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# "We Know Where We Stand": Contesting and Constructing Knowledge in Nicaragua's Chronic Kidney Disease Epidemic

Sarah Leister

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**“WE KNOW WHERE WE STAND”: CONTESTING AND  
CONSTRUCTING KNOWLEDGE IN NICARAGUA’S  
CHRONIC KIDNEY DISEASE EPIDEMIC**

**by**

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**THESIS**

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**by**

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**ABSTRACT**

Sugarcane workers in northwestern Nicaragua are suffering from chronic kidney disease of non-traditional causes (CKDnt) at extremely high rates. In the small town of Chichigalpa alone, CKDnt causes 46% of male deaths (Kurzrok et al. 2013). This paper examines the CKD epidemic as a fundamentally structural problem, not merely a biological abnormality, because it is closely linked to labor exploitation, poverty, human rights violations, and historical context. Grounded in literature from medical anthropology and medical sociology and based on two months of ethnographic field research in northwestern Nicaragua, it analyzes how knowledge production interacts with scientific uncertainty about CKD’s specific biomedical causes. It posits that scientific knowledge does not close controversy, but rather proliferates uncertainties, thereby forestalling the potential for rights claims. A strictly scientific understanding of CKD diffuses responsibility for addressing its structural causes, distracts from structural violence, and diverts attention away from the urgency of CKD deaths.

## TABLE OF CONTENTS

<b>LIST OF TABLES .....</b>	<b>viii</b>
<b>INTRODUCTION.....</b>	<b>1</b>
What is CKD?.....	2
Methodology.....	7
Description of Actors.....	8
Situated Knowledge.....	12
Health-Based Social Movements and Biopower.....	15
 <b>CHAPTER 1: SOCIAL MOVEMENTS, SUGARCANE, AND POLITICAL POWER .....</b>	 <b>22</b>
A History of Nicaragua from Colonization to Revolution.....	22
The Sandinista Revolution.....	27
Neoliberal Era.....	30
History of the Sugarcane Industry Globally.....	33
Sugarcane in Nicaragua.....	34
History of CKD Social Movements.....	39
Conclusion.....	41
 <b>CHAPTER 2: EXPERIENTIAL KNOWLEDGE, SCIENTIFIC KNOWLEDGE, AND NONKNOWLEDGE .....</b>	 <b>42</b>
Ways of Knowing.....	42

Experiential Knowledge and Certainty about Causes.....	44
Poverty, Labor Conditions, and Human Rights .....	49
Roberto’s Story .....	50
Poverty .....	52
Labor Conditions .....	53
Human Rights .....	57
Power and the Devil.....	60
Conclusion .....	62
Scientific Knowledge Production about CKD .....	63
Scientific Uncertainty .....	70
Narratives of Self-Care .....	73
Urgency and the Limitations of Scientific Research .....	75
Nonknowledge .....	78
Myths, Silences, and Censorship .....	79
Conclusion .....	84
<b>CHAPTER 3: LA ISLA FOUNDATION – “BE PART OF THE SOLUTION” .....</b>	<b>86</b>
LIF, Scientific Uncertainty, and Urgency.....	90
Controversy and Structural Responses to CKD.....	92

Conclusion: Structural Approaches and Research Limitations ..... 95

**CHAPTER 4: CONCLUSION..... 98**

**REFERENCES.....103**



**LIST OF TABLES**

Table 1. Causes categorized by likelihood from 2012 SALTRA conference (Wesseling et al. 2013) .....	66
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## INTRODUCTION

La Isla (“The Island”), a small community in northwestern Nicaragua, is in crisis. Chronic kidney disease (CKD) causes 46% of male deaths in La Isla (Kurzrok et al. 2013), lending it the nickname “The Island of the Widows”. The community is described as an island because it is surrounded by a small stream and sugarcane fields. However, despite its borders and its somewhat remote location relative to Nicaragua’s largest cities, journalists, scientists, and human rights activists from around the world have converged on this community and those surrounding it in the region of Chichigalpa. Rather than an isolated island, La Isla is a place of global encounter.

I paid my first visit to La Isla during my “new volunteer orientation” when I started interning for a non-governmental organization called La Isla Foundation (LIF) in the summer of 2014. After two hot, crowded bus rides from León, we arrived in the city center of Chichigalpa. Nine volunteers, many of whom were from the U.S., piled into a motorcycle taxi built for five passengers, attracting stares from local residents. As I felt the debilitating heat of my own body intensified by other hot and sweaty bodies, I hoped that the ride would not be too long. We told the taxi driver to take us to “el puente,” the small bridge into La Isla. From there, we walked on dirt paths to Doña Josefina’s<sup>1</sup> house, passing local residents on bikes and some roaming animals. After a delicious meal of rice and beans, co-director of LIF Juan Salgado and Josefina shared their experiences of living in the midst of an epidemic of chronic kidney disease. As an *enfermo* sick with CKD, Juan Salgado told us that he feared his immanent death. Josefina became a widow

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<sup>1</sup> All names from my field notes and interviews are pseudonyms except for Juan Salgado and Roberto Valdivia, who asked me to use their names publicly.

in her 20s when she lost her husband to kidney disease. She pointed to nearby houses indicating recent deaths in her neighborhood. Death was all around us.

While the image of an island evokes a sense of isolation, the devastatingly high death rates of kidney disease indicate an externally-produced crisis. Just a short walk from Doña Josefina's house was a sugarcane plantation of the Ingenio San Antonio, the only sugarcane company in Chichigalpa and the largest in Nicaragua. During the harvest season, many residents of La Isla work in the fields to plant, irrigate, cut, and spray the sugar cane. Residents worry that there are chemicals contaminating their water supply. It is common to hear Chichigalpinos (people from Chichigalpa) use the word *veneno* (poison) instead of pesticides or agrochemicals. Despite these concerns, most residents have few job opportunities and must work in the fields to support themselves and their families.

#### What is CKD?: Structural Violence, Knowledge Production, and Scientific Uncertainty

While death, illness, and exploitation have been routine in the sugarcane industry since its beginnings, the high prevalence of CKD has brought international attention to La Isla and surrounding communities in northwestern Nicaragua. A variety of actors have converged upon the CKD crisis in Chichigalpa. Biomedical and public health researchers have published studies on the prevalence and character of CKD, asking what biological mechanisms are causing a high prevalence of the disease among young people without a history of diabetes or hypertension. Despite multiple hypotheses, these scientists talk about CKD with uncertainty, naming it CKDu (chronic kidney disease of unknown origins) or CKDnt (chronic kidney disease of non-traditional causes). Scientific

definitions of CKD that emphasize internal etiological factors, therefore, lead to many uncertainties.

In contrast to purely biological definitions of CKD, I argue that CKD is a structural problem, not merely a biological abnormality, because it is closely linked to labor exploitation, poverty, human rights violations, and historical context. In line with the certainty with which workers framed CKD in my interviews, my definition counters scientific uncertainties by expanding beyond internalized biological definitions and illuminating contextual factors contributing to disease. Furthermore, it challenges scientific authority by acknowledging multiple forms of knowledge at play in the controversies surrounding CKD.

In my exploration of knowledge production, I will examine three types of knowledge: experiential knowledge, scientific knowledge, and nonknowledge. While sugarcane workers, ex-workers, and their family members often use experiential knowledge to express certainty about CKD and its causes, scientists and international media frame CKD's causes as uncertain, unknown, or mysterious. At the same time, the Ingenio San Antonio (ISA) and the state use nonknowledge in order to censor and cover up information about labor conditions for workers and disease, attempting to maintain the status quo. These three forms of knowledge are not mutually exclusive; rather, they intersect, interact, and overlap in various ways.

My discussion of knowledge production will illuminate how scientific uncertainty has opened up spaces for contestations over knowledge. I use uncertainty as a starting point for my analysis because scientific knowledge has the most clout in controversies about the illness. Due to scientific authority and the strong ties between power and

knowledge, scientific uncertainty becomes a dominant means by which different actors express their claims. Even critics of scientific uncertainty, including the workers that I interviewed, social movements, and LIF, must navigate around this uncertainty in their narratives.

This paper will describe such uncertainties within a case of biological citizenship (Petryna 2003), in which biology becomes the primary means by which workers and outside actors such as LIF demand social benefits from the state and the Ingenio San Antonio. While historically, social movements in Nicaragua did not use biology as a primary collective frame (Benford & Snow 2000) through which to express their demands, today this frame has been successful in mobilizing multiple actors around a public health crisis. However, despite its effectiveness in bringing international attention to the plight of sugarcane workers, there are many limitations to biological narratives, as they link suffering to a need for scientific proof. Accordingly, my paper will argue that scientific knowledge does not close controversy, but rather proliferates uncertainties, thereby forestalling the potential for rights claims. These claims include demands for economic rights, legal justice, increased access to social security benefits, labor rights, medical care, and the mere recognition of workers' suffering through narratives of responsibility. As biological definitions of CKD intensify uncertainties, they have the following effects:

1. Diffusion of responsibility: The Ingenio San Antonio claims that it is not responsible for causing CKD because science has not proven the specific role of labor practices in producing disease. The government represses protests against social security policies without reforming its own policies. Demands from many actors that workers care for

their own health (e.g. by eating well or avoiding certain foods) place responsibility on individuals. Social movements call upon ISA and the government to take responsibility and acknowledge the roots of their struggles. A primary focus on uncertain scientific discourses makes all of these narratives of responsibility debatable and unable to hold significant weight.

2. Distraction from multiple forms of structural violence: Poverty, human rights violations, labor exploitation, poor housing, inability to afford medical care, and other labor-related illnesses are all forms of structural violence that impact workers' health and well-being. A focus on CKD internalizes disease definitions as uncertainties destabilize the links between structural violence and disease. Accordingly, biology and biomedicine divert attention away from these very certain forms of suffering that impact workers, ex-workers, and community members on a daily basis.
3. Distraction from the urgency of CKD deaths: While science <sup>2</sup> aims to prevent future cases of CKD, CKD remains an urgent issue. Due to uncertainties, much of the energy that has been spent by scientists is towards finding the causes rather than seeking urgently-needed relief for communities. Looking at La Isla Foundation's blend of urgent attention to community needs and pursuit of scientific knowledge will illuminate how a more structural approach to CKD can bring assistance to community members at the same time that it can intensify political controversy.

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<sup>2</sup> By "science" I am referring primarily to biomedical research, but also to public health research that is driven primarily by biomedical definitions of disease (e.g. the Boston University 2010 study under the CAO or the recent BU research under the CDC Foundation). In other cases, however, public health leaves more space for interventions that take structural causes of disease into account. I will analyze public health interventions by LIF that take structural causes such as labor conditions into account in Chapter 3.

Given these characteristics of biology-based narratives in Nicaragua's CKD epidemic, this paper will analyze knowledge production in order to critique the use of biology as a primary claim to rights. It will counter dominant biological discourses of disease that place it inside of the body through an emphasis on workers' experiential forms of knowledge and structural violence.

Chapter 1 will provide a historical context that focuses on health, labor exploitation, and elite-state alliances in Nicaraguan history, the global history of exploitation in sugarcane industry, and the history of social movements that have addressed CKD epidemic. It will illuminate the significance of a crisis about CKD given years of labor exploitation in the sugarcane industry.

The complexities of biopower and knowledge production are highlighted in Chapter 2 through ethnographic data. While workers often use experiential knowledge to express certainty about CKD and its causes, scientists and international media frame CKD's causes as uncertain, unknown, or mysterious. At the same time, the Ingenio San Antonio and other powerful actors use nonknowledge in order to censor and cover up information about labor conditions for workers and disease. Chapter 3 will examine the role of La Isla Foundation. Finally Chapter 4 will offer an analysis of my data in light of the above sections.

In what follows, I will analyze the CKD epidemic and the controversies surrounding it through relevant literature in health and social movements and biopower, review of relevant historical contexts, and ethnographic data. I will start with a methodology section explaining the nature ethnographic field work. Then, I will give a description of the actors involved in the CKD epidemic using information from my field

work, followed by a description of my situated knowledge and a review of relevant academic literature. Literature on health-based social movements illuminates how knowledge production occurs through interactions between lay or popular knowledge and scientific knowledge. The biopower literature will look at CKD social movements through the lens of biological citizenship. Biolegitimacy addresses an answer to why expressing claims to social rights through biology has been so effective in this case. But biopower can also be demobilizing in the case of self-care and internalizing discourses of disease.

### Methodology

This paper is based upon two months of field research in the cities of León and Chichigalpa, as well as some follow-up conversations after leaving Nicaragua. I conducted my field research while interning for La Isla Foundation for 40 hours per week. Co-founded in 2008 by Juan Salgado, a CKD-affected ex-sugarcane worker, and Jason Glaser, a documentary filmmaker from the United States, La Isla Foundation seeks to address the CKD epidemic through its four pillars: public health, human rights & law, community development, and media & communications. While conducting my research, I worked from LIF's main office in León or from its newly-established satellite office in Chichigalpa, which I visited 1-3 times per week. As an intern, I did research on barriers to health care; assisted with a community needs assessment in which I helped facilitate meetings and focus groups with local health promoters; met with local and international professionals involved in research and advocacy around CKD; and attended various meetings with staff members about community outreach. LIF graciously assisted me with



recruitment and logistics for my interviews. On some days, I helped with LIF's other projects, such as the community garden and the after-school "kids club" on La Isla. Outside of my work with LIF, I attended a tour at the Flor de Caña rum factory geared towards tourists who wanted to learn more about the production of Nicaragua's famous rum (and participate a couple of tasting sessions as well). I presented a summary of the tour at an LIF staff meeting.

In addition to my work with LIF and my outside visits, I interviewed 10 individuals: eight current or former sugarcane workers, one widow of a sugarcane worker who died of CKD, and one scientific researcher. Three of the sugarcane workers that I interviewed had been diagnosed with CKD. At all of the interviews except for two (the scientific researcher and the widow) I had a field assistant from León, Nicaragua who was another LIF volunteer that was assigned to me at LIF's request. I transcribed and coded the interviews upon return to the United States.

At LIF I got a comprehensive view of how biomedical science, public health, and human rights interact at an international level as well as the inner workings of an international NGO. My interviews and meetings at the Chichigalpa office allowed me to gain insight from community members who are most deeply affected by CKD. I will weave these rich sources of ethnographic data throughout this paper.

### Description of Actors

My research in Nicaragua exists in the context of various forms of knowledge production and meaning-making surrounding the CKD epidemic. Given the devastating rates of kidney disease in Chichigalpa, many actors have converged upon Chichigalpa in

order to address and make sense of the epidemic. Epidemiologists, public health researchers, biomedical scientists, and occupational health specialists from Nicaragua and elsewhere have revealed excess deaths from CKD. Their research as well as that of biomedical scientists is looking for the internal etiology of CKD. Inconclusive scientific results about CKD's causes and its links to occupational factors have created political controversies. As the Ingenio San Antonio uses scientific uncertainty to deny its role in causing the epidemic, workers critique this uncertainty for denying their experience as they witness ex-workers dying of CKD in their neighborhoods and towns.

As scientists look for the causes, La Isla Foundation is looking for a solution. Their slogan "be part of the solution" has mobilized researchers, volunteer tourists (Mostafanezhad 2014), international media, donors, and local community members. With a primary focus on the intersections of human rights and public health, LIF staff issue statements against police repression, they write public reports about human rights abuses in the sugarcane industry, they collaborate with occupational health, epidemiological, and biomedical researchers, they attend regional research conferences about CKD (Wesseling et al. 2013), and they conduct community needs assessments in conjunction with their funders' requirements. They have found ways to merge certainties about CKD with scientific uncertainty by focusing on readily-addressable potential causes, such as heat stress and dehydration. During the time I was there, a tourist in the large city of León walking by the main office might notice that La Isla Foundation offers Spanish, yoga, and salsa dancing classes. A potential volunteer might see its website, and be moved by its poignant videos that feature stories of CKD-affected individuals and their families. Some Chichigalpino community members might seek an opportunity through LIF to speak to

international staff and media about their suffering, while others may be afraid to speak out under the threat of retaliation from the sugarcane company (LIF 2012a). I came across LIF's website in search of a research topic that aligned with my own interests in health in Latin America, and found appeal in its ability to accommodate short-term visitors.

Another actor in the CKD controversy is the Ingenio San Antonio (ISA). Owned by Nicaragua Sugar Estates Limited (NSEL), it is the largest sugarcane company in Nicaragua. ISA is just one of over 20 companies within Grupo Pellas that together make up 13% of Nicaragua's GDP. Carlos Pellas, the head of this lucrative conglomerate, is the first billionaire in Nicaragua, the second-poorest country in the Western hemisphere (Schmidt 2014). Almost all of the sugarcane workers in Chichigalpa work for ISA directly or through a subcontractor<sup>3</sup>. ISA's major products are sugar, ethanol, and Nicaragua's famous Flor de Caña rum. They also generate electricity from the byproducts of sugarcane production (Ser San Antonio 2014). The Ingenio San Antonio takes pride in its corporate social responsibility and environmental responsibility programs, which include building local parks and schools, reforestation campaigns with school children, and the provision of food stipends to its workers. However, the Ingenio has also consistently denied its role in producing the epidemic, pointing to scientific uncertainties, individual behaviors of community members, and its own practices to protect workers on the fields, such as offering rehydration packs and safety equipment.

