and three hours of walking to get there and we brought with us oral re-hydration salts, a small assortment of medicines, a megaphone, sterile containers to gather feces samples, chlorine, and copies of the Ministry of Health's epidemiological surveillance forms. We were also carrying water and snacks for the trip

and a photocopy of the 2003 Epidemiologic Surveillance Protocol, which I had studied the night before to make sure we did everything in accordance with the norms.

According to the protocol for acute diarrheal disease, we were supposed to identify suspected cases, take feces samples, give them treatment and fill out the surveillance form for each suspected case. In addition, the protocol guided us in assessing the levels of chlorine in the water systems and in identifying other sources of infection. If we found sources of infection we had to take action in coordination with the community to disinfect them. We also needed to report our findings to the Ministry of Health's District, which would report to higher levels and dictate if other actions needed to be taken. We classified two kids as suspected cases, had a thorough conversation about the rotavirus situation and what to do to control it, and tried to carry out the recommendations about the water systems but in Chuisacabaj there are no community water sources.

With 161 inhabitants, Chuisacabaj was one of the smallest and most remote communities in that region. It was at least a 3 hour-walk from the closest drivable road. Its 24 households were composed of monolingual K'iche' nuclear families, who practiced subsistence farming. There were no phones, electricity, sewage, latrines or any form of tap-water system. However, although the villagers lived at the margins of Guatemalan society, they somehow were able to control the outbreak; nobody died and life went on as usual. By mid afternoon, Tomás and I returned to the town, prepared all the paperwork related to our visit to Chuisacabaj and handed it in to the Ministry of Health's District office. And our lives went on as usual.

Although neither Tomás nor I were epidemiologists, we were carrying out epidemiological work at the local level. We were linked to Guatemalan epidemiologists through the epidemiological surveillance protocols, the forms we filled out and the samples we collected. We both followed the protocols thoroughly and did our job well. We were epidemiology's "invisible workers" (Star 1995a, Forsythe and Hess 2001), or those workers that are made invisible in epidemiology's narratives. Epidemiology's most obvious invisible workers include a series of secretarial, administrative and technical "support staff", among which "*estadígrafos*" (whose work traditionally consists of all the mechanical tasks involved in collecting forms, filling out other forms, and all the arithmetic involved) are the less invisible because in many parts of the country they have been the ones who have done the work of epidemiologists until recently when epidemiologists began to be hired. *Estadígrafos* coexist with their more modern counterparts in *digitadores* (charged with feeding computer-based information systems), and who often are women with secretarial functions. At the CNE office there now is an information management specialist whose work has become essential but who is still hired on short-term contracts paid for by the CDC.

But at the bottom of the epidemiology invisible worker ladder there are hundreds of physicians, nurses and nurse aides who do the vast majority of the work that involves: identifying epidemiologically important cases and situations, following the relevant protocols, and notifying to the epidemiology network. The vast majority of these health care workers are not trained in epidemiology and have dozens of other tasks that involve all the preventative and curative health care offered by the public health system plus related administrative work. They work in more than three hundred health centers, more

than one thousand health posts and more than ten thousand community health houses. Roughly 90% are either health promoters or nurse aides, with an average of 9 years of formal schooling and between six months and two years of health care training and with a salary just above the minimum wage (\$271.74/month, at \$1 for 8 Guatemalan Quetzales). The public health care system in most low resource countries rests on the shoulders of nurse aides, such as Tomás, and so does the epidemiology system. At least two thirds of nurse aides in Guatemala are female. Although this is no secret, this fact is rarely made explicit in epidemiology's accounts. Among the epidemiologists I interviewed, most of them did not mention it, and three of them pointed to it as the basis of the inefficiencies of the epidemiology system. *“What we need is to get rid of all those nurse aides who do not know how to make a diagnosis... and sometimes are half illiterate... and hire doctors... only then will our system work,”* This statement was made by one of CNE's epidemiologists in charge of strengthening the national epidemiology network. One epidemiologist at CNE, who is also a nurse, told me *“as always, physicians despise nurses [...] It's in their genes”* Only one epidemiologist who is also a nurse – the vast majority of epidemiologists are physicians - made reference to nurses and nurse aides as the backbone of the system, arguing that:

“[N]urses are often seen as less than doctors, but the truth is that without nurses and nurse aides the system would collapse [...] and that is why I feel it is so important that I, being a nurse, became an epidemiologist [...] although I often feel like epidemiologists who are doctors see me as less, [...] and I try to remind them with my actions that I am as epidemiologist as they are”. (Epidemiologist at CNE)

In relation to the contributions of invisible workers, I need to make special mention to the feminization of health professions and how it plays out among Guatemalan epidemiologists. Although there is no hard data available, more than half of medical students in Guatemala have been female at least for the last ten or fifteen years. This trend is also reflected in most specialties, with the exception of those that involve surgery. According to Guatemalan feminist scholar Walda Barrios (personal communication) most lucrative health professions are still dominated by men, but the less lucrative have been increasingly filled up with women. There is also another trend, women physicians are more likely to look for jobs that offer stability than men, and jobs in the public health system fit this expectation (Vásquez Vega 2010). As a result, public health and epidemiology are among the professions with a stronger tendency to attract more women than men, which I noted at the CNE and at Guatemalan public health programs. This is the way the “horizontal segregation” manifests in epidemiology, but it is complemented with a strong “vertical segregation”, where almost all directive positions are still held by men.

In any case, it is impossible to know if Tomás and I had anything to do with the lack of deaths from that particular outbreak, or if Chuisacabaj’s people were already handling things on their own to prevent anyone from dying. But one thing is evident: we did not address the causes of the outbreak. When we left, with our forms and samples, the lack of infrastructure and more broadly, the social exclusion in which Chuisacabaj’s people lived would remain. Other epidemics were surely to come: rotavirus, hunger,

illiteracy, lack of opportunities, racism. Should epidemiological work address these other epidemics?

I was convinced that the answer was an unequivocal yes. I was beginning my fourth year after I had finished medical school and I also had spent two years studying in a Master in public health program. More importantly, I had been exposed to the fundamental literature of Latin American Social Medicine, much of which has to do with epidemiology. For example, Asa Cristina Laurell (1989) insists on the need to look at the connections between the biological and the social aspects of disease. Naomar de Almeida Filho (2001) proposes an “ethno-epidemiology” that listens to social processes and human experience. Jaime Breilh (2003) calls for a critical epidemiology that addresses the political and economic causes of health problems. I was aware of this literature and had a personal conviction of the need to go beyond the limitations of epidemiology, so why then did I not address the social causes of the outbreak in Chuisacabaj? Was it a lack of personal commitment or was I constrained by epidemiology’s discourses and practices in Guatemala? Were Tomás and I the embodiment of a timid epidemiology unwilling to face the more fundamental consequences of its work? Were we experiencing the impotence of knowing that there are other people with political power who can allocate resources to address the deeper roots of health problems, just as in Dr. Zeceña’s experience with the Minister of Health? Is this what the quixotic character of epidemiological work is about?

Latin American social medicine scholars are marginal in the discourses of epidemiology in Guatemala. They are not even part of public health and epidemiology curricula. Why is that?

A cynic's view of what the CNE is currently doing

“In recent times, although many things have been the same from the very beginning, the fact is that now the CNE is almost as if it were one of [the Ministry of Health's] main departments, although we are not exactly one division but we are at the same level, or almost at the same level... well we have the status of “staff”, we are “staff to the Minister”, so we are like direct advisers to the Minister. [With this situation] some of the technical vision we should have gets lost, because, as I see it, the CNE should not be constantly subjected to the political sways and to the media, and [should not be used] only for providing information to the Minister's office. Because we have been turned into, as I see it, just information givers in response to – in response to politicians or the media. “The media wants such and such” or “the Minister wants such and such”, or “the President wants such and such”, or “the First Lady wants such and such” or “social pressure wants such and such” ... So, they have not allowed us to develop from the point of view of “Ok, we analyze all the available information, and on the basis of our analysis”, we can tell the [Ministry of Health] Technical Council or the Minister, “listen, the media may say such and such, the President may want A, B, or C, but here is what is really happening and the health sector should focus its efforts here and here”.

So for instance, with under nutrition I have been participating in lots of meetings every week, and have made presentations to the Technical Council. So if we talk about mortality for acute under nutrition, the department where more children die of acute malnutrition is Alta Verapaz. Almost 60% of deaths related to undernutrition happened in Alta Verapaz. [I think just seventy] out of the two

hundred deaths that happened last year, did not happen in Alta Verapaz. So, I showed them the chart and the map and told them “if we want to have impact, we should focus our efforts in Alta Verapaz.” But no, because the President, SESAN [Food security secretary that reports to the President], and whoever else [only wanted to prioritize] the Corredor Seco [dry corridor, a strip of land with high poverty rates, yearly drought, and high prevalence of chronic malnutrition], there we were focusing all our efforts to the Corredor Seco, and children dying in Alta Verapaz. There is a source of frustration for me as an epidemiologist, because you would like your work to make a difference, but we also need to gain credibility, which we have not been very successful at doing.” (Epidemiologist at CNE)

The tension between the technical work epidemiologists should be doing and the political priorities they ended up being part of was present in every interview and in every meeting I attended. This tension was embraced with some ambivalence, however. In a post-colonial institution - weak and vulnerable to the political climate - like the Ministry of Health, serving the Minister or the President can be personally and institutionally advantageous, until the good relationship ends, or until the Minister is changed. Although every single epidemiologist I interviewed acknowledged the tension between “the technical and the political” (lo técnico y lo político), most of them said it was good to have the CNE administratively so close to the Minister of Health, and just a few recognized that such closeness could jeopardize the technical nature of epidemiological work. When talked about, this dichotomy between the technical and the

political, seemed to very easily distinguish the technical as the good pole and the political as the bad one, but, in practice, epidemiologists seemed to only complain about the political when it was perceived as an obstacle or burden to their interests, but were happy about it (and some times even bragged about it) when it supported their interests. The dichotomy is misleading, however, because “the technical” can be problematic, as I argue in the next chapter, and because the dichotomy is really false, as I argue in the final chapter.

