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Buscando el Moro: A Constructivist Approach to Health Decision-Making in a Dominican Batey

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BUSCANDO EL MORO: A CONSTRUCTIVIST APPROACH TO HEALTH
DECISION-MAKING IN A DOMINICAN BATEY

By

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The field of public health has long sought to improve health and well-being.

Originally incorporating socially embedded views of health, the field of epidemiology

has largely abandoned this perspective in exchange for statistics-based approximations in

population health research. However, a new movement in public health has been gaining

momentum slowly that legitimizes other ways of approaching this research. In particular,

value has been placed on lived health experiences, and supporting both social justice and

community-based health research.

By challenging the epistemological grounds of traditional epidemiological

research, an argument is put forth for a constructivist epistemology in health research.

Simply put, researchers should view health within the context of the lived experience of

persons. Accordingly, health research should seek to interpret and understand the ways in

which people construct definitions about health and their decisions related to pursuing

care. Only through this interpretive understanding can relevant interventions be devised.

This theoretical argument is applied in a yearlong qualitative study of a

community in the Dominican Republic. The research goal is to understand the

construction of health and resultant health-relevant decision-making in the community.

The specific community is a former sugarcane plantation (*batey*) populated mostly by

people of Haitian descent. This community was chosen as the study site, in part, because

of the economic and social marginalization of these persons, in relation to the larger

Dominican society, largely due to contention between Haiti and the Dominican Republic.

The study is conducted from a phenomenological perspective that supports a

constructivist methodology. The motivation of the research is founded in a social justice

perspective and, as such, is informed by a community-based approach.

The analysis of interviews, contextualized by the researcher's participation in

community life, revealed ways in which experiences both inside and outside of the health

system influence how these persons construct their definitions of health and the

decisions made about appropriate care. Five main themes emerged that open a path for an

outsider to understand how persons make sense of their health and that of their families.

First, people define health in broad socioeconomic ways. Second, their immediate

worldview often becomes normalized, thereby obscuring other possibilities. Third,

limited resources shape the ways in which people make decisions regarding health.

Fourth, decisions that reflect the greater socioeconomic context carry meaning for their

daily lives and current situations. And finally, gender norms and expected roles were an

organizing influence in many person's lives in ways that affected their health.

These analytical findings led to several broader conclusions. Primarily, people

engage in an active epistemology and construct their definitions of health. This process

must be appreciated by planners who hope to achieve effective health interventions,

especially in marginalized communities. Holistic approaches must be employed because

a.) people conceive of their health broadly and b.) many aspects of life influence health

beyond what is considered traditionally to be relevant. Appropriate holistic approaches to

improving health can be developed only after their biographies vis-à-vis health are

understood. Accessing these narratives is a crucial point of entrée for health researchers, in order to enter the *lebenswelt* (life-world) of a community and develop appropriate health improvement projects.

ACKNOWLEDGEMENTS

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Chapter 1: Overview

Medical sociologists have an important role to play in health research that is often subsumed by professionals in other fields, such as epidemiology and medicine. The field of medical sociology is often seen as a "soft" approach to identifying and solving epidemiological problems and is looked down upon as being weak in scientific methodology, especially in light of epidemiology's increasing reliance on complex biostatistical models. This claim is even truer for qualitative health research which, in epidemiology, usually occupies a low rung on the research ladder. This point begs important questions: How is science defined? Is it appropriate to study human problems within the same definitional framework that researchers use to answer physical science questions? How does the research community construct an appropriate understanding of complex social and health issues?

These epistemological questions about how to define knowledge are engaged in this research by applying a qualitative approach to studying health in one community in the Dominican Republic. The study community is called Batey Algodón and is located in rural, southwestern Dominican Republic. *Bateyes* are communities that formed around sugarcane plantations starting in the 1950's (CIIR 2004; Grasmuck 1982). Sugar is still the country's largest agricultural product, and the communities that support this industry are characterized by extreme rural poverty, lack of education, tenuous citizenship, and high morbidity (CESDEM 2007). This study focuses on one *batey* in order to identify the causes of ill health and suggest solutions, in coordination with community members, which might alleviate common health problems and improve the quality of life in a sustainable way in this locale.

Epistemology in Health Research

This research offers a critique of decision-making models that predominate in health research in both epidemiology and medical sociology. The limited scope of rational choice health models (Vernberg 1998) is discussed vis-à-vis the underlying epistemology of this approach, and an argument is made to adopt a non-dualist approach and include the perceptions of people as inherently necessary for understanding barriers to health. The field of research on health and illness has been dominated by decision-making approaches that are dualist, in that they attempt to separate human perceptions from objective reality in order to identify factors that promote or hinder health (Wainwright and Forbes 2000). This approach is a result of attempting to replicate the success of the natural sciences by imitating the same methodologies and applying them to the social sciences. However, whereas in the natural sciences researchers deal with facts selected with a goal of fitting these data into the procedural rules of empiricism, social sciences are more complicated (Schutz 1953). Constructs in social sciences are "second degree," since social scientists create models of the constructs used by people as they function in their social worlds (Schutz 1953). This epistemological orientation has resulted in a body of research with the aim of eliminating interpretation, so that objective facts and natural laws may be uncovered. In this realist epistemology, interpretation and values are supposed to be eliminated through scientific and technical rigor, with the findings touted to be objective and reliable.

This kind of dualism in epidemiological and social research is problematic, because these health behavior models often miss crucial social and cultural factors that are relevant to the people making decisions about their health (Smith 1998). For

positivist social scientists, only knowledge that is separated from judgment is truthful, and the way to attain this information is through the implementation of technical tools that represent the scientific method (Murphy 1992). Examples of commonly used health models in this tradition include: the Health Behavior Model, the Theory of Reasoned Action/Planned Behavior Model, the Health Belief Model, Social Cognitive Theory, Self-Efficacy Models, and the Transtheoretical Model (Redding et al. 2000).

In effect, these models approach human decision-making as if people are statistical computing boxes that are constantly evaluating objective indices pertaining to health. Researchers work to refine these models by identifying "missing" variables to improve the accuracy of predictions, instead of seeking a true understanding. Assumed by these models is that the definitions of health are clear, and that the same factors influence people when they make decisions that relate to health. Some critics contend that the cost-benefit analysis at the root of these models is inappropriate, while others contend that the human mind cannot deal with large amounts of information. In the end, the point is that human decision-making is different from a mechanized process.

Traditional epidemiology approaches health in terms of objective risk factors that place people with specific demographic characteristics into different risk levels for contracting illness. However, this methodology overlooks how people construct actively the reality in which they live. The argument here is that people do not necessarily think of themselves as composites of risk factors, and quite often decisions and events that are not overtly about health influence how they think about their well-being. The traditional mechanistic approach to assessing health has limited the scope of possible health

interventions to those that can be neatly operationalized, thereby narrowing the knowledge base that can be used to design such correctives.

For example, attempts to address an increasingly female HIV epidemic around the world have focused on knowledge about disease transmission and the promotion of condom use. While necessary, these interventions by themselves ignore many important social factors that would make prevention more feasible for women, in particular. Examples of research that go into depth with participants show how researchers can more sincerely address deeper social issues within HIV research, for example, a woman's ability to insist on condom use (Pulerwitz, et al. 2002; Dunkle et al 2004), or whether women in high-risk sexual relationships have alternative ways of surviving economically if their current relationship fails (Parker, Easton and Klein 2000).

These brief examples from the area of HIV research demonstrate the need to understand the social context and meaning of decision-making regarding health, and the impact of social phenomena on health that are not traditionally thought of as health-relevant. In order to attain an informed understanding of how people make health-relevant decisions, researchers must move beyond the simple identification of risk factors and grasp how people interpret or construct meanings of things, events, and relationships. Only then will sustainable progress toward improving health be possible.

Realist input-output health interventions do not often explore *how* decisions are made by actors, along with the factors that are experientially relevant to them. The present research takes a constructivist view of health decisions and asks the question: What leads to health problems and health benefits in the community? Specifically, what are the *perceived* barriers to health? Instead of seeking structural or individual factors

that contribute to poor health, this research asks people about the barriers they assume they face when trying to achieve health for themselves and their families within the context of their community. In addition, many events happen in daily life that may or may not be considered in terms of their potential health impact, for example, the recreation space of children. Accordingly, in this research, the decision-making and perceived impediments that surround everyday decisions will also be analyzed.

What differentiates this perspective from Andersen's (1995) health behavior model, for example, who talks about perceived boundaries, is an important issue. That is, writers such as Andersen equate perception with what various experts assume are typical barriers to treatment. What actual community members believe is not the focus of attention. The community's world is thus overlooked. The strategy that is taken in this investigation, on the other hand, is in line with phenomenologists who argue that people, in addition to using the "facts" they have at their disposal about health, also use their beliefs, values, and commitments when making daily decisions (Murphy 1992). This is not to say that these phenomena (beliefs, values, and commitments) are "missing variables" in health behavior models, but that this human and interpretive context is both crucial and localized when seeking a true understanding of the decisions people make about themselves and their families.

The search for knowledge is not simply a technical issue of identifying all the correct input factors, but instead is an interpretive process that is located in the *lebenswelt*, or life-world, of any given individual or group (Husserl 1964). This research takes the position that the search for knowledge about health decisions must be made in this localized and interpretive context and focus on the *relevance* of information.

Therefore, the present research does not seek to modify the current health models, but instead rejects the epistemological background of these models, and turns to a constructivist framework whereby the researcher seeks to understand challenges to health by grasping how the daily lives of persons relate to health.

In order to contextualize appropriately health decision-making, and to understand individual decisions within the framework of social relations, this research calls for an idealist epistemology that presupposes that facts are interpretive, the mind is active, norms are based on agreement, and truth is socially manufactured. This shift requires an informed understanding of how people define their situation, and the possibilities and limitations that they perceive to this end. In addition to looking at traditional risk factors, this research seeks to enter the "life-world" of people in order to understand their "bounded rationality" and "intuitive rationality" vis-à-vis health decisions (Simon 1983).

As described by Simon (1983), bounded and intuitive rationality are, in short, cognitive shortcuts that allow people to make decisions by both parceling their world into smaller parts, and using intuition that is gained from past experiences to make decisions. In this regard, Weber argues that the subjective world is important, and that increasing rationalization or objectification of the world is dehumanizing and obscures the human element. Weber's methodology of *verstehen*, i.e., "to understand," emphasizes the need to enter *the sinnsuzammenhang* (webs of meaning) of research subjects to understand how they organize the world in which they live, and to appreciate that persons arrange the world in different ways, so that there is no such thing as one

objective reality (Weber 1971). Accordingly, Weber argues that the focus of sociological attention should be the "substantive rationality" that persons exhibit.

This research also draws on a phenomenological standpoint in which the "mundane reasoning," or contextual interpretation of rationality, must be grasped to derive accurate meaning about the behaviors and decisions that people make (Pollner 1987). As Schutz (1945; 1953) puts it, the world of daily life is created inter-subjectively through social relationships and communication that result in collective acts. The main goal of phenomenology is to understand the experiential world of another human being (Cohen 1995), or how these individuals experience the reality of their world, the "world within [their] reach" (Schutz 1945). A phenomenological approach is also interested in the myriad of future states of mind and reality and what people anticipate as possible for the future, or the "world within attainable reach" (Schutz 1945).

The driving epistemology behind phenomenology is non-dualistic, and thus views reality as experiential instead of solely mental or material (Omery and Mack 1995). This position is significantly different from the realist epistemology that drives much "scientific" reasoning, which has the goal of removing any subjectivity from the search for knowledge. Phenomenologists argue that knowledge cannot be separated from the knower and that truth is intertwined with the lived experience of persons or a community (Rogers 1983).

Community-Based Research

While understanding the community construction of health and illness, this research also seeks to connect the ongoing findings from the community to larger social

processes that may either undermine or enhance health. Critical community psychologists argue, for example, that community-level and macro-social determinants of health must be understood as related to each other, and that to isolate an understanding of health to the community can easily lead to a victim-blaming that ignores the ability of its members to become empowered vis-à-vis broader struggles for equality (Campbell and Murray 2004; Lavery et al. 2005). The present research seeks to offer an alternative to study health that differs from the traditional risk-factor epistemology and methodology that is dominant in the social and epidemiological sciences. This change is especially important in communities that have been historically marginalized, still suffer from poverty and inequality, and may exhibit a unique cultural outlook. In accordance with this goal, this research is driven by an epistemology that gives weight to the ways that people construct their reality, and what they view as problematic, and tries to interpret accurately the world through the voice of these persons. The members of a community, accordingly, participate directly in giving research guidance by serving as the focal point of reality construction.

The researcher, in the initial phase of gaining access to the community, found that residents of the research site indeed view that some of the constraints of their position are due to limited access to legal, health, economic, and political resources. These issues were brought up by residents in preliminary discussions about the major health and community issues they face. While trying not to create *a priori* assumptions, these are examples of ways that local community issues may link to broader social issues. Connecting the perspectives of community members about their health to so-called macro-structures does not mean that the view of the participants is subsumed under

larger social processes. Analysis of interviews and the participants' perspectives on these processes and institutions, which may have different levels of involvement and relevance to the community, will allow for the identification of starting places for potential change in the future. Nonetheless, while the larger institutions and processes may expand beyond the community, their identities are also socially constructed. The community, in other words, constructs how these organizations are viewed and the limits to their legitimacy.