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<sup>3</sup> While ISA directly employs many workers, the majority of employees work for subcontractors. A recent LIF study states that "subcontracted workers generally labor under worse conditions than directly contracted workers, receiving less pay and fewer health benefits" (LIF 2015: 24-25). When I refer to ISA in this paper, therefore, I am referring to both ISA and its subcontractors, as they both have obligations to protect workers under Nicaraguan law (LIF 2015).

Local social movements have played a key role in bringing CKD to public light. Different groups have demanded social security benefits for CKD-affected individuals, governmental attention to the epidemic, better labor conditions, improved access to health care, economic support for people who are impoverished and sick, and increased accountability from the government and the Ingenio. While ASOCHIVIDA (Chichigalpa Association for Life) has negotiated with the Ingenio to launch research on CKD and seek charitable resources from ISA, it is criticized for how closely it works with the Ingenio San Antonio. ASNAAPIRC (The Nicaraguan Association of CKD-Affected Persons and Their Allies) was founded by a group of individuals who had been kicked out of ASOCHIVIDA for collaborating on a news story with Univision (LIF 2012a). This organization has demanded pension benefits from the government and maintains more independence from ISA (Cobo 2014). Differing narratives of responsibility among community groups add to controversies over the perceived role of international actors such as LIF.

Both ISA and the government have participated in repression and censorship against workers and social movements for workers' rights. State police repress protests, state media refuses to report on the CKD epidemic (Valdivia 2014), and governmental social security policies prevent access to benefits for many former workers. The Ingenio San Antonio has been known to use its social responsibility programs, such as food stipends for CKD-affected families, as a way to keep people from speaking out. Those who openly criticize the Ingenio risk losing their jobs or their family members' jobs (LIF 2012a).

Finally, the local particularities of CKDnt interact with its framing as a regional and global phenomenon. CKD of non-traditional causes (or unknown etiology) has been observed in regions other than northwestern Nicaragua. El Salvador, Costa Rica, India, and Sri Lanka have high rates of CKD with significant regional variations within each of these countries. For example, Nicaragua and El Salvador experience mortality rates from CKD that are 4 times higher than the global average, and men die at rates 3 times higher than women (Almaguer, et al. 2014). Central American regions that are affected are often in the Pacific lowlands and affect agricultural and mining workers (Brooks & Rubio 2013). In Sri Lanka, the North Central Province has the highest prevalence and the biomedical etiology is also unknown (Jakobsson & Jayasumana 2013). Scientists hope that studying CKD in one place will give them clues to the nature and etiology of CKDu in other areas.

In sum, all of these actors have different stakes in knowledge production about the causes of CKD. As scientists conduct research, the Ingenio censors and La Isla Foundation looks for solutions. Different actors either emphasize or downplay the severity of the epidemic, as some kinds of knowledge are prioritized over others.

### Situated Knowledge

In my analysis of knowledge production among the various actors involved in the CKD crisis, I will emphasize my own “situated knowledge” (Haraway 1988). Donna Haraway critiques how “objectivity” in science often implies a disembodied “conquering gaze from nowhere,” that usually originates from “the unmarked positions of Man and White” (1988: 581). Instead of discarding objectivity altogether or promoting the idea

that certain oppressed members of society have better claims to knowledge than others, she calls for feminist approaches to science studies that promote “embodied objectivity” through situated knowledges:

“We seek not the knowledges ruled by phallogocentrism (nostalgia for the presence of the one true Word) and disembodied vision. We seek those ruled by partial sight and limited voice--not partiality for its own sake but, rather, for the sake of the connections and unexpected openings situated knowledges make possible” (Haraway 1988: 590).

Acknowledging positionality, she argues, is essential for the accountability and responsibility of the researcher (Haraway 1988). Accordingly, this paper will situate my own embodied knowledge among other partial forms of knowledge. My goal is not to find one answer or “the solution,” but rather to critique knowledge production and biology-based rights claims from multiple angles. Therefore, I will begin with a description of my experience in the field.

I went to Nicaragua in June of 2014 to study the chronic kidney disease epidemic. The CKD crisis captured my attention when I found information on it through a simple internet search. I came across a “mysterious” epidemic of chronic kidney disease in Central America that was affecting agricultural workers at young ages. I learned about La Isla Foundation, an international NGO that asks its funders, staff and volunteers to “be part of the solution” to this epidemic. With previous academic experience in Central America and some knowledge of kidney disease from two years of work at a health clinic in the U.S., I pitched my research ideas to La Isla Foundation and found support from their public health department. LIF invited me to be a volunteer intern on their public

health team, through which I would help with their barriers to care research and would receive their assistance with conducting my interviews. While I had previously worked with individuals that had CKD in the U.S., upon arriving in Nicaragua I learned that CKD in Central America is an entirely different illness. While it affects the same organ, the political, economic, and social context were entirely new to me.

As an able-bodied, white woman in my mid-20s conducting research for my Master's thesis, I faced my privilege each day. I felt a frustrating sense of detachment from the place that the epidemic was most devastating due to the fact that I was new to Nicaragua and living about an hour-and-fifteen-minute bus ride away from Chichigalpa. LIF's main office was in León, the second largest city in Nicaragua that attracts many tourists. I lived with a host family near the center of the city and worked most weekdays from 9am-5pm. On work days, staff and volunteers could take breaks in the hammocks that were hanging in the main room of the office, and we could take a dip in the office pool after work ended. Most volunteers rented rooms or beds in a luxurious volunteer house around the corner where LIF also offered yoga classes and salsa dancing classes for any tourists or volunteers who wanted to "be part of the solution" by supporting LIF. Therefore, while my workplace environment and my location gave me opportunities to develop connections with international staff, international volunteers, and both local and foreign researchers, it also detached me culturally, economically, and spatially from the center of the epidemic.

While perhaps there was not much that could unite my subjectivity with that of a Nicaraguan sugarcane worker, what I did feel in common with other people that I interviewed and encountered (although not always at the same intensity) was a

debilitating heat. The heat made me lethargic and exhausted every day. The only escapes from it were the very few air conditioned locations in León and Chichigalpa (including one of the rooms in LIF's Chichigalpa office), a rainstorm (rare when I was there), a cold shower, or swimming in a pool. I made negotiations with the heat each day by trying to walk on the shaded sides of the road on my way to work, carefully directing the fans, and dressing in lighter clothing. Because the heat was such an intense part of my experience, I found it even harder to imagine how workers toil in the fields at such intense temperatures and even less surprising that illness would be so prevalent. Even I got sick from dehydration once or twice without performing manual labor outdoors.

In sum, my position as an intern for La Isla Foundation, a Master's student from the United States, and a former employee in the U.S. health care system shaped my situated knowledge. Along with my positionality, my embodiment of heat, my emotions, my feelings of detachment, and other factors shaped my experience. I will continue to weave these aspects of my situated knowledge throughout my paper.

### Health-Based Social Movements and Biopower

As I situate my own knowledge in the CKD epidemic, I situate my case study among literature on health-based social movements and biopower. There are many other cases in which biology has been a mobilizing force as well as a source of controversy. My review of literature on health-based social movements will focus on how scientific knowledge and experiential knowledge interact with one another in the context of uncertainty. In these cases, scientific uncertainty has led to lay expertise (Epstein 1995), pharmaceutical determinism (Barker 2011), popular epidemiology (Brown 1992), and



larger social uncertainties that prevent the formation of large-scale social movements (Auyero & Swistun 2009). Essential to the study of social movements is the process of framing, or the process by which meaning-making either mobilizes or demobilizes groups of people around a certain issue (Benford and Snow 2000), and scientific authority, which leads to prioritization of scientific knowledge over experiential forms of knowledge. My discussion of the biopower literature will examine how biopower can either mobilize or demobilize social groups around the category of disease.

In Epstein's case, AIDS activists developed lay expertise by learning how to speak the language of science and gain credibility within scientific institutions (Epstein 1995). Kristen Barker looks at how the marketing campaigns of the drug Lyrica legitimated the contested illness of fibromyalgia while they also remained inconsistent with patients' experiences (Barker 2011). Therefore, while Epstein describes how experiential knowledge was used to shape scientific knowledge production, Barker looks at how science can delegitimize patient experience through pharmaceutical determinism and the corporatization of health care. Both of these interactions are characteristic of the CKD case, and I will describe them later.

Phil Brown examines in depth the role of experience in knowledge production. He introduces the concept "popular epidemiology" in his case study of lay activism surrounding environmental health risks in Woburn, Massachusetts. According to Brown, popular epidemiology is "the process by which laypersons gather scientific data and other information, and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease" (Brown 1992: 269). Brown differentiates it as a unique form of knowledge production that is separate from traditional epidemiology, in

that it “emphasizes social structural factors as part of the causal disease chain” and involves structural responses to disease (Brown 1992: 269). By illuminating different ways of knowing, Brown argues that neither science nor lay expertise is value-free, and that lay knowledge can be “good science” in that it illuminates aspects of illness that science cannot (Brown 1992). Therefore, as Brown’s case shows, community members can play a leading role in both scientific knowledge production and in their own separate forms of knowledge production that stem from their experiences. Popular epidemiology’s structural lens on disease is helpful for understanding experiential knowledge in the case of CKD.

In *Flammable*, Auyero and Swistun present a case study of environmental toxicity in an Argentine shantytown. The shantytown is located next to a Shell oil refinery, a landfill, and a toxic waste incinerator. The authors use the term “toxic uncertainty” to describe the inherent uncertainties of environmental contamination. As a result of toxicity, residents suffer from widespread illnesses such as lead poisoning, neurological problems, skin problems, respiratory problems, and birth defects. However, residents are notably uninvolved in social movements or organized responses to the contamination. Auyero and Swistun attempt to unpack this “black box” of symbolic violence, arguing that uncertainties about illness, responsibility, the future, and governmental programs prevent organized responses to environmental toxicity (Auyero & Swistun 2009). Therefore, uncertainties related to environmental toxicity diffuse different community-based claims, rendering communities unable to sustain large-scale social movements against the oil company or contamination.

All of these examples of health-based social movements show how collective framing, or “the struggle over the production of mobilizing and countermobilizing ideas and meanings” (Benford & Snow 2000: 613), motivates social mobilization. Often these mobilizations occur in contrast to a more powerful form of meaning or knowledge. The authoritativeness of scientific knowledge in these cases is key to understanding these politics of knowledge production. Scientific authority is not inherent to science, but rather has historical roots (Whooley 2003; Gieryn 1983). Gieryn discusses how scientists have engaged in “boundary-work” in order to distinguish “science” from “non-science”. He argues that “descriptions of science as distinctively truthful, useful, objective or rational may best be analyzed as ideologies: incomplete and ambiguous images of science nevertheless useful for scientists’ pursuit of authority and material resources” (Gieryn 1983: 792-793). Furthermore, the ways in which science is adopted is dependent upon a variety of political and economic factors (Stepan 1978; Whooley 2013; Latour 1988). Michel Foucault has discussed the relationships between knowledge and power, by emphasizing how subjugated knowledges resist scientific discourses not only for their content, but primarily for the power that underlies them (Foucault 1980). The literature on scientific authority is useful in explaining why scientific forms of knowledge are considered to be more legitimate and “real” than experiential knowledge within debates about the causes of CKD.

Foucault’s literature on biopower looks at the ways in which state power establishes control over individual bodies and populations (Foucault 2003). He defines biopower as “what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life” (Foucault 1978).

Recent interpretations of Foucault's work and the concept of biopower emphasize biological citizenship, biolegitimacy, regimes of self-care, and internalizing discourses of disease. These interpretations demonstrate how biology can either mobilize or demobilize struggles for social rights in different circumstances.

Biological citizenship refers to the ways in which narratives of biological suffering and illness are used to claim social rights, either at an individual or collective level. Adriana Petryna describes how citizens of Ukraine had to prove their illnesses in order to gain access to social rights from the state after the Chernobyl disaster (Petryna 2003). Didier Fassin suggests that the emergence of biological citizenship is related to a current trend in biopower called biolegitimacy. The concept of biolegitimacy asks why biology is seen as a legitimate claim to rights, especially in legal contexts. Fassin uses biolegitimacy to explore the morals and values tied to life under biopower rather than the mechanisms of power over human conduct, as Foucault discussed in his work (Fassin 2009). He argues that life as such has power in itself as a claim to rights within social movements and as a way to harness legal benefits. Therefore, as biological citizenship links the political with the biological, biolegitimacy can validate social claims that are framed in terms of biology (Fassin 2009). I consider the CKD epidemic a case of biological citizenship, in which widespread social mobilization occurs around a biological category. It reflects the power of life itself to mobilize diverse actors through biolegitimacy.

While biolegitimacy motivates mobilization around biological categories, self-care can serve as a demobilizing, atomizing force in cases in which social struggle is framed biologically. Rabinow and Rose discuss self-care as a current trend in biopower

characterized by “modes of subjectification through which individuals are brought to work on themselves, under certain forms of authority, in relation to truth discourses, by means of practices of the self” (Rabinow & Rose 2006: 197). Some examples of these regimes of self-care include diet and exercise. These individualize illness and risk of disease, making them a personal responsibility rather than a societal problem. In the case of diet and exercise, structural causes of disease such as environmental contamination, poverty, and racism are elided in favor of individualized responses to disease. My case briefly describe some of these regimes of self-care, and their potential for drawing attention away from structural causes of disease.

Compounding these factors is a tendency among biomedical practitioners to see disease as internal. This is both a current trend in biopower and a result of the history of biomedicine. Historically, biomedicine has viewed the body on the dissection table, locating illness internally rather than in its environmental and social context. These internalizing discourses have taken different forms over time. Recent scholarship on biopower has pointed to molecularization and genetic determinism as common forms that these internalizing discourses take today (Rose 2001; Conrad 1999). Biomedical scientists view the body at the molecular level, such as through DNA or laboratory tests that measure for molecular abnormalities. This is how biomedicine comes to see disease as real, and these molecules are seen to determine the manifestation of illness in the body. In Nicaragua, as CKD is viewed as an internal, biomedical category, knowledge production about the disease produces uncertainties. Because scientists have not yet found a specific biological mechanism linking labor conditions to disease, they remain uncertain about its links to structural causes, leading to various implications for

knowledge production and rights claims. Other health-related disciplines have begun to challenge these internalizing discourses. Public health, for example, often takes into account the social determinants of disease by looking at the links between disease and labor, poverty/wealth, race, gender, and other factors through epidemiology and community-based interventions. Public health research on CKD is prevalent in Nicaragua and this paper highlights studies from both biomedicine and public health. While this paper explores some of the ways in which biomedicine and public health interact, the scope of this paper does not allow me to explore their intersections and divergences in depth.

These bodies of literature on social movements and biopower will help me to explore the politics of knowledge production in the CKD epidemic at the intersection of structural violence, labor, international NGOs, powerful corporate industries, the state, and science. I will explore why social movements have come to be framed in terms of biology despite a long history of many forms of suffering in the sugarcane industry. In order to foreground my argument, I will present a historical context followed by a presentation of ethnographic data about contestations over knowledge. Finally, I will present an analysis of my historical and ethnographic data.

## **CHAPTER 1: SOCIAL MOVEMENTS, SUGARCANE, AND POLITICAL POWER**

In order to understand the significance of the current CKD controversy, it is necessary to examine the history of Nicaragua and the sugarcane industry. Through an analysis of Nicaraguan labor, the sugarcane industry, and social movements, this section will illuminate the context that foregrounds the CKD epidemic. As medical anthropologist Paul Farmer has argued, analyses of structural violence must be “geographically broad” and “historically deep” (Farmer 1996: 274). The social, political, and economic histories of Nicaragua and the sugarcane industry are extremely complex. Because I am looking at health, labor exploitation, and elite-state alliances today, I will focus on these aspects of Nicaraguan history in my account.

### A History of Nicaragua from Colonization to Revolution

The Spanish began to colonize Nicaragua in the 1500s. At the time, there were many polities of indigenous groups. Europeans categorized these peoples linguistically into three major groups--the Chorotegas, Nicaraos, and Chontal--but these categories do not tell us how they self-identified. Widespread epidemics of disease and slavery led to a drastic depopulation of these native peoples (both due to exploitation and exportation of slaves). At this time, the Spanish forcibly exported large numbers of indigenous slaves to Peru to work in the mines (Staten 2010). According to Clifford Staten (2010), the native population decreased from 825,000 at the time of conquest to 50,000 to 60,000 by 1581. By 1570, Nicaragua was a “colonial backwater” due to its relative lack of riches compared to other Spanish colonies and the small indigenous population. In part due to

this rapid depopulation, cattle raising became a major industry because it did not require large amounts of manual labor. Therefore, the main industries were subsistence farming, cattle-raising, and the cultivation of cacao and indigo for export (Staten 2010; Biderman 1983). While some of these industries required exploitative labor practices (e.g. indigo), the industries others that required fewer laborers, such as cattle, became dominant due to the large demographic collapse and exportation of slaves.

Nicaragua's two major cities were León and Granada. León's main economic industry was ranching while Granada specialized in trade of tobacco and cacao, along with the breeding of cattle and donkeys. By the 1700s, León and Chinandega were centers for cattle raising and the export of animal hides. The Pacific ports near León made it important for trade with other Spanish colonies (Staten 2010).