Chapter 5: Epidemiology as Technology

Introduction

When apparently healthy individuals started showing episodes of violent spasms, demonic visions and physical struggles with invisible enemies, concerned individuals and leaders took action. Different experts intervened. Public health officials could not determine the cause but labeled the problem “collective schizophrenia”, and did not offer any concrete treatment. Catholic church leaders saw a clear case of demonic possession, but attempts to exorcise the victims made the symptoms worse. A group of *Ajq’ijab’* (individuals with the gift of interpreting the energies of the earth and skilled in communicating with the dead, according to the Mayan tradition) traced the problem to the victims of an eighteenth century massacre whose human remains had been recently moved during the construction of a building. They recommended honoring the memory of the victims and giving proper ritual to the remains so that the energies in the community could be brought into balance. The outbreak ended after the people followed the recommendations of the *Ajq’ijab’*.

The incident has received many labels, but the most consistently used are “craziness” outbreak (*epidemia de locura*, in Spanish), collective hysteria, demonic possession, collective schizophrenia, spirit possession, and collective psychosis. Different actors contest each of these labels. More importantly, the few residents of the town with whom I have explicitly spoken to about this have a hard time labeling it. Pushing them a bit, some would say this was a “call for attention by the town’s residents” to prioritize in their lives what really matters, and in general they do not want to talk about it. I consider

the notion of “call for attention” essential to approaching the incident. This is why my aim in this paper and in my work is not to reconstruct the case exactly, but to examine the different responses that were given to it with a special focus on the responses by the public health system. As shorthand, I will refer to what happened as an outbreak; although this is an imposed label, I choose to use it because it is how it connects to my research.

An *Ajq'ij*'s statement regarding the case points to the insufficiency of current notions of “multiculturalism and health”, as he suggests the divergent perspectives to the outbreak are not symbolic but epistemological and technological:

“We take into account every element from nature: water, fire, air, ground and God... Westerners, scientists they call themselves, talk only about the five senses: it only exists if I can see it, touch it, hear it, taste it or smell it. But maybe one day they will develop more sophisticated apparatuses, with the ability to capture and see what we see... perhaps in that way they will realize...” (Sandoval, 2009)

In this chapter, I examine what this outbreak tells us about epidemiological practice and the right to health in Guatemala. After describing the outbreak, I recuperate from previous chapters the idea that epidemiology's handling of outbreaks can only be explained if we understand the continuum between ‘normal times’ and ‘times of epidemiological crisis’. In doing so, I show the mechanisms by which epidemiologists who handled this case turned a dramatic collective crisis into an outbreak that never happened. Then I analyze the potential light the notions of ‘multiculturalism and health’ and ‘medical pluralism’ can shed on this case, as well as their shortcomings, with a

special attention to implications for the notion of the right to health. Following the argument presented in previous chapters, in the sense that both right to health practices and epidemiological practices need to be understood as overlapping sociotechnical systems (Brooks 1980: 65-66), which simultaneously overlap with contemporary biomedicine as a sociotechnical system (Clarke et al 2003, Lock and Nguyen 2010), this chapter shows how different technologies call different things into existence, precisely because technologies are never just physical objects, but also the knowledge, practices and social relations they produce and reproduce (Wajcman 1991: 14-15). Just as power is embedded in knowledge and knowledge is embedded in power (Foucault), power-knowledge inhabits and is inhabited by the technologies and practices it creates, and is created and re-created by those technologies and practices. In other words, knowledge, technology, power, and social worlds co-construct each other, and are in fact, inseparable in everyday practices, which is why it is not enough to talk about changing social practices when that talk is not accompanied by careful engagement with changing the words, knowledge and technologies they are part of.

In fact, as I delved into analyzing this case and the more I spoke with people involved in it or who knew of it, I was struck by the crucial role that certain artifacts played in the attempts at solving it. Exorcist's crucifixes and holy water, epidemiologists' protocols and data collection forms, and *Ajq'ijab*'s fire and *tzite*' seeds (seeds from a plant, used as "adivinary tools") each had the ability to call into being either demons, epidemiological cases, or massacred ancestors, and they did so in ways that seemed as mysterious as the outbreak itself. It is as if they had magical powers. But at the same time these artifacts would not perform their alchemy without the right kind of expert

manipulating them for intervening in the right kind of problem in the right kind of context. For instance, not any priest (or any person for that matter) is able to competently use a cross and holy water in line with the exorcism section of the Roman Ritual of 1614, or its revised version of 1999, “Of Exorcisms and Certain Supplications” (De Exorcismis et Supplicationibus Quibusdam). Moreover, exorcisms can only be performed if those afflicted by the presumed demons (or their beloved ones) assume the role of being possessed and collaborate with the exorcist. Analogous observations apply to the fire and *tzite*’ seeds, and to the epidemiological protocols and forms. The artifacts are necessary but not sufficient for calling demons, cases, or ancestors into being.

Given the centrality of epidemiological protocols and forms to the practice of epidemiology, I set to analyze them as tools, or more precisely, as technologies, that go hand in hand with ideologies, but are not exactly the same. While popular culture often portrays technology as an essential driver of human evolution (i.e. the utilization of tools drove the leap from ape to human) and of economic and social development (i.e. the steam engine drove the industrial revolution), anthropology scholars disregarded the study of “technology alone” as “scientifically sterile”, but as an “indispensable means of approach to economic and social activities” (Malinowski 1935:460). Similarly, Kroeber affirmed that the then-called division between material and nonmaterial culture was just an idea but that it was a mistake to study “material culture” alone (Kroeber 1948). Nevertheless, throughout most of the 20th century, anthropology was more concerned with language, ideology and knowledge than it was with artifacts, tools and technologies, until the 1980’s and 1990’s, when anthropologists showed an increased interest in the social studies of science and technology (Pfaffenberger 1992).

The word ‘technology’ can refer to artifacts, knowledge, or activities (Wajcman 1991:14), and more often it refers to the interactions between the three. A computer is an example of technology because it involves an artifact that was designed and built applying knowledge about physics, engineering, information, mathematics and so forth, and it serves the function of managing and administering information in novel and more efficient ways than previous technologies. The same relation between physical object, applied knowledge, and human function can be applied to cars, microwave ovens, knives, trains, elevators, kitchen blenders, and guitars. My point here is that not any physical object or artifact is a technology and that in order to be considered a technological object its physical being has to be an expression of knowledge that serves a social or human function. Epidemiological protocols and data collection forms are technologies in this sense, as well as holy water, crucifixes, fire, and *tzite*’ seeds. Moreover, technology is often conceived as an “applied science” (Marx 1997, Winner 1986, 1997) and that is exactly how epidemiologists conceived of their protocols and data collection forms.

But technology is not exactly just applied science, and it is more than knowledge applied for the fulfillment of a human activity. For an artifact to become a technological innovation it has to succeed in aligning the social, economic, legal, scientific, and political context that will allow it to be developed, legitimized, and widely applied (Pfaffenberger 1992:498). From this perspective, electric lighting was successful only after Edison was able to develop the high-resistance bulb filament, find the way for lowering the cost of power transmission, show it had a better price than natural gas, and obtained support of influential politicians (Hughes 1983, cited in Pfaffenberger 1992). Similarly, the railroad was not only a consequence of the development of the steam

locomotive, but also of the coordination of various kinds of equipment (tracks, bridges, tunnels, rolling stock, and signal systems), a corporate business model based on large capital investment, a specialized technical discipline (telegraphy, engineering), a specialized workforce (engineers, telegraphers, conductors, firemen, and brakemen), labor conditions allowing constant functioning of the system, and legal changes (standardized track gauges, standardized time zones) (Marx 1997). Hence the need to talk not just about technology, but about sociotechnical systems, or “heterogeneous constructs that stem from the successful modification of social and nonsocial actors so that they work together harmoniously- that is, so that they resist [...] dissolving or failing in the face of the system’s adversaries” (Law 1987, cited in Pfaffenberger 1992) This implies that promoters of the system need to find ways to control or modify its adversaries (Pfaffenberger 1992).

Given that sociotechnical systems’ content and boundaries are intentionally blurry (Adams 1997), when examining such sociotechnical systems as the right to health, epidemiology, or biomedicine, we can distinguish overlaps, but it may be hard to define their boundaries. For instance, are right to health practices inevitably intertwined with contemporary biomedical practices and if so, what are the implications for epidemiological practice? If biomedicine is co-constructed with certain technologies, is the right to health inevitably co-constructed with them? How do the practices of epidemiology and right to health respond when confronted with things – such as spirits, demons, or the dead - called into existence by unexpected technologies, knowledges, and practices such as those used by the *Ajq’ijab’* in this episode.

But what exactly did the *Ajq'ijab'* see back in 2009 in this small town? What is it that “Westerners” apparatus are unable to capture? In a nutshell, the *Ajq'ijab'* saw and talked to the victims of a massacre that happened in 1723 in this town, and whose remains had been accidentally desecrated in 2009, triggering the events that I characterize here as an outbreak. Let me now summarize the events of 2009 and their context.

The outbreak

It was February of 2009. “They found him at the edge of a cliff. His clothes were torn, as if he had been in a head-on fight with a fierce animal. The ripped pieces of his clothes stuck to his chest from sweat and his disheveled hair on his forehead bothered him. When Carlos left his house he was going to work and now he was there, about to jump off the cliff without understanding why he would. The news spread through the whole town, the men crossed themselves and the women covered their kids’ faces with blessed water. A strange cloud was passing over their homes... “Carlos is possessed”, they muttered. Including him, there were already at least four who were acting in an irrational way, those who walked without knowing who was guiding their steps” (Sandoval, 2009).