This theoretical and epistemological approach to understanding health must drive any methodology that expects to gain access to the world constructed by persons. This claim is especially important to health decision-making, since intuitive and subtle interpretations influence the decisions that people make (Dreyfus and Dreyfus 1986). Strategies that are grounded in this epistemological tradition, such as phenomenology, grounded theory, and action research, are used to understand not just knowledge about disease transmission, but how people view their possibilities, impediments, and the likely success of a particular intervention.

Research Themes

This research has two main themes. One is a challenge to the traditional epidemiological approaches to health. The other is a more applied theme of having sociological research translate into benefits for the study population, as opposed to maintaining distance between research and social change.

The first theme is epistemological, with the goal of furthering the discourse on how to conduct meaningful health research to create sustainable change. By throwing out the rational choice health decision-making models, this study attempts to

understand the constellation of ways that people make direct and indirect health-related decisions for themselves and their families, especially within the context of limited material resources. A constructivist interpretation of knowledge is adopted by attempting to understand the contextual ways that individuals attain knowledge about health in their biographically determined social settings, where people structure the moments of their lives in different levels of clarity and precision based on their experiences and those around them (Schutz 1953; 1970). This research seeks to not only address directly decisions made about health, but day to day events and decisions that ultimately impact health.

The second main theme is one of applying community-based sociological methods and research to inform change in a marginalized population from a social justice standpoint, whereby research not only understands and describes the world, but also maps out ways to challenge inequalities and create alternative social relations that enhance health (Campbell and Murray 2004). Research in this field tends to draw heavily on Paolo Freiere's concepts of *praxis*, consciousness raising, and participatory research with the goal of liberation (Lavery, Smith, Esparza et al. 2005; Seng 1998). In this regard, including and valuing the ideas of the members of a community in health research has been shown to improve community health, in large part by directing control and power to those most affected (Leung, Yen, and Minkler 2004). Communities can both restrain and enhance health, but these groups are located in a broader context of social relations in which poverty, racism, gender inequalities, and other axes of stratification translate into vulnerabilities in individual lives (Campbell and Murray 2004; Link and Phelan 1995).

Even the sheer fact of being involved in identifying and elaborating health problems and solutions has been shown to improve health in communities (Wallerstein 1993; Campbell and Murray 2004). Accordingly, this research has a general orientation of engaging in research that enhances directly the lives of people. While giving primacy to the experiences of participants in this research, ultimately, these local factors will also be contextualized in the broader setting of inequalities, restrictions, and opportunities that, in the case of Haitian descendants in the Dominican Republic, has much to do with national and international inequality. In the end, health inequality is underpinned by social injustice and access to economic and political resources. Involving the affected community in research can raise a group's critical consciousness and lead to more successful and sustainable challenges to restraining social contexts (Campbell and Murray 2004).

Research Setting

Estimates of Haitian immigrants in residence in the Dominican Republic range from 200,000 to two million. The *batey* under study has been involved in prior research conducted by both national statistical entities (CESDEM 2007), and researchers from a Dominican hospital-based organization (Perez-Then 2009). Several studies have done rapid epidemiological assessments in *batey* communities (Brewer et al. 1998; Cohn et al. 2009; Collier, Cobb and Cortelyou 2011), but in order to take the next step to facilitate sustainable health improvements, this study takes a holistic approach and looks at broader aspects of life from a constructivist perspective to understand the world of the people who live in the *batey*.

Batey Algodón is a community of approximately 137 families located in the province of Barahona in the Dominican Republic. This *batey* formed around a sugar plantation that is still in operation, and still employs many male members of the community during the *zafra*, or harvest season. In Algodón there is high unemployment, and what work there is, is often temporal, day to day agricultural work. This type of work earns about 120 pesos (~$3.24 USD) for a half day of hard labor. Many residents, especially women, engage in informal work such as selling avocados, sweets, cheese, or other available produce and products alongside the highway.

Several homes in the community house multiple families, and there are some families who rely on community support for food and sustenance. Many adult residents of Batey Algodón do not have documentation to be in the country, which becomes a problem for their children. There is often a combination of a fear of authorities, a shortage of money to file for citizenship, a lack of general education, and a paucity of knowledge about one's legal rights. This situation has led to many of the children in Batey Algodón (many of whom do have rights to Dominican citizenship) never being registered in the country. This condition is important, because without documentation children cannot sit for the mandatory national exams that occur after the first year of secondary school. Therefore, many children from Batey Algodón are at risk for terminating their schooling after only elementary education.

The physical layout and location of Batey Algodón is described below in order to provide context, especially because location and the quality of living characteristics have a great impact on health. Batey Algodón is located along a highway about forty-five (45) minutes outside of the large provincial city of Barahona, and about four (4) hours driving

distance from Santo Domingo, the capital. This community is located between sugarcane fields and the highway, with an irrigation ditch running through the middle that contains large amounts of garbage and likely runoff pesticides from the fields. There is a footpath that leads through the sugarcane fields to a town called Fundación where there is a rural public health clinic.

Houses are largely constructed out of wood and sheets of metal, although a few are made of poured concrete and cement blocks. Common to the Dominican Republic, the houses are not sealed and those made of wood are especially permeable to both the elements (rain, dust, airborne contaminants, vehicle emissions) and rodents and insects (mosquitoes, cockroaches, rats, mice). Roofs are almost all made of corrugated zinc. Many of the houses in the community are shared structures that people have built onto houses by using existing walls, with these additions made of scrap material varying from wood, metal, cardboard, and burlap bags.

There are no paved roads in the community and the main dirt road through Batey Algodón is also where children play barefoot among puddles and litter. Many people cook in front of their houses over open fires, because they do not have gas stoves, or cannot afford to refill the gas tanks to their stoves. A few households have motorcycles at their disposal.

In Batey Algodón there are some communal structures of note. First, there are two churches, one of which is quite large and sturdy, and is inhabited by members of the community when there is a hurricane or other impending natural disaster that is not severe enough to warrant fleeing to Barahona. The floor of this church is slightly raised, so although water has entered during extreme flooding, for most storms this shelter is

safe. There are also about 35 latrines that were built in the community by a US-based non-profit organization called Foundation for Peace. Prior to the building of these latrines, residents urinated where they could, and used the cover of the sugarcane for privacy to defecate. However, as revealed during interviews, these latrines have not had the intended impact as many residents complain of their locations being too close to their houses. There is also a newly built six (6) room school that was also erected with funding and assistance from Foundation for Peace. Located on the school property is a kitchen where government provided meals are cooked daily for all school children.

Methodology

There are two general approaches to sociological methodology, and the epistemology that guides each is distinct. Driven by a realist epistemology, the methodological position of the *naturwissenschaften* seeks to reflect a supposed objective reality (Ermarth 1978). The purpose of such a methodology is to classify accurately events, focus on technical aspects of data collection, emphasize objective information, eliminate biases, and quantify as much as possible all research practices. In the end, the thrust of *naturwissenschaften* is to remove any human interference and reveal an objective world.

The other methodological approach, and the one used in the present research, is associated with the *geisteswissenschaften*, which is in line with an epistemology that rejects Cartesian dualism (Makkreel 1975). The goal of this approach is not to distil away the human element, but to interpret appropriately the world and events in light of the existential condition of persons (Ermarth 1978; Dilthey 1988). The goal of a *geisteswissenschaften* approach, accordingly, is to be socially sensitive and develop

culturally relevant constructs. As Habermas (1984) contends, the task is to be "communicatively competent", as opposed to technically efficient, as a researcher. Through communicative competence, a researcher can enter the life-world and understand the relevant meanings and negotiations of persons.

Consistent with an idealist epistemology and a *geisteswissenschaften* methodology are tools from qualitative research. In addition to the work of Weber and phenomenology, this research has also been influenced by grounded theory and action research. The source of knowledge in this research is the experience of people as they interpret their realities (Omery and Mack 1995). Additionally, grounded theory and action research supply a theoretical context where interaction is expected and knowledge is accumulated through this activity. Generally, qualitative methods include techniques such as focus groups, interviews, observation, participant observation, and content analysis (Singleton and Straits 2005). Guidelines from grounded theory inform the data collection and analysis of this project while using observations and interviews. In this way, the aim of grounded theory is to allow data to guide the analysis and conclusions in an interpretive way, while recognizing that researchers bring their own assumptions and worldviews into the analysis (Glaser and Strauss 1967).

Throughout the data collection process, interpretations from previous interviews and participant observations were used to develop an open-ended interview schedule and inquire further about processes and issues that were revealed to the researcher (Charmaz 2006). Blumer (1969), for example, referred to this strategy as indicative of a "sensitizing methodology". This method is meant to allow for flexibility and growth as the research continues based on the experiential knowledge of the participants (Blumer

1969; Esposito and Murphy 1999). The use of participant observation is in line with an idealist epistemology, in particular because a.) the social context is of great import to the study of health and b.) the researcher is not local. That is, the research context is a population with which the researcher was only somewhat familiar. In order to understand the social situation more fully, the researcher engaged in social activity in the community, while reflecting on the dynamics of being both a member and an outsider to the community (Spradley 1980). Because this research was also informed by community-based action research, the idea was taken seriously that the people who are affected by an issue should be involved in the research into this situation and any resolution of problems (Stringer 2007).

Goals of Research

The overarching goal of this investigation is to build a ground-up framework of health-related decision making that is cognizant of how persons contextualize their social setting. Often the instrumentality of people is overlooked by health researchers. Since the present research seeks to address this issue, this study design takes a phenomenological approach and attempts to understand how people define health and illness, health information, interpret these data within their situation, and make decisions in accordance with their own worldview. From this standpoint, the situation of individuals within their social contexts is of utmost importance and is why this study takes a community-based approach to viewing and gathering knowledge.

Driven by the theory and methodological strategy described above, this research was undertaken through qualitative interviews and observations. The qualitative methodology is consistent with the general research question that seeks to

understand how people make decisions that have an impact on their health and that of their families (Lincoln 1992). This methodology facilitates entrée into the framework that people use to make decisions and interpret the world (Charmaz 2006).

This project seeks to employ a ground-up collaborative methodology that looks at health decision-making, while contributing to advances in medical sociology and epidemiology that can improve the ways in which health and illness are studied and interventions are designed. Despite the advances of modern medicine and epidemiology, adherence to treatment and preventive practices for many common illnesses are lacking. Through the lens of a constructivist framework that seeks to understand health-relevant decisions at varying levels of analysis, the idea is that novel insight can be gained into how, for example, persons understand illness, seek treatment, and evaluate interventions. The orienting research themes guiding this research are as follow:

Understand the health problems from the perspective of the community.

Understand the practices that the community believes lead to health problems.

Understand how people perceive impediments to achieving health.

Understand how persons in the *batey* construct practices to protect their health.

Identify how community members define adequate interventions and acceptable outcomes.

Contribution of the Research

The objective of this dissertation is to provide a strong theoretical critique of traditional epidemiology while laying out a theoretical and methodological solution to address these criticisms. Additionally, the goal is to apply this methodology to a

community in which this type of epidemiological health assessment has not been applied. The community is a *batey* in southwestern Dominican Republic whose residents have many health problems and social issues. The goal of the in-depth assessment of health problems is to capture elements that are out of the regular purview of epidemiological research, in addition to understanding the community health issues from the perspective of people who are living in the community. This approach to health research has not been applied to this particular community, or to other *batey* communities in the Dominican Republic. Epidemiological and social assessments have been done, but rarely using in-depth qualitative data to inform practices. This research addresses interventions at different levels from technical construction to identifying the social changes that could improve health outcomes of *batey* residents.

Organization of the Dissertation

The dissertation has six chapters including this Overview. The remainder of the dissertation is described below:

The focus of *Chapter Two* is to both review and critique traditional epidemiological approaches to health problems. This task includes a critique of the realist epistemology that is habitually taken for granted in quantitative medical sociology health models. In particular, the dualism that is inherent in these approaches is analyzed to reveal the theoretical assumptions behind the scientific methodology often used in health research. This tendency is problematic, because these health-behavior models often miss crucial social and cultural factors that are relevant to the people making decisions about their health (Smith 1998). This critique goes further than the simple inclusion of social and cultural factors into models, but moves from the model-building

paradigm to a different perspective based on a constructivist epistemology. The risk of not making this maneuver is that health researchers narrow the knowledge base that can be used to design correctives.

In *Chapter Three* community-based research is discussed in conjunction with key theoretical influences. In this regard, the methodological focus of this in-depth understanding draws on the interpretive work of entering the life-world of research participants. The goal is to tease out how people try to make their lives meaningful. Instead of attempting to separate objectivity from subjectivity, the focus of this non-dualist approach is to embrace the fact that these elements are united inextricably in the lived reality of people. Instead of identifying risk factors for disease, for example, the idea is to understand how people navigate their lived reality and pursue health-relevant behaviors and care seeking.