During the 18th and 19th centuries, competition between elite families in León and Granada intensified. While Liberals in León favored open trade policies, Conservatives in Granada preferred a close relationship with the Catholic Church, and they benefited from restrictive Spanish trade policies (Staten 2010). In the early 1700s, the Spanish lessened restrictions on trade as a parallel black market trade with the British flourished. As creoles demanded more control over trade, the Spanish responded in the late 18th century by lessening trade restrictions. Nevertheless, resistance towards Spanish rule grew. The struggles for independence from Spain in 1821 and from the rest of Central America in 1823 were marked by conflicts between Conservative elites in Granada and Liberal elites in León. Like elsewhere in Latin America, struggles between the Liberals and Conservatives characterized political life in the 18th, 19th, and 20th centuries. As Spalding notes, "the scarce and relatively expensive labor supply, along



with the constant warfare of the postindependence period, retarded the process of accumulation” (Spalding 1994: 33).

Political actors from the United States have historically intervened in many of Nicaragua’s violent conflicts. Political scientist Rose J. Spalding (1994) states that the Nicaraguan elites were historically “characterized by weak entrepreneurship, organizational fragmentation, and political incompetence” (32), and part of this weakness stems from the many U.S. interventions during Nicaragua’s history. In the mid-1800s, William Walker, a filibuster from the United States, arrived in Nicaragua with the support of the Liberals. As part of the United States’ mission of “Manifest Destiny,” Walker seized the presidency. He declared English the official language, took over land from conservatives, and legalized slavery. Other Central American countries intervened in order to prevent Walker from annexing Nicaragua and other areas of Central America for the United States. Walker was defeated by opposing armies in 1857, marking just one instance in a series of U.S. interventions in Nicaragua (Staten 2010).

Economic recovery after this period was aided by an increase in coffee production in the late 1800s, which was centered in the North-Central Highlands. A port in Corinto on the west coast of the department of Chinandega was built in 1859. Exportation was facilitated by a railroad from Corinto to Lake Managua and a steamship line to Managua (Staten 2010; Spalding 1994). The expansion of this industry resulted in further displacement of indigenous peoples as communal lands were privatized, and indigenous resistance was met with state repression (Staten 2010).

During another period of intense U.S. influence from 1911-1933, “the U.S. government took control of most of the economic and military functions of the

Nicaraguan state; the U.S. collector general of customs took charge of the collection and dispersal of state revenues, and the marines set up a military academy and constabulary national guard” (Spalding 1994: 35). During this time, Augusto Sandino emerged as a leader of an anti-imperialist struggle against the United States. Meanwhile, the U.S. handpicked Anastacio Somoza as the commander of the National Guard. Somoza’s troops killed Sandino in 1934 and launched a coup d’etat in 1936, initiating “a long era (1937-79) of personalistic and familial control” (Spalding 1994: 35).

Under the Somoza regime, there was a cotton boom in the 1950s in León and Chinandega. This marked a turning point in Nicaragua’s economic history, as cotton displaced coffee to become Nicaragua’s major export. In fact, the cotton industry experienced one of the highest growth rates in the world (Biderman 1983). The harvest of cotton was reliant upon exploitative labor, as well as occupation and contamination of the land. Jaime Biderman notes that “indiscriminate use of insecticides and generally unscientific pest control practices” was characteristic of the cotton industry (Biderman 1983: 15). He further explains,

“The absence of soil conservation measures (particularly on rented land, which accounted for half of all cotton land) led to declining fertility, erosion, and dust storms in the Pacific costal region as well as increased fertilizer use (cotton growers used 80 percent of all agrochemicals in the country by the 1960s). The combined effects of credit, agrochemical inputs, research and extension and other government-subsidized services provided for cotton growers were evident in Nicaraguan cotton yields.” (Biderman 1983: 15)

Two of my interviewees told me that pesticides have existed in the soil for 100 years (David 2014; Roberto 2014), and it is likely that many of these contaminants are left over from the cotton industry and the sugarcane industry in the northwestern region. Therefore many of the discourses around the CKD epidemic and its potential links to pesticides harken back to this era.

Other important industries during the 20th century included coffee, bananas, sugar, and sesame (Biderman 1983). As Jaime Biderman notes, “the development of capitalism in Nicaraguan agriculture was firmly established in the three decades after 1950” (Biderman 1983: 19). However, this development was uneven geographically, and was most advanced in the Pacific coastal region (Biderman 1983). I will talk more specifically about the sugar industry in this region later.

The Somoza regime began to lose legitimacy among diverse economic sectors by the 1970s. After a 1972 earthquake, international assistance came into the country and highlighted governmental corruption (Spalding 1994). Business elites were threatened by the political situation: “The heavy-handed use of public power for private gain and the fundamental corruption of the judicial and legal systems undermined the predictability of the economic system and cut into the resources of the private sector” (Spalding 1994: 50-51). Therefore, business elites and popular sectors alike began to organize against the Somoza regime.

The Frente Sandinista de Liberación Nacional (FSLN), or the National Sandinista Liberation Front, began to emerge as a significant political group in the 1960s, launching guerrilla campaigns and other strategies of resistance that were often met by repression from the National Guard. They recognized the stark economic inequalities that were

intensified during the Somoza family's rule and were opposed to widespread political exclusion (Staten 2010). Staten (2010) notes that by 1975, 75% of the land in Nicaragua belonged to 12% of landowners (75). By March of 1979, the Sandinistas had overcome their internal divisions and launched an organized military campaign against the ruling regime (Spalding 1994). They took control city by city until they finally declared victory on July 19, 1979 in Managua (Staten 2010).

### The Sandinista Revolution

The Sandinista Revolution was a period of political crisis and transformation in Nicaragua. Many accounts of the revolution have emphasized how this period of political transformation opened up new identities, political hopes, and forms of knowledge production. Anthropologist Les Field (1999) notes how Sandinismo “unleash[ed] the production of discourses of identity by local intellectuals who never before had challenged elite intellectuals” (3). These new configurations of identity and class relations impacted many sectors of society, including the artisans that Field discusses in his book, labor movements, and health care providers. Moreover, it attracted international visitors to Nicaragua who were eager to experience life in a revolutionary country. This period of transformation finds some parallels to the current CKD epidemic crisis, where political upheaval attracts international visitors and molds new concepts of health. Therefore, I will cite examples of how this period of political crisis and transformation played out within health care, and its influence on bringing international visitors to Nicaragua known as *internacionalistas*.

John Donahue (1986) examines the drastic changes that occurred in the realm of health care under the Sandinistas. He explains, “Before the revolution only about 28 percent of the population had regular access to health care. Of the health resources made available by Somoza 90 percent went to 10 percent of the population” (12). There were high rates of preventable disease, high infant mortality, and extreme poverty. A vertical, top-down health-care delivery system led to “an individualistic response to health and illness” that ignored the structural roots of disease (Donahue 1986: 17).

The Sandinista government made health one of the major priorities of the revolution after defense, economic reforms, and education. It worked under the principle of health as a right and focused on community-based delivery networks (Donahue 1986). According to Laura Tesler (2010),

“Over the next few years [after 1979], the number of clinics more than tripled, with the establishment of new facilities in rural areas taking precedence, and accessibility to health care services extending to cover 70% of the population. Declaring health care to be a fundamental right of the population, the government promised free care in government facilities, and the number of visits to physicians per capita more than tripled by 1983, as did surgeries and prescriptions filled” (3).

In addition to this astonishing expansion in access to health care, Donahue (1986) notes that community health educators “tend[ed] to define health in social as well as biological terms and stress[ed] a more popular and preventative strategy rather than an institutional and curative one” (26). Therefore, the underlying class-based goals of the Nicaraguan revolution that challenged elite ideologies impacted the ways in which health care was delivered.

Meanwhile, international visitors, also known as *internacionalistas* or *sandalistas*, were attracted to learning about Nicaragua's revolution. As anthropologist Florence Babb (2004) explains,

“Journalists, artists and writers, engineers, and activists of many backgrounds made their way to the country, often in delegations, from the United States and elsewhere. Some stayed for a time and wrote books....Some visitors came simply to see the revolutionary society for themselves and others determined to stay a year or longer in order to contribute to what many of them viewed as the most significant process of social transformation in the Americas since the Cuban revolution.” (543)

Therefore, as the Sandinistas transformed political consciousness, the international community converged upon the revolution in order to experience these developments first-hand. In sum, the Sandinista revolution was a transformative historical period that affected the provision of health care, shaped identities, changed class relations, and attracted widespread international attention and curiosity.

In the 1980s, counterrevolutionary forces, trained and funded by the United States, began to undermine and attack the Sandinistas and their social programs. This war was part of President Ronald Reagan's plan to curb the influence of Marxist ideologies in Central America. The Reagan administration's economic restrictions and the war prevented economic growth by the mid-1980s. As Staten (2010) explains, “With the war effort taking more than half the budget, Sandinista education and social reforms came to a halt. The health care system was over-burdened by the growing number of *contra* war casualties and could no longer meet the needs of the people because of the lack of

medicine and drugs” (113). The contra war ultimately left over 30,000 Nicaraguans dead (Staten 2010).

### Neoliberal Era

Following ceasefire negotiations led by Costa Rican president Oscar Arias, a neoliberal era was ushered in under president Violeta Chamorro, who was elected in 1990. This period also brought drastic transformations to the country. Spalding notes that neoliberal policies opened up space for economic elites to increase their influence on national politics, assisted by an influx of international aid (Spalding 2013). During this time Nicaragua reduced spending in health care, decreasing real health spending by 12% between 1992 and 1996. In addition, 36.5% of health costs were being covered directly by households rather than the state (Tesler 2010). International lending institutions motivated these types of reforms through structural adjustment loans that required cuts in social spending and the privatization of state-owned industries (Spalding 2013).

When I took a taxi to León from the airport upon my arrival in Nicaragua, I noticed huge billboards on the side of the highway featuring images of President Daniel Ortega and his slogan, “Cristiana, Socialista, Solidaria” (Christian, Socialist, Solidary). Ortega is a prominent Sandinista leader who played a fundamental role in the revolution, and he had already served as president during Sandinista rule in the 1980s. Given my study of Nicaraguan history, I was a bit confused as to why there was a labor-related CKD crisis in a country that called itself socialist and had declared health care a right. I decided to ask some of my interviewees about this question. An ex-sugarcane worker named David, who was involved in the struggle against Somoza and fought in the

revolution, passionately told me how he came from a political family and participated in popular demonstrations throughout his life. In fact, he came to work at ISA in order to get involved in the labor movements and “make [the workers] see that what they were doing was favoring the Pellas family” (David 2014). At one point, he told me about why Nicaragua, despite the discourse of the government, is not a socialist country:

“Socialism cannot exist here. Because for socialism to exist, all of these businessmen would have to disappear....Having a bad headache that doesn't go away and you go to the pharmacy and they tell you...100 cordobas per pill. That's not socialism. Socialism is, the doctor arrives...[and] tells you, 'take the pill', 'take it'. 'What do I owe for it?' 'You don't owe anything.' That is socialism.”  
(David 2014)

José, another ex-employee of ISA, echoed this sentiment when he told me that there are no Sandinistas in Nicaragua anymore. There are only ‘Danielistas,’ supporters of Daniel Ortega (José 2014). Therefore, despite a state discourse of socialism, neoliberal policies have failed to protect the poor and guarantee equal access to health care.

Ortega's socialist discourse also seems inconsistent with elite-state alliances. When Daniel Ortega was elected in 2007, members of a group of business leaders founded in 1972 called COSEP (El Consejo Superior de la Empresa Privada) initiated a dialogue with the new FSLN government. Carlos Pellas, the current owner of ISA, was one of the major advisors to the Ortega government under these dialogues. COSEP successfully lobbied the government, collaborating on over 60% of all laws passed in 2010. The Pellas family's influence on multiple industries under their 21-business conglomerate, Grupo Pellas, gives them a great deal of influence within the political



system. They have encouraged growth of burgeoning industries in Nicaragua such as tourism and renewable energy (Spalding 2013). Meanwhile, Ortega has positioned himself as “a unifier and agent of development,” offering a series of loopholes and exemptions to spur economic development and maintain the support of elites (Spalding 2013: 42). Referring to Ortega’s controversial re-election in 2011, Spalding (2013) states, “Ortega’s continuation in power, and business sector collaboration, ensured a predictable political terrain, with labor peace and improved prospects for growth” (43). While the CKD social movements and international attention to the CKD epidemic have disrupted labor peace, the business sector remains extremely influential in national politics.

Writing in the late 1990s, Field (1999) notes that Nicaragua’s post-revolutionary state is different from postsocialist states in Europe.

“Instead, the post-Sandinista state is a weak, vastly underfunded rerun of an old-style, agro-export-driven state, obsessed with the machinations of elite factions and fashions, in which the poor majority are almost entirely left to fend for themselves.” (226)

This is an appropriate characterization of Nicaraguan politics and economics today, and echoes much of what informants told me in interviews. In Chichigalpa, the agro-export sugar industry surely does leave the poor to “fend for themselves” as disease and poverty become a cycle of death for community members. Following from this history of exploitation, elite-state alliances, social movements, and neoliberal reforms, the CKD epidemic becomes a new crisis period.

### History of the Sugarcane Industry Globally

Before delving into the specifics of the CKD crisis, I will present a history of the sugarcane industry, noting its historical ties to exploitative labor practices and high rates of death, suffering and illness. The production of sugar for consumption can be traced back to the 4th-8th centuries in the areas of the Indus delta, Persian Gulf, and Tigris-Euphrates delta. By the 900s, sugar cultivation was well-established in North Africa and Sicily, and expanded to other areas of Europe in later centuries. The European Crusaders took over sugar plantations in the eastern Mediterranean, using slave labor on the fields. While relatively little is known about Arab labor practices, slavery became integral to the European industry, and may have been used to compensate for high mortality rates from the Black Death (Mintz 1985). Furthermore, the harvesting and processing of sugar cane is labor-intensive, making slavery a fundamental part of the industry during much of its history.

Slavery continued when sugar cane plantations were established in the Americas. Columbus brought sugar cane from the Canary Islands to the New World on his second voyage in 1493. The industry first boomed in Santo Domingo and later in Cuba, Puerto Rico, Jamaica, smaller Caribbean islands such as Barbados and Martinique, and Brazil. The importation of African slaves for labor on these plantations was essential to maintaining triangles of trade between Africa, the colonies, and Europe. Describing the British colonies, Sidney Mintz (1985) writes, “The wealth [slaves] created mostly returned to Britain; the products they made were consumed in Britain; and the products made by Britons--cloth, tools, torture instruments--were consumed by slaves who were themselves consumed in the creation of wealth” (43). Therefore, consumption of products

and consumption of bodies were intimately connected within the colonial industries, including the sugar industry. Once slavery was abolished in the colonies during the 19th century, the industry continued to wear down on workers' bodies albeit in different ways (Mintz 1985). As Mintz explains, "planter classes sought to re-create pre-emancipation conditions--to replace the discipline of slavery with the discipline of hunger" (1985: 70). Indeed, high rates of death and illness have nearly always been linked to working in sugarcane. In *Death Without Weeping*, anthropologist Nancy Scheper-Hughes (1993) discusses hunger, illness, suffering and death in a sugar-producing community in northeast Brazil. She writes,

"The history of the *Nordestino* sugar plantation is a history of violence and destruction planted in the ruthless occupation of lands and bodies. Fortunes were made in sugar and black bodies....I can never smell the rotting fermentation of cut sugarcane without smelling death, an association further etched in memory by the *Nordestino* custom of covering the tiny bodies of dead babies with cloyingly sweet, tiny white flowers" (36).

Therefore, given this historical overview, it is clear that the nature of harvesting sugarcane has almost always entailed exploitation, leading to disease, suffering, environmental destruction, and poverty.

### Sugarcane in Nicaragua

In Nicaragua, exploitation in the sugarcane industry has not gone unchallenged. Jeffrey Gould (1990), a historian who has analyzed labor movements in Chichigalpa from 1890 - 1979, argues that "any consideration of the development of Nicaraguan capitalism

must take into account the history of the Ingenio San Antonio [ISA]” (21). In Gould’s historical accounts, ISA’s wealth and ties to the oligarchic Pellas family are juxtaposed with social movements for labor rights. As the following section will show, exploitation and suffering were explicitly problematized by labor unions at certain points of political crisis.

Although small-scale sugar production existed in Nicaragua since 1526, the Ingenio San Antonio (owned by Nicaragua Sugar Estates Limited) was the first sugar mill to operate in Nicaragua (CNPA n.d.). Nicaragua Sugar Estates Limited (NSEL) was founded in 1890 by Italian immigrants Francisco Alfredo Pellas and Luís Palazio (Gould 1990: 22). Pellas went to Nicaragua in 1875 to take over his father’s steamship business (Guacalito de la Isla 2012). Since then (except for a 4-year period following the Sandinista revolution) Nicaragua Sugar Estates Limited and its Ingenio San Antonio have been owned by the Pellas family.

As I explained before, much of the early 20th century was marked by political rivalries between Liberals and Conservatives. While ISA’s owners were Conservative and had close ties to the state, workers tended to ally themselves with Liberal political ideologies. Large-scale strikes and worker uprisings occurred in 1912, 1926, and 1936. Following these events and others, both the Ingenio and the state used different techniques in order to increase social divisions between workers, co-opt labor movements, repress dissent, and promote the continued accumulation of economic wealth (Gould 1990). Furthermore, Gould (1990) points out a significant pattern: these strikes happened during national political crises. He writes,

“ISA, because of its relatively remote geographical setting, its economic importance, and its company-paid police force, resembled a national enclave....Workers correctly considered such an enclave as a separate republic....The workers’ awareness of the essential falsity of San Antonio’s claims to represent the best interests of its workers could only come during political crises that revealed the basic interests of the company as a political and economic actor.” (45)

Therefore, when political crises began to weaken the economic alliances between the Ingenio and the state, workers’ movements strategically brought their demands to the table, organizing both large-scale and small-scale protests.