A 19-year old girl directly affected said that every night, at about 6 o’clock she saw dozens of strange beings talking to her, and asking her to help them gather all their body remains, and that if she did not help them, they would never rest in peace. When she told them she would not help them, they fought her and beat her. This kind of incident lasted several hours and is consistent with testimonies by other witnesses. A witness recalls:

“It was awful and out of control. It was as if youngsters were not themselves, they were very violent... and hit and screamed... There were spirits inside them. It was without precedent... frightening... it was really scary.” (Interview to anonymous witness)

It all happened between February and May of 2009. According to official Ministry of Health data, there were 45 people affected, although officials acknowledge there were more that were never registered in the official information system. People interviewed set the number of those affected somewhere between 15 and 66. They were between 8 and 26 years old, but most of them were in their late teens. Male and female seem to have been affected equally. It affected people living in each of the three neighborhoods in which the town is divided, as it affected both Catholic and Evangelical Christians, the two most prevalent religions. It also did not seem to affect impoverished people to a larger extent than the non-poor. Tourists and recent immigrants (both Guatemalan and foreigners) seem to have been the only immune population, but they are also typically older than those affected.

A Ministry of Health psychiatrist who was involved in the official response to the outbreak explained in retrospect that those affected were an “emotionally weak” group due to poverty, lack of employment, lack of attention to potential post-traumatic stress (derived from recent natural disasters or from the recent history of war), and a general lack of access to health care. He said, “what happened is not endemic to [the town] and while [social and economic] exclusion and marginalization remain in [Guatemala, we are] condemned to see the repetition of this kind of phenomena” (interview with

anonymous witness). The Ministry of Health sent a team with epidemiologists, an environmental engineer, a psychiatrist, several physicians, nurses and psychologists. They looked for infectious or toxic causes and even hospitalized five “patients” to run more specialized tests. They found nothing. The epidemiologist involved in this response attributed the outbreak to “emotional stress” while the public health regional director went further and affirmed that those affected were the children of alcoholics or drug addicts, and that these children had adaptation problems or lived in families with other kinds of problems. (Prensa Libre, 2009) Residents in the town reject these explanations as they enumerate cases where there clearly were not problems of this kind. An author in a Catholic blog who also owns a hotel in the town gave his perspective in his blog:

“... I saw several of the 43 possessed youngsters and they were spitting foam, beating people who happened to be nearby, screaming in the cemetery, totally irrational, the same as assassins, robbers, etcetera. Protestant Christians prayed halleluias to expel the devil, the [Indians] made their acts of witchcraft, and tourists were having fun. [It was like this] until the Catholic priests came and started the exorcism. They, who know about exorcism, advised me to read some literature [which I did] and found out how Satan acts. If he tempted Jesus... how was he not going to possess these youngsters...” (Jochin, 2009)

But the Catholic interventions did not stop the problem either. First, they had a mass at the cemetery, but as the priest spoke, known affected youngsters began to experience episodes to the astonishment of the community that was gathered. They fell to the floor and seemed to be fighting against invisible people. New people got affected

during the mass, so they hurried up to finish the mass. A few days later, the church brought a priest specialized in exorcisms, but the manifestations of “possession” worsened as the priest administered holy water and there was even a case where the “sick” person hit the crucifix and broke it. “It was as if you were watching one of those Exorcist movies”, recalled a witness.

Meanwhile, the town’s life was severely affected. Public transportation stopped coming to the town affecting people’s mobilization and trade. The school was closed fearing an outbreak there. Those that were not affected stopped working to be able to take care of their affected relatives. Tourists stopped coming and residents wondered if the origin of the malady was in the water, or in the air. Rumors about the moral behavior of those affected spread and affected social relations. Simultaneously, people were looking for ways to address the problem. In addition to going to the health post, the priest and the town’s several Evangelical churches, a group of neighbors organized rounds to detect when someone started with the attacks and offer help to their families, given that it normally took several people to hold the affected and prevent them from hurting themselves or others.

At some point the town’s authorities decided that nothing was working and that the problem needed to be addressed as a communal problem. They asked the Ministry of Health team investigating the problem to leave the town and made arrangements to bring a group of *Ajq`ijab`* to help address the situation. Four *Ajq`ijab`* came (they were brought with the support of a local NGO, with long-standing presence doing development work in the area covering health, education and microcredits; the directors of the NGO have a good reputation in the area, and they also own a hotel in the town where the outbreak

happened), performed their rituals and determined, as explained above, that the “invisible people” or “spirits” were the victims of a 1723 massacre performed as part of the evangelizing efforts conducted by the Catholic church where more than two thousand people had died. Their remains had been desecrated earlier in 2009 during the construction of a wall for the Catholic Church. According to the *Ajq’ijab’*, the ancestors had been disturbed and now the only way to reach a solution was to negotiate with them. And the *Ajq’ijab’* were able to on “a clear and warm night, before the sacred fire, candles and incense... [the ancestors] expressed they had manifested because they wanted not to be forgotten, and they had selected the youngsters so that they would become midwives, *Ajq’ijab’*, or teachers”. (Sandoval, 2009) A witness recalls, “those affected were young and gifted, with important *nahuales* (companion animals defined by date of birth and markers of an individual’s mission in the world, in the Mayan tradition, see Saler for further details), that’s what the *Ajq’ijab’* said. They were people with a mission but they were not paying attention” (Anonymous community leader)

Following the *Ajq’ijab’*’s directions, the town celebrated three ceremonies (out of the four that were prescribed) and began the process of figuring out how to influence the youth to remember the ancestors and follow their missions. And the outbreak stopped.

“The Ministry of Health did not do anything, it just worsened the situation... what they did was to tie and inject and take away some youngsters without even asking their families... The situation calmed with Mayan ceremonies and faith and prayers, but this is not permanent... there are things we have to do, we need to bring back respect for our traditions and to make ceremonies and altars every once in a while...” (Anonymous woman from the affected town)

“The Ajq’ijab’ reached an understanding with our ancestors... and the proof that they did is that the situation calmed down.” (Sandoval, 2009)

Making sense of plagues, seeing epidemics

Chaos, fear, and blame are part of the collective experience of an outbreak, as has been vividly depicted in the first part of *The Plague* (Camus 1947) and many scholarly accounts (Herring and Lockerbie 2010, Littleton et al 2010; see also the authors in Herring and Swedlund 2010). In fact, bringing chaos into control and making sense of the outbreak are among the initial tasks experts and institutions take on in such a situation. Making sense of the outbreak involves creating a convincing narrative that both explains what happened and points to a feasible solution. In other words, epidemiologists’ work in such circumstances involves the ability of turning plagues –chaotic out-of-control experiences - into epidemics – controlled, bounded entities (Herring and Swedlund, 2010).

The ways by which plagues are turned into epidemics have raised many anthropological questions, such as when do epidemics begin and end, or who decides what is an epidemic and how (Trostle 2010). In other words “when is an epidemic an epidemic” (Herring and Swedlund 2010: 9). These questions acquire an interesting – almost magical - twist in this mysterious outbreak, because through the Guatemalan epidemiologists’ work this “plague” was not turned into an epidemic, but into something else: a non-epidemic, an epidemic that never took place. How did this happen?

If we understand epidemiology as a sociotechnical system in the sense sketched earlier in this chapter, we ought to remember that practice, knowledge, power and technology co-construct each other through the objects they produce. Different

technologies call different things into existence, and for the case we are examining here, epidemiological reports and protocols are the devices capable of calling an epidemic into existence or, in other words, a plague turns into an epidemic through the use of such reports and protocols. But as we will see, both devices depend on the identification, counting, and classification of ‘patients’, so that in order to turn a plague into an epidemic, epidemiologists need first to turn afflicted bodies into patients.

But let us go one step at a time. While I was in Guatemala in 2011, different epidemiologists from the Ministry of Health and from other institutions assured me there was an epidemiological report about this outbreak because they had seen early versions of it. Three epidemiologists, independently, even offered to get a copy of it for me. When I followed up on their offer, they were not able to get an actual copy of the report, so they offered me draft versions (very rough) and even some patients’ records, which I did not accept because my human subjects permissions in the U.S. and Guatemala did not allow me to use such records for this research project. I followed up with two epidemiologists into 2012 and finally they both told me there was no report. I asked one epidemiologist for clarification:

EPIDEMIOLOGIST: *“The report was never finished, so there is no report.”*

ME: *“Why”, I asked*

EPIDEMIOLOGIST: *“they [the epidemiologists] did not find anything, so there was nothing to report”.*

ME: *“But what about the forty-plus affected people?”*

EPIDEMIOLOGIST: *“Well, they [the epidemiologists] followed the [epidemiologic research] protocols and everything was negative”.*

ME: *“Does it mean that this outbreak is not going to be registered in the epidemiological records?”*

EPIDEMIOLOGIST: *“No”*

ME: *“As if it never happened?”*

EPIDEMIOLOGIST: *“As if it never happened”*

So, if epidemiologists do not find anything of what they look for when they follow the epidemiological protocols, then the plague never turns into an epidemic. But what are those protocols and how do they frame what epidemiologists looked for in this outbreak?

The National Public Health Surveillance Protocols (CNE 2007d) are contained in a 449-page document prepared by the CNE and approved by the Guatemalan Ministry of Health. It is an official document. It contains the necessary technical information for the implementation of the National Epidemiologic Surveillance System at the operational level. Without introductions or conceptual explanations, it presents the surveillance protocols for 30 infectious diseases (ranging from influenza to cholera, Chagas disease, measles, and diarrhetic syndrome), 6 non-communicable health problems (arterial hypertension, diabetes, cancer, external injuries, undernutrition, and pesticide intoxication), mortality (general, maternal, and child), syndromic surveillance, and surveillance of pharmaceuticals' effects. All of the included problems deal with very specific conditions and actions, with the exception of syndromic surveillance, the protocol used to investigate our mysterious outbreak.