Chapter Four provides a thorough description of the research setting, the role of the collaborating local organization, human subject research institutional review board processes, and the interview schedule. This chapter also contains a description of the methodological approach that is employed in the study. In-depth interviews with community members, and participant observation by the researcher, are employed to understand how people view health in the community of Batey Algodon.

Chapter Five discusses the findings from the research that were discovered through analysis of the interview transcripts and field notes described in the previous chapter. This chapter is organized by main themes that are relevant to health in the *batey*.

Chapter Six discusses the findings and draws linkages to larger social processes that help and hinder the way that community members engage with their health.

Discussion focuses on lessons learned as to how epistemology influences health research. Particular emphasis is placed on how planners can access relevant knowledge through understanding the biographical narratives of community members.

Conclusion

In sum, this study attempts to employ an interpretive methodology to understand how people construct their health and illness experiences. The point is to understand how people, in an impoverished and overlooked community, experience health and health care. This study is viewed as a first step of information collection that can later inform health interventions, and provide support to the community as they seek improvements in their own community.

Chapter 2: Traditional Health Research

Traditional Public Health

Epidemiology is the study of population health. This work is most commonly done by empirical assessments of populations, in order to identify risk factors and calculate the odds that persons with certain characteristics will contract a disease. Medical sociologists and epidemiologists use the concept of risk factors to identify characteristics of a sample and link these to incidence or prevalence rates of disease through a pathway of intermediary behaviors and exposures to certain conditions. For example, race, socioeconomic status, and behavioral variables such as smoking, alcohol use, and exercise are correlated with disease outcomes, while using increasingly sophisticated mathematical models to calculate the odds that a person with certain attributes has of acquiring a pathogen.

Risk factors are used, in part, because they provide fast and simple answers to guide public health policy. On the other hand, these attributes can be considered proxies for other characteristics that actually have a deeper meaning for a person or group. For example, the variable *race* is often used as a proxy to understand both ancestral bio-geographical characteristics for disease susceptibility and the psycho-social meaning and resultant physiological effects of being a member of a given race (Kittles and Weiss 2003). Unfortunately, in most epidemiological and even most medical sociological studies, these deeper meanings are often not teased out or even analyzed theoretically, and thus only cursory explanations are provided of meaningful characteristics. This issue is problematic because without this sociological lens, readers can conclude that any outcomes for different groups are based on immutable biological characteristics. In fact,

in traditional epidemiology, people are categorized according to social, demographic, or behavioral traits. This treatment of actors can easily lead to a misrepresentation of a given community. In other words, a profile established on these characteristics may be simply inaccurate.

More and more, epidemiologists and others who work in the area of public health have broadened the scope of their assessments, and these advances should be commended. One of the major organizing concepts within modern epidemiology is that of the epidemiological triad (Page, Cole and Timmreck 1995). The epidemiological triad places agent, host, and environment each at the apex of a triangle. This conceptualization of what epidemiology covers demonstrates a high level of flexibility and holism, but studies are often relatively shallow. And while this research may include context variables, how these factors are interpreted is not the focus of attention. For example, the concept of a community is not well thought out and defined clearly in most studies. Ideally, the concepts in the triad would be explored thoroughly, but this rarely happens, especially in quantitative studies. Most often, several convenient contextual variables are highlighted but rarely elaborated.

Public health is still heavily burdened by the influence of a biomedical model of health due to the historical context of the discipline. The science behind public health, or epidemiology, formed in the 19th century, and focuses on population characteristics and group comparisons (Morabia 2007). The focus of public health has been on infectious diseases, and largely took the form of environmental and sanitation improvements. In this regard, the famous Broad Street cholera study by John Snow is often cited as the first study in modern epidemiology. In 1854, there was a cholera outbreak in London before

the cholera pathogen and disease mechanisms were understood. Snow, a physician, first drew a map of the city and marked where disease cases were located. As a result of interviews, he then came to understand that cholera was being transmitted through two of the city's public water pumps. Famously, he removed the handles from these pumps, thereby curbing the epidemic. Although Snow suggested that the epidemic was actually ending naturally at the time of the handle removal, he is often identified with modern epidemiology and a number of sanitation and public health reforms.

At its inception as a discipline, epidemiology sought to address the spread of infectious diseases, because that was the major health problem at the time. Today's standard epidemiological methods are focused not on theoretical premises or even advances, but on improving study and statistical designs (Saracci 2007; Morabia 2007). Generally, epidemiological research focuses on improving clinical trial approximation through the use of increasingly complex mathematical models of health problems. Often critics claim that this methodology is inappropriate for a field that is supposed to be as much about humans in their environmental context as about pathogens and disease. Nonetheless, the discipline of epidemiology has succeeded in many ways by focusing on disease vectors and their causal pathways (Agar 2003).

When epidemiology was a nascent discipline, the world of human disease was different from the current situation. Nowadays, epidemiology and public health focus much more on chronic diseases. This switch from infectious to chronic diseases is called the "epidemiological transition", and in the developed countries is related to the technological revolution and the demographic transition, whereby life expectancy increases and, in turn, fertility decreases (Omran 1971). Omran proposed different

models and time frames to conceptualize this transition, but the crux of the argument is that countries and regions progress through various stages that exhibit distinctive characteristics and population health burdens (Omran 1971).

In "developed" countries that have undergone this transition, the focus of epidemiology has moved to individual level behavioral changes. In places that have not undergone this shift, there is still a heavy emphasis on infectious diseases. But gradually this individualistic approach has begun to emerge also in the "developing" world. The problem is that this individual level strategy often gives rise to victim-blaming, whereby collective issues are ignored, even if this is not the intent. There are exceptions to this general trend and the definitional boundaries between infectious and chronic diseases are not always clear. With pharmacologic advancements some diseases are both infectious and chronic, such as HIV/AIDS, which may not be "curable" but are no longer immediately fatal and can certainly be managed for long periods of time.

Another grey area in the epidemiological transition is that the world is now witnessing the resurgence of diseases that were historically under control, for example, the ongoing outbreak of cholera in Haiti and the Dominican Republic and the resurgence of polio in central Africa and southeast Asia. Additionally, previously treatable infectious diseases are reemerging in new forms, such as Multi Drug Resistant Tuberculosis (MDR-TB), Extreme Drug Resistant Tuberculosis (XDR-TB), and, in a few countries like India and Iran, Totally Drug Resistant Tuberculosis (TDR-TB) (McKenna 2012). Many places, such as the location of the present research in a rural developing country, are characterized by the presence of both infectious and chronic diseases. In short, the

modern epidemiological world is a complicated place, where these traditional

classifications and strict definitions are no longer simple.

Because quantitative indicators seem straightforward and manageable as a starting

point, policy makers often rely on such studies to inform interventions. While this

strategy can be useful, especially for a rapid assessment, these studies may not capture

the reality of the people who will be affected by such programs. As a result, many of the

projects are irrelevant and, in some cases, harmful.

Epistemology and Traditional Epidemiology

A major philosophical influence at the time epidemiology emerged, and still today

in most sciences, was René Descartes who argued that the way to truth is to separate the

subjective (mind) from the objective (body). This Cartesian dualism is the epistemology

that sustains the scientific method and led to the use of the experimental design as the

gold standard for clinical medicine. Simply stated, dualism is a central principal in the

development of epidemiology.

As a consequence of dualism, the study of human illness became viewed as a

natural (objective) science, in which the mind (subjectivity) had no part (Winkelman

2009). As a result, the biomedical model began to permeate the field of epidemiology.

Associated with this model are five (5) key characteristics. The first is a way of knowing

that is *dualistic*, whereby the goal is to separate and isolate objective factors from those

that are merely perceived. Second, the body is envisioned to be a machine that is either

functioning correctly or incorrectly, mechanically speaking. Together with this

mechanical characterization of the human body is the value placed on *reductionism*. That

is, researchers seek explanations at the smallest bacteriological/ viral/ mechanical levels

of dysfunction in the human body (Weitz 2004). The last two characteristics support the epidemiological search for unique causal agents. The overriding ontological characteristic of the biomedical model is that knowledge is generated through observation and experimentation, and verified through an *empirical* test. And last, the biomedical model is *interventionist* with the goal of fixing whatever components are wrong with the body (Weitz 2004). The predominance of the biomedical model is based on epistemological assumptions that were heavily influenced both by Louis Pasteur's work in germ theory in the mid 1800's and bacteriology that gained momentum with Robert Koch's breakthroughs particularly in the late 1800's.

Koch is the bacteriologist who first isolated the pathogens that led to anthrax acute disease, tuberculosis, and cholera (Gradmann 2009). At the time, understanding the causal bacterial agents behind diseases was a huge advance due to the magnitude of impact these diseases wreaked on society. As a result, the prestige of bacteriology grew and greatly influenced other areas of medicine including epidemiology. In the early 1900's bacteriology was prestigious, but clinically distant since bacteriologists such as Koch studied pathogens in petri dishes rather than human bodies. The goal of bacteriology, however, was to link the disease vectors to the human hosts. During Koch's time of great scientific advancements, physicians viewed bacteriology as the way of improving health and believed that focusing on bacteria was the correct path to cure disease (Gradmann 2009). This belief is still dominant today, and bacteriology's reductionism and isolationism permeates both medical practice and the field of epidemiology, in the search for one unique causal agent.

Hence, epidemiology has the methodological goal of refining experimental designs through the use of sophisticated statistical models. But the question remains whether this method is the best way to understand the intersection of pathogens and the human context. In other words, epidemiologists are supposed to study disease in the human context, not merely the biological mechanisms of pathogens. In this regard, experiments create a very strict situation with minimal variety. This process limits severely what is considered relevant to studies in health. Nonetheless, the assumption is that general laws can be found through these restricted cases, and further assumes that these laws are similar to those found in physics (Winograd and Flores 1986). This elevation of experimental design, especially in relation to something as tentative as human decision-making, may be too reductionist to generate meaningful insights.

A dualist ontology assumes that people inhabit a "real world" made of objects with properties that exist outside of interpretation (Murphy and Choi 1997). This ontology supports today's society and generally reinforces a rationalist tradition that emphasizes the rules and processes that are assumed by society to be logical (Winograd and Flores 1986). The dualism that has invaded the social sciences and epidemiology is due, in large part, to the prestige of the natural sciences. The social sciences, in an attempt to be seen as legitimate, have tended to mimic the natural sciences. In doing so, the social sciences may not be acquiring knowledge that is relevant to actual human beings. Using the language of science, and deriving meaning from realist perspectives and methodologies, may be leading to a body of knowledge that is invalid for the study of human health and decision-making.

Attempting to distil objective facts from the whole of the lived experience is counter-productive to the study of human behavior. In addition, this narrow focus on specific definitions of rationality limits the questions, theories, and methodologies that can be employed by researchers (Winograd and Flores 1986). This strategy is the result of applying the same scientific principles, tools, and realist epistemology from the natural sciences to social processes and human behavior, in an effort to be viewed as value-free and scientific. Nonetheless, the dualist epistemology that dominates in epidemiology and medical sociology can obscure the real actors and the way they think about health. In fact, dualism in epidemiology has the goal of separating the mind from the body to identify "objective" risk factors.

But this dualism has been criticized in light of more modern philosophical ideas. Indeed, many scholars argue that the study of human beings and their social worlds should not mimic the natural sciences. Instead of separating the world into objective facts and subjective perceptions, philosophers such as phenomenologists, for example, understand that separating the human element from "facts" is neither possible nor desirable because the act of knowing always involves the knower (Schutz 1967). In other words, facts are always entrenched in some perspective. In this regard, the classic epidemiological triad that seeks to understand health in terms of agent-environment-host demonstrates that the goal of epidemiology is to understand disease in the human context (Page et al. 1995). But by embracing a realist epistemology, the context revealed by this triad is obscured or reified, as a result of eschewing interpretation.

Critical Overview

Critics of realism argue that the social sciences are more complicated than the natural sciences. Specifically noteworthy is that constructs in the social sciences are "second degree," or models of the concepts that are used by people as they function in their social worlds (Schutz 1953). Due to the realist epistemological orientation that is dominant in epidemiology, these abstractions are thought to be more valid (meaning that a research measurement is capturing the concept that it is intended to be measuring) than the recipes persons use to make sense of their lives. However, this method may not be appropriate to conceptualize how they think about their health or any other issue. Valid concepts, in other words, may be more closely tied to the strategies persons use to interpret events (Berger and Luckmann 1966).

Traditionally, epidemiology evaluates health by grouping people by specific demographic or behavioral characteristics into groups, in order to predict their propensity for contracting a disease. A development within epidemiology called the "new public health" is an attempt to refocus these efforts, and include community input in evaluations of health and the planning of interventions (Frenk 1993). However, the dominant epidemiological methodologies overlook how people actively construct the reality in which they live. The point is that people do not necessarily think of themselves as composites of risk factors, and quite often, decisions and events that are not overtly about health influence how they think about their well-being. Furthermore, the imagery used in risk factor modeling does not coincide with how people think of themselves and their health (Raphael 2003). As a result, the traditional approach to assessing health has

limited the scope of health assessments to variables that can be neatly circumscribed and introduced into predictive models.