As the Somoza dynasty was more harshly critiqued nationally, workers’ strikes became more frequent. The next large strike that took place in the Ingenio San Antonio occurred in December 1964. Workers demanded the firing of two administrators for their harsh treatment towards workers and asked for wage increases. While the National Guard repressed strikers, workers were persistent and continued their strike for four days. Finally, ISA conceded on the wage increases (Gould 1990). This was considered a significant victory for workers who “had shattered the aura of ISA invincibility, acquired valuable organizational experience, and inspired other Nicaraguan workers” (Gould 1990: 247). In a 1974 strike, workers similarly demanded wage increases and other improvements for workers, and strikers again won their demands. Following this protest and in the midst of national political upheaval, ISA carefully negotiated its position in order to maintain its relationships with both the regime and the opposition (Gould 1990).

By the late 1970s, many employees, including some of ISA's general managers, supported the FSLN. ISA workers participated in nationwide strikes in 1978, which led to repression by the National Guard who arrested and assassinated individuals who were assumed to be Sandinista leaders. Again, ISA conceded on the workers' economic demands. In December 1978, five hundred canecutters occupied the Ingenio and shut it down. In the process, a group of cutters captured Coronel Kautz, an administrator known for his mistreatment towards the workers (Gould 1990). Gould describes the scene:

“But in one cane field, a slow, irregular chopping sound could be discerned amidst the sound of laughter. The canecutters were teaching Manuel Coronel Kautz how to cut cane. His hands were bloody, his face was cut and stained black from the burnt cane.” (285).

Workers noted that after this incident Coronel Kautz gained more respect for the them. Gould (1990) notes how this action symbolized the class-based project behind multi-class opposition to Somoza. He argues that “the workers demonstrated their revolutionary struggle involved not only the defeat of Somocismo but also the abolition of authoritarian relations of production” (286). A political crisis was opening up revolutionary organizing in the fields.

During Sandinista rule, the government expropriated many private industries, including the Ingenio San Antonio in 1988. In an interview, David explained to me what happened during these four years: “When we, as workers, were in control of the Ingenio San Antonio following the triumph [of the revolution], we began to direct the production areas...That's how we produced five million *quintales* [100 lbs] for the first time” (David 2014). The Sandinista takeover put the company into the hands of the workers, and they

produced more than ever before according to David's account. In 1992 the Nicaraguan government returned ISA to the Pellas family following negotiations between Carlos Pellas and President Violeta Chamorro (Spalding 1994; Schmidt 2014). As David suggests, these four years surely must have changed workers' consciousness about their role in the Ingenio and their ownership over their work.

There is not much writing about labor movements in San Antonio during the post-revolutionary period. However, there have been small-scale protests against the Ingenio that are detailed in a report by CENIDH (Centro Nicaragüense de Derechos Humanos, or the Nicaraguan Center of Human Rights). In 1993, state police violently repressed demonstrations by a group of workers that were demanding that the Ingenio comply with labor standards, leaving 6 wounded, 1 dead and 63 people detained. Again in 2010, Chichigalpa erupted in widespread protests after the police killed two young people, one of whom was accused of stealing scrap metal from the Ingenio. The second person was killed as state police repressed the protests (CENIDH 2014). Juan Salgado, co-director of LIF and ex-sugarcane worker with CKD, explained to me that unions were co-opted by the Ingenio following the 1992 negotiations in which the Ingenio was returned to the Pellas family (Salgado 2015). Also during this time, the Pellas family promised that they would give 25% of the Ingenio's property to the workers, which would have equaled about \$3,000 per worker (without interest). Most workers have still not received the promised 25%, and workers still protest this issue (David 2014; Salgado 2015).

### History of CKD Social Movements

CKD-based protests have occurred parallel to the mobilizations for the 25% that the Ingenio owes workers. Movements that drew attention to CKD did not emerge until 1998. According to Juan Salgado, a co-founder of LIF, these protests started in response to an increase in CKD deaths among community members. While CKD was prevalent before, it was called something different, such as a general “kidney infection”. However in the 1980s, the Ingenio hospital started to put a name to the disease after doing ultrasounds that showed a physical shrinking of the kidneys and administering blood tests that looked at indicators for kidney function. Protests in the late 1990s and early 2000s called upon the Ingenio to take responsibility for its role in producing these high rates of disease. Some of these protests resulted in charitable handouts from the Ingenio to affected individuals, but the Ingenio did not take responsibility or implement sustainable, long-term programs to support workers (Salgado 2015).

Recent protests have been harshly repressed by state police. In March 2013, police detained 19 people during a protest by ex-workers affected by CKD. During a January 2014 protest against the Ingenio San Antonio’s labor practices and the high rates of CKD, police shot and killed former sugarcane worker Juan de Dios Torres and severely injured a teenager (CENIDH 2014).

Other groups have used negotiations in order to win reforms in the Ingenio. In 2008, the Center for International Environmental Law submitted a complaint on behalf of a group of CKD patients and their families called ASOCHIVIDA and other community members of Chichigalpa and León to the Office of Compliance Advisor/Ombudsman (CAO), which is the independent recourse mechanism of the International Finance



Corporation (IFC). As the lending arm of the World Bank, the IFC had granted a \$55 million loan to Nicaragua Sugar Estates Limited in 2006 (CAO 2008). The CAO office mediated and coordinated a dialogue between ASOCHIVIDA and ISA/NSEL.

Community members demanded that ISA address links between labor practices and the high rates of CKD among sugarcane workers, restrictions on forming labor unions, harsh labor conditions, pesticide use, and environmental contamination (CAO 2008). This process brought in Boston University's School of Public Health to launch studies on the disease and led to the implementation of a variety of charitable programs from the Ingenio San Antonio, such as food stipends for ASOCHIVIDA members, the construction of 100 homes for CKD-affected families, and a donation for a new public health clinic in Chichigalpa (CAO 2012). I will elaborate more on this dialogue process and its outcomes as well as the history of scientific knowledge production about CKD in a later section.

In sum, social movements have been resisting the structural violence to which they have been subjected for almost two decades. High rates of death among workers has motivated an expression of biological citizenship, in which citizens' biology becomes the grounds for demanding social rights. Demands of the movements include access to hemodialysis, financial assistance, and social security benefits. More fundamentally, they demand that the Ingenio and/or the government take responsibility for the CKD epidemic.

## Conclusion

In this section, I have discussed a long history of structural violence in the form of labor exploitation, elite-state alliances, poverty, and disease. Social movements have sought to resist or mitigate structural violence through strikes, protests, negotiations, and even revolution. This historical background shows how the CKD crisis is shifting from historical ignorance of the plight of workers to current mobilizations around workers' rights. National and international actors are now converging upon Nicaragua in order to address biological suffering in the CKD epidemic through science, human rights, and media-based advocacy. The following sections will explore the CKD crisis through various forms of knowledge production.

## **CHAPTER 2: EXPERIENTIAL KNOWLEDGE, SCIENTIFIC KNOWLEDGE, AND NONKNOWLEDGE**

In this chapter I will present ethnographic data about different forms of knowledge at work in northwestern Nicaragua in order to highlight the ways in which knowledge is produced under conditions of scientific uncertainty, controversy, and structural violence. I will divide them into experiential knowledge, scientific knowledge, and nonknowledge. While these forms of knowledge are produced in different ways and with different goals, they overlap at many points and cannot be understood as separate entities. I will use my analysis of knowledge production in order to foreground my argument about the limitations of biological framings in contexts of social claims. In what follows, I will introduce the diverse types of experiential knowledge, scientific knowledge, and nonknowledge operating within the CKD crisis.

### Ways of Knowing

Phil Brown notes that “experiential knowledge usually precedes official and scientific awareness, largely because it is so tangible” (Brown 1992: 270). This is the case with CKD as well. Workers knew that they were getting sick and had explanations for how they were getting sick before scientists began to launch studies. Labor conditions were an obvious cause of a variety of illnesses that the workers contracted because of their jobs. My interviews corroborate the many ways in which chemicals, environmental contamination, heat, and labor exploitation are embodied, producing certainty around the causes of CKD.

Scientists, on the other hand, produce knowledge through studies under the guise of disembodied objectivity. Scientific ways of knowing are considered to be “value-free” and “devoid of self-interest or bias” (Brown 1992: 273). Objectivity and standards of proof distance science from experiential ways of knowing (Brown 1992). As Brown notes, “epidemiologists prefer false negatives to false positives--i.e., they would prefer to claim falsely that an association between variables does not exist when it does than to claim an association where there is none” (Brown 1992: 274). My interview with a scientific researcher, whom I will call Gerardo, and a review of some of the biomedical and public health literature demonstrates many of these trends within scientific knowledge. In general, scientists characterize CKD in Nicaragua as uncertain due to their inability to identify a specific biological cause for the high prevalence of disease.

I will also discuss how the Ingenio and the state create spaces of nonknowledge. I am borrowing the term “nonknowledge” from Adriana Petryna’s book about biological citizenship in post-Chernobyl Ukraine. She uses it to refer to the ways in which the state withholds information about the biology of the population such as medical statistics in order to prevent opportunities for dissent (Petryna 2003). I will expand this concept to refer to how the Ingenio San Antonio and the state withhold information about biology, science, the plight of workers, and labor conditions. In other words, these actors prevent the circulation of experiential and scientific knowledge, attempting to divert attention away from crisis and maintain the status quo. They accomplish this through censorship, silencing, discourses of corporate social responsibility, secrets, and erasure of privilege.

These three types of knowledge intersect in various ways. Workers cite scientific studies and biological descriptions of CKD, as scientists launch research in response to

the outcries of social movements. The Ingenio San Antonio manipulates scientific research in ways that support the status quo. They organize the Flor de Caña rum tour to encourage tourists to form their own types of experiential knowledge that distract from the realities of labor exploitation. La Isla Foundation exists at the intersection of experiential and scientific knowledge, which I will show in Chapter 3. It serves as a bridge between scientists, community members, and international organizations. At the same time, it often faces opposition from the Ingenio, the state, and some community groups. My data will emphasize the ways in which knowledge production occurs at the intersections of experiential knowledge, scientific knowledge, and nonknowledge.

#### Experiential Knowledge and Certainty about Causes

“We know where we stand. We know what we have and where you get it because we know well what we know. And no president or doctor or scientist is going to come to spread lies among us. Because we know what it is that we have. We know what produces it.” - Roberto Valdivia (2014)

Workers, ex-workers and family members of CKD-affected individuals all talked to me about CKD with certainty about its causes, weaving them in and out of descriptions of structural violence. This section will bring out their voices in an effort to give a picture of the character of experiential knowledge among workers, ex-workers, and their family members. A 22-year-old man that I interviewed, whom I will call Edgar, identified two major causes for CKD as well as many of the politics surrounding the disease:

“Well, the first cause is in this entire company, because through the poisons [venenos, commonly used to refer to agrochemicals or pesticides], all of the waste

that this company throws out, that's where it came from, that's where this disease has come from. Because when my dad got sick, my dad got sick [*salió pegado*] in 2001, [...] with that disease, from that period until now the disease has been getting more prevalent....Lots of people dying, just *creatinina* [creatinine, the local name for CKD]. So the disease depends on the company. The company is to blame. What happens is that they have a lot of money, they have their good lawyers....So what has been done is a strike [referring to the protests for the 25%] in order to be able to maybe get a little bit of money to be able to sustain the poor person, to be able to eat. Do you understand?" (Edgar 2014)

In line with Edgar's statement, the two major causes of CKD that informants consistently identified were working for the Ingenio San Antonio and environmental contamination tied to agrochemicals. Woven throughout their attributions of cause were narratives of structural violence and responsibility that often implicate the Ingenio San Antonio.

Links between labor and CKD were a prominent feature of all of my interviews. Tomás, a man of few words who was not affected with CKD, told me that the only cases of CKD that he knows of are among people who have worked in the Ingenio San Antonio (Tomás 2014). Felipe went even further to tell me that one day everybody would have *creatinina*. Prevention, he stated, was "a lie," impossible because of the power of the Ingenio and the necessity to work there in order to eat (Felipe 2014). Similarly, Roberto told me that the only way he knows of preventing CKD is "not working in the Ingenio San Antonio" (Valdivia 2014). CKD is not the only illness that arises from working in the fields. *Creatinina* scares, skin diseases, psychological distress, injuries, and heat stroke were all mentioned as effects of working conditions. These embodied experiences are

manifestations of the close links between labor in sugarcane fields and health.

Informants' certainty about CKD's causes is a form of experiential knowledge, shaped by witnessing the deaths of family, friends and neighbors and by sensing the health effects of working in the fields.

In addition to working for the Ingenio, another major cause that informants identified is environmental contamination. Interviewees described how they experience pesticide use and environmental destruction at a sensory level. Their experiential knowledge about how contamination is embodied is worth citing at length.

“The worker enters and his body is wet with the dew on the cane. It seems like dew. But when you enter the first cane fields....the first thing you're going to feel is (*sniffs*) the smell of pesticides. Pesticides.... (*sniffs*) You breathe it in. But afterwards you don't feel anything....That means that your body already welcomed it. Inside, you no longer feel what you are breathing in. The *campesino* who enters, the cane soaks his body. He applies herbicides....He sweats. The sweat mixes with the cane. At about 11 in the morning or 12 noon, he leaves really sweaty from work. He's done....Everything that he got wet dries up again. The agrochemicals go away with his sweat....After just two months, the agrochemical is already threatening [his health]....So he finished drinking his water for the day....And he grabs some bottles and fills them up. That water is from...Nicaragua Sugar [Estates Limited]. That water is the same water that has been under the land where cane has been planted for over 100 years. And the studies from organizations of MINSA [the Ministry of Health], like non-governmental organizations and health organizations from any part of the world

have come and we are drinking pesticides in the drinking water of Chichigalpa....So we drink contaminated water and we are filled with contamination. Why else would we need to suffer from chronic kidney disease, *creatinina* two months after entering the Ingenio?" (Valdivia 2014)

Roberto uses sensory descriptions to reflect how his experience of being in the fields informs his perceptions of CKD's causes. He inhales the chemicals, he drinks them, and his body becomes accustomed to them as they slowly poison his body. Similarly, David describes how contamination is embodied and how this impacts even the smell of a dying person's body:

“[After] eating contaminated foods, you expel them. You eat them again and keep contaminating yourself. In other words, what you expel is contamination, you absorb it [...] the contamination is enormous so [...] all of the waste that the person throws out are contaminants. You know? Have you ever experienced the smell of a person who is dying from chemicals?...It is a stench of rotting. The person expels a smell of waste, of decomposition.” (David 2014)

David described to me how contamination does not only result from coming into contact with pesticides, but it is present in the food that people eat. As they ingest chemicals their bodies incorporate them; someone dying of CKD (caused by contamination) has a distinctly horrible smell to their body.

While food and water are mechanisms through which contamination is embodied, it is clear from interviews that labor conditions exacerbate contact with chemicals. When Mario worked in irrigation, he came into contact with pesticides every day. As a result, he suffered from labor-related illnesses:



“They make like big lakes with all [of the waste], which we call *cachazas*...That water from which I sprayed, sometimes I had to even go inside of the water....And you always had to get soaked in that water. The water has a very unique smell of waste, and that sticks onto your skin. And it comes out of your pores even when you are not working; it used to come out of my pores and many people said, ‘you smell bad’..... A friend told me, look if you are here [in irrigation], you are always going to suffer; it gives you a disease in your nails, more so in your toenails, so that they don’t grow regularly as they should grow; instead they grow a little bit deformed....It is...something very dangerous for your skin working with all of those chemicals in the water. You would have...many allergic reactions.” (Mario 2014)

Mario swam in contamination and handled contaminated water used to irrigate the sugar cane. Embodiment of contamination was manifested in illnesses in his skin, and he told me that he still suffers from an allergy to his sweat. While Mario also thought that CKD was partially caused by toxic chemicals in the water, he expresses here the immediate effects of contamination on the body, regardless of whether it impacts the kidneys.

Therefore, both contamination and labor in the Ingenio San Antonio were commonly cited as major causes of the CKD epidemic. Other causes identified by informants include dehydration (José 2014; Mario 2014; Tomás 2014), high temperatures (especially those caused by burning the cane fields) (Mario 2014), exposure to the sun (José 2014; Mario 2014; Felipe 2014), and lack of attention to workers (Antonio 2014). Many interviewees acknowledge the likelihood of multiple factors contributing to CKD.

However, regardless of perceived causes of CKD, it is clear among informants that working in sugar cane causes a variety of health problems.

In sum, these examples demonstrate how experiential knowledge circulates. Senses and emotions mediate illness experience and meaning. Individuals see, feel taste, and smell contamination in their bodies. They experience illness in many forms as a direct result of their jobs. This knowledge shapes their perception of themselves, their communities, and the CKD epidemic at large. In these examples, structural violence through labor conditions is a prominent feature of discourses about etiology.