The National Syndromic Surveillance System was included for the first time in the 2007 version of the protocols, following the World Health Organization's revisions to the International Health Regulations, which in 1998 modified the traditional international notification system and incorporated the concept of 'syndromic surveillance', defined as "the surveillance of a group of diseases which are similar in signs, symptoms, and physiopathology, but have a diversity of etiological agents" (CNE 2007d: 392). The main

purpose was to include in the surveillance system not only well-known diseases of epidemiological importance, but to also include those of unknown origin. The six syndromes included in this protocol are: a. acute hemorrhagic febrile syndrome; b. acute respiratory syndrome; c. acute diarrheic syndrome; d. acute icteric syndrome; e. acute neurologic syndrome; and f. other notifiable syndromes (CNE 2007d: 392).

The inclusion of syndromic surveillance was justified by the World Health Organization for its ability to detect problems with a high potential of dissemination or with at least one of the following features: rapid propagation and transmission, high lethality, lack of efficacious treatments with known antibiotics, diseases that are new to the affected locality, high potential to impair travel or trade, and high political notoriety (CNE 2007d: 393). In Guatemala, the Syndromic Surveillance System was set up with the goal of “identifying in a timely fashion the presence of diseases of importance for national health, for implementing control and prevention actions” (CNE 2007d: 393)

The mysterious outbreak was treated as an ‘acute neurologic syndrome’ and was investigated accordingly by the local representatives of the CNE and the Ministry of Health at large, with technical and logistical support from the Centers for Disease Control and Prevention Central America Program’s laboratory infrastructure through the VICO program, a program established for influenza surveillance at the community level (i.e. diseases acquired outside of hospitals). Acute neurologic syndrome is defined as the emergence of neurologic dysfunction of less than three weeks, with at least one of the following signs: seizures, involuntary movements, paralysis, memory loss, abnormal behavior, or any other sign of sudden neurologic malfunction. Diseases of concern, according to the protocols, are rabies, meningitis (viral, bacterial, amoebas), cysticercosis,

botulism, and those caused by enterovirus or poliovirus (CNE 2007d:395 and 397). A suspected case is anyone with the described signs or symptoms, but a confirmed case only happens when laboratory tests are positive to one of the investigated diseases (CNE 2007d:396).

When I asked separately two Ministry of Health workers involved in the case (a physician and an epidemiologist) what they were looking for in this outbreak, they both referred me to these lists of diseases, and added the possibility of chemical toxins in the water. So, not finding evidence of any of these infectious diseases is what the epidemiologist cited above meant when she said they did not find anything, which led to the suspension of the investigation and ultimately turned this plague into a non-epidemic.

But there is still another level in which epidemiology as technology shaped this outbreak in particular ways. When the investigation occurred, fieldworkers under the supervision of epidemiologists used a standardized data collection instrument taken from the protocols (CNE 2007d:399-400). The two-page form is meant to register relevant information about each affected individual, and asks for his or her name, age, sex, ethnicity, occupation, and address, after which there are two lines to write the ‘history’ of the disease for the individual in question, and then a checklist for the different signs and symptoms of interest. Using this form, an affected individual will be classified as a “suspected” case, and therefore someone who will need to give laboratory samples which, for acute neurologic syndrome, involve: stool, skin biopsy, cerebrospinal fluid, blood, nasal secretion, ocular secretion, and vomit (CNE 2007d:397). It was not possible to collect all samples on site, so the public health workers had to convince a few of those affected to be brought to the nearest hospital with the required infrastructure, about three

hours away, and then stay there for several days. This task proved to be the source of conflict between the community and public health authorities. But the whole procedure of filling forms and classifying people as suspected or confirmed “cases” dramatically shows a total lack of assessment of any kind of interaction between those affected and their social and ecological environment. In other words, the task is not only one of decontextualization, but also one of turning afflicted bodies into patients. Epidemiologists’ difficulties and ultimate failure to turn all those bodies into patients was the initial step in the process of turning this plague into a non-epidemic.

In fact, the efficacy of the epidemiological technologies used by epidemiologists involved in this case is based on the assumption that the category of “the patient” is universal, as are the roles and expectations associated with it. But on the contrary, “patienthood is neither a universal nor an intuitive way of being-in-the-world but, instead, a role produced and principally acquired in biomedical clinical interactions” (Harvey 2008: 578). In other words, while epidemiologists expected to find patients to turn into cases, in reality they first needed to produce patients through their process of data collection. The social production of patienthood involves the assignation of a particular kind of (Western) individual identity and autonomy to the afflicted person, and the transformation of his or her context into a reduced set of sociodemographic variables and behaviors with the potential of being “risk factors” for the diseases of epidemiological interest. The production of patients through the assignation of individuality, autonomy and decontextualization happens primarily through the process of registration (Harvey 2008: 585), which in this outbreak was guided by the epidemiological surveillance form used in the epidemiological investigation. This process was so taken for granted and

unquestioned in this outbreak that epidemiologists expected that afflicted individuals would automatically perform the patient role, which involves subjecting to the mandates dictated by the epidemiological protocols. But the process of patient production did not work smoothly for epidemiologists in this case, as a community member pointed it out:

“We did not like that some of the affected had to be hospitalized, taking them away from their families... and I felt it did not make sense to keep taking more blood samples from them... We thought the problem was caused by changes in the community, although we had different ideas of what those were, perhaps people had forgotten about God, or about our ancestors, or perhaps tourists have brought drugs and other customs... So having people in the hospital was just adding to the problems” (Anonymous community leader)

In this way, the epidemiological technologies – and the sociotechnical systems they are part of – used in this case were unsuccessful in producing the needed patients and instead produced “non-patients” or “partial patients” (Harvey 2008: 591), that is individuals unwilling or incapable of fully fulfilling the patient role expected by epidemiologists. This technological failure in bringing patients to existence – an essential necessity in the co-production of patients, cases and epidemiological protocols – led to the technological failure in turning this plague into an epidemic.

What does “health” mean in the right to health?

When I look at what different stakeholders claim to know about what happened in this outbreak, and how they talk about others’ knowledge claims, I see individuals trying to make sense of their own experience – as physicians, as Christians, as *Ajq’ijab’* –

through the “epistemological unconscious” of which they are part of (Foucault 1978). They are all – consciously or unconsciously – making strategic choices that allow them to separate out the acceptable explanations from all the possible explanations. Although they seem to be talking in terms of what is true and what is not, they are really choosing what is acceptable and compatible with the ideological apparatus they are willing to accept. Thus the search for explanations becomes a field of contested meanings in which different ideologies compete for hegemony (Comaroff and Comaroff 2002), not for the sake of understanding this outbreak, but because what is at stake is larger than the outbreak itself. Knowledge claims are expressions of power/knowledge.

For instance, when the psychiatrist says he finds the *Ajq'ijab*'s explanation unbelievable, or when the Catholic blogger disregards the Mayan ceremonies as “Indians’ superstitions”, or when the *Ajq'ij*-physician denies the religious character of the *Ajq'ijab*'s intervention, what is at stake is more than just the explanations of this outbreak. They are reflecting a political struggle with deep historic roots that goes beyond the immediacy of the outbreak. Although it is correct to say – paraphrasing Good (1994) - that each of their knowledge claims is grounded within local worlds of experience and human action, and that their differences reflect a diversity of phenomenological perspectives that shape their interpretations of the outbreak, or that the different knowledge claims are made from within distinctive cultural worlds that have cultivated each of the stakeholders’ perceptions, allowing them access to particular dimensions of reality, it is also insufficient to acknowledge this without accepting that the strategic choices they make are serving the reproduction or transformation of concrete power relations. The strategic distinction between knowledge and belief is made from the lived

experience of those involved, but at the same time it is made from a relation of power they are part of, that shapes the ways they experienced the outbreak. Although the distinction between knowledge and belief is rooted in deeply symbolic networks, it is also immersed in power relations that shape those networks and the distinctions between what is acceptable for each stakeholder (Good, 1994) (Good, 2012) (Saler 2009).

But a focus on the criticisms to the belief-knowledge dichotomy, even if it assumes the indivisibility of power-knowledge, does not address the role of technologies and practices in co-constructing the notion of health implicit in right to health discourses. In other words, understanding the right to health as a sociotechnical system ambiguously overlapped with biomedicine as technology, offers new angles for an anthropological understanding of the right to health in a mysterious outbreak like the one presented in this chapter. But such an approach needs to use as a starting point the vast literature on medical pluralism generated mainly by medical anthropologists, as well as the distinction between contamination and configuration explanations of epidemics suggested by medical historians.

Previous efforts by anthropologists interested in epidemics have attempted to influence how epidemiology is conceived and practiced. For example, there is a trend in Latin-American medical anthropology concerned with socio-cultural anthropology (Haro 2006, Menendez 2008). They call for an epidemiology that affects avoidable health harms [daño evitable] and that takes people's perspectives and experience as a central concern (Hersch-Martínez and Haro 2007). In the United States, Marcia Inhorn (1995), Susan DiGiacomo (1999), Robert Hahn (1995, 1999) and James Trostle (2005) also have made efforts to use anthropological perspectives to broaden epidemiology's views.