But this orientation is problematic, because these health behavior models often miss crucial social and cultural factors that are relevant to the people who are making decisions about their health (Smith 1998). For positivists, only knowledge that is separated from judgment is truthful, and the way to attain this knowledge is by equating reliable and valid information with technical operations (Murphy 1992). By seeking to operationalize neatly the factors that persons consider when making decisions regarding their health, researchers lose sight of the context or the web of meaning surrounding health relevant phenomena. While there is a place for these types of studies in epidemiology and social science, the first step to any meaningful understanding of health phenomena should not be the obfuscation of the human element.

To be able to understand a phenomenon and create valid constructs that truly represent a group of people, researchers must be comfortable with getting close to the data. Having data that do not fit easily into categorical variables should be valued in research, especially when first investigating a health issue or health behavior in a previously under-studied social or environmental context (Quimby 2006). In order to attain an informed understanding of how people make health-relevant decisions, accordingly, researchers must move beyond the simple identification of risk factors and grasp how people interpret or construct meanings of things, events, and relationships. In a new environment, knowing these issues may be particularly important.

Much of the crossover from epidemiological to sociological approaches to public health have focused on creating models that attempt to take into account variables that are beyond the traditional scope of epidemiology. Some of these efforts have focused on neighborhood disorder (Ross and Mirowski 2001; Browning and Cagney 2003; Hill, Ross and Angel 2005), cultural traits (Lee, Sobal and Frongillo 2000; Abraído-Lanza, Chao and Florez 2005), inequality (Subramanian and Kawachi 2003), and the resulting health outcomes. These studies are not without merit, but usually do not do an adequate job of seeking in-depth information and so they remain inherently dualist. For example, much of this information is attained through questionnaires or through analysis of medical records. These types of studies are prevalent in both epidemiology and medical sociology and work toward the goal of developing path models based on rational choice decisions (Winograd and Flores 1986).

Rational choice theory has been adopted by many disciplines, and has become widely used in sociology to explain a wide range of behavior. Rational choice theory focuses on the cost-benefit analyses that actors purportedly make when deciding to take certain actions or non-actions (Boudon 1998). Most important at this juncture is that rational choice theory underlies many of the behaviorally-based models applied to public health problems, and assumes that people make decisions designed to maximize health outcomes. Uncovering and recognizing this epistemological influence is incredibly important, especially since research shows that the human mind often does not necessarily work "rationally" (Boudon 1998). That is, persons seem to make relevant decisions that vary along a continuum, instead of pursuing an idealized logic.

Epidemiology and Medical Sociology are rife with models that attempt to describe the decision-making of persons with respect to their health. These models are all within the rational choice paradigm and attempt to create formulae designed to predict expected behavioral or disease outcomes. But sometimes a person simply does not have the means to act, let alone the luxury to make an informed decision. Examples of commonly used health behavior models in this tradition include: the Theory of Reasoned Action/ Planned Behavior Model, the Health Belief Model, Social Cognitive Theory, Self- Efficacy Models, the Transtheoretical Model, and the Health Behavior Model. Because these approaches are so pervasive in social scientific health research, they will be summarized briefly. These models can be described as follows:

(a) The *Health Belief Model* is widely used in medical sociology and is a social psychological model of reasoned behavior. The Health Belief Model originated in the 1950's to help explain the limited success of many health programs aimed at early detection and prevention of illness, and was later expanded on to include preventive actions towards illness in general (Rosenstock, Stretcher and Becker 1994; Strecher and Rosenstock 1997). According to this model, people change their risk taking behaviors when they perceive that their susceptibility to infection is high, or when the consequences of illness are severe (Rosenstock, Strecher and Becker 1994). The Health Belief Model uses the concept of *self-efficacy* as a mediating variable between socio-demographic variables and behavior change outcomes (Redding et al. 2000).

(b) The *Theory of Reasoned Action/ Planned Behavior Model* is a widely used but simplistic rational choice health model that looks at whether people have the intention to change health behaviors. The Theory of Reasoned Action proposes that people calculate the cost of changing an unhealthy behavior with respect to the health benefits of engaging in other activities (Montaño and Kasprzyk 2008; Redding et al. 2000).

(c) *Social Cognitive Theory* views health-related actions as an interaction between the individual, the environment, and behaviors that are learned responses to stimuli. This theory also relies heavily on the concept of self-efficacy and whether a person has confidence to carry out behavior change (Bandura, 1986; 1990).

(d) The *Transtheoretical Model* is another individually based model that views behavior change as a series of steps in a process. Interestingly, this model has been implemented largely by using computer models that apply algorithms based on the supposed reasoning patterns of human experts (Prochaska and Velicer 1997; Redding et al. 2000).

(e) The *Health Behavior Model* (1995), based on the work of Andersen, attempts to explain or predict the use of health services, and evolved over time to incorporate eventually social-psychological characteristics at varying levels of analysis, including perceived health status. This model is touted to include perceived pathways to treatment, but these assessments reflect mostly the judgment of experts with respect to how resources should be utilized.

These models range from simplistic to complicated and include varying levels of contextual variables. The problem is that they all rely on the assumption

that human thought and behavior follow a set of predictable rules. Some of these researchers, such as Andersen, who include contextual information, such as barriers to treatment, tend to reify the researchers' definitions and assumptions in terms of identifying these obstacles. What actual community members believe is not the focus of attention. The community's world is thus overlooked.

These types of realist models, which attempt to map human cognition and decision-making, are inaccurate representations of the human mind. In reality, this mechanistic view of the human mind is based on only one of many philosophies regarding human decision-making, but has been oft promoted and supported by work in artificial intelligence. Many critics argue, however, that the human mind is not as simplistic as a computer.

The core of these health decision-making models is based on the way that computers use 0's and 1's to "make decisions". This assumption is risky when applied to the human thought process, because of the reliance on binary rules, with binary sub-rules that finally culminate in a discrete answer. But experts such as Dreyfus and Dreyfus (1986) argue that the human mind is not like a computer, and therefore having a mechanistic view of the human thought process is oversimplified. Indeed, extensive experimental evidence supports their arguments that human beings, and especially human experts, do not think like computers.

One trait that distinguishes the human mind from computers is called *intuitive intelligence*, which informs the decision-making of experts. As a result, computers cannot achieve expertise beyond the level of an advanced beginner because human experts act a-rationally, use judgment, intuition, make inferences,

and are flexible (Dreyfus and Dreyfus 1986). Simply put, human thinking is much more complex than computers, especially at expert levels. But with the value placed on formal logic as a defense for decisions, computer simulations in the social sciences are often not only inappropriate, but actually threaten to eliminate the human elements of wisdom and cognitive complexity.

Even within the philosophical area of phenomenology, theorists have developed differing ways of conceptualizing the human mind. Edmund Husserl, the originator behind the information processing model of the mind saw the human mind as analogous to that of a computer in his early works (Smith and Smith 1995). On the other hand, Heidegger was influenced early on by his professor, Husserl, and understood that people follow rules and logic, *but* that this process is embedded in a deep cultural learning that influences decision-making. (Dreyfus and Dreyfus 1986). While going further, Merleau-Ponty argued that human thought does not follow rules, but that through perception, reality is constructed step-by-step (Dreyfus and Dreyfus 1986; Matthews 2002).

Nonetheless, traditional models approach human decision-making as if people are statistical computing boxes that are constantly evaluating objective indices pertaining to health. All of these strategies attempt to understand how people make decisions by replicating a progressive series of binary answers. The limited scope of rational choice health models is a direct outcome of the underlying realist epistemology of this approach (Vernberg 1998). As researchers work to refine these models, they often seek to identify "missing" variables to understand how to better predict human decisions. But these models assume that the parameters of choosing health are clear, like the rules of a game

(Murphy 1992), and that identical factors influence, although perhaps with different weighting depending on socio-demographic characteristics, the computations of people when they make decisions about their health or seeking treatment.

For theorists who argue that human behavior is predictable, in the manner presupposed by health behavior models, a common critique hinges on the argument that humans are simply cognitively insufficient. That is, these theorists do not reject the notion that decisions reflect a cost-benefit analysis, but contend that people do not have either a.) all the necessary information or b.) the cognitive capacity to compute all the input at hand (Etzioni 1988). Supporting this orientation is the commonsense assumption that the world is dualistic, and that persons must strive to comprehend this reality.

Consistent with this approach to decision-making, behavioral analyses have tended to be a main focus in risk factor oriented research in both epidemiology and sociology. Specifically, researchers operationalize variables in order to isolate certain aspects of behavior or the environment (Riffenburgh 2006). But this rational choice modeling approach to health overlooks how people actively construct the reality in which they live. For example, comparing studies of condom use based on a rational choice health model versus a more holistic approach provides a useful demonstration of the reductionism in these studies.

As HIV becomes an increasingly feminized epidemic, public health researchers try to understand how women decide to use protection such as condoms with sexual partners. Attempts to study this issue have focused traditionally on knowledge about disease transmission and condom use. While necessary, such interventions that focus merely on proximal factors miss more fundamental causes of illness or behavior that are

sociologically rich and incredibly influential. Medical anthropologists, for example, have delved into this topic and find that some of the underlying social determinants of condom use are a woman's power to insist on condom use (Pulerwitz, et al. 2002; Dunkle et al 2004), how trust, fidelity, and self-esteem are constructed in relationships (Sobo 1995; Sterk, Klein, and Elifson 2004), whether women who are at high risk have alternative economic options aside from receiving financial assistance from their primary partners (Parker, Easton and Klein 2000), and the social meaning for women of being perceived as having a faithful partner (Sobo 1995). These types of in-depth studies that look at the social meaning of condom use can more accurately assess the situation from the perspective of the actors, and therefore lead to more socially sensitive, and thus effective, interventions.

Advances in Epidemiology

Like all disciplines, public health has gone through different stages of development (Tulchinsky and Varavikova 2009). The first era of public health was characterized by the sanitation revolution and general environmental and hygienic advances. The second stage focused on individual health behaviors, and is the target of the critique undertaken. The third era of public health is what has been called for since the 1970's, but has yet to be fully realized. The third era is described by the World Health Organization's "Health for All" goals, and abandons the emphasis on individual level behaviors in exchange for understanding health more comprehensively and aiming to improve quality of life as a human right (Kickbusch 2003).

One of the major institutional documents that changed the way that public health is approached originated in Canada in 1974 and is called the Lalonde Report (Lalonde

1981). This document set off what is considered the third era of public health and challenged the purely biomedical view of health care. This document was the beginning of a redefinition of health promotion that shifts the focus from individual public health interventions and supports a holistic approach to health.

In the mid 1980's, an international discussion began that embraces this new public health. Essentially, several important documents were published by the World Health Organization that situated health outcomes in the center of development policy, redefined the goal of health policies to include social and economic well-being, and called for a serious reorientation away from individual risk factors towards addressing context and meaning in the social environment (Kickbusch 2003). Simultaneous discussion in academia stressed the need to modernize the field of public health that led to an attempt to promote a public health model that better connects both with the needs of people and communities, along with broadening of the disciplinary base to include other fields to address more holistically the health of populations. Specifically, a call was made in the field to commit to reducing inequality in health and to promote community well-being (Frenk 1993). While much research in the discipline remains stuck in the second wave, the individual and behaviorally focused era of public health, there are subfields of epidemiology that have accepted the challenge to move public health forward.

In view of this trend, some epidemiologists are pushing to include qualitative data in analysis of public health issues. For example, Agar (2003) outlines how the epidemiological triad of host-agent-environment paradigm that runs through epidemiology can be greatly enhanced by broadening this scheme to consider the "person-in-context". Because the components of the epidemiological triad are defined

traditionally very simplistically, Agar redefines these three elements by introducing ethnography in such a way that promotes an in-depth understanding of health issues.

First, he changes the use of "disease" to "illness" in order to move from biological definitions to a more experiential viewpoint. Additionally, he argues for conceptualizing the "host" as an actor who treats health or illness as having meaning. And last, he argues that "environment" should be conceptualized as a wide-ranging context. In this way, Agar's redefinitions provide a way for epidemiology to join ethnography and qualitative in-depth research, while retaining the disciplinary focus of population health.

Conclusion

As a discipline, public health is struggling to advance the third wave that moves beyond individual level behaviors to understanding critically health in the community context. This transition includes more holistic definitions of health and broadens what is thought to fall under the purview of health, including a critique of the dualistic assumptions that underpin epidemiology and health care. Understanding the assumptions of traditional epidemiology is important to appreciate their impact on decision-making about pursuing treatment.

The connection between philosophy and epidemiology is important, particularly in view of recent theoretical maneuvers that define knowledge and alter how decision-making is evaluated (Ferguson 2007). This chapter critiqued traditional epidemiology, while in the next chapter, the theoretical justification for these changes are discussed. The point, however, is that the process of overanalyzing variables is impeding the process of gaining insight into the experiential-based pathways persons follow when seeking health

care. In this regard, knowledge creation and the community have been elevated in

importance.