Furthermore, they express etiology with certainty. As Roberto expressed in the quote at the beginning of this section, *enfermos* and their loved ones know what they have. They do not need a scientific study to prove it for themselves (although interviewees recognize the authority of scientific knowledge in bringing legitimacy to their suffering). Carla, a woman who lost her husband to CKD, expressed this:

Sarah: “And do you think it is necessary for scientific studies to be conducted about the disease [CKD]?”

Carla: Yes, it would be good. And they will realize that *that* [pesticides that the Ingenio sprays on the sugar cane] is what is killing people.” (Carla 2014)

### Poverty, Labor Conditions, and Human Rights

Workers’ accounts also highlight other frames of structural violence that can be used to explain and analyze CKD’s causes. In this section, I will analyze CKD and its causes through the themes of poverty, labor conditions, and human rights. These discussions will illuminate the various forms of structural violence that affect sugarcane

communities in Chichigalpa, thereby showing how this structural violence shortens “life as such” (Fassin 2009). Discussions of structural violence are important in defining CKD as a structural phenomenon, as I do in this paper and as interviewees did during my field work. They remind us that social movements’ claims to rights are not just about treatment for illness, but about comprehensive responses to disease and labor exploitation.

### *Roberto’s Story*

Roberto Valdivia (2014) is an animated man with a preacher-like style to his speech. I invited him into the air conditioned room of La Isla Foundation’s Chichigalpa office on my first day of interviews. A 31-year-old ex-employee of the Ingenio San Antonio, he passionately told me about his experience as an *enfermo*, an individual who is sick with chronic kidney disease. Roberto began working for Nicaragua Sugar Estates Limited at age 13. He held a variety of positions throughout his time there: field supervisor, health promotor, quality analyst in the laboratory, and factory worker in Flor de Caña where he was involved in the production of rum and ethanol. He has two children and a wife and lives in Chichigalpa.

When Roberto became sick with chronic kidney disease at age 29, he was no longer allowed to work for the Ingenio since the Ingenio fires workers once their creatinine level reaches 1.4 mg/dl (Laws et al. 2015). He told me, “the Ingenio has thrown me out like garbage, like *bagazo* [sugar cane pulp], now that I am sick with chronic kidney disease.” His inability to work has put more pressure on him to support his wife and two children, so he started working on a tricycle taxi, pedaling passengers every day through the hot, sunny streets of Chichigalpa. “The tricycle is bad for me,” he

told me. Not only is it bad for his kidneys, but he also suffers from five herniated discs in his spine. In order to endure the pain as he works on his tricycle, he takes his medicines all at once in the morning, against the recommended dosage instructions.

Roberto's economic security decreased once he lost his job, and he worries about his son who suffers from a seizure disorder. He spoke about how his life circumstances have caused him and other *enfermos* to feel severely depressed.

“We are living in plastic shacks, desiring to make a place with four walls and we cannot. Our children are in need, just as our wives are in need. It wears us down, it causes us desperation, it makes us want to cry, it makes us want to shout looking at how we live and can't get ahead, having sick people in our homes without the ability to give them what they need because we don't have money.”

(Valdivia 2014)

Roberto aptly describes how poverty, exploitative labor conditions, and lack of respect for human rights interact to produce disease, depression, suffering and death. I was struck by how passionately he told his “testimony,” as he called it. He seemed to find hope in the fact that I was a foreigner who could take his story to the United States, although I was not so sure that I would be able to make much of a difference through a thesis and some academic presentations. Nevertheless, his willingness to share such personal details and his insistence that I make his name public reflect a deep commitment to making his own suffering and that of others known. I will examine similar narratives through the lenses of poverty, labor conditions, and human rights.

*Poverty*

“I didn’t even have this sickness before and now I got it. That means that I gave a lot to the Ingenio. Rather, I gave much of my life to the Ingenio San Antonio. And I’m going to continue working because it is the only way that I can eat.” - Felipe (2014)

Felipe was the youngest person that I interviewed. Just 19 years old, he had been diagnosed with CKD shortly before I met him. As he states here and many other times in his interview, working for the Ingenio is a means of survival because it is the only way he and many others in Chichigalpa can feed themselves. La Isla Foundation has termed this situation a “cycle of death” (LIF 2011). Poverty pushes people into high-risk jobs, and these jobs make them sick. Workers are fired from the Ingenio after they are diagnosed with CKD. In order to continue making money, many seek employment with subcontractors under a false identification number, despite being ill. Others, like Roberto, get jobs outside of the Ingenio. It is difficult to obtain social security benefits after getting sick because one must prove that the illness is work-related and comply with other strict requirements (LIF n.d.), and even those with benefits find it hard to survive on the low payment amounts. As people continue working, they are likely to accelerate the progression of their illness. Once individuals die of CKD, their families must find ways in which to support themselves. Many times this means that the surviving family members seek work in the sugar cane fields, putting their lives at risk. Felipe’s story is an example of the devastating familial implications of disease; his mother is also sick with kidney disease and on dialysis, and he is unfortunately following in her footsteps.

Regardless of working conditions, poverty can also directly contribute to illness; it is embodied as pain, suffering, disease, and death. David, a 67-year-old man with CKD,

explained to me that his pain medication is the same price as two meals, so he can either eat or take the medication on an empty stomach. He explained that he usually chooses to live with the pain and eat instead of taking medication (David 2014). Therefore, poverty, as a form of structural violence, increases risk for illness, exacerbates illness, and shortens life.

### *Labor Conditions*

Labor conditions are also a direct cause of illness, as described by the workers and ex-workers that I interviewed. Mario is a 21-year-old ex-employee of the Ingenio San Antonio, but his maturity exceeded his age. Since age 14, he has worked in a variety of areas of the Ingenio, including operating machinery, irrigation, planting, cutting, and fertilization. Here, he tells me about his time working in machinery:

“You work from 5:00 in the afternoon. I left at 7:00 in the morning to be in my house and I would sleep all day so it was like, I felt like I was a slave...And I didn’t have, like, freedom....And it was like being in an oven because...I drove a small machine that got really hot....It didn’t have a roof or anything to protect you from the sun, so I was...exposed to the sun for a long time....Sometimes it was torture to work in those very hot climates, so it was difficult. And there were a lot of people that got sick....

At night [the work in machinery] was a little bit lighter. [You could] take a break because it [was] nighttime and there’s a lot of danger at night with the machinery because you could have an accident....But, compared with other jobs, that’s the easiest job I’ve had.” (Mario 2014)

Mario's use of the metaphor of a slave who did not have freedom reflects the intensity of the working conditions and hearkens back to the history of the sugarcane industry.

Working in sugarcane is brutal due to the oppressive heat, the harsh labor policies of the Ingenio, and the high risk of accidents and illness. Nevertheless, working in machinery was the easiest job that he had.

The harvest season takes place during the months of the dry season in Chichigalpa, making it the hottest time of the year in an already hot place. When I was there, which was not during the harvest season, I would sweat almost constantly, and the heat drained my energy. It was hard for me to imagine how so many people work in the direct sun every day in that heat.

In addition to the oppressive heat, accidents are another means by which working conditions become embodied as illness. According to a study by the Pacific Institute of Resource Management that is cited in a report by La Isla Foundation, "85.5% of workers report having suffered cuts; 7.5% have suffered burns, and 3% suffered fractures" (Hutchinson 2014: 6). Mario told me that every harvest season, three or four workers die from accidents (Mario 2014). Furthermore, working in sugarcane is very likely to cause illness. In addition to CKD, workers regularly experience dehydration, skin conditions, and heat stroke.

Laborers are expected to work long hours and those who cut cane are paid by how much they cut, thereby discouraging them from taking breaks for food, water, and rest. Some informants described how hard it was to take time off for illness. Sick days mean a day of lost pay for workers and supervisors blame workers for having drunk too much alcohol when they take time off (Antonio 2014). Similarly, when a worker wants to take

a long period of time off, the Ingenio or subcontractor considers that they quit their job and will not hire them back (Mario 2014). Mario told me about a friend that took extreme measures in order to make sure that he could take a break from working and have a chance of getting hired again.

“I had a friend who did not want to continue working a *zafra* [harvest season]. And I think he had a [medical] exam but [in our] job...we had a lot of pressure [*presión*] because if you left work for any reason, you knew that you would not return to work. So what he did was make himself get sick quickly, something that only with him I have seen. It was really weird because he decided to not take care of himself as he should have taken care of himself, and he worked very hard one day before getting checked....And after that I don't know what he did to control it. It was like an experiment that he did to himself.” (Mario 2014)

In this case, Mario's friend attempted to make himself sick with kidney disease in order to have a legitimate excuse to take a break from his job and get hired back in the future, given that his kidney function returned to normal levels. While this is a rare example, it illustrates the intensity of harsh labor policies and lack of control that workers experience.

Another informant, José, talked about the pressure put on workers when he told me about his experience working as a field supervisor. He left his job because his supervisors were criticizing him for treating his workers too well (José 2014). He told me,

“There the role of the supervisor is to maintain the worker working, like a *yugo* [yoke]...So, many times from what I knew...about the treatment of workers, I did



not respect those dirty politics that they had. So what I did was I always tried to maintain a good relationship with the workers and I was always like, let's go rest, let's sit down, sit down, drink water, food, want to rest? So many times what the highest supervisors did was take that as a deficiency. So they would come and get my attention saying look...it's your fault. They're working less. They aren't accumulating enough work so that brought me some problems until the point that I decided to stop working because of that....I was never going to respect what they said." (José 2014)

José's account is another example of the harsh labor policies at the Ingenio and how the hierarchy of workers promotes these policies.

In Chichigalpa, the word "presión" has two meanings: pressure on the job (as Mario mentioned above) and a certain kind of oppressive heat that one feels when there is no breeze. Both the heat and labor practices combine to produce extremely harsh labor conditions. When a worker is dehydrated from working hard without breaks, her water bottle is burning hot from being in the direct sun, and she fears that the water is contaminated, what is she to do?

Despite labor conditions that render workers' skills and lives replaceable, I noticed in interviews that many of my informants expressed pride in their skills as sugarcane workers. I started each interview with cane workers or ex-workers by asking in what areas they had worked in the Ingenio. These discussions taught me about the diversity of skills and techniques involved in working in sugar cane (and I learned quite a bit of new vocabulary words in Spanish). As they described how they planted, cut, irrigated, or transported sugarcane each day of the harvest season, the workers

highlighted the science of sugarcane harvesting techniques that formed part of their expertise and experiential knowledge. Roberto explained to me that he had a “professional job” (Valdivia 2014), and Felipe’s (2014) statement, “I gave much of my life to the Ingenio San Antonio” can be interpreted as an expression of pride (as well as a disturbingly literal interpretation of his disease). Although workers took pride in their skills and expertise, labor practices and silencing techniques failed to foster their dignity as workers and as human beings. Losing one’s job due to a diagnosis felt dehumanizing, as Roberto expresses in his statement “the Ingenio threw me out like garbage” (Valdivia 2014). As workers juxtaposed these narratives of pride, expertise, and dehumanization, they highlighted how the Ingenio’s labor practices not only exploit workers and damage their bodies, but they undermine the ways in which workers make meaning of their lives and their bodies. Therefore, juxtaposing narratives of skill, expertise, and dehumanization further emphasizes how the Chichigalpa sugarcane industry considers both workers’ skills and lives as replaceable. Labor conditions not only damage workers’ bodies, but also the meanings that workers tie to their lives.

### *Human Rights*

A human rights perspective also illuminates how the government and corporate entities perpetuate a cycle of death. While the Nicaraguan constitution contains many protections for workers and enshrines a right to health, these rights are not always protected in practice. A report from La Isla Foundation cites human rights violations such as child labor (LIF 2015), restrictions on unionizing, inability to access judicial

mechanisms, and threats and intimidation from local government, state police and the Ingenio (Hutchinson 2014).

Most of my informants agreed that the force behind these abuses and threats is the economic alliance between the Pellas family and local and national governmental authorities. This alliance stems from a long history of elite-state alliances in Nicaragua, as I described in Chapter 1. Mario told me that there is Ingenio propaganda inside of the mayor's office. Students from the public schools also participate in yearly reforestation campaigns organized by the Ingenio. Additionally, a mayor once sold public streets in Chichigalpa to the Ingenio that are now closed off to the public (Mario 2014). As I walked through the city of Chichigalpa, I noticed some places where the government and the Ingenio seemed to blur the line between public and private. For example, garbage bins with the words "Ingenio San Antonio" or "Nicaragua Sugar Estates Limited" sat outside of many of the public buildings I passed, including the mayor's office and the Municipal Library.

These corporate-state alliances manifest themselves in how the law is applied. Roberto explained to me what he called "the law of the poor".

"The law works like this in Nicaragua. If there is a faucet over there and you tell me to bring you water, okay. I turn it on, fill it up with water...and I turn it off. And it's sitting there in the cup. [...] I'm going to get *randon* [a pesticide]. I'm going to fumigate over there to burn the weeds....*Ssshhh*...

The police investigation comes and says, 'this water had poison in it.' -- 'Do you know what happened here? I fumigated with *randon* and I didn't realize and poison fell into the cup.'

-- 'Oh, so you knew that this glass shouldn't have been there before you fumigated. You should have taken it away from there before you touched the fumigation hose.'

So, the constitution says that you committed a voluntary homicide. So they bring me to the court and give me a sentence--*boom*--for homicide. I go to jail for my 20 or 30 years. That is the law of the poor....

The owner of the sugar factory is named Carlos Pellas. Carlos Pellas uses a *ton* of tanks with wheels and planes and tractors that go around fumigating pure poison....And Pellas knows, Pellas and Pellas' hospital know that when we arrive at the hospital what they find is poison in our blood. He knows. And the government knows...We as poor people can go to jail, but he as a millionaire cannot go..." (Valdivia 2014)

Here, Roberto gives an example of how the law applies differently to the Pellas family and to the poor. While the poor can receive large sentences for small crimes, or even accidents in this case, Carlos Pellas will never go to jail. Roberto subsequently told me that a lawyer who represented a group of people with kidney disease went to jail because, according to him, the judge did not want to address any legal complaint against the Ingenio San Antonio. When the group wanted to protest, the police said they could protest silently, but then showed up with riot police and beat and killed protestors. "It was really a trap," Roberto told me (Valdivia 2014).

*Power and the Devil*

One of my informants, David, was a 67-year-old ex-cane worker with CKD. His characterization of the power of the Pellas family was of supernatural proportions; he explained to me matter-of-factly that their wealth originates from a pact with the devil. While I originally wanted to laugh at what seemed like a strange notion to me, upon giving it more thought and hearing David speak, I realized that this characterization reveals a great deal about the historical and present context of structural violence under which Chichigalpa's communities live. He told me not of the Pellas family, but of the Pellas clan, "because only clans have pacts."

"Because I have seen it. I have felt it, its presence. And not only me. Many people....[The pact] is what causes accidents in the Ingenio because I call it the collector [*cobrador*] of life. Because the pact gives life. Year after year before...the start of the harvest season and at the end of the harvest season deaths occur, which is the payment. Including the 13 *quemados* [burned people]..."

(David 2014)

Here, David conceptualizes how the power of the Ingenio directly causes death in the fields. In order to maintain its power, the Pellas clan must pay in lives during each harvest season. Accidents are part of this payment, which is why so many inexplicable accidents occur during each harvest season. He told me about stories of such accidents, including the "13 *quemados*" (burned people). After these 13 workers had cleaned out the tanks at the end of a harvest season, the tanks mysteriously filled with boiling molasses. The molasses fell on top of them and burned them to death (David 2014). Mario also told me stories of inexplicable deaths and occurrences in the fields, some of

which he had witnessed firsthand. For example, a worker died mysteriously in the fields close to where Mario was working. His family members and friends looked for his body for weeks, only to find it after two or three weeks right where they had already looked. Mario found it strange that although he was working so close to it, he could not smell the man's body decomposing. "It's like something illogical but they are things that you see, I don't know," he told me (Mario 2014). While Mario did not directly attribute these occurrences to a pact, he explained that "people believe it is like a payment of souls" (Mario 2014).

Interestingly, David links the history of the pact to the current labor practices. He describes how the Pellas family came over from Europe. I had read that they were Italian, but he specified that they were Sicilian, "and the Sicilians are the ones who control the Vatican". With this supernatural power, they came to Nicaragua.

"They came here and overnight, my grandfather told me that overnight, a great fortune. Money [...] and to buy slaves. They had 50,000 slaves in this entire zone. And that is why they have the ID number 50,000. Because the same numbers that they used on the slaves are those that the workers use today because they consider everyone who comes to work at the Ingenio to be one more slave." (David 2014)

Slavery involves a totalizing power over the bodies of workers, and David suggests that conditions are similar today. This power is backed up by an inexplicable amount of wealth.

Stories of devil pacts are not new in Chichigalpa. In fact, Gould (1990) describes different devil pact stories in the early 20th century. He compares devil pact stories in Chichigalpa and rural Ometepe:

“Despite their different origins in economically developed and relatively urban San Antonio versus undeveloped and rural Ometepe, these similar devil pact myths reveal a common facet of Nicaraguan rural mentalities in the early part of this century: a perception of the diabolic sources of the accumulation of wealth and the identification of rural wage labor with bestiality. Such myths attempted to make sense of the exploitative nature of wage labor and the loss of land, to a Nicaraguan audience that was undergoing the transition from a peasant-based to a wage labor economy” (Gould 1990: 29).