Inhorn (1995) identified the perceptions that medical anthropologists have about epidemiology and suggested that they could be seen as gaps to be bridged. The gaps she identified can be summarized in terms of dichotomies between epidemiology and medical anthropology; while the first is perceived by medical anthropologists as disease-oriented, reductionistic, positivistic, risk-oriented, and medicalizing, the second is seen as illness-oriented, holistic, humanistic, macro-level oriented, and interested in the sufferer. DiGiacomo (1999) draws on her experience working in a team of epidemiologists to highlight the irreconcilable notions of culture that epidemiologists and anthropologists have. As culture is seen by epidemiologists as a variable, they tend to reify the notion of cultural beliefs, create the notion of cultural risk and medicalize the concept of culture. Robert Hahn (1995, 1999) and James Trostle (2005) have pointed to the potential collaboration between epidemiology and anthropology to serve public health goals. Nancy Krieger (2001) urges epidemiologists to use social theory as part of the framework that allows them to define problems and ask questions and interpret findings. But these efforts have focused on the disciplinary differences as they translate into theories, methods, and practices.

A more practical perspective that comes from the professional and political circles of public health and international health is what has come to be widely known in Latin America as “interculturalidad y salud” (multiculturalism and health), which has been surveyed in several volumes edited by Gerardo Fernández (2004, 2006, 2010). Although as a notion it has been embraced by multiple governmental and non-governmental institutions and international aid organizations (Fernández 2006:12), nobody really understands it or knows how to apply it (Fernández 2004: 11). However, everybody

involved would agree that it deals with – paraphrasing Fernández- experiences and situations that have to do with idiosyncratic difficulties associated with indigenous disease categories, therapies and conceptions about the body and the person, as they relate to Western medicine, and the relations between physicians and sick people (2004: 11). Fernández states that any attempt towards ‘interculturalidad y salud’ needs to start with mutual respect and permanent dialogue, two requisites that are hard to achieve in health practices marked profoundly by striking power asymmetries (2004: 8), which leads him to question if ‘interculturalidad’ is just a resource advocated by anthropologists’ snobbism when the real challenge is wealth distribution (2006:10).

In any case, the ‘interculturalidad y salud’ agenda has been inspired in theories and methods conceived primarily in the U.S., the U.K., and France in the 1940’s and 50’s, but institutionalized throughout Latin America in the 1960’s and 70’s as part of assimilationist policies known as “indigenismo” (Menéndez 2006: 55), that is, nation-building policies aimed at integrating indigenous peoples through their ‘westernization’, known in Guatemala as ‘ladinización’. The ‘re-discovery’ of ‘interculturalidad y salud’ in Latin America in the 1990’s was influenced by the exacerbation of poverty in the region, that led to poverty reduction programs promoted by international financial institutions such as the World Bank and the International Monetary Fund, through non-government organizations or ministries of health. But the re-discovery was also influenced by its re-discovery in countries of the Global North, where public health programs faced demands posed by the growing immigrant populations that may be described as economic and/or political refugees. This re-discovery in the Global North led to theoretical and methodological renovations, primarily generated in the U.S. On the other hand, the re-

discovery of ‘interculturalidad y salud’ in Latin America was a secondary effect of the indigenous people’s rights movements that converged around the commemoration of the Spanish invasion to the Americas in 1992, and that centered their struggles in demands for cultural and political autonomy.

The legacy of all this, according to Menéndez (2006) is that ‘interculturalidad y salud’ in Latin America is understood in two trends: a cultural approach, and one centered on achieving political autonomy of subaltern groups. The first trend is the most widely spread in the terrain of health and is mostly based on conceptions about culture from the 1930’s and 1950’s in the U.S. It understands ‘interculturalidad’ as impaired communication due to cultural conditions that need to be modified in order to improve the interaction. Therefore, it emphasizes the modification of beliefs and knowledges through education of both health care providers and patients, to improve information, tolerance, and mutual respect. It does not address representations or practices in terms of social class or ideology. The second trend is stronger in struggles over natural resources and land ownership, and assumes that poverty and social inequalities are part of intercultural relations. Therefore, it advocates addressing processes of domination, exclusion, exploitation, and stigmatization promoted by competing interests of social groups. These two trends are at the same time antagonistic and complementary. As a result, ‘interculturalidad y salud’ is not a central issue in the agenda of groups promoting indigenous people’s rights, but it is in the agenda of politically progressive health care institutions, and health care providers, for whom it has translated in a few strategies – cultural competency, introduction of ‘traditional indigenous healers’ in biomedicine’s health care facilities, training ‘traditional indigenous healers’ in biomedicine’s priorities -

that have not been fully adopted and therefore have not been effective even at improving communication between health care providers and patients (Fernández 2010). These trends have been observed in Guatemala, where ‘interculturalidad y salud’ has become part of the national health policies established by the last two governments, but it remains more of a wish list than as a set of operational programs, partly because the vast majority of health care workers are not truly interested in it and hold discriminatory attitudes towards indigenous health knowledge and practices (Arévalo 2009).

In any case, as it has been pointed out, the culturalistic approach promoted by advocates of ‘interculturalidad y salud’ would be insufficient for addressing an outbreak such as the one described in this chapter. Framing this outbreak and the different interpretations brought by experts of all kinds as a case of medical pluralism that could be better addressed attending to the distinct explanatory models involved to find ways to ‘bridge the gap’ between different cultural understandings would not shed enough light into the outbreak itself, or into its implications to a right to health perspective on epidemics.

This is why many medical anthropologists have insisted since the 1990s that explanatory models need to always be analyzed in their social political economic and historic context, with close attention to the dynamics of power. Contextualization is profoundly important when addressing an outbreak, as anthropologists and historians have repeatedly shown (Rosenberg 1999, Lindenbaum 2010, Anderson 2010). In fact, Lindenbaum (2010) has suggested that addressing outbreaks through a “double dialogical mode” in which attention is paid at the same time to explanatory models and contexts, would improve our understanding of mysterious health problems of our times. She draws

on the distinction introduced by Rosenberg (1999) and developed by Anderson (2008, 2010) through their historical investigations into outbreaks, between ‘contamination’ and ‘configuration’ approaches to epidemics. While a contamination approach points at understanding how the context explains why the outbreak happened in the time, place, and people it occurred, a configuration approach points at finding explanations within the bodies that were affected. As they suggest, understandings of the context and body constitution are historically and culturally mediated, and a serious investigation would need to address such mediation.

In this outbreak, context played an important role, as the violent history of evangelization collides with contemporary social relations surrounding religious, class, and ethnic relations in the town. But still, it seems to me that understanding this context does little for unpacking the implications of this outbreak for the notion that health is a human right. Let me present a snapshot of the town’s context and then discuss how an understanding of the right to health as a sociotechnical system helps pose questions.

The town

The town of San Marcos la Laguna has changed its location at least five times throughout its history. According to the legend, the original location was not in Lake Atitlan’s shore, but further south, in what is now called Pak’ip. As the story goes, in colonial sixteenth century, a priest paid for the construction of a church for the people of San Marcos la Laguna, the Marqueños, to use, but they did not use it, preferring to practice their vernacular rituals rather than to adopt Christian customs. As a result, the priest abandoned the town as he issued an omen: lions would eat Marqueños as a penalty for their disrespect. As some Marqueñas began to disappear while washing clothes in the

nearby river, the community decided to relocate the town. So in 1580 they relocated to the Southeast shore of Lake Atitlán, close to today's Cerro de Oro, but they were forced to vacate the property in 1701, moving to the lake's West shore, near present day Santa Cruz la Laguna, in the lands where the village of Jaibalito is located today. But in 1724 a flood that wiped out the town forced the survivors to move once more to the lake's Northwest shore, where they were granted possession of land by Sololá's mayor. It was here where the town was registered for the first time as San Marcos la Laguna. Yet another flood destroyed the town in 1881, forcing Marqueños to relocate once more, this time uphill to its current location.

San Marcos la Laguna is one of the smallest towns in Guatemala and the smallest municipality in the country, with an area of 12 square miles, surrounded by the towns of San Pablo, and Santa Lucía Utatlán, and the village of Tz'ununa'. Locals divide the town into three sections or neighborhoods (*barrios*). Barrio 1 (*Chwi Nimab'aj*) is the largest of the three and it occupies the town's southern part. The main public buildings – such as the police station and the municipal building - are located in this neighborhood. Barrio 2 (*Xelema'*) occupies the town's northern edge, along the main road that is next to the neighboring town of San Pablo la Laguna. Mostly comprised of residences, it houses the main Evangelical church. Barrio 3 (*Cheb'en*) is in the town's Eastern side, next to the lake. Although the Catholic church is the main building in this neighborhood, it is surrounded by multiple small stores, diners, other public buildings and the two public schools (primary and secondary). Barrio 3 is often affected by flooding during the rainy season, and the church was damaged in 2005 by hurricane Stan. The area located right next to the beach has undergone recent development, especially by foreigners, which is

why it is known as the “Barrio Gringo”. Trying to find patterns, one could say that barrio 1 is inhabited mostly by Catholics, barrio 2 residents are mostly Evangelical Christians, and barrio 3 houses most of the non-locals that have immigrated to San Marcos (from the U.S., Europe, South America and Guatemala City). Barrios 1 and 2 are mostly residential, while barrio 3 contains most of the tourism-oriented businesses, such as hotels, spas, bars, and language schools. San Marcos is considered to be a spiritual tourism destination by the main tour guides, because although it is very close to other important tourist destinations such as Panajachel it has been relatively isolated from them until recently (see Tally 2006 for a comprehensive and critical account of spiritual tourism in Guatemala, including this town).

Most local Marqueños live in small houses known as “*sitios*”, which range in size from five to thirty square meters. The sitio’s size and construction materials reflect the wealth and social status of a household, and there does not seem to be segregation in the town’s residential portions, finding sitios of different sizes and materials next to one another. Although the average household size is of five members, typically for a nuclear family, extended families often live in adjacent sitios. Many homes are built out of cinderblock walls and sheet metal roofs, but others are only formed from three poles tied up with vines, with walls made out of cane covered with mud. Sitios often look as if they were stacked on top of one another. Children spend most of their initial years pretty much confined inside their family’s sitio, but they start working at young ages to supplement their family’s income. Most children start going to the public school but the majority never complete primary education. For those who do, there is a free-of-charge Instituto

Básico (three years of pre-vocational education), after which their options are to travel to a larger city to complete a high-school diploma.