Chapter 3: Constructivism and Study Context

Sociological research has the potential to translate into benefits for groups that have been societally marginalized, as opposed to the traditional maintenance of distance between research and social change. The previous chapter set forth some of the problematic issues with traditional measures used in epidemiological research. This chapter outlines ontological advances and their application in the field of medical sociology. This chapter also serves to contextualize the specific study, as per the argument put forth here that context is crucial to understanding in medical sociology.

Constructivist Approach

Now that critique has been offered of positivist research in health studies, the point here is to discuss how to conduct meaningful health research that can create sustainable change. From this point forward, human input will no longer be seen as an impediment to understanding, but instead vital in the search for valid knowledge (Max-Neef 1998). In order to accomplish this aim, priority is given to the perspective of the research participants, with the goal of grasping, or achieving empathetic understanding of their interpretation of health. This redirect begins with a fundamental epistemological shift and a rejection of dualism, so that the world is conceived as constructed by people through their experiences and relationships with others. Contrary to positivism, the plan is to resurrect the human element rather than reveal an objective reality.

The philosopher who inaugurated this shift was Immanuel Kant. Kant represents the height of Enlightenment philosophy by undermining the dualism of Descartes. Descartes' philosophy, based on mind-body dualism, was the dominant ontological vision at the time, and held that there is an objective and factual reality independent of a

subjective, perceived world. Prior to Kant, the existence of an objective world was taken for granted. In many ways, Kant's work was the precursor to modern idealist philosophies whereby the mind creates multiple experiences of any phenomenon (Callinicos 1999). This philosophical maneuver established the foundation for a new way to envision the world, which is still heavily in use in modern, post-modern, phenomenological, and social interactionist perspectives in sociology.

Kant argued that the portrayal of the human mind as a passive *tabula rasa*, blank but waiting to receive externally generated input, is inaccurate. Instead, he claims that the human mind is active, and that the world is experienced through cognitive categories. In this regard, Kant differentiates between *a priori* and empirical knowledge. *A priori* knowledge is independent of experience and, in fact, establishes the framework for organizing information. The mind, in this sense, is active in carving up reality in any number of ways.

Kant's stated objective, in his influential book the *Critique of Pure Reason*, is to evaluate the worthiness of a transcendental critique that focuses on cognition rather than empirical objects. The general theme is that empirical data are meaningless until they are identified and regulated by cognitive acts. In the end, every kind of understanding is defined by cognition, and therefore truths are multiple and always approximations. In Kant's language, concepts in the philosophical sciences are "cognized" or "expositions," as opposed to descriptions of concrete objects (Kant 1787).

Similar concepts are later used by phenomenologists such as Schutz when he accuses positivist social scientists of using "secondary concepts," rather than trying to understand the primary ones that people use to make sense of their worlds (Schutz 1953).

This critique means that in philosophy, as well as the social sciences, the goal is to describe, understand, and explain, but without the possibility of access to universal definitions. Because the human mind intervenes in the world, the possibility of an objective reality fades from sight. This shift by Kant to emphasize experience resulted in the inauguration of what historians refer to as a Copernican Revolution in philosophy (Creighton 1913). That is, Kant's proposal definitively undermines Cartesian dualism because the knower and the known are intertwined and inseparable.

This change allowed for a new way of thinking about the nature of objectivity and subjectivity. Later, phenomenologists and neo-Kantians, including Max Weber, build on this seemingly simple distinction to advance a new way to study social life that emphasizes the meanings created by persons. Many argue that Kant's work serves as the basis for constructivism in the social sciences (Jonassen 1991; Freeman 2003), although this is debated by others (Krasnoff 2009). For the present purpose, Kant is relevant as a constructivist for providing a foundation for subsequent theorists who built off of his work. The thrust of this approach, accordingly, is that empirical referents never have permanent parameters, and that various people may have different interpretations of the same object (Kant 1787). Reality, in this sense, is thought to be constructed.

Consistent with constructivism is phenomenology. A key concept in phenomenology is "intentionality", although it has been defined with some variation. Husserl discussed intentionality as consciousness always being conscious of something, while Sartre viewed the world to be mediated by consciousness (Husserl 1999; Daigle 2010). The overall implication of the idea of intentionality is that consciousness informs everything that humans do, think, and act in the world. Through use of the concept of

intentionality, phenomenology builds on Kant's radical ideas about the influence of

cognition on all experience of the world. As a result, key to the constructivist approach is

the *lebenswelt*, or "life-world." That is, every person has a life-world that is constructed,

and thus does not live in the prescribed reality offered by empiricists.

Standardized measures have little or no human significance, considering the

multitude of life-worlds that are constructed. In effect, this type of empiricism in social

research has the effect of colonizing the life-world, since empirical data or external

referents are substituted for lived experience (Habermas 1987). Sociologists can adopt

empirical indicators to represent life-worlds, but referents must be based on *relevant*

classifications. At this juncture, the premise is that the world is constructed, and thus

facts are not things but *accomplishments* (Garfinkel 1967). Borrowing this assertion made

by ethnomethodologists, a branch of social science that is compatible with

phenomenology, reality is viewed to be a constant construction among actors. This

position is a direct rebuttal to Durkheim's positivism, whereby he argued that social facts

are things (Udehn 2001). Viewing facts as accomplishments, instead, implies a constant

negotiation and an agreed on reality that people create together.

A phenomenological approach in sociology relies on seeking primary concepts, or

the categories that actors use to carve out and construct their reality, in this case, how

persons define illness and identify likely paths to remedies. Therefore, the human

experience of health and illness should not be viewed as any less legitimate than the

physiological determination of pathology (Kleinman 1995).

This act of uncovering the way that people shape their reality constitutes a search

for truth, but using alētheia as discussed by Heidegger (Heidegger 1972). The basic idea

is that rather than being objective, truth is mediated by the human presence. While accepting the principle of multiple realities, the unconcealing of alētheia involves separating competing versions of the truth. The point of introducing the concept of alētheia is to show that truth is implicated in various modes of interpretation and is, in essence, elusive. Applied to medical sociology, the idea is that illness and health are not solely empirical features of persons, or represented by a checklist of pathological symptoms. So, reality, or at least a commonly agreed on version, can be uncovered, but without the goal of being empirically verifiable (Heidegger 1972).

In many ways, Weber builds on Kantian philosophy, while focusing on the rationalization of society and the removal of the human element. In general, Weber argues that sociology should be the study of social action and the meaning that people attach to their activities. Similar to the use of the concept of *lebenswelt* by phenomenologists, Weber maintained that sociologists should study the *cosmos* of research participants, referred to in Latin America as their *cosmovisión*. Through the lens of substantive rationality, making decisions based on comparisons within one's field of vision, persons create a meaningful world that has coherence and longevity. For this reason, Weber uses the term *sinnsuzammenhang*, which means literally "meanings that hang together," to describe this reality (Weber 1971).

These life-worlds are able to interact and gradually form a shared reality. In the case of this study, a particular *batey* community is understood to have a constructed reality that represents a confederation of experiences. Furthermore, based on the constructivist tradition, the life-words of communities are not necessarily isolated but are open to so-called outside realities. These outside realities, it should be noted, are

constructions also, but nonetheless have very real consequences in the lives of people. Analyzing the lived experiences of the participants in their social worlds is to study the coming together of culture, so-called macrosocial influences, and psychological processes (Kleinman 1995). These things together constitute the mediated world in which people act. Although large institutional forces often appear to be neutral, they are the product of human construction and their seeming objectivity is also a construct (Berger and Luckmann 1966). Any study of a community, from a constructivist perspective, should take into account these dynamics.

This shift in philosophy is very important in medical sociology, because of the dominance of the biomedical model in health research. In the biomedical paradigm, the health practitioner must translate the illness experience as expressed by the patient into the "black box" of traditional epidemiology. As a result, biomedical approaches insist on material evidence as the basis for knowledge, specifically a single causal chain to specify pathogenesis, structural language, and the elimination of non-empirical elements (Kleinman 1995). As a caveat, Dreyfus and Dreyfus (1986) argue that experienced doctors actually use intuition and holistic understanding rather than technical diagnostics, but clinical decisions are not thought to be legitimate unless they are based on empirical evidence.

However, as a solution to disease, and as the commonly accepted way to study health, the approach of biomedicine was developed in a certain climate and in a certain historical context (Kleinman 1995). This method gained predominance within the context of the elevation of positivism, but also Western monotheism where the belief in one God legitimates the idea in medicine that there is one underlying rationale for illness and

treatment (Kleinman 1995). Max-Neef (1998) considers the Christian version of monotheism to be the first major "agglutinating" element of Western civilization, which occurred when this belief system was transmitted to the New World, directly to the country of this study, present day Dominican Republic. The point is that biomedicine is also a system that has been constructed in a certain societal and globally historical context.

Within a constructivist framework, research must begin with lived experience, not with external indicators. The purpose is not to produce universal and essentialist findings, but to provide a positioned view (Kleinman 1995). The local world, or experience, is characterized by what is important to the members of that community, and thus the point is to understand as closely as possible the relevance that community members give to illness, health, and treatment expectations. As opposed to empirical explanations, the goal is to uncover murkiness, the messiness of real conditions, inherent moral contradictions, and the social action that does not pause for the convenience of sociological observation (Kleinman 1995).

Community-Based Research in Medical Sociology

The importance of the *sinnsuzammenhang* is reflected in the present study by the community focus that is taken. Specifically noteworthy, community-based research in sociology is conducted from a social justice standpoint, whereby the point is not only to understand and describe the world, but also to challenge inequalities and create alternative social relations that enhance health (Molano, 1998; Campbell and Murray 2004). The present study is a first step toward initiating social change to improve lives.

Research in this field tends to draw heavily on Paolo Freire's work and his focus on social change (Lavery, Smith, Esparza et al. 2005; Seng 1998). The idea of community in health research is also theoretically important, because human beings invent themselves in light of their social world and relations to others (Berger and Luckmann 1966). In this regard, including and valuing the ideas of the members of a community in health research has been shown to improve community health, in large part by directing control and power to those most affected (Leung, Yen, and Minkler 2004). Community health can even be improved simply by being involved in research and being part of the identification of health issues. This type of experientially derived knowledge, in effect, provides crucial insight into health problems. While giving primacy to the experiences of participants in this research, these local factors will contextualize health with respect, for example, to inequalities, restrictions, and opportunities that, in the case of Haitians and Haitian descendants living in the Dominican Republic, has much to do with history, politics, and human rights. In the end, health is not simply a matter of environment, buffers, and supports, but how persons experience these contingencies. These interpretations include a community's conscious awareness of various domains of inequality (Campbell and Murray 2004).

This questioning of reality, and offering a more nuanced and contextualized understanding of health and illness, is especially important in research conducted in a marginalized community, and must be linked with an examination of inequities (Dakubo 2011). The people living in the community in question have been overrun many times by the dominant society. This experience of power has in part defined this community and others with similar histories and demographics. In addition to any epistemological benefit

of doing so, there is also a moral obligation to take these experiences into account. Accordingly, and consistent with the constructivist tradition, the persons studied have been involved intimately in this project. In fact, this participation is the hallmark of community-based research (Minkler and Wallerstein 2003).

The basic theme of community-based research is that local persons know best the conditions where they live. This is especially true for the goal of looking at health beyond biomedical factors, because there are a myriad of ways that behavior is shaped by experiences. In this case, the decisions persons make are key to understanding their search for treatment and managing health. Yet how they define health and illness does not imply a personal affair. The pool of information they use, referred to by phenomenologists as a "stock of knowledge" (Schutz 1967:80), contains a history of degradation, political regimes, and cultural hegemony. Those who live in *bateyes* have a "biography," in other words, that influences how persons identify symptoms, recognize sickness, and understand the prospect for remediation. To overlook this story, at least in terms of constructivism, leads to misunderstanding of health behavior.

This research, in seeking to understand how people construct their reality around issues of health, draws on the Heideggerian concept of *dasein*, or, "being there" (Heidegger 1992). People work to invent themselves and create the "there" where they exist. The point, therefore, is to grasp this situation. But while seeking to understand the view of participants, and the ways in which they carve out reality and create their life-worlds, an effort was made to understand broader societal factors that have entered into their experiences and influenced their views of health. The obligation of a community-based researcher is to link these worlds and identify the ways whereby the local

community is shaped in conjunction with broader society, with the intent of working with those persons to improve their lives and society as a whole (Labonte 2005).

Beyond Social Indicators

All of this leads to the current approach for studying health in a Dominican *batey*. In a constructivist approach, the social world should not be reduced to a body of social indicators. These empirical referents are not useful or accurate with respect to understanding the construction of health in a group, specifically in a group that has been historically marginalized and socioeconomically abused. Simply knowing, for example, the quality of housing or demographics of a community will not give much insight into how this group views these issues. Developing policies on these data, additionally, will lead to speculative interventions. But maybe even more important, fundamental issues of access and health outcomes will not be addressed adequately until these experiences are documented.