While David’s account is from a different era than that described by Gould, he and Mario show that supernatural accounts of labor exploitation still exist today. I posit that they represent a form of meaning-making in the face of extreme structural violence. Paul Farmer, referring to political violence and AIDS in Haiti, states, “these afflictions were not the result of accident or of force majeure; they were the consequence, direct or indirect, of human agency” (Farmer 1996: 271). Therefore, while structural violence is often talked about as accidental or natural, the pact with the devil makes these “accidents” direct and certain. Wealth and power directly cause death.

### *Conclusion*

As these examples evidence, chronic kidney disease is part of a web of structural violence that ties together history, human rights, poverty, labor practices, environmental contamination, and exploitation. Experiential knowledge shows the various forms of structural violence that are producing suffering and illness in Chichigalpa as well as local forms of expertise. Poverty, labor exploitation, and human rights violations are not

isolated from the past, but rather stem from neoliberal policies, state-elite alliances, and the nature of working in sugarcane. Workers and ex-workers make meaning about CKD and structural violence through the senses, theories of the supernatural, and emotions. Therefore, structural violence is very clearly embodied in people's experience, as demonstrated by these accounts. I highlight these narratives not only to show that CKD is a result of structural violence, but also to emphasize the comprehensive nature of rights claims in Chichigalpa that are both health and non-health-based. Even if scientists could cure kidney disease, workers would still be living under various conditions of structural violence. However, as the next section will show, science has been unable to fully make sense of CKD and its causes, thereby adding to uncertainties that distract from these forms of structural violence.

#### Scientific Knowledge Production about CKD

At the end of my stay in Nicaragua, I interviewed one of the foremost researchers of CKD in the region. I was relieved to feel the air conditioning permeating his university office, a short respite from the heavy heat. I was more nervous for this interview than any other interview; perhaps the authority of a scientist brought out my nerves. This researcher, whom I will call Gerardo, discussed how research topics have been identified and carried out about kidney disease in Nicaragua, spitting off statistics that he knew by heart. He was well-versed not only in biomedical knowledge, but also in public health and the social determinants of health.

The first studies about CKD among agricultural workers in Nicaragua and El Salvador were from 2002 and 2003 (Cuadra et al. 2006). Around this time, Gerardo and



his research team began by looking at mortality statistics through which they located the departments of León and Chinandega (where Chichigalpa is located) as having the highest mortality rates. After a regional meeting that was held in 2005 and hosted by an occupational health program at the National University in Costa Rica called SALTRA (Program on Work, Environment, and Health in Central America), they carried out more studies looking at prevalence of CKD by occupation. Gerardo described these studies to me:

“In 2007...we began to work on epidemiological studies. This was just a statistical revision to see if [CKD] is really a problem or not a problem to say that we need to do studies. But since it was known at that time that people were just dying, and young people, but the cause was not known, in 2008 [...] we started to do a study in five different communities. These communities were selected according to, because people said that it was the cane workers, that it was the banana workers, but...in the end we didn't know who it was....We saw on the one hand that the zone of Larreynaga was more affected so we decided to choose these five communities by...occupational category....So we took one community of cane and banana; we included one mining community that was next to Larreynaga...; we took one fishing community...; we took one service community that [...] works in anything but agriculture and sugar cane...; and one coffee-growing community. All of these five communities were divided between the departments of Chinandega and León. And what we did was take the group of the population between 20 and 60 years of age....The interesting thing in the end of the whole study was to find people between 20 and 29 years old in stages 3, 4, and 5 [of

kidney failure], which shouldn't happen....And that the risk factors that the literature said were causes of chronic kidney disease were not what was present in the population. They were different factors, and it could not be said yet what were the causes.” (Gerardo 2014)

After La Isla Foundation was founded in 2008, Gerardo's team began to collaborate with them on studies in La Isla and Candelaria. Again, they found high rates of CKD. Gerardo told me “It is surprising to think that a population is 55% affected (*alterado*). It is probably half of the population.” Given these surprisingly high mortality statistics, scientists began to look for the causes.

“We have been ruling out possible theories and hypotheses that have been generated. And among the hypotheses that have stuck as possible causes...[are] heat stress, dehydration, the organization of work, for example long work days, *trabajo a destajo* [being paid by how much you produce]..., high consumption of sugary beverages is probably playing an important role, among other risk factors that might be important. In other words, we don't think in this moment that it is unicausal, but that it is multicausal.” (Gerardo 2014)

Therefore, scientific research is now asking what is causing this globally uncommon form of CKD, and research is being conducted in order to find if and how labor conditions are linked to CKD. Another SALTRA conference was held in 2012 in Costa Rica with the goals of finding gaps in scientific knowledge about CKD and exploring the etiological hypotheses about the disease. Table 1 lists potential causes categorized by priority from the conference report. Major participants in the conference included representatives from La Isla Foundation, the Karolinska Institute in Sweden, Rajarata

<b>Table 1 - Proposed Priorities for Exploring Hypotheses for Causes of MeN</b>
<i><u>Highly Likely, High Priority to Investigate Further</u></i>
Heat stress and dehydration (including electrolyte imbalances)
Non-steroidal anti-inflammatory drugs (NSAIDs)
<i><u>Possible, High Priority to Investigate Further</u></i>
Arsenic
Fructose intake
Nephrotoxic medications, including homeopathic medications
Leptospirosis and other endemic infections
<i><u>Possible, High Priority but Logistically Difficult at this Time</u></i>
Genetic susceptibility and epigenetics
Low birth weight and other prenatal, perinatal, and childhood exposures that increase susceptibility
<i><u>Unlikely but strongly believed, Medium Priority to Investigate Further</u></i>
Pesticides
Urinary tract diseases and sexually transmitted diseases (STDs)
<i><u>Little Information, Medium Priority to Investigate Further</u></i>
Calcium in drinking water, or water 'hardness'
Medication contamination and use of homeopathic medicines and non-approved drugs
<i><u>Unlikely, Low Priority for Further Investigation</u></i>
Lead
Mercury
Cadmium
Uranium
Aristolochic acid

**Table 1.** Causes categorized by likelihood from 2012 SALTRA conference (Wesseling et al. 2013)

University in Sri Lanka, the Boston University School of Public Health, the National Autonomous University of Nicaragua in León (UNAN-León), the National University in Costa Rica, the Ministry of Health of El Salvador, the Centers for Disease Control in Atlanta, and many others (Wesseling et al. 2013).

While each of these actors has played a different role in research, Boston University's (BU) research has been especially controversial. Boston University's School of Public Health entered the scene in 2009 when it was chosen out of a pool of nine applicants by ASOCHIVIDA and the Ingenio San Antonio as they participated in negotiations regarding the \$55 million loan from the International Finance Corporation (CAO 2008). The BU studies were widely criticized among social movements, outside organizations, and the research community because part of its funding came from the Nicaraguan sugarcane industry. The conclusion of one of the Boston University studies has been widely cited:

“We have concluded that none of the current work practices or the chemicals used by ISA are generally accepted causes of CRI [chronic renal insufficiency]. This conclusion does not rule out the possibility that one or more of these agents might in fact cause CRI, but new scientific knowledge and insights will be necessary to establish whether any link actually exists. To develop this new knowledge, subsequent phases of our work will focus on gathering additional exposure and health data and investigating their possible connection to CRI both within ISA and in other areas of Western Nicaragua.” (McClellan et al. 2010)

This vague conclusion denies a clear link between labor practices and CKD. While some might attribute the conclusion to the slow nature of scientific knowledge production and

high standards of proof, others claim that conflicts of interest with the studies' funding sources influenced the conclusion. Additionally, the Ingenio San Antonio has cited this study in order to deny its responsibility in producing the CKD epidemic.

BUSPH came out with a statement in 2014 that accused the IFC of oversimplifying the studies' conclusions:

“The IFC’s supporting documentation for the new loan states: ‘No direct relationship between the sugar sector and the disease has been established.’ This is the IFC’s summary of our and other’s work but it is a serious oversimplification of the research to date” (BUSPH 2014)

They review their research in the rest of the statement, noting their findings of possible contributing factors to CKD, such as dehydration, muscle damage, and exposure to agrochemicals (BUSPH 2014). Most notable for my discussion is how the BU studies have added to the construction of scientific uncertainty about the disease, allowing different powerful actors to capitalize on these spaces of uncertainty.

A more recent group of three BUSPH studies also received \$1.7 million in funding from the sugarcane industry. This research will look at CKD etiology through occupational factors, possible genetic factors, and early-onset kidney damage in adolescents. The outcomes of these studies are yet to be seen, but have been criticized for their funding sources and their focus on causes that are non-“modifiable” such as genetics<sup>4</sup> (Chavkin 2014; Lenzer 2015; Glaser & Weiss 2015). At the University of

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<sup>4</sup> Medical anthropologist Lindsay Smith (2015) provides historical examples of the utilization of genetic technologies to show the ethical challenges of tying genetics to social justice. She argues that “genetics best coalesces with the goals for social justice in cases where technology is governed by a politics of humility, owned and managed by social rather than scientific actors, and conceived of as one tool within broader social and political movements rather than a magic bullet capable of quickly cutting through messy social issues” (Smith 2015: 969). Boston University’s

Colorado, biomedical scientists are carrying out studies on kidney function in mice in order to determine the potential interactions between renal function, dehydration, and sugar intake (Roncal Jimenez et al. 2013).

In January of 2015, Boston University published another study that concluded that “one or more risk factors of CKD are occupational,” in contrast to their previous 2010 conclusion that denied a clear link between CKD and labor (Laws et al. 2015). While the 2010 BU study (McClellan et al. 2010) was published on the CAO website rather than a peer-reviewed journal, a recent peer-reviewed study found that one or more risk factors for CKD were occupational. The data for the 2015 study came from research carried out under the CAO process and was funded by the CAO and the sugarcane industry (Laws et al. 2015). Critics point to BU’s failure to publish their 2010 study as an indication of conflict of interest and find it curious that it utilized similar data sets. This study had a variety of political implications that I will discuss in detail in Chapter 3.

This historical progression of scientific research about CKD shows interactions between science and workers as well as interactions between science and power. Workers’ outcries brought scientists’ attention to high rates of disease, prompting epidemiological research. At the same time, scientists’ research in Nicaragua must get approval by the Ministry of Health and research inside of the Ingenio must be approved by the company. While BU was critiqued for conducting research with company funding, it was the only research team able to access workers inside of the Ingenio. Therefore, nonknowledge, scientific knowledge, and experiential knowledge always interact.

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use of genetics in this case brings a variety of ethical challenges, especially given its financial and historical ties to the sugarcane industry, that should be explored in future social science research.

### *Scientific Uncertainty*

A major question in current scientific research on CKD is about the disease's biomedical causes. Why are causes that are so certain to workers so mysterious to science? This section will look at scientific inquiry into CKD etiology and how it is tied to a history of scientific thought about the body. It will use examples to argue that etiological uncertainty allows a diffusion of responsibility and distraction from structural violence.

Western biomedicine has historically conceptualized disease through specific, internal mechanisms (Rosenberg 2002). Dissection, a characteristic practice of biomedicine, led to anatomical views of the body that took it out of context of its social environment (Rose 2001). Visualization of the body was essential to understanding it (Kuriyama 1999). In the early 20th century, visualizing the body at the molecular level became increasingly common in constructing scientific knowledge, and in the late-20th century genes became more salient in scientific knowledge production (Rose 2001). On the one hand, science is certain in describing CKD as an anatomical failure of the kidney. On the other hand, the internal etiology is unknown. Researchers wonder what causes its interstitial tissues to stop filtering toxins in the blood properly. Therefore, scientists are not satisfied when people say that working for the Ingenio causes kidney disease. While most of my informants and LIF publications argue that scientific knowledge is important in order to at least give legitimacy to experiential knowledge claims, uncertainty can make legitimation difficult.

Uncertainty opens up spaces for contestation that are capitalized upon by different actors involved in the CKD controversy. As scientists use uncertainty to drive further

research, social movements and community members use science to add legitimacy to their experience. At the community level, many of my interviewees cited studies that show a presence of chemicals in their environment (Valdivia 2014; David 2014) and that show the efficacy of natural remedies (David 2014). In this case, the authority of scientific knowledge is helpful in corroborating the community's experience. They also tend to downplay or challenge scientific uncertainty, especially with regards to the Boston University study:

“The study that [Boston University] carried out is evidence of contamination. And that coincides with all of the other laboratories [that look at] what causes chronic kidney disease in young people....The Ingenio San Antonio takes out a document. [*Roberto opens up a piece of paper to reenact how the Ingenio San Antonio announced the results of the Boston study to the media*]. And he says, ‘Boston University did the study.’ They give him a microphone. ‘And it says that none of the agrochemical contaminants that we [use] in the cane fields...has to do with the people who are sick with chronic kidney disease’. What is Boston trying to do with this? It is throwing out the investigation that...scientists have gone through the trouble to do. And it is throwing out its prestige because Boston isn't going to trick us [*no nos va a dar atol con un dedo*].” (Valdivia 2014)

Roberto accuses Boston of manipulating its data in order to give the Ingenio San Antonio a good image. He cites other studies that corroborate the presence and negative health effects of contamination. Accordingly, he challenges the prestige and authority of Boston University as well as their scientific objectivity.



At the Ingenio, scientific uncertainty opens up spaces for contestations over structural causes of disease and Ingenio responsibility. For example, Nicaragua Sugar Estates Limited has dedicated an entire website, [laverdadnsel.com](http://laverdadnsel.com) (“the truth NSEL.com”), to denying the links between the practices of the Ingenio San Antonio and the prevalence of CKD in the region. On the home page, they display the BU study with the vague conclusion that I cited above. Their “Questions and Answers” section of the website demonstrates how scientific knowledge can be used and manipulated to discredit experiential knowledge claims, using scientific objectivity as a powerful claim to authority.

## “2. What is Chronic Renal Insufficiency?”

Chronic Renal Insufficiency (CRI) is a multi-causal disease consisting of a progressive loss of renal function, ranging from partial kidney damage to total kidney failure, and can have different genetic, environmental, and/or behavioral causes, which has acquired the characteristics of an epidemic at world level.

In Nicaragua, the disease is most prevalent in the Pacific region (León, Chinandega, Managua, Masaya, Granada, Carazo, and Rivas), including territories where no sugar activity takes place, such as some municipalities of the department of León (Larreynaga, La Paz Centro, Nagarote), which reports the country's highest prevalence rate.

Known causes of CRI mainly include diabetes and high blood pressure. In the United States, for example, the main causes of CRI are diabetes (43.7%), arterial hypertension (26.5%), renal polycystic disease (19.2%) and others (10.5%).” (NSEL 2014)

This example demonstrates how NSEL manipulates and misrepresents scientific knowledge about the etiology of CKD (e.g. the main causes are diabetes and hypertension) and employs the prevalence statistics (e.g. CKD is prevalent in non-sugar-producing areas) in order to deny responsibility for causing CKD. This discredits the experiential knowledge that I cited above. By denying that CKD in Nicaragua is any different from elsewhere in the world or non-sugar-producing regions, it claims that nothing is wrong and that this is a “natural” phenomenon. Denial of responsibility by NSEL makes it one among many corporations that have disavowed their role in causing widespread disease by capitalizing upon scientific uncertainty (Michaels 2008). As different actors either challenge scientific authority or utilize it to forward their own agendas, it is evident that scientific uncertainty holds great political power and is a major driver of this controversy. Power circulates through uncertainty as knowledge is produced, manipulated, and hidden. This allows different narratives of responsibility to thrive under scientific knowledge, thereby diffusing it among different actors.

### *Narratives of Self-Care*

Another way in which scientific uncertainty shapes narratives of responsibility is through narratives of self-care. While self-care is a mechanism through which to create more certainty surrounding an uncertain disease category, it potentially distracts from structural causes of disease by placing blame for disease on workers’ behaviors, thereby undermining collective rights-based claims. These self-care narratives have been widely critiqued in social science literature about various diseases, including obesity (Guthman 2011), cancer (Jain 2013), and addiction (Garcia 2010). Biological definitions of CKD

facilitate these regimes of self-care by looking for etiologies within the individual body rather than structural causes of disease, and therefore are another example of how scientific knowledge can forestall rights claims.

Most of the potential causes of CKD that have been identified can be interpreted to adhere to a narrative of self-care. For example, company officials or doctors might claim that workers are not drinking enough water (Gerardo 2014), eating unhealthy foods, or failing to use protective gear while spraying chemicals (NSEL 2009). Often self-care regimes promote health education, hoping that it might encourage healthy behaviors in individuals. For example, the International Finance Corporation suggested in a letter to the CAO “that there be increased focus on proper hydration and on education campaigns to decrease the high consumption of artisan-distilled alcohol, and increase CRI [chronic renal insufficiency] awareness” (Chemerinski 2009). These types of programs threaten to place blame for CKD on sick individuals themselves rather than on the structural causes of their illnesses. This seemingly easy fixes overlook how poverty prevents a healthy diet, the failure of the Ingenio San Antonio and subcontractors to provide adequate water and protective gear for all of their workers (Hutchinson 2014), and the overall brutality of working in sugarcane.

In addition to these self-care narratives, many workers that I interviewed also adhered to regimes of self-care by avoiding certain foods. They recognized that while these regimes may prolong life, they are certainly not a preventative measure for CKD (Roberto 2014; Antonio 2014; Mario 2014). These were also often based on internalized notions of disease that pictured the kidney as a filter (Roberto 2014).