Employment opportunities are scarce for Marqueños. Most women work in the home, but some sell produce in the streets and the beach. Most men work at the coffee plantations in San Marcos or as far as Guatemala's Pacific coast. A small proportion of Marqueños work in the hotels or construction crews in the Barrio Gringo, but locals own only a few of the tourist-oriented businesses.

Although the town's native language is Kaqchikel, most residents speak Spanish. While men and boys do not use the traditional outfit that once characterized the town, women still don the characteristic bright red, hand-made *huipil* (top) and the dark-blue *corte* (skirt) secured to the waist by a twisted multi-colored *tzut* (wrap, scarf, shawl).

Relationships between the people of San Marcos and that of neighboring villages and towns are tense and filled with stereotypes. Marqueños lived until the past twenty years, in relative isolation without good roads to connect to other settlements, so they had to travel great distances by foot in order to trade basic goods. For instance, they would walk for two and a half hours north, and uphill, to Santa Lucía Utatlán, or take a canoe to San Pedro la Laguna. Although there is a road now and a bus service in and out of town every day, San Marcos' material wealth and infrastructure are less than those of their neighbors, who portray Marqueños as somewhat backward or inferior.

***Ajq'ijab'* intervention**

The essence of what the *Ajq'ijab'* did is communicating with the dead and interpreting the energies of the earth. They did it through a combination of rituals where

the use of fire was fundamental, as was the interpretation of other elements such as *tzite* (seeds that look like beans). They also used interpretation of the Mayan calendar as part of their intervention. The group of *Ajq'ijab'* involved in this case was not from the town or nearby villages. They were invited to come by an anthropologist, Elba Villatoro, who had done work before in this town and who was asked by the town's authorities to help out with the outbreak. The *Ajq'ijab'* came from three different parts of Guatemala and are part of a national and international network of people who combine their knowledge and abilities derived from indigenous spirituality, with indigenous rights activism. But on a daily basis, they work in private or public institutions in issues totally unrelated to their role as *Ajq'ijab'*. That they can do their rituals without being persecuted shows recent changes in Guatemalan laws, as they reflect a shifting power relationship between different ideologies around religion.

But it was not always like this. Prior to the Spanish invasion of the 16th century, there were religious and medical practices and specialists in the Mayan region that suggest some continuity with that of the *Ajq'ijab'* of the 21st century. Among the pre-Hispanic Maya, there was a religious hierarchy (interpreted by Spanish chronicles of the time as bishops and priests of different categories) that “performed communal and private rituals aimed at communicating with supernatural beings, manipulating cosmic energies and interpreting the future. [...] Disease prevention and curing were among the most important purposes of their work” (Marcus, 1999) All these sound like what the *Ajq'ijab'* do today.

In addition to a diversity of specialists in health-related problems, such as specialists in animal bites, bonesetters, herbalists, midwives, dentists, and surgeons, there

were specialists in different forms of “divination”: there were specialists in predicting the future, interpreters of the omens (*augurios*), and interpreters of dreams. Others specialized in determining if a day was good or not for a certain ritual or action, or more generally the type of energy of a particular day. According to Fuentes y Guzmán, among the diviners, there were the “aj kij” who used some form of “maize-grain counting as a diagnostic procedure”, and also used some form of calendar for predicting when war, famine, or pests would come. (Orellana, 1999)

In 1569, the first two branches of the Spanish inquisition were established in Mexico and Lima and, although the rigor with which they were enacted was milder and more flexible than in the Iberic Peninsula, they were very active (Jiménez, 2009). As in other parts of the Americas and Europe, the Inquisition was not only about religious beliefs, but also about legitimate forms of knowledge as they related to religious faiths, colonial domination, political power and economic interests. This is illustrated in the Guatemalan colony, where the representative of the inquisition was initially one of the staff members of the cathedral, but when the University of San Carlos was founded in 1676, the university’s rector became the local representative of the inquisition. The inquisition did not have direct jurisdiction over indigenous peoples, unless their activities involved Spaniards or if the “heresies” were collective or notorious to the Spaniards. There are no documented cases of immolation of people by the inquisition in Guatemala, but there are documented cases where large numbers of indigenous people were whipped and their “idols” burned. Performing ceremonies and communal dances, such as the *Tum-Teleche*, were also prohibited. (Chinchilla Aguilar, 1999)

But there are well-documented cases of immolation in colonial Mexico (keep in mind that the inquisition in Guatemala was under the jurisdiction of the New Spain – Mexico – as it was for most administrative and political aspects during the colony). See this chronicle from the early 17th century,

“That year they burned don Carlos [Ometochtzin Chichimecateuctli], tlatohuani de Tetzaco Acolhuacan e hijo de Nezahualpilli Acamapichtli, who governed for eight years; this was done following orders from don fray Juan de Zumárraga, first bishop of Mexico, who was the prosecutor when don Carlos was burned. He was accused of idolatry, since it was proved that he had not stopped adoring idols of the devils to whom the people from the past adored.” (Cited in Jiménez, 2009)

This fragment from some sort of guidebook of methods to make suspects confess idolatries shows inquisition’s policies in 1692,

“When the Lord says idolatry must be destroyed, He also says, he will erase the names of the Ministries that keep it, and the false priests that encourage it: [The Lord] is telling us the efficient method to remove [idolatry] is to erase the mind of their dogmatists, teachers and priests, since it is them who keeping books, and transmitting the books of their diabolic rituals from parents to children, in which they study the practice of their pernicious teachings, superstition gets passed to the populace, as they pass the cult to the devil...” (Cited in Jiménez, 2009)

Persecution changed over time in forms and intensity, but never disappeared in Guatemala. All through the years since the independence from Spain in 1821, different religious and civil authorities have passively or actively attacked the practices of the

Ajq'ijab'. For instance, when in the early 1990s a group of *Ajq'ijab'* started the first officially recognized society (*Asociación de Sacerdotes Mayas de Guatemala*), the Guatemalan civil authorities made them ask for permission from the Catholic church's Archbishop (Bastos & Cumes 2007). They have also been and are currently condemned by most denominations of Pentecostal Christians, both catholic and protestant (Bastos & Cumes 2007, (Cantón Delgado, 1998)).

But despite persecution and attempted destruction of everything related to these practices and knowledge, they have persisted, evolved, and transformed in different parts of Guatemala, sometimes in complicated relationships to catholic rituals and institutions (Bricker 1981, Marcus 1999, Bunzel 1952, Cancian 1965, Fabrega & Silver 1973, La Farge & Byers 1931, Oakes 1951, Orellana 1999, Saler 1964, Saler 1969, Siegel 1941, Tax 1941, Wisdom 1952). In the last twenty-five years, they have been part of an energetic revival as they become more public and become one of the concrete forms of indigenous peoples' rights struggles in Guatemala (Molesky-Poz 2006) (Bastos & Cumes 2007). Unlike most of the Mayan professions related to healing - "traditional healers" such as midwives, *chayeros*, *sopladores*, bonesetters, and herbalists – the *Ajq'ijab'* seem to be growing in numbers and in prestige (Peretti, 2010), although they are still seen and portrayed by Guatemalan popular culture as folkloric at best.

The *Ajq'ijab'* of Guatemala are today a heterogeneous group, with a heterogeneous belief system and a heterogeneous set of practices and rituals. Scholars have grouped them in three types with blurry boundaries (Bastos & Cumes 2007, Morales 2007, (Tally, 2006)) that I will call community traditionalists, pan-Mayan activists, and New Age cosmopolitans.

The *Ajq'ijab'* I label as community traditionalists usually live and work in smaller towns or villages (or have migrated from them to the city but maintain ties with their home villages), remain close to agricultural duties, and they base their knowledge and practice on a combination of oral tradition, intuition and exchanges with *Ajq'ijab'* of neighboring locales. Their discourse and rituals use Catholic references in combination with references to “*la costumbre*”, a term that loosely refers to traditions from the ancestors or from “our culture”. Those I have spoken with see what they do as a religious duty and they often are important members of the local Catholic structure (i.e. *cofradías*) and civil government (i.e. *principales, alcaldes auxiliares*). The ones I label as pan-Mayan activists are more often part of organizations that implicitly or explicitly fight for indigenous peoples’ rights. They are part of a more sophisticated discourse that stresses the relationship between Mayan ways with those of other indigenous peoples in Latin America and the world. They are interested in studying, documenting and educating about knowledge, culture and history underlying their practices, and make efforts to find commonalities between the practices of *Ajq'ijab'* in different parts of Guatemala. Finally, the New Age cosmopolitans see Mayan spirituality and religious practices as part of a larger set of esoteric practices that are in a process of revival especially among young people from the First World (Tally, 2006).

In the past twenty-five years, *Ajq'ijab'* have been called in Guatemala “*sacerdotes mayas*” (Mayan priests), “*guías espirituales mayas*” (Mayan spiritual guides), and *Ajq'ijab'*. For most people these seem to be synonymous terms, but some scholars see their use as reflecting a tendency in moving from a religious, local, and non-political emphasis towards a more explicit articulation with the pan-Mayan political movement

and away from religious alliances (Bastos & Cumes 2007). But to the best of my knowledge, all scholarship and activism around the *Ajq'ijab'* of Guatemala focus either on its spiritual/religious character, its articulation to the Mayan movement, or both.