Context is extremely important so that data are properly situated, and the intersection of individual, community, and larger social (institutional) biographies are taken into account. In this sense, sociologists have a special perspective to link social conditions directly to health and illness. For example, Link and Phelan (1995) critique traditional epidemiology for emphasizing individual level risk factors, and thus call for public health researchers to include the experiences of poverty, racism, and sexism in their analyses as they directly impact health outcomes. They describe this proposal as seeking to go beyond the typical empirical models that focus on personal risk, and instead understand how certain social conditions will always have deleterious consequences (Link and Phelan 1995).

McKinlay (1974) uses the analogy of a flowing river to demonstrate this point. Social and behavioral scientists, instead of focusing on immediate causes of illness, should look more upstream in the illness process to understand why the person fell into the rushing river in the first place. In this analogy, the role of doctors and nurses is to pull people out of the illness stream. At a different level of intervention, social scientists can prevent the person from falling into the stream. Therefore, McKinlay (1993) encourages the use of qualitative methods for conducting upstream disease research, so that the lure of the stream is understood. He further argues that traditional quantitative methodologies are fairly appropriate when trying to identify risk characteristics, but understanding the confluence of experiences that influence health requires a more holistic study. How experiences fit, or "hang together", as Weber (1971) suggests, should be the focus of attention.

Community-Level Approach

Community psychologists and sociologists have long understood the importance of context. However, with increasing specialization in the social sciences, these contextual, historical, and political situations are frequently overlooked (Farmer 2004). Human beings act their roles and live their lives in specific environments, with particular constraints, opportunities, visible networks, and stimuli for action (Rieger 1993). Even individual-level concepts, such as psychological empowerment, are necessarily embedded in sociopolitical and contextual experiences (Zimmerman 1995).

The community is important because this group often plays a large role in people's behavior (Rieger 1993). In particular, community cohesiveness can be a particularly salient component, especially when there is shared hardship and conditions of

poverty or oppression (Panzetta 1971). In the community under study, for example, people often give food to neighbor children, or send a bowl of rice to someone without food. In fact, community cohesion may be even more important under impoverished conditions because survival may depend on interpersonal solidarity.

The *batey* that is the focus of this research is what Panzetta (1971) terms a *gemeinshaft* community. Gemeinschaft communities are increasingly rare, and are characterized by implicit ties much like an extended family (Panzetta 1971). This classification does not mean that the community is an idealized place. Communities are where lives are lived and often where work is conducted, and can be sources of both suffering and assistance, but communities embody a confluence of biographies, and these constructions are reworked constantly to form new histories (Kleinman 1995).

Lived-in social spaces contain the everyday practices of morality (Kleinman 1995). The concreteness of history, social constraints, interpersonal pressures, and conflicts come to life in real ways in these places. For these reasons, how these elements are experienced, reinterpreted, and possibly remade is vital to appreciating the health of a community. In order to interpret the grounded perspectives of community members, a phenomenological analysis is necessary that views a community to be a matrix of life-worlds (Ricouer 1986). Furthermore, in order to analyze appropriately the data collected through interviews, the participants must be encouraged to convey their biographies, including the connection between the Dominican Republic and Haiti and the related construction of stratification because these things can become embodied as illness (Farmer 2005).

A community-based approach must take into account power relationships manifested particularly through race, class, and gender, because power determines access to resources (Minkler 2005). Some of these broader contextual influences are reviewed next. These are just some of the institutions that contribute to the life-worlds of the participants. These institutions are important because they represent a shared history and a habituated pattern of action (Berger and Luckmann 1966). Because institutions have a temporally durable impact they become integrated into the collective memory of a people in a way that often becomes detached from the original construction of the norm, and therefore are seen as natural. Bordieu introduces these influences, which he calls 'a feel for the game,' to explain how people engage a world that appears to be objective (Bourdieu 1990:66).

Dominican Health System

The Dominican health care system is widely criticized for being ineffective, costly, and inequitable (La Forgia et al. 2004), and possibly a tool for neocolonial American influence in the country (Whiteford 1990). Implemented in the 1970's, the primary health care system fails to meet common standards of primary health care; the costs are high, dispersed populations are over-looked, access is limited, and morbidity and mortality outcomes have been poor (Whiteford 1990). However, she argues that this health care system has been very successful in terms of the "imperialist capitalist world system," in that those in power complied with U.S. demands to finance the creation of the health care system with foreign money (Whiteford 1990).

The health care system is divided into three parts: public, social security, and private. For the present purposes, the focus is on SESPAS (Ministerio de Salud Pública y

Asistencia Social), the public sector health care, because the majority of the country and

most of the rural poor treat this health system as their primary health care provider. The

stated goal of the public system is to provide free health care for the poor, but some argue

that weak and poorly planned governmental involvement has led to inefficient and low

quality health care, while at the same time not regulating an abusive private sector

(Lewis, LaForgia, and Sulvetta 1996). In addition, people seeking health care often have

to pay for services rendered through SESPAS. In fact, the public system is not only

inefficient but staffed mostly for political reasons, and while 70% of the SESPAS budget

is used to pay staff (Lewis et al. 1996). This trend has been to the detriment of providing

treatment; for example, over half of all drugs are purchased out of pocket by patients

(Lewis et al. 1996).

The health care system is tiered and consists of rural health clinics, sub- centers,

centers, community health promoters, health supervisors, zone supervisors, and

physicians (Whiteford 1990). Public hospitals are in the major city of each region. In the

case of this study, the hospital is in Barahona, which is about 15 minutes away from the

community by car. There are also health clinics scattered throughout rural areas for more

common ailments and minor issues. These clinics are generally the first places a rural

resident visits to receive treatment. If their situations require additional care, they are

referred to the hospital in the city for evaluation and any lab work. In cases where the

regional hospital or private laboratories are unequipped to treat something locally, and

often when children are seriously ill, people are sent to the capital, Santo Domingo, to

receive treatment. If an emergency occurs, especially in a rural area, there is often no

primary care available. Ambulances and emergency responses, even in the capital, are

rare. Persons, in effect, must learn to navigate this heath care reality. This health care system and the process of seeking care constitutes part of their biography and contributes to their conceptualization of their life-world, especially with regard to health and illness.

Legacy of Colonial Constructions of Race

Dominican society is one of the most heavily racially mixed countries in the world, and certainly in Latin America (Sidanius, Pena and Sawyer 2001). But there is a strong tendency to frame *dominicanidad* (Dominicanness) in both Europhilic and Afrophobic terms (Torres- Saillant 1999). Most racial animosities in the Dominican Republic center on Haitians and Dominicans of Haitian descent, who generally have darker skin than Dominicans. The black population in the Dominican Republic comes from descendants of both slaves and Haitian immigrants, which creates further challenges for creating a common black identity since these groups are culturally distinct (Usanna 2010). *Antihaitianismo* (anti-Haitianism) permeates society in the form of social norms, common phrases, policing and legal practices, and media representations. Calling someone "Haitian" carries a heavy connotation of fear and hatred (Wucker 1999).

Everyday symbolic culture shows Dominicans distancing themselves from Haitians. For example, Dominican women rarely braid or wear their hair naturally, because these styles are seen as symbolical markers of being Haitian. Despite 73% of the population being mixed-race, there is strong evidence of pigmentocracy in the Dominican Republic, and this racial hierarchy is recognized across people with different skin color (Sidanius et al. 2001). Race and economics go hand in hand in the Dominican Republic, and the color line runs mainly concurrent with income whereby the lowest paying jobs in the Dominican Republic are held by Haitians and Afro-Dominicans (Howard 2001).

Throughout history there has been much back and forth aggression between Haiti and the Dominican Republic that today is retained in the collective memory. Modern day Haiti was a French colony (Saint-Domingue) and modern Dominican Republic (Santo Domingo) was controlled most often by the Spanish with interludes of French and, later, Haitian rule. While the French colonists in Saint-Domingue were concerned with gaining freedom from France during the French Revolution, freedom movements began among mulattoes and slaves. The French Assembly declared freedom for all in France in 1791, and in 1793, former slave Toussaint Louverture, led the slave rebellion in Saint-Domingue that the mulatto class quickly joined (Wucker 1999). In 1804 former slaves established the Republic of Haití. Dessalines, the Haitian general who declared victory, ordered all the French in the nation to be killed, thus creating fear in neighboring Santo Domingo (San Miguel 2005). Santo Domingo declared independence from Spain in 1821, and Boyer, the president of Haiti, sent 12,000 troops to defend the island. However, this "defensive" force was really in place to ensure some control in Santo Domingo, and in 1822 Haiti invaded Santo Domingo and annexed this land to create one country.

In 1825, Haiti began negotiating with France and agreed to pay property restitutions to the order of 150 million francs. Incredibly, these reparations were for the loss of slave property, as a result of the Haitian Revolution (Farmer 2004). Boyer's plan to pay this was through appropriating Dominican property and Dominican labor, and resentment towards Boyer and the occupation in Santo Domingo grew (Wucker 1999). Boyer was ousted in 1844 and Santo Domingo declared independence from Haiti. The repercussions of the reparations paid by Haiti to France still reverberate in material effects on health, disease, and development in Haiti (Farmer 2004).

In many ways, Haiti has still not recovered from this financial blow, thus providing an example of how a historical international agreement has led to many Haitians seeking low wage labor in the Dominican Republic. In many respects, this colonial history and subsequent revolution shapes the collective biography of participants, in form of both pride and injustice. Pride is a result of being the new world's first black republic, yet a sense of injustice at the way Haiti has often been exploited by countries in the region in the modern era. This history also informs the biographies of Dominicans both in the *batey* and outsiders with whom community members interact.

In modern history, during the thirty-one (31) year dictatorship of Rafael Leónidas Trujillo, from 1930-1961, the social policy of the Dominican state was one of *antihaitianismo*. As demonstrated by the notorious massacre of an estimated 30,000 Haitians and Haitian- looking Dominicans along the Haitian- Dominican border in 1937, Trujillo and his supporters embarked on a "whitening" campaign of Dominican society through state- sponsored ideology (Sagás 2000). Especially important is that this attempted genocide happened within the last century in the Dominican Republic, and is revealed when speaking of race relations in the country. Of course, most Dominicans are ashamed of Trujillo's actions of ethnic cleansing, but, nonetheless, newer forms of *antihaitianismo* have emerged. This massacre, too informs the biographies of people in both countries, and is particularly salient for Haitians living in the Dominican Republic.

This ideology, imposed by the elite, was in turn accepted by other Dominicans, and even internalized. The *Trujillato* ingrained *antihaitianismo* into the national psyche and Dominicans still struggle with this issue today. Dominican historian Pedro San Miguel (2005) argues that the discipline of history in the Dominican Republic has been

so permeated by positivism that history came to be simply the "biography of the State",

while Trujillo's cultural beliefs became "natural fact" for Dominican society. Given this

context, ethnic conflict is often used deliberately by those in power to support their own

political, social and economic well-being (Payne and Nassar 2006). In the case of the

Dominican Republic, this strategy was shown clearly throughout the dictatorship of

Trujillo. While racism was the state ideology under Trujillo, race relations between the

Dominican Republic and Haiti nowadays takes a much more covert form.

Sugar Industry

This more subtle racism is also confounded by the economic and lower class

status of many the Haitians who live in the Dominican Republic. Simply put, Haitians

were needed for the sugar industry. Although they were not technically enslaved, they

were still "unfree" and granted limited civil rights and economic maneuverability

(Martinez 1999). Workers brought in from elsewhere for sugar production were thought

to be much more controllable than Dominicans, who had other agricultural labor options

that provided better money than working in sugar plantations (Martínez 1995, 1999).

Haitians began going en masse to the Dominican Republic by 1915 to work in

sugar plantations. The Dominican state has long been complicit in bringing workers from

Haiti to sustain this lucrative industry. Furthermore, Dominican police have been used

often to round up both illegal and legal Haitian descendants and relocating them to work

on these plantations (Martínez 1999). Martínez (1999) argues that over time, Haitian

migrant workers lost significant freedoms when the system of control shifted from the

labor market to a government-managed form of exploitation. This co-dependency for

trade represents a long tradition in the borderlands, despite trade and migration laws imposed from Santo Domingo (Derby1994).

Different organizations and institutions have widely varying estimates of the numbers of Haitians residing in the Dominican Republic, depending on their political needs (Derby 1994). In 1985, most Haitian immigrants lived in *bateyes* and were therefore a confined and isolated population (Martinez 1999). While many Haitians and their descendants still live in *bateyes*, many now have gone to urban areas seeking jobs in other labor sectors.

According to Eduardo Bonilla-Silva (2001), the process of creating a racialized society is variable, but results in hierarchical arrangements where different races are assigned to distinct strata in society. His theoretical contributions can be applied to the Dominican Republic. In this country, the creation of a racialized society began with formal, public, and brutal genocidal campaigns against Haitians and dark-skinned Dominicans under the Trujillo dictatorship. *Antihaitianismo* began not only as racism based in skin pigmentation, but as a conglomeration of factors related to language, cultural colonial rivalry, and the Haitian occupation of the Dominican Republic (Derby 1995).