All of these narratives of self-care are complex and must be interpreted within structures of power. While I do not doubt that dietary changes may give a sense of control to individual workers and that self-care programs may be less politically controversial, I argue that too heavy of a focus on such regimes of self-care distracts from the structural causes of disease. Because CKD is intertwined with poverty, labor conditions, and human rights, self-care programs alone are unlikely to have widespread impact. This is not to say that they should be discouraged, but rather critically analyzed in context and intentionally combined with more structural approaches to disease<sup>5</sup>.

### *Urgency and the Limitations of Scientific Research*

From these examples, it is clear that debates over scientific studies are occurring among many different actors. Some, however, are critical of the usefulness of scientific research in the first place. Antonio, a 24-year-old driver for a subcontractor with the sugarcane industry, critiqued science's seemingly endless search for causes. Instead of asking what the causes are, he points to the certainties of the CKD epidemic that can be addressed without scientific certainty.

“[They should] stop focusing on what it is that produces [CKD]...Scientists come from other countries to see if it is the soil, to see if it is the water, to see if it is the chemicals that they use. And in the end, they end up giving the same response: we don't know what it is. So they should stop doing that and...help people who are sick....help them to have a little bit better life.” (Antonio 2014)

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<sup>5</sup> An example of a program that adheres to practices of self-care (e.g. hydration) and structural causes of disease (e.g. labor conditions) is evidenced in La Isla Foundation's intervention program in El Salvador. I discuss this program in detail in Chapter 3.

As Antonio describes, scientific uncertainty obscures the lived suffering of those with CKD under conditions of structural violence. It draws attention away from the suffering of those who already have CKD, leaving them to die. His argument shows how scientific uncertainty searches for causes in the past and hopes for results in the future rather than dealing with a present crisis. Instead of asking, ‘how do we fix this epidemic’, science asks ‘what happened to make people sick’ and ‘how do we prevent it in the future’. In order to do this, it looks retrospectively at causes rather than urgently-needed solutions. In the process, it diverts attention away from the multiple forms of structural violence under which community members live. It discounts the experience of trying to take care of a dying family member without being able to afford a decent house or adequate food. As Antonio points out, the CKD crisis is urgent.

While I have emphasized scientific uncertainty because of its ubiquity in public health literature and international media accounts, some argue that the scientific research is not as uncertain as the sugarcane industry, scientists, and the media portray it (LIF 2014a). Instead, they claim that the sugarcane industry or scientific researchers have manipulated data. Similarly, it is clear that scientific research is more certain about some potential causes than others. However, the multiplicity of potential causes and logistical and political difficulties of researching some of these potential causes, especially pesticides (Gerardo 2014), grounds my argument that science is largely uncertain. It has not yet proven a specific cause and high standards of proof may delay scientific certainty for years (Antonio 2014; Brown 1992). Therefore, my argument is not meant to distract from scientific certainties that do exist, but rather I want to offer a critique of scientific knowledge production under conditions of uncertainty.

Other authors have pointed to cases in which science is relatively certain about the causes of disease, and corporations manipulate scientific knowledge regardless of scholarly certainty (Michaels 2008). In light of these cases, it is likely that even if science becomes more certain about CKD's causes, the sugar industry will continue to deny responsibility. For example, despite scientific certainty about the negative health effects of sugar (Corliss 2014), the sugarcane industry in Nicaragua continues to advertise supposedly beneficial impacts of sugar on health. For instance, a 2014 special edition to the national newspaper *El Nuevo Diario* published by the National Committee of Sugar Producers stated that “the incidence of cavities is not related to what one eats, but with the level of dental hygiene” and “natural sugar does not affect the behavior of children; rather, it helps to improve memory” (CNPA 2014). This furthers my argument that a focus on biology may be limiting when it comes to attributing responsibility to actors who tend to deny their role in causing illness, regardless of whether scientific knowledge is certain or uncertain.

Despite the potential for scientific certainty in the future, I argue that scientific uncertainty is an essential part of the CKD controversy. While I agree that creating more scientific certainty about CKD's causes (e.g. through self-care and continued scientific studies) may be helpful in addressing disease and legitimating experiential knowledge, it would not systematically address the underlying crises of poverty, labor, and human rights. By internalizing disease, scientific knowledge distracts from structural violence. Scientific uncertainty increases controversy among multiple actors, thereby preventing workers' claims to rights from holding traction. The next section will show how

nonknowledge contributes to uncertainties about CKD by prohibiting scientific knowledge production and by silencing the rights claims of workers.

### Nonknowledge

A whiff of air conditioning hit my face as I passed my \$20 bill and passport under the half-moon cut-out of the ticket window. The ticket agent, who I could not see behind the opaque glass, handed me my receipt, and told me to wait to be called into the entrance of the Flor de Caña rum factory for our tour. Once we were let in, we embarked upon a glorified tour of the Pellas family and their famous sugar enterprise. We tasted aged rum in a private, underground tasting room, traced the process of rum production, learned about the Ingenio's history, and visited the museum and gift shop. At every step, we were reminded of the "secrets" of the Ingenio San Antonio, which banned us from taking pictures at certain stops on the tour and from knowing certain statistics about their rum production. As we passed by the fake sugarcane plantation on an eco-friendly tram, saw pictures and videos of mechanized harvesting techniques, and watched a video about the Ingenio San Antonio's social responsibility programs, I could not help but think about what was missing. My interviews certainly revealed a different story than what the company tour presented.

While the secrets on the Ingenio's tour gave visitors a sense of awe and wonder at the Flor de Caña products, encouraging them to buy more products, interviewees cited different implications of secrets; they facilitated exploitation, produced disease, contaminated the environment, and increased the Ingenio's power at the expense of workers' lives and livelihoods. Secrets are just one aspect of what I term spaces of

nonknowledge. Spaces of nonknowledge are both physical and discursive. While uncertainty opens space for controversy, nonknowledge prohibits controversy. It withholds knowledge from certain groups in order to present an image that is consistent with the status quo and therefore reinforces hierarchies of power.

*Myths, Silences, and Censorship*

“When you go to the tourist areas of San Antonio or Ser San Antonio or the Ser rum factory, they are only showing you the myths....Why don't we do a tour in the fields?...When we went to work, they did not let us take photos. Sometimes we took videos secretly..., look how many packets we can carry! Because sometimes we had to carry up to 200 pounds to be able to remove the cane. And sometimes we had to work quickly...And that is the process to be able to get rum and sugar, to be able to obtain the energy that San Antonio generates. Why don't they show you the septic pools that they have, which are what they use to water the cane, which are handled by people?...That's why us Nicaraguans give it the term that we use, 'Empresa M' [Company of Shit].” - Antonio (2014)

As Antonio notes here, the tourists get one story. I noticed that of all of the movies and museum panels that we saw on the Flor de Caña tour lacked pictures of people harvesting sugarcane or working in the fields. The only visual depictions of the harvest showed machines. The myths of the sugarcane process hide the exploitation of workers.



These myths are reinforced by the tour's focus on social and environmental responsibility. As we rode from the first to the second stop on the tour on the electrically-powered tram (a distance that we could have easily walked), the man on the loudspeaker told us about the eco-friendly production process. I noticed a row of three garbage cans labeled 'Recyclable', 'Non-Recyclable', and 'Organic' in front of the fake sugarcane plantation, and a statement on the back of each tram car: "committed to the environment". The video we watched in the air-conditioned theater told us that 100% of the water that the Ingenio uses is recycled, and it subsequently cited the numbers of tons of paper and cardboard that they had recycled that year.

The video also mentioned ISA's commitment to corporate social responsibility, pointing to its annual investments in health, nutrition, and construction of parks. It built a school called the Colegio Ser San Antonio, and it gives free health care for its 'colaboradores' and their families.

These images of responsibility, environmental preservation, and cleanliness enhance the images the tour guides gave us of the rum's purity. A section of the video entitled "Health" did not talk about the health effects of working in sugarcane or even the health programs that the Ingenio provides for workers, but it reminded visitors that Flor de Caña has fewer calories than beer, whiskey, and vodka! It is an alcohol of "maximum purity," meaning that once processed there is no sugar left in it.

When the tour guide brought the large tour group (four volunteers and staff from LIF plus 40 Nicaraguan university students) into the tasting room at around 9:30am, we were all excited to taste the prized rum that the video had glorified. In an underground, darkly-lit room, we each sat on a stool in front of a large glass with a large shot of rum.

We were supposedly in the private tasting room of the Pellas family, and therefore we were not allowed to take pictures. This secret increased our sense of excitement to try this special, high-quality aged rum. We were instructed to experience the rum with our five senses. We had to observe the color and swoosh it around to look at the part that stays on the glass. We had to smell it while closing our eyes. We had to pour some onto our hands to feel that it is not sticky because it does not have any traces of sugar or artificial additives. As the suspense kept building among all of the tour visitors, we were permitted to clink our glasses and put a small bit on our tongue. Then we were finally allowed to drink the rest.

Purity, responsibility, and health are lucrative myths. Secrets not only sell products, but they produce a certain kind of knowledge that prevents non-workers from seeing the dirty, hot, unhealthy, deadly, destructive process that is the planting, harvesting, irrigation, and processing of sugarcane. As Antonio told me in an interview, “Why don’t they put a photo where there’s a person who is all dirty [...], without a shirt on with pants or shorts and a machete [*rula*] cutting cane? Because the first thing that foreigners will think [is], what a hard job! They are exploiting them” (Antonio 2014). Indeed, while I saw plenty of tourists in León wearing the popular Flor de Caña tank tops, I hardly ever saw images of sugarcane workers, except through my work at LIF. These spaces of nonknowledge, therefore, are essential to the power of the company and the lure of its products. Furthermore, they allow for an erasure of the privilege that makes a deadly secret exciting and delicious for outside visitors.

Silences are another prominent form of nonknowledge in Chichigalpa. Here, I will use two quotes from Mario and Roberto to explain how silences and silencing protect economic interests.

1. “If you are in a protest, or if you are making claims against the Ingenio, they might not be able to do anything against you because you don’t work for them. But if your family member is a worker then...they will retaliate against your family.” - Mario (2014)
2. “We are in a belt of crisis. We cannot scream to the heavens because nobody hears us.” Roberto Valdivia (2014)

Mario and Roberto describe both silences and silencing that result from powerful economic interests. According to Mario, threats of retaliation by the Ingenio combined with the stress of living under economic poverty with little food to eat prevent individuals from speaking out. Some people lose their jobs or their food stipends from the Ingenio’s “corporate social responsibility” programs resulting from the CAO negotiations if they choose not to remain silent. The process of silencing impedes the dissemination of community-based knowledge about the Ingenio’s exploitative practices and the character of the CKD epidemic.

Even despite these threats, community members are speaking out and resisting this silence; they are ‘screaming to the heavens’. However, their screams, protests, and calls for assistance often fall upon deaf ears in the government and the national media. Many individuals attribute the cause of this silencing to the close relationship between the Pellas family and the government. “Any complaint against the Ingenio San Antonio or the distillery, the media...says, ‘we can come. But if you speak out against Pellas or

against the Ingenio San Antonio's distillery, nothing will be put on the air. The television channels do not transmit anything against them because the government warns us that if we do that, they will close our station” (Valdivia 2014). Therefore, using Roberto's metaphor, while many people are prevented from screaming in the first place those that do scream are not heard, producing different spaces of silence and preventing the circulation of community-based knowledge. Therefore, silences, as another form of nonknowledge, maintain the status quo by preventing structural interpretations of CKD to even be heard.

Censorship and other forms of nonknowledge also prevent scientists from conducting research on CKD and withhold personal medical information from workers. Scientists have had trouble conducting research within ISA due to censorship by the state and the Ingenio San Antonio. Gerardo expresses how his research team has been unable to carry out studies in the Ingenio:

“We try to do the majority of our studies at the community level....meaning following workers to see or identify the possible relationship or appearance of the disease during the harvest season. But it has never been possible....[The Ingenio] doesn't let us enter because they say that we are in favor of the workers. And the workers say that we are in favor of the Ingenio.” (Gerardo 2014)

Political tensions prevent Gerardo's research team from conducting studies inside of the Ingenio, which prevents scientific knowledge production about the disease. This potentially contributes to uncertainties surrounding the disease.

Another setting in which nonknowledge operates is in health care. Some interviewees told me that their health care providers in the Ingenio's hospital did not give

them their test results after their yearly tests and withheld medical information from patients (Valdivia 2014; Antonio 2014; Mario 2014). Mario told me he never received his level of creatinine or blood sugar at the Ingenio hospital. They gave the information directly to his supervisor, who would tell him if he could work or not (Mario 2014).

In sum, nonknowledge closes off spaces for debate by inhibiting knowledge production and the sharing of knowledge. As ISA states it is socially and environmentally responsible, it silences workers' voices by threatening their economic livelihoods. Similarly, the company praises its health care for workers as it withholds health care information from them. Nonknowledge, in this case, is essential to how power works within a context of scientific uncertainty about disease. It maintains structural violence and profits off of the status quo.

### Conclusion

I organized this section into three types of knowledge in order to explore the multiple dimensions of structural violence, scientific uncertainty, and power. By organizing my data in this way, I do not mean to suggest that these forms of knowledge are mutually exclusive. Experiential knowledge draws upon scientific accounts of disease. Science draws from the outcries of social movements and at times supports their calls for research. Scientific uncertainty allows actors like ISA to divert attention away from narratives of responsibility and structural violence that are common in the experiential knowledge of workers. As the Ingenio prevents some research teams from accessing the fields, it allows Boston University to conduct research that the sugarcane industry has partially funded. The Flor de Caña tour relied on creating a unique sensory

experience for tourists that was isolated from the realities of sugarcane production. Similarly, it prevents experiential and scientific knowledge from circulating. My next chapter will look at the role of La Isla Foundation, locating it at the intersection of experiential and scientific knowledge.

### **CHAPTER 3: LA ISLA FOUNDATION - “BE PART OF THE SOLUTION”**

Among all of the actors involved in addressing the CKD epidemic, I locate LIF at an intersection between experiential knowledge and scientific knowledge. LIF has many faces. To scientists it is an ally for research funding and support. To some community members it is an advocate against the practices of ISA and a bridge to speaking to the international community. To other community members it is a foreign organization creating unnecessary political controversy. To international volunteers it is an avenue through which they can “be part of the solution” to a devastating epidemic. Due to its multiple faces, LIF holds a controversial position among some local actors (e.g. the national government, the Ingenio, and ASOCHIVIDA) as it serves as a bridge between local and international actors. Organizations such as PAHO, the national government of El Salvador, and international NGOs such as Fairfood International have collaborated with La Isla Foundation in order to construct their own CKD-related interventions. While many NGOs around the world focus on charitable programs, LIF takes a broader approach that emphasizes human rights and labor exploitation. Its combination of biologically- and structurally-based responses to the CKD epidemic resists techniques of nonknowledge by the government and the Ingenio in various ways and puts it at risk of critique and censorship from powerful entities like the state and the Ingenio.

I will start by describing LIF’s programs. Then I will provide an analysis of its work towards knowledge production about CKD, highlighting its emphasis on urgent responses to the epidemic, despite scientific uncertainties. I will subsequently analyze its controversial position in the politics surrounding the CKD crisis.

La Isla Foundation prides itself upon its work in terms of “four pillars”. They recently added a fifth pillar to refer to their individual donors.

1. Public Health: “Facilitate research to identify the cause of the CKDnT epidemic in Western Nicaragua and implement necessary interventions to support affected workers and prevent future generations from becoming ill” (LIF 2012c).

Programs within this department include research on mortality statistics, research on barriers to health care with a recent focus on peritoneal dialysis, the provision of educational materials about scientific research on CKD for community members, and collaboration on scientific studies. They have partnerships with medical schools in the U.S. and often receive interns from those schools.

La Isla Foundation has collaborated on a variety of pivotal studies focusing on CKD. For example, they funded and/or supported the first community-wide prevalence study in Chichigalpa, a municipal prevalence study in León, additional prevalence studies (see Raines et al. 2014, Kurzrok et al. 2013), the first kidney biopsies, and a 3-year community cohort study. LIF staff has co-authored many studies as well, including a recent publication looking at the effects of dehydration and sugar consumption on the kidney function of rats (see Roncal et al. 2013). LIF collaborates on teams of researchers from a variety of institutions for these studies. Their major partners include UNAN-León (National Autonomous University of Nicaragua in León), Colorado University-Denver, Karolinska Institute in Sweden, and the Icahn School of Medicine at Mt. Sinai in New York, NY. LIF is also a member of the Consortium for the Epidemic of Nephropathy in Central America and Mexico (CENCAM), through which they have participated in regional conferences to share research and information on the disease.



A recent public health project has extended LIF's work to El Salvador. After finding a sugarcane mill willing to work with them, they launched a research project that would implement the Occupational Safety and Health Administration's (OSHA) "Water.Rest.Shade" recommendations among field workers. The OSHA guidelines are aimed at preventing heat stress and advise workers to take frequent breaks in shaded areas and drink water even when they are not thirsty. Break time and water consumption must increase as temperature goes up (OSHA n.d.). Additionally, this program seeks to increase worker efficiency through ergonomic techniques such as customized machetes based on individual workers' stature. As these changes are implemented in the fields in El Salvador, LIF's partners will monitor sugarcane cutters for health outcomes and productivity (LIF 2014c).