And it is here that I want to go back to the two quotes at the beginning of this chapter. When one *Ajq'ij* challenged me to find ways of articulating the knowledge and practices of the *Ajq'ijab'* with those of epidemiologists, and when another *Ajq'ij* challenged “Western science” to come up with instruments to “see what they see”, they are moving away from the religious and spiritual character of what they do and what they claim to know. They are saying that communicating with the dead ancestors and using the fire to open windows to let the cosmic energy flow are not just their cultural beliefs, or part of the symbolic network that gives meaning to their lives. They are saying their knowledge claims and the practices around them are real. Not in the way that cognitive or symbolic anthropology would acknowledge their reality, but in another way that makes it hard for me to ignore it or dismiss it which is what the default answer from public health officials has been.

Conclusion

This chapter shows how, when the tension between the technical and political aspects inherent to the practice of epidemiology is resolved by blindly applying epidemiological protocols, the humanity of those affected gets erased, with very practical consequences. This kind of conundrum was expressed by a group of epidemiologists at one of the Monday SEMEPI meetings (Semana Epidemiológica Meetings, where epidemiologists at CNE analyze the previous week and plan the following one), when

they had asked me to present my research project in 5 minutes and then receive comments. After several generally positive comments, the following exchange:

EPIDEMIOLOGIST 1: Let me just insist that you should base your work in the Declaration of Indigenous Peoples Rights, and be very explicit in your definition of health, to make sure you are including the visions from the Mayan people.

EPIDEMIOLOGIST 2: I just want to say [...] that I think that maybe epidemiology is being too contemplative without focusing on actions.

EPIDEMIOLOGIST 3: I think your study will point to dehumanization of epidemiological practice. I think sometimes we forget that numbers represent people.

EPIDEMIOLOGIST 4: I dissent, because I always remind my colleagues in this very meeting room, for instance in the cases of rabies deaths, that even if they were just a few, they should not have suffered in that way, especially if they are just kids. We should not forget that.

After a few other comments, people thanked me for my presentation, offered me applause, and we left.

Chapter 6: Conclusions: working with feet on the ground towards a Post-Colonial Epidemiology

When the epidemiologist I interviewed at the CNE in early 2011 told me, as I presented in the introduction of the first chapter of this dissertation, that he “needed to do research because [he] wanted to get to the root causes of problems [in order to] find real solutions to those problems, not just fix problems but find solutions. [...] so [he] went to get a masters in public health with an emphasis in epidemiology and then was offered a job at the CNE, which, to [him], was like a dream come true”, I felt inspired. I honestly thought it was a great sign to find people who felt so committed to and fulfilled by their jobs as epidemiologists.

In February of 2012, I ran into the same epidemiologist in one of the Ministry of Health’s hallways – one that was not near where the CNE offices are- and briefly chatted with him:

ME: How’s it going?

HIM: OK. Have you finished your thesis?

ME: I am working on it. Right now I am going to the CNE to present my preliminary results. Are you coming?

HIM: No, I am not there anymore... Now I am with the World Bank’s Malaria project.

ME: How come?!

HIM: Well... I received the offer and could not reject it. You know: better pay, less stress, clearer goals... Excuse me, I need to go back in to my meeting.

Take care!

ME: Take care. Nice to see you!

I did not even have the chance to think too much about this conversation at the time. I also had not realized back then that the epidemiologist whose dream-come-true was to work at the CNE was going to leave at the first chance he got. With some distance and as I advanced with the analysis of my data I realized that “brain drain” is part of the expected professional trajectory of Guatemalan epidemiologists. Although I did not explore brain drain as a part of my research during the interviews, I went back to the transcripts and found it there, always present. Sometimes it was mentioned as a professional hazard, but other times it was clearly seen as a professional promotion. Although I would say that in most cases it was referred to as a possibility for epidemiologists who wanted to resist the mediocrity of the status quo, and at the same time as a form of claudication. Perhaps in the end it is just a way for giving up the ideals without feeling too dishonored when you look in the mirror. Perhaps it is a courageous way of following the ideals despite the institutional affiliations, the way of facing the challenges and frustrations of being immersed in neo-colonial epidemiology.

In the introduction to chapter 1 I also presented myself as having being seduced by epidemiology’s promise of addressing “the real causes of health problems”, but in the end I also ended up being part of the “brain drain” trend. Whether brain drain is a form of resistance or of claudication, or a mix of both, what seems clear to me is that it is a

product of neo-colonial epidemiology, but that at the same time epidemiology will not be decolonized if the brain drain trend is not addressed.

The need to de-colonize Guatemalan epidemiology

During one of my visits to Sololá in 2011, I met a foreign physician who was part of an international humanitarian mission in Guatemala. After introducing myself as a physician and anthropologist interested in epidemiology, we had this conversation:

PHYSICIAN: What? I can't believe there is a Guatemalan physician who's even interested in epidemiology!

ME: Why do you say that?

PHYSICIAN: Well, the day that serious epidemiological work is done in Guatemala, a lot of interests will be affected.

ME: Can you give me an example?

PHYSICIAN: Oh, I can give you many! Physicians in hospitals, for instance, public or private hospitals... they will not be able to get away with what they are doing now... People die in hospitals and nobody knows why! But it's not just doctors who would get affected. What do you say about business (las empresas)? Air and water pollution from business, or so many accidents caused by crazy public transportation, or food manipulation in markets and restaurants... If epidemiologists start to look into all those problems, people's interests would be touched...

And I agree with her. Little problems and big problems could be better understood and addressed if serious epidemiological work could be done. And, from my own

experience and my interviews with epidemiologists, there would be many epidemiologists very happy to do precisely this kind of work. But the current system of Neo-Colonial Epidemiology will not permit such work, and the key to change it would be a commitment to people's suffering, such as the one implied in the right to health.

A right to health inspired epidemiological practice – such as the one stated in CNE's mission statement - needs to include social participation in its methods, and needs to aim at the elimination of health inequalities as its goal. Social participation and health inequalities are both context specific, so Guatemalan epidemiologists need to develop and learn how to do an epidemiology that promotes and contributes to social participation at the same time that it addresses health inequalities in the Guatemalan context. These two features are impossible to achieve if the current form of Neo-Colonial epidemiology stays in place. In other words, a right to health inspired epidemiology needs to be a Post-Colonial Epidemiology.

De-Colonizing Epidemiology

Neo-Colonial Epidemiology needs to be decolonized and, in the process, give life to Post-Colonial Epidemiology. A post-colonial epidemiology should move from a practice that sees people as spaces of pathogenic behavior, and looks at individuals as highly mobile vectors of infection, to a practice that, acknowledging epidemiology's pitfalls and stereotypes of the past, brings back people's wellbeing as its aim and purpose (Kelm 2010). A post-colonial epidemiology should start with epidemiologists understanding that their apparently scientific and authoritative discourses and practices have the effect of merging their desire for a scientific truth with a repulsion of people's knowledge and situation (Anderson 2002,) that leads epidemiologists to perform a role

filled with ambivalence and mimicry, resembling attitudes during the colonial period (Bhabha 1994). A post-colonial epidemiology acknowledges the existence of the epistemic violence inherent in dominant epidemiologic practices, and embraces alternative modernities and the challenges they pose to contemporary knowledge production (Anderson 2002). A post-colonial epidemiology accepts that the legacies of colonialism are actively shaping Guatemalan social life, but at the same time takes on the challenges of building a new, more just society. A post-colonial epidemiology, finally, understands epidemiological practice as a “technopolitical regime” (Winner 1998[1986]:55), where *technē* – applied knowledge – and *politeia* – the proper order of society – co-constitute each other.

Saying that epidemiological practice is a technopolitical regime goes beyond accepting that epidemiology is a sociotechnical system – as I argued in chapter 5 – and brings back the discussion about the political nature of defining who is the “human” in the right to health – as I presented in chapter 2 – as well as what counts as “health” in the right to health – as I discussed in chapter 5. Saying that epidemiological practice is a technopolitical regime implies that Guatemala’s epidemiology is shaped by Guatemala’s social, political and economic order, but it also implies that such order gets reproduced or transformed through epidemiological practice. To be clear, I reject the notion that epidemiological practice is a mere reflection or effect of social order, which would imply that the social order is some sort of independent variable and epidemiological practice the dependent one. What I want to argue is that the social order could be disrupted and challenged through epidemiological practices, but in order to do it, the institutional reality presented in chapter 4 and the ideological foundations presented in chapter 3 need to be

addressed, with the goal of moving from a Neo-Colonial Epidemiology to a Post-Colonial Epidemiology.

As I argued in chapter 1, the main characteristics of Neo-Colonial Epidemiology are institutional chaos, disciplinary conformism, global health international relations, and social relations at the national level. In what follows, I synthesize and offer some ideas of how to address these four features, and add including social participation and addressing health inequalities.

Institutional chaos

“The [creation of the] CNE was a step in the right direction, but there have been some political decisions that haven’t been made [such as creating the] position of epidemiologist [in the Ministry of Health’s structure], or [turning] the CNE into [one of the Ministry of Health’s main departments] the Epidemiology Department. There have also been lots of [institutional] divisions, or as I always say, fiefdom disputes... hospitals don’t want to give up their freedom, SIGSA people [Ministry of Health’s official information system] don’t want to open up to our suggestions, SIAS people [Ministry of Health’s care provision department] want to be the ones making all the important decisions... I have come to see the [creation of the] CNE as a lost opportunity.” (Epidemiologist at CNE)

Institutional chaos has many manifestations, some of which have been laid out throughout the preceding chapters, but I group the manifestations and their causes in three large sets of problems. First of all, the Ministry of Health’s institutional weakness (itself a manifestation of the Guatemalan state’s weakness) is a reflection of the lack of

political priority public health has had in the social and political agenda. For instance, the debates surrounding the appointment of the current Minister of Health in 2012 made it clear that the priorities at stake had to do more with who would benefit from large government contracts (related mainly to pharmaceutical products and medical equipment purchases) than with a public health agenda. Public health's lack of priority and institutional weakness results, for instance, in a lack of capacity to enforce public health related regulations, such as the compulsory reporting of epidemiologically relevant events by private physicians, clinics and hospitals, as was shown in previous chapters.