In the post-Trujillo era, racism has been transformed into a more covert racialization process through hegemony. The racial divides in Dominican society are pervasive, and stem from fear of the "other" and the historical conflict between Haiti and the Dominican Republic, in addition to current fears of Haitians taking jobs from Dominicans. Post-Trujillo *antihaitianismo*, accordingly, is framed in the context of nationalism and the resistance to blackness, vodú religions, and African slave heritage.

For example, children are indoctrinated with black as representing "the other", and media portrayals through political cartoons and sensationalized headlines portray Haitians (and blacks) as a threat to Dominican culture (Sagás 2000).

The national identity of the Dominican Republic is expressed in direct opposition to being Haitian, and thus is a form of racialized nationalism (Howard 2001; Derby 1994). Terms of classification and identification have developed to avoid the use of the term "black". Particular to the Dominican case is the use of the word "indio" to describe a range of skin colors. This maneuver avoids the use of adjectives such as "negro" or "mulato", and gives preference to Native American (Taíno) heritage over the history of slavery and Haitian immigration (Howard 2001). Through an ongoing process of cultural construction, Haitians are labeled and inferiorized in the Dominican Republic. This scenario, accordingly, begins to infiltrate the biographies of all persons.

Economic Inequality

Today's relationship between the Dominican Republic and Haiti is characterized by economic inequality. While many Dominicans leave their nation looking for jobs in New York to escape the economic difficulties of the Dominican Republic, citizens of neighboring Haiti look to the Dominican Republic for economic opportunities, often seeking work in the sugar industry, construction, or informal labor. The inequality between labor exporting Haiti and labor importing Dominican Republic is what drives this migration, and the characteristics of the migrant labor force are an expression of such socioeconomic conditions (Grasmuck 1982). Haitian migration is often referred to as an *invasión pacífica* (peaceful invasion).

A pattern of "dependent development" has generated an exodus of workers from Haiti into the Dominican Republic, both documented and undocumented. Dependent development often refers to the economic dependency of an undeveloped nation on a developed nation (Koo 1984). On the demand side of Haitian-Dominican migration is the benefit to the Dominican Republic sugar production companies of having cheap labor in this sector. The meaning and often injustice of all this history is not lost on people. In even more recent history, the collective memory of the devastating earthquake in Port-a-Prince in 2010 has impacted all Haitians whether they live in Haiti, Dominican Republic, or elsewhere.

Gender

The majority of the literature about *bateyes* in the Dominican Republic focuses on the men who work there, on whether current labor conditions constitute a form of neo-slavery. A review of the literature within the social sciences and medicine finds few studies on women in any capacity within the *batey* system. When women are mentioned at all, they are depicted as purely functional, related to reproduction, domestic tasks, and support in the community. Even epidemiological studies portray Haitian women in the Dominican Republic simply as carriers of sexually transmitted diseases, which reinforces both racial and sexual stereotypes, without ever even discussing social conditions and poverty (Brewer et al. 1998).

Jansen and Millan (1991) published what appears to be one of the only comprehensive studies that describes the women's world of the *bateyes*. Their findings a.) focus on women's triple discrimination based on class, race and gender, and b.) refute many common generalizations made about women working on the *bateyes*. The

predominant role of women in domestic work and the informal economy means that such labor is diminished in importance (Benería 2003). Since capitalism is the dominant structure, women's invisible work in the economy prevents them from achieving any power.

Jansen and Millan find the classification of women as housewives contradictory to reality. Of their sample of bateyes in three distinct regions of the Dominican Republic, 83% of women reported having worked in exchange for monetary payment. Women maintained all household and childcare duties, and in addition the majority were working outside of the home, 24% with two or more jobs (Jansen and Millan 1991), usually in the informal sector. The concept of the "second shift" (Hochschild 1989) has much stronger implications in the *batey* population than in the developed world where the original concept was developed.

Similar to race, a discourse has been developed and implemented that challenges women and pervades Haitian society. Their identities, accordingly, emerge from this particular construction. As long as patriarchy, class structure, and racism leave this group of women voiceless, their health issues will continue to be overlooked. Gender norms and stratification comprise part of men's and women's biographies and worldviews, and is another important aspect of health care.

Conclusion

Due to the break with Cartesian dualism, nothing escapes construction. The person, community, and larger society merge to form the world of a community. Community-based research, due to the required participation, must pay attention to the biography created by this confluence of experiences. Rejecting positivist definitions of

what constitutes science, subsequent to the rejection of dualism initiated by Kant, is essential to interpretive research.

The ensuing epistemological shift will be evident in the next chapter, where methodology is discussed. The work of Kant, Weber, and phenomenologists will be reflected in the process of constructing and acquiring knowledge. In this regard, the life-world of persons is particularly significant. Accordingly, understanding and incorporating the historical and social context into the study of health is particularly noteworthy for medical sociology. At the same time, however, this context is not simply natural, since history does not define completely a group of people. In this sense, hegemony is often real and becomes a key part of a community's biography, but can be reinterpreted and overcome.

Chapter 4: Methodology

The methodology for any study should be informed by theory. Accordingly, a qualitative methodology, accompanied by an interpretive analysis, is appropriate for the constructivist approach to knowledge and truth that is adopted in this study (Lincoln, Lynham and Guba 2005). The goals of understanding how community members construct experiences of health, health care, and illness requires an approach that is dialogical, and can elicit explanations about how people view their world. In view of the theoretical arguments on the shortcomings of rationality in alleged expert knowledge, and the elevation of participants' voices as informed witnesses (Chambers1998), thirty-four (34) interviews were conducted and analyzed. In addition, as supplementary material to the interviews, observations were made about community life in Batey Algodón.

Social Theory and Methodology

As noted in Chapter One, sociology has seen a debate between two methodological approaches to social research. The two approaches are the *naturwissenschaften* and the *geisteswissenschaften*, and they each reflect very different ontological and epistemological premises. The *naturwissenschaften* (natural or physical sciences) are associated with the scientific method, while the *gesiteswissenschaften* (human sciences) study the social world (Rapport 2004). Both are frequently employed by social scientists, but debate remains about which approach is appropriate to the study of the social world. A key difference between the two is that a *naturwissenschaften* orientation emphasizes technical competence, such as precise measurement, classification, standardization, and procedural rigor. The *geistesswissenschaften*, on the other hand, have the goal of "communicative competence", and thus stress interpretation,

social sensitivity, and creation of relevant constructs (Habermas 1981). Clearly, a *geisiteswissenschaften* strategy is commensurate with the research questions and epistemology of this study, which emphasizes the lived experiences of health and illness.

The qualitative approach taken here draws heavily from phenomenologists, such as Husserl and Schutz, and the constructivist framework for conducting social research (Husserl 1999; Schutz 1953). Research within a constructivist paradigm can have the goal of both describing accurately an experience and focusing on social justice (Mertens 2012). However, the action and results coming out of such research are not viewed as contaminants (Lincoln, Lynham and Guba 2005). Although not meeting all of the requirements of a full community-based study, this research draws from the field of community-based research, and thus requires solidarity with research participants and a desire to collaborate with an underserved community to solve problems (Badiee, Wang, and Creswell 2012). Specifically, this research seeks to describe accurately the experience of people living in Batey Algodón, but eventually expand into future collaboration with the community.

Conducting research outside of one's own social group, with a community of people with different ethnic, cultural, and linguistic backgrounds from one's own, requires culturally sensitive research skills and nuanced strategies (Nagata, Suzuki, and Kohn- Wood 2012). There are pros and cons of being an outsider to the community that is studied, and the ways in which participants perceive a researcher will affect the type of information that is shared during interviews. In some situations, being an outsider can be beneficial, for example, when interviewing asylum seeking political refugees (Suzuki and Quizon 2012).

While the participants in this study are not seeking asylum, there are some similar characteristics, and thus they may have been fairly comfortable talking to a perceived outsider about their experiences with immigration and being Haitian in the Dominican Republic. For example, one participant described the abusive wage tactics used by the sugar company in the course of his interview, and divulging this information may have been made easier because the researcher was a foreigner and uninvolved in this local history. The researcher was keenly aware of her position not only as a foreigner, but also as a citizen of a country that people perceive to be much more affluent than both the Dominican Republic and Haiti. This social distance likely helped some aspects of the research and hindered others. For example, a lot of time was devoted to "getting in" to the community and coming to share the interests of the persons in the community. These types of dynamics were constantly the focus of reflection and attention during the course of conducting the study.

Situating the Researcher

Because this research is being undertaken from an interpretive standpoint, the situation of the researcher is very important. She is a white, American graduate student from a middle-class background, and therefore is an outsider to Batey Algodón. She began travelling independently to the Dominican Republic at age 19, has had a lot of different experiences with various groups of people there, feels very comfortable functioning in Dominican culture, and has acquired fluency in Spanish and some basic Haitian Creole. She has worked with different NGO's and also has long-standing friendships and collegial relationships in the country, as well as a healthy self-awareness of cultural differences. The site of this study, Batey Algodón, however, was a new locale.

She had visited *bateyes* before in the Eastern part of the country for an HIV outreach program, but had never travelled to this area prior to the initiation of the study.

The link with the host organization developed out of a friendship formed in an epidemiology class at the University of Miami, with a colleague who returned to the Dominican Republic and his research position with CENISMI (National Center for Maternal and Child Health Research) after completing his MPH. With the support of this colleague, collaboration with CENIMSI was initiated, and an office of helpful colleagues, affiliation with a reputable public children's hospital, and a physical workspace were acquired for the duration of the study. The director of CENISMI completed his own dissertation work in the same community, and this relationship provided access to the study site.

Initial Access

The first stage of this project was initiated in the summer of 2010 during a visit to Batey Algodón and some nearby *bateyes* for about a week to become familiar with daily life and common issues that people in rural sugar production oriented communities face. A colleague at CENISMI facilitated introductions to this community. This method of entry, while simple, is an effective way to recruit participants for a study; a trusted person is, in effect, lending approval to a project (Vallance 2001).

As part of a week-long stay with multiple tours around the area, people offered information, and questions were asked about various topics including health, environmental problems, the local economy, and local history. During this process an evangelical group was witnessed bringing medicines to the community, and

community members were asked about how they perceived this type of intervention. This necessary first step was enacted to develop a relationship with the community and become oriented to local concerns regarding health, and thus was an intentional component of the methodology. Care was taken not to appear critical, but interested in learning about and helping in the community (Berg 2004). While intentional, this initial approach came very naturally to the researcher, who stays current on literature about *batey* communities, both non-fiction and fiction, which provides cultural entree, and was excited to be there and learn about the community.

In order to begin designing the interview questions, informal observations were made and discussions initiated with community members. Many questions were directed to the pastor in the community, who was the main point of contact established through CENISMI. The pastor served as a gatekeeper, but also provided lodging with his family at times throughout the study. Gaining the favorability of a community leader proved to be helpful to attaining access to the community and encouraged members to speak openly about many topics (Berg 2004). In one conversation, the researcher, the pastor, and some other community residents discussed at length the possible directions for research regarding health in the community. These conversations helped to inform the direction of the study and the research questions that would be meaningful in this particular context.

The Study

After the initial visit to the community, a plan of study was devised with colleagues at the University of Miami. After writing and defending a proposal, applying for research grants, and fulfilling the University of Miami Human Subjects

Research IRB requirements, eleven (11) months of research began in the Dominican

Republic. The lengthy amount of time spent was, in part, a way of acquiring

background information and understanding Batey Algodón (Suzuki and Quizon 2012).

As these authors suggest, conducting quality research in a culturally diverse setting

depends greatly on the degree of linguistic and cultural immersion (Suzuki and Quizon

2012). The years of travel to and intermittent work and collaborations in the

Dominican Republic provided great preparation for this project.

Participants

Interview participants were all adults aged 18 and over who live in the

community. Some people were born in the community, some were founding members of

the community, and some had lived there for under a year. Thirty-four (34) interviews,

twenty-two (22) women and twelve (12) men, were conducted.

Observations were made generally of the community to offer some broader

context. Observations were recorded as field notes about moments of interest that were

visible in public. No individuals were named specifically to avoid any potential violations

of privacy.

Procedure

Human Subjects Research Permission

This research project was submitted to the University of Miami's Human Subjects

Research Institutional Review Board (IRB). As part of this process informed consent

forms were created in English and Spanish (Appendix A). Approval for the project was

given by the University of Miami IRB, and after arriving in the Dominican Republic, the

 project was also submitted to an accredited Dominican IRB at CENISMI and approved (Appendix B).

Confidentiality

Papers and audio tapes associated with the study were carefully protected, as per the protocols approved by the University of Miami and CENISMI review boards. Informed consent forms and the tape recorder were kept under lock and key. Audio files and transcripts were kept on a laptop and were protected both by assigning pseudonyms that respondents had chosen, and by passwords that prevent both access to the computer and the specific files. Once transcriptions were made, the audio files were erased.