2. Human Rights and Law: "Document labor conditions and influence corporations and governmental policies to address this epidemic and ensure that such work-related epidemics do not occur in the future" (LIF 2012c)

The human rights department accepts interns with interest in law, issues statements against abuses by state police during protests (see ASDECOSI et al. 2014; LIF Legal Department 2013) and publishes extensive reports on human rights abuses related to labor in the sugarcane industry. These include "Sickly Sweet: Human Rights Conditions for Sugarcane Workers in Western Nicaragua" (Hutchison 2014) and "Cycle of Sickness: A Survey Report on Child Labor in the Nicaraguan Sugarcane Fields of Ingenio San Antonio" (LIF 2015).

3. Community Development: “Empower community members to take charge of their own health and rights through organization, education, and infrastructure development” (LIF 2014c).

This department focuses on community outreach, and their volunteers when I was there included both undergraduate students from the U.S. and Canada and volunteers from Chichigalpa. In a relatively recent project, they installed four deep water wells in communities in Chichigalpa, including La Isla, in response to communities’ fears about water contamination. Other projects assigned to volunteers in this department during my time there included teaching English classes to local adults and children at the Chichigalpa office, maintaining a community garden, and directing the biweekly “kids club,” an after-school program for children on La Isla.

Finally, this department has directed a variety of education programs for local community members. As an article on the LIF blog states, “Education alone may not be the solution to the CKDu epidemic in Guanacastal Sur, Nicaragua, but while the cause is still unknown, education is the best bet in keeping the next generation safe and healthy” (LIF 2013). LIF has sponsored tuition for local community members to take computation, English, welding, and beauty technician classes at a local government-run trade school, hoping to allow them to break out of the cycle of poverty that necessitates a job in the sugarcane industry.

4. Media and Communications: “Create a broad base of international support for an intervention that includes consumers, workers, and producers, by fostering media attention and creating original media content” (LIF 2012c).

LIF has launched successful media campaigns that draw attention to the devastating effects of CKD in Chichigalpa. With a documentary filmmaker as one of their co-directors, they are especially gifted at making YouTube videos, Instagram posts, and website material for the international public to view. Additionally, they receive visiting journalists and are mentioned in most of the major articles about the epidemic in international media.

5. Donors: “You are the forefront of ending the CKDnt epidemic. Be part of the solution.” (LIF 2012b)

On LIF’s website they ask potential donors to join their fifth pillar. While much of their money comes from grants, their development department asks individuals to donate to their work.

#### LIF, Scientific Uncertainty, and Urgency

All of LIF’s programs operate amidst scientific uncertainty about CKDnt’s exact biomedical causes. As I stated previously, science often looks to the past in order to find ways to prevent CKD in the future, while CKD-affected individuals and their family see CKD as an urgent issue that they are dealing with in the present. Taking these dynamics of time into account, I locate LIF between experiential and scientific knowledge. LIF certainly prioritizes scientific research and directs much of its funding and energy towards it. At the same time, however, they emphasize that CKD’s biomedical causes are not totally uncertain and that there are likely causes of CKD that can be addressed now. This urgency is expressed in a recent article on LIF’s website about why LIF and other researchers now call the disease CKDnt rather than CKDu. The article states, “Where the

‘unknown causes’ of CKDu inscribed a permanent sense of mysteriousness, ‘CKDnT’ acknowledges the positive findings of scientific research to date” (LIF 2014a). This name locates LIF between the local name for CKD, *creatinina*, and its scientific name-- between experiential certainty and scientific uncertainty.

LIF has focused primarily on two likely causes of CKDnt: heat stress and chronic dehydration. These are the focus of their intervention program in El Salvador and are widely mentioned in their online articles. A 2014 article published by LIF co-director Jason Glaser and director of public health Ilana Weiss states,

“In the research community, there is consensus that sugarcane workers are the most affected population in the most-studied countries, El Salvador and Nicaragua. Most researchers also agree that the epidemic’s cause is multifactorial and merits further investigation. In the interim, however, the evidence points towards workplace interventions that could prevent and/or slow onset and progression of the disease. This does not diminish the need or importance of further work into specific etiological components of CKDu, but ethically we are bound to save lives when and where we can. By making a workplace intervention a first step forward, we open the door to the collaboration needed to further understand and eventually end this epidemic.” (Glaser and Weiss 2014)

Through workplace interventions, LIF is locating itself in a middle ground between urgent community needs and scientific research. While they value the importance of future scientific discoveries, they look for certainties in research that has already been conducted in order to seek ways to address CKD urgently. Therefore, while their work adheres to the urgency of experience, it frames this urgency through science.

### Controversy and Structural Responses to CKD

While LIF focuses on funding scientific research, its work does not only revolve around internalized notions of biology. Rather, it emphasizes many of the structural causes of CKD, such as poverty, labor conditions, and human rights. LIF has assumed a critical approach to responses to CKD that are tied to the interests of the Ingenio San Antonio, to scientific research that receives funding from the sugarcane industry (Glaser and Weiss 2014), to scientific research that focuses on non-modifiable factors such as genetics (Glaser & Weiss 2015), and to state repression of CKD-based social movements (ASDECOSI et al. 2014). Because of its critical position, it faces opposition from many different angles. This approach sets LIF apart from international NGOs that are charity-based.

One example that highlights LIF's controversial position can be found in a variety of online blog posts allegedly authored by a member of ASOCHIVIDA (and/or a part of ISA's public relations sector as many workers' advocates believe) that are dedicated to critiquing LIF's US-born co-director Jason Glaser. ASOCHIVIDA spoke out publicly against Glaser on various blogs after he allegedly burst into one of their meetings in July of 2012. While it is not totally clear from the blogs what Jason said or who wrote the posts, it appears that he accused ASOCHIVIDA of corruption and being co-opted by the company. While some community members might support Jason's claims, it is evident that his presence as an international actor who is intervening in local affairs has caused controversy, at least among the writers of the blogs, the leaders of ASOCHIVIDA, and their supporters. Below are three quotes from the blog (which was posted in both English and Spanish online):

- “**Glaser takes advantage of the sick.** He films us in our sad agony in order to go out and get resources for his La Isla Foundation, and then uses those resources against us.”
- “**Glaser manipulates [sic] scientific reports.** He tells people that Boston University studies have no validity and that he is preparing studies that are valid. ASOCHIVIDA chose Boston University and relies on its work. We want them to work faster, but we believe in them and not in the studies of Glaser that only serve to keep misleading us.”
- “For all these reasons, ASOCHIVIDA denounces Jason Glaser and La Isla Foundation for interfering in the internal affairs of our organization, declares them unwelcome, and calls for their expulsion from the country and for the end of all their operations here. ASOCHIVIDA will not allow anyone to make us fight among ourselves and to arrogate the right to speak for us.” (Nicaragua Sugar y la IRC 2014)

While I cannot speak directly to what happened in this specific incident, these quotes highlight the tensions under which LIF works. It is clear that ASOCHIVIDA does indeed have close ties to the Ingenio San Antonio, as they are the distributors of the food stipends and other ISA benefits (LIF 2012a). Regardless of whether Jason Glaser was justified in his intervention, ASOCHIVIDA’s critical statements highlight how LIF’s structural approach challenges both working conditions in the sugarcane industry and charity-based responses to CKD. They also highlight the tensions that come with international NGO work, which I will discuss further later on.

More recent developments evidence how actors, this time state actors, have opposed the work of LIF. In January of 2015, Boston University published a study, which came from the research it conducted through the CAO process. This study tested workers' serum creatinine levels and estimated glomerular filtration (eGFR) rates before and after the harvest season, categorizing workers based on whether they were cane cutters, irrigators, seeders, seed cutters, drivers, or factory workers. It found that field workers' eGFR rates decreased during the harvest season, and that cane cutters experienced the sharpest decrease (Laws et al. 2015). As I mentioned above, the study produced the following conclusion:

“The decline in kidney function during the harvest and the differences by job category and employment duration provide evidence that one or more risk factors of CKD are occupational.” (Laws et al. 2015: 1)

This groundbreaking scientific development (which was not so groundbreaking in terms of experiential knowledge of links between labor and disease) was publicized on LIF's website and in the international media. International organizations seemed hopeful that this conclusion would finally implicate the Ingenio San Antonio more certainly in causing CKD.

Following the release of this study, Jason Glaser, who now lives in the United States, flew to Nicaragua on February 16, 2015 and was denied entry into the country. Immigration authorities in Nicaragua told him that this was due to an “official government order,” and he was sent back to the U.S (Fairfood International 2015). La Isla Foundation subsequently closed its doors and some international staff and volunteers

left the country. They hoped to reorganize and reopen, according to a conversation I had with co-director Juan Salgado (2015).

News reports on Jason's denial of entry posit that it is not a coincidence that this happened so shortly after the BU study was published and publicized (Fairfood International 2015). This incident is another example in which state techniques of nonknowledge stem from elite-state alliances, thereby illuminating controversies surrounding LIF's presence in Nicaragua. Despite a new biological discovery, CKD is clearly a structural and political phenomenon.

#### Conclusion: Structural Approaches and Research Limitations

As I have argued throughout this paper, a focus on biology alone can forestall rights claims. Linking biology to structural conditions can certainly enhance controversy, as shown in the case of the 2015 Boston University publication and subsequent denial of Jason Glaser's entry into Nicaragua. La Isla Foundation combines biological definitions of CKD with structural definitions as it acknowledges the legal, political, economic, and social roots of CKD. It attributes responsibility to ISA and the government while prioritizing urgent responses to a public health crisis. Combining biological and structural approaches to ending CKD allows LIF to serve as a bridge between scientists, local community members, and international organizations. At the same time, this approach often makes it a target of critique from multiple actors.

LIF's controversial position does not only originate from its critical approach; it also stems the gradients of power and privilege under which it operates. Its positionality among historical and political contexts leads some actors, including community groups



like ASOCHIVIDA and the government, to view its work with skepticism (Edgar 2014; Nicaragua Sugar y la IRC 2014). On a global level, international NGOs exist in a unique and controversial space, as they are often removed from the democratic structures of the state, and are culturally different due to the presence and leadership of international staff members (Ferguson & Gupta 2002). Different levels of privilege mean that within NGOs, there is much more at stake for local staff and volunteers than for international actors. For example, international volunteers working at LIF often spend money out of pocket to travel to Nicaragua, while local staff and volunteers might risk their own jobs or their families' jobs with ISA when they associate themselves with LIF's work and mission. In addition, when examining LIF in the context of historical interventions by international actors that have led to increased structural oppression (e.g. the 1912 San Blas massacre by the U.S. Marines in Chichigalpa [Gould 1990], U.S. training of the Contra fighters, IMF structural adjustment programs that exacerbate poverty [Nouvet 2014], Chinese developers who are currently displacing communities to build a canal through Nicaragua [Watts 2015]), it makes sense that LIF might be viewed with skepticism despite its good intentions. While I am certainly not saying that LIF's work is directly comparable to these violent interventions throughout Nicaragua's history, I believe that it is important to note the historical and political context under which LIF and other international NGOs operate. Structures of power, history, global positionality, and privilege interact to place LIF in a controversial space.

In this chapter, I have described LIF as a bridge between experiential and scientific knowledge and between local and international actors, noting how this informs their search for urgent interventions and how this enhances its controversial positionality.

Because I was an intern for LIF, these elements have also informed the ways in which I have carried out my research. While I praise LIF's urgent attention to the effects of structural violence, I find it important to mention what anthropologists Joao Biehl and Adriana Petryna have argued about international public health organizations. They note that as these organizations work quickly to save lives, they often become impervious to academic critique as they address urgent necessities such as saving lives (Biehl and Petryna 2013). On the other hand, writing critically about a controversy has the potential to add fuel to government- and Ingenio-based critiques of La Isla Foundation. Because academic critiques amid controversy can work against NGOs, I am leaving some of my critiques about La Isla Foundation and international NGO work out of this paper. This certainly limits my ethnographic approach to CKD and is a point that should be explored in further research.

## CHAPTER 4: CONCLUSION

In summary, the CKD crisis in Nicaragua involves multiple actors and multiple knowledge claims. Through the language and experience of illness, these actors articulate the ongoing suffering caused by poverty, human rights, and labor exploitation that are grounded in Nicaragua's history. Framing suffering in terms of disease opens up a variety of forms of knowledge production, which I have categorized as experiential knowledge, scientific knowledge, and nonknowledge. Varying forms of certainty, uncertainty, and denial circulate among actors involved in the CKD crisis.

Consistent with recent literature on biolegitimacy and biological citizenship, this health-based discourse has been successful in mobilizing scientists, researchers (including me), social movements, La Isla Foundation, and international volunteers around a common cause. However, there are limitations to framing labor exploitation and bodily suffering through disease due to its inevitable links with scientific knowledge production. In this way, my research diverges from much of the literature on health-based social movements that have largely focused on the positive associations between social movements and health.

When examining the CKD case in light of biopower literature, it is evident that biopower functions in different ways. On the one hand, it mobilizes local, national, and international actors around the concept of CKD through biolegitimacy. On the other hand, it individualizes disease, threatening to atomize individual actors to care for themselves or seek charitable handouts rather than to search for solutions to the many forces of structural violence that operate in Chichigalpa's sugarcane industry.

Through the exploration of experiential knowledge, scientific knowledge, nonknowledge, and their intersections, this paper has juxtaposed scientific uncertainties about CKD with experiential certainties that are linked to the embodiment of illness, labor, poverty, and human rights violations. Scientific uncertainty bolsters strategies of nonknowledge that tell the public that there is no “real” problem or that the problem is the individual workers rather than their social context. These mechanisms of knowledge fragmentation discount experiential knowledge as well as other forms of structural violence that have been historically more constant and widespread in the sugarcane industry over time: poverty, labor exploitation, human rights abuses, social exclusion, and other types of illness. While CKD may draw attention to these other forms of suffering, it also distracts from them when a great deal of energy is spent proving CKD scientifically. Furthermore, as Auyero and Swistun (2009) showed in their study, scientific uncertainty can be a factor in preventing organized resistance.

Given the authority of scientific knowledge, the widespread prevalence of CKD is legitimated through biomedical and epidemiological research. As a result, rights claims largely fail to hold traction when the Ingenio and the state construct their discourses and action (or inaction) upon the uncertainties of scientific knowledge and biology rather than the certainties of structural violence. As long as scientific uncertainty remains the dominant discourse about CKD, it will be difficult to implicate ISA and the state as responsible for the epidemic. Furthermore, this uncertainty will make it difficult to demand urgent responses, as it leads to a waiting game that expects communities to patiently hope for a future certainty. However, the urgency of the epidemic leaves little time for waiting.

Addressing CKD is no easy feat, as shown by the experiences of La Isla Foundation which recently found itself in its own battle against censorship when its US-based co-director was barred from entering Nicaragua. The ways in which CKD must be addressed requires a careful balancing act. However, my paper has argued that in this balancing act, actors must not be on an equal playing field (as they were in the ASOCHIVIDA-ISA negotiations through the CAO, for example). Instead, addressing CKD must prioritize experiential knowledge and structural solutions that challenge the power of scientific authority, the power of the state, and the power of the Ingenio San Antonio and/or the sugarcane industry.

Many programs have been successfully implemented towards this end. Social movements like ASNAAPIRC have called for direct assistance for workers at the same time that they call for company responsibility (LIF 2014b). La Isla Foundation has constructed a well in response to community demands, despite a lack of scientific proof that water contamination is a direct cause of CKD. At the same time, LIF and community members continue to connect water contamination to labor conditions (e.g. pesticides seeping into surrounding communities' water supply) and poverty (e.g. communities' inability afford to build wells on their own or move away from contaminated water sources due to economic hardship). These programs balance urgent community concerns with structural causes of disease, and do not fall into a long-term search for scientific proof. In this balancing act, embodied experiential knowledge, community demands, and structural solutions are prioritized over scientific authority and the elimination of controversy. Controversy and conflict are bound to happen in cases in which power is challenged and therefore should not be interpreted as failures in these cases.

Another way in which power must be challenged is through a critical examination of structures of power and privilege. At the most disparate level, we find billionaire Carlos Pellas juxtaposed with workers who cannot afford food without risking their lives in order to work in the sugarcane fields of the Pellas-owned Ingenio San Antonio. While it is unlikely that Pellas will challenge his own privilege and power in relation to his workers, it is possible for actors such as La Isla Foundation, scientific research groups, and even social movements to critically examine their own privileges and power, thereby allowing spaces for community voices from historically-oppressed groups to speak and be heard. Stepping back and stepping up at strategic moments is necessary to mount structural responses to the CKD epidemic. This, too, might play a part in finding a balance that encourages resistance rather than conformity.

When considering the differing forms of knowledge that are currently circulating around CKD in Nicaragua, there is a notable lack of scholarship in the social sciences. A great majority of the studies that I have found are from public health and biomedicine. Accordingly, this paper also calls for social science research that might look at CKD historically, economically, and politically rather than in a primarily biological sense. This is even more urgent as science remains uncertain about CKD. Due to CKD's structural roots, there is much more to explore surrounding CKD within the realms of social science.

Overall, every actor in the CKD crisis has their own source of situated knowledge and the convergence of these knowledges will create overlaps, divergences, conflicts, and controversies. I expect that my paper has prioritized and validated experiential knowledge, which, combined with a structural analysis and a self-critique of my own

place in hierarchies of power, may promote a comprehensive and radical approach to CKD in Nicaragua. I hope that my approach to understanding CKD adds to ongoing discussions and debates by opening up spaces for different ways of knowing.

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