Secondly, institutional chaos shapes and is shaped by job instability, which is endemic in the Ministry of Health, but manifests in particular ways within the CNE. Job instability here is marked by about half of the CNE's personnel being hired on a yearly basis (with no benefits) and the remaining half being tenured but shifting specific job positions very often. As an illustration of the kind of job instability I am talking about, I noticed that between 2009 and 2013, the period between the beginning of my pilot research and the end of my dissertation writing, there were six different CNE directors. Similarly, none of the sixteen CNE epidemiologists I interviewed in the first half of 2011 was doing the same work by April of 2013, with ten of the sixteen not even working at CNE anymore. Even if all these epidemiologists were highly committed and technically capable, there is just no way to give continuity to the processes with such a high job turnover rate.

Finally, institutional chaos is also influenced by a varied set of –sometimes-contradictory demands posed to epidemiologists by different institutional and extra-institutional actors. For instance, health authorities and health care workers all throughout

the country expect timely technical and logistical support when faced by an epidemiologic outbreak, but the CNE is not able to respond to that expectation, mainly because this has not been defined as a priority. Similarly, top-level officials such as the Minister and Vice-Ministers see the CNE as technical advisers for their political and administrative goals, which is a role highly prioritized, with the CNE director participating in weekly high-level technical meetings and prioritizing actions derived from those meetings. Moreover, the SIAS department (in charge of health care provision) would want the CNE to help out with the training and monitoring of the operational aspects of epidemiological surveillance in charge of physicians, nurses and nurse aides, but the CNE does not see that as its function. At the same time, a variety of actors want the CNE to provide thorough and in-depth analysis of the health situation and to do research that helps identify the causes of health problems. And yet others want the CNE to participate in setting up norms, procedures and protocols for a variety of health problems. These contradictory demands add to the level of chaos.

Many epidemiologists I spoke to identified the source of this chaos with the lack of institutional space for epidemiologists within the Ministry of Health. To this date, the job position of epidemiologist does not exist within the institutional organization, so everybody working as an epidemiologist is serving the “functions of epidemiologist” but is actually hired as something else. So epidemiologists are “lent” from other job positions. Despite efforts to have this changed, the bureaucratic process needed is so complicated that every attempt made so far has failed. But the CNE also has a rather arbitrary place in the Ministry of Health’s organizational chart, mainly because it was created through a Ministerial Decree, rather than through a Presidential or Legislative action. This means

that any Minister of Health could make the CNE disappear and, more likely, the CNE's functions and priorities change with every new Minister. And because this is so, opinions among epidemiologists are divided as to whether the CNE should remain as a technical adviser to the Minister, or if it should become a department on par to the department of regulations and the department of health care provision.

From my perspective, the Minister advisory role is an important one, but there should be a way of separating this role from the other roles the CNE needs to play, such as outbreak control, operational training/monitoring, and research. In fact, I think it would not be complicated to organize the CNE's work in a way that all those functions could be fulfilled without too much trouble. But, the problem of instability and lack of political priority would remain, and they will remain unless there is a major political shift in the country that results in a strengthening of public health and other social policies and institutions. Such an effort, as impossible as it may seem, needs to be undertaken as a part of a larger social change effort. However, I think the only way the CNE could strengthen itself despite a more systemic public health weakness would be through the promotion of a more stable leadership and the development of strategic and loose alliances with actors outside the Ministry of Health, such as researchers, social activists, and universities. Such alliances should be around specific projects and specific individuals, rather than trying to conceive of a larger, more institutionalized alliance.

Disciplinary conformism

“Look, I received the FETP training [CDC’s Field Epidemiology Training Program] and learned a lot from it, but I also see the program as a sort of maquila [sweatshop] that produces “field epidemiologists”. And I think the CNE

should include a mix of people with the FETP training and public health training from different universities, and even some specialists in social sciences. I even think there should be an effort to offer epidemiology training to nurses, psychologists, and nutritionists to improve what we do. Because, look, if we conform to only having a lot of doctors with the FETP [training], we will be stuck... as I think we probably already are.” (Epidemiologist at CNE)

I heard similar insights from several epidemiologists during my fieldwork. There was an acknowledgement about the conceptual and methodological limitations of the epidemiological practice for understanding and addressing many epidemiological problems. I heard in different moments the potential benefit the CNE would get from lawyers, nutritionists, nurses, sociologists, psychologists, biologists, toxicologists, environmental experts, social workers, and educators. I also heard some discussions around the convenience or not of having some of those disciplines represented within the CNE, and the general thought seemed to be that it would be impossible to have such interdisciplinary staff, but that it would be very good to be able to at least have those specialties available for consultation in specific cases. Some epidemiologists also rejected the idea of having anything other than epidemiologists within the CNE.

From my perspective, epidemiological work would benefit from an interdisciplinary approach particularly when it comes to performing health situation analysis and epidemiological research. But I also think that epidemiological work would be better and more useful if epidemiologists find ways for including the perspectives of indigenous peoples, women, residents of rural areas, residents of urban impoverished

areas, sexual minorities, people with disabilities, and workers. Finally, Guatemalan epidemiologists would greatly benefit from establishing cooperation with institutions (universities, research centers, and NGOs) that are already doing social epidemiology, sociocultural epidemiology, and critical epidemiology.

Given the institutional chaos I referred to in the previous section, I see some alternatives in generating alliances that are tied to specific individuals and specific projects. For instance, CNE could reach out to universities and research centers, or even better to specific researchers, to develop shared projects with the aim of addressing specific epidemiological research projects. With this approach, the institutional weight of CNE would work in synergy with the flexibility of other institutions for committing to getting involved in epidemiological projects, and wider opportunities for applying for research funds.

A similar approach could work for specific projects with civil society organizations that represent or give voice to social minorities that are usually excluded from epidemiological discussions, and that very likely are receiving the worse side of health inequalities in Guatemala. Research projects could be collaboratively conceived and executed, but there is also a nice potential for developing some kind of participatory health situation analysis that incorporates the perspectives of such social organizations. This approach could also use the potentially powerful synergy of an official public institution such as the CNE with the flexibility and dynamism of civil society organizations.

Finally, the potential for building productive working relations with institutions outside Guatemala that are already doing epidemiological work and research could

diversify the conceptual and methodological frameworks, but also the topics and sources of funding that would allow for actually implementing some of the research that needs to be done.

Global health international relations

“Look, don’t get me wrong. I don’t have anything against international cooperation... Only god knows how would we be doing without it! But... how can I say this... HIV/AIDS has been one of the worst things that have happened to the development of epidemiology from an institutional perspective. Don’t get me wrong, I know it is an important disease and people with it need as many resources as possible, but from an institutional point of view, HIV initiatives have received such a tremendous amount of money that they can give themselves the luxury of working on their own, without paying attention to the Ministry of Health. But it is not just HIV, look at malaria, for instance. The World Bank decides malaria is a priority and they give money earmarked for malaria, and they hire some of the most successful epidemiologists and, because they have the money, and their own goals, they end up doing work that weakens the Ministry of Health’s efforts. The same goes for USAID’s prioritizing birth control. There is nothing wrong with those priorities, but they come here with all their money, and the impact they have on us as an institution, with our very scarce resources, is huge. [...] You can even see it with the H1N1 case, where all our resources ended up going towards controlling a pandemic that was not even what it was supposed

to be... and we have other priorities in the country, right?" (Epidemiologist at CNE)

This is one of the more troubling aspects of Neo-Colonial Epidemiology. The problem as I have come to understand it is three-fold: while international agencies have clear agendas tied to relatively large budgets, the CNE does not have clearly defined priorities, and at the same time there are private researchers and institutions better placed for accommodating international agencies' projects. Moreover, the CNE finds itself having to respond to Guatemalan government international commitments as they relate to international epidemiology, such as the International Sanitary Code I mentioned in chapter 4. In addition to the CNE's lack of a clearly defined agenda, it does not have the infrastructure for generating its own research funds. These conditions, combined with the institutional chaos and the ambiguous place of epidemiology within the Ministry of Health, exacerbate the vulnerability to the effects of an international agenda that conceives Guatemala as a potential source of contagion and as a country that needs to catch up in terms of international indicators such as the Millennium Development Goals. All these elements become part of a vicious cycle that results in epidemiologists who are unable to generate their own ideas, and more importantly, who are incapable of interrogating the reality they are part of. Guatemalan epidemiologists are, generally speaking, unable to generate a research question, as they are unable to come up with a set of locally conceived priorities that guide research efforts and health situation analyses.

From my perspective, this vicious cycle can be interrupted through a more constant and engaged relationship with civil society groups, as I have suggested in previous sections.

Social relations at the national level

“I find all that ‘interculturalidad’ stuff to be fascinating, but I would find it even more interesting to see what would happen if we had some epidemiologists who were indigenous, because look at us at the CNE, we are all Ladino, we do not reflect the larger Guatemalan society where half of the population is indigenous. We are doing a little better now in terms of women, because there are now more women working here, but what about indigenous people?” (Epidemiologist at CNE)

All Guatemalans are immersed in a social dynamic that generates social exclusion and discrimination. Guatemalan social relations are marked by sexism, racism, and classism, as they are marked by discrimination of sexual minorities, people living in rural communities, and people with disabilities. Health inequalities go hand in hand with all these forms of discrimination. The only way Guatemalan epidemiologists and the CNE will be able to address these unequal relations is through an intentional and sustained effort to become more like the larger society they are part of (as the epidemiologist in the quotation suggests), and to develop collaborations with groups that represent the most excluded social groups in Guatemala’s society. In other words, Guatemalan epidemiology will only be de-colonized when it embraces addressing health inequalities as its goal, and engages social participation as its main method.

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Vita

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