Participant Recruitment

The goal of sampling in qualitative research is not to achieve a probability sample that is representative of the population under study. A randomized sample is not appropriate for qualitative research for several reasons: (1) sample sizes are fairly small so sampling error would likely be very large, (2) for a complex qualitative study, relevant population characteristics are unknowable, (3) it is unlikely that the values and beliefs that are relevant to the investigation are normally distributed, and (4) people are not equally skilled at providing rich insight during interviews (Marshall 1996). Instead, sampling is used to identify participants who can contribute to understanding the phenomena under study (Mays and Pope 1995). The deliberate selection of a diverse sample allows for a range of experiences to be included in the data (Belgrave, Zablotsky and Guadagno 2002). In this case, some of the axes of differentiation that were considered "diverse" in recruiting participants include the following social characteristics: age, gender, relative economic standing, education, parental status,

longevity in community, longevity in country, employment status, family composition, and geographic location within the community.

The interviewees were identified initially by spending time in the community and talking to people, learning about their lives, and building rapport. Initial interviewees were selected through *purposive sampling* to gather information from a variety of perspectives (Charmaz 2006; Singleton and Straits 2005). Specifically, the aim was to identify people who are knowledgeable, experienced, and have differing perspectives on issues related to health (Rubin and Rubin 2005). For example, the first three interviewees were a young Dominican-born woman pregnant with her first child, a young man who had immigrated recently from Haiti, and a forty-eight (48) year old grandmother who cares for two of her grandchildren.

As the research developed, based on the ongoing interviews and observations, additional participants were identified through different sampling methods. Continued use of purposive sampling was used to reach a broad cross-section of the community. On slow days, when particular interviews were not scheduled, *snowball sampling* was used. In this case, former participants were asked to refer friends to be interviewed. And last, simple *convenience sampling* was also in play. The community is small enough to travel around by foot, and often encounters with persons resulted in interviews. Therefore, as the research progressed, participants were identified both by the researcher being embedded in the community and through referrals by personal acquaintances in the community.

Interview Site

Interviews were conducted wherever participants wanted to be interviewed to ensure comfort, privacy, and convenience. Most interviews were done on the stoop of the participant's house while sitting on rocks or in a chair. Often somebody would interrupt the interview for neighborly business, but the process would resume once these issues were resolved. Additionally, some people liked having friends or family around during the interview, in which case stories were often double checked with the friend or family member. The presence of others did not appear to inhibit respondents. The suggestion was always made to sit somewhere private, thereby giving all interviewees the opportunity to be alone. In some cases, having others around is the only way that data would be collected, and these cultural norms and preferences must be responded to with flexibility and respect (Roulston 2010). In particular, the concept of privacy in the community is fairly rare, especially when multiple families share spaces in close proximity.

If two people were together, they were told that both could be interviewed jointly to save them time and provide a higher degree of comfort. This type of interview was selected only on two occasions, once with two neighbors, and once to address a language barrier. In one instance, the interview was done with a Creole-only speaker, in conjunction with a trusted friend who helped to translate between Spanish and Creole. The Spanish-speaking friend served as a "cultural broker" (Lefley 1994), or cultural mentor and interpreter, for her friend who was both linguistically and culturally Haitian and not yet confident in navigating Dominican culture alone.

In this case, a Spanish-speaking friend was a helpful intermediary. But to build rapport, the researcher did her best to speak Creole throughout the course of the interview. In addition, the Creole-speaker was encouraged to speak Creole to feel more comfortable and to delve deeper into her thoughts, while the friend was consulted for corroboration. Initially, this issue of Creole-only speakers was anticipated to be a concern, but most of the community members were able to express themselves and understand Spanish enough for a meaningful interaction. In the end, nobody was overlooked for being a speaker of Haitian Creole.

Interview Process

The first visit to the community to begin the study consisted of walking around the entire community and making introductions to every available adult. A sixteen (16) year old girl served as a guide. The point of this inaugural foray was to make acquaintances, explain the project, and tell persons about the interviews for the future. At the end of the walk, about twenty (20) children had joined this activity. This event provided a chance to "return" children to their homes, talk with the parents, and to be viewed as someone responsible and trustworthy.

Local church services were also attended, at which the pastor introduced the researcher to the congregation and asked for their support with interviews. Although at first the researcher was ambivalent about this announcement, especially being in a religious setting, this introduction proved to be very helpful and word spread quickly throughout the whole community.

With respect to the interviews, people were approached in the community and asked if they would be willing to talk at that time, or if they would be willing to do so

later. Three people declined to participate. The interviewer and interviewee would then find a place to sit, usually just inside or outside the main door, as a result of the heat. The informed consent form was then explained, which interviewees could either read or have read to them. When the latter option was chosen, the form was read verbatim. The interviewee and the researcher then signed the consent form. Most people signed with a symbol.

One respondent, who did not appear to know how to hold the pen, asked if the researcher would sign the form for her. She was asked again if she agreed to be interviewed and recorded, and a note was made that verbal consent had been given. After the forms were signed, the use of the tape recorder was explained and the interview proceeded.

Interviews were conducted during the daytime for a few reasons. One was for safety and consideration for the hosting family. Almost always, the electricity cuts off in Batey Algodón around 7:30 PM, just before dark, due to rolling blackouts. This condition not only makes for a more dangerous setting, but also can be quite uncomfortable with people negotiating the heat inside homes and malaria and dengue carrying mosquitoes, especially at dusk which is a peak biting hour. Many persons felt that walking around at night was not safe, and thus most of the interviews were conducted during the day. Additionally, engaging in dialogue and taking notes is difficult in the dark.

Conducting the interviews only during the day, among other factors, resulted in more interviews with females than males. During these hours, men are often working or seeking work on a day to day basis. Of course, women work outside of the community too, but tend to come home earlier, especially those who have young children.

Additionally, although many women reported that they have a male partner, these men live often in the capital, or elsewhere, for work, usually in construction. Finally, many household heads in the community are female. Men have more mobility culturally and economically than women in the Dominican Republic in general, and thus women are often the ones who maintain a stable home and are more accessible.

Instruments

Semi-standardized Interview

In-depth interviews were conducted to delve deeply into decision-making, daily life, and experiences related to health. Thirty-four (34) interviews were conducted, as per the goal set in the research proposal to interview between 20 and 40 participants. Because of housing logistics and travel time, between one and three interviews were conducted in a day, typically during two to five-day stays in the community. These interviews followed a schedule that was designed to be flexible, in order to pursue lines of questioning that emerged from the respondents (Appendix C). This flexible design is meant to privilege the knowledge that comes from the respondents, as opposed to *a priori* assumptions made by the researcher. The method of interviewing is referred to as *responsive interviewing*, whereby the interviewer engages and follows up with detailed questions when an interviewee answers a probative question (Rubin and Rubin 2005). This type of active interviewing process is conceived as a collaboration between interviewer and participant, and is particularly recommended for cross-cultural interviewing (Sands, Bourjolly and Roer-Strier 2007).

The interview was semi-standardized, meaning that there was a set of questions asked to all participants, but with the expectation that the interview schedule was a

starting point that would be expanded as information was discussed through the course

of an interview (Berg 2004). The interview schedule was established based on

discussions with community members, input from CENISMI colleagues, a review of

relevant literature, and health and social issues that have arisen during the course of

personal and work experience in the Dominican Republic. New questions arose as

interviews progressed, which allowed different lines of thought to be pursued. The

active interview process was recursive; that is, issues raised by one interviewee could be

addressed by others (Charmaz 2006). All of the interviews were conducted and

transcribed by the researcher.

Participant Observation

Throughout the course of the year in residence in the Dominican Republic,

observations were made while staying in the community. A lot of time was spent simply

talking with people casually and experiencing daily life. Through these types of

interactions, a researcher seeks to acquire sensitivity to understand and participate in the

assumptions that community members make about reality, and this helps lead to quality

data and appropriate interpretation (Murphy 1989). For example, one afternoon the

researcher sat with a woman on her porch and helped pick through and sort a large bowl

of pigeon peas, chatted about life and family, talked with passing neighbors, and helped

her granddaughter complete her math homework. This kind of interaction was imperative

for gaining access to the life-worlds of community members and crucial to establishing

sincere relationships. This research, therefore, consisted in moderate participation, which

is a balance between insider/ outsider and participation/ observation (Spradley 1980).

The researcher did not live in the community, but stayed as a guest with a host family for

several days at a time. In exchange for this housing, groceries were brought from the capital to alleviate the financial burden on the family of feeding an additional person. No other remuneration was provided in any part of the study.

Field notes about experiences, community life, and moments witnessed that had potential health implications were made. For example, one day, while walking in the community and visiting with people, children were found playing barefoot in a mud puddle of standing water with debris and a decomposition odor. This type of activity, and other less obvious moments were later recorded. Field notes were sometimes dictated directly to the tape recorder and later transcribed. This activity was done at different points of the day, but not in public. Additionally, field notes were written, again in privacy, usually during the midday lull in activity, and at night after participating in community activities.

Data Analysis

Written observations and transcripts of interviews and focus groups were analyzed for themes relevant to the research questions.. Transcriptions, interviews, and analysis were recursive, in order to incorporate ongoing findings into future interviews as issues and themes became clear. The goal of this process was to find themes in the transcriptions and field notes as they were analyzed. These themes were considered "significant truths", since they are based on the being and existence of the participants (Cohen 1995).

These themes are also interpreted during the write-up vis-à-vis so-called macro-social factors that are applicable to the lives of the research participants. The researcher also reflected constantly on the research and interview contents to attempt to expose her

own preconceived ideas and restrict their influence on the research enterprise. In the end, the point of an investigation inspired by phenomenology is to go to the "things themselves", as Husserl (1964:6) says, without being constrained by *a priori* truths and expectations. To achieve this end, phenomenologists use the method of "bracketing" prior experience, so that researchers deliberately disconnect the phenomena they observe, both from assumptions about causality in the outer world, and from internal preconceived ideas within the researcher's consciousness (Koch 1995). Experience, in other words, is the focus of all significant truths.

Interpretive Method

The goal during the data analysis process, as recommended by interpretive researchers, is to understand how details and experiences of events fit together, and with a larger whole, which in turn allows an investigator to understand better a situation (Todres and Holloway 2004). Two technical tactics of data analysis were used. In some instances, the qualitative analysis software program NVivo was used to code the interview transcripts (NVivo 2010). In other instances, themes were highlighted manually. This tactic was done sometimes out of necessity when NVivo software was unavailable, but also when re-living the interviews seemed to work better when dealing with a hardcopy of the transcript.

Interview transcripts and field notes were analyzed using an interpretive analysis to understand how the experiences that participants described, and their expressed perspectives, fit together to portray the construction of health in this community. Common patterns were sought, but unique experiences were not overlooked. Since the goal is not generalizability, important experiential data can be gleaned from so-called

outliers, or people with atypical experiences. A close examination of deviant cases, usually traded for generalizability in quantitative research, can bring attention to routine processes by comparison (Barbour 2001). Through analyzing these documents, the goal is to explain how community members operate, think about health and illness, initiate correctives, and manage their daily lives (Berg 2004).

Coding

The coding process began with *open coding*, which is designed to generate ample room for inquiry into the data (Berg 2004). In this phase, the transcripts and field notes were examined, with certain segments labeled, in an attempt to categorize salient elements. The goal was to determine concepts and categories that fit the data (Strauss 1987). Following Berg (2004), the researcher also made many theoretical notes as ideas emerged. These notes were later used when interpreting themes and examples, and informed the next stage of coding.

Identifying *coding frames*, similar to *axial coding* in grounded theory, was the next phase of analysis, which involved sorting the openly coded segments and creating rules for applying codes to certain elements (Berg 2004; Charmaz 2006). The grounded codes that were found in the detailed coding of phase one were collected together to form new categories. This process was not linear, and categorical groupings changed throughout the process as the documents continued to be analyzed.

Finally, having been immersed in the data through the coding process, the search began for patterns in the coding. At this stage, with codes grouped together, the relationships became clearer both between personal experiences, and how linkages are constructed to broader social issues.

Conclusion

This chapter attempts to illustrate, through a discussion of methodological issues, how constructivism is put into practice. Issues related to conducting culturally appropriate and sensitive work are reviewed, while addressing the methodological tactics employed in the design and implementation of this study. The study design is outlined and the rationale for the process of analyzing data described. The next chapter will present the findings from the analysis of the interviews and participant observations.

Chapter 5: Analysis and Findings

La interpretación de nuestra realidad con esquemas ajenos solo contribuye a hacernos cada vez más desconocidos, cada vez menos libres, cada vez más solitarios.

The interpretation of our reality through paradigms not our own serves only to make us ever more unknown, ever less free, ever more solitary.

~Gabriel García Marquez, Nobel Prize acceptance speech, 1982.

The usefulness of health programs, illness prevention, and treatment policies is dependent on the relevance of interventions to the people who make decisions about the quality of their lives. By using participants' own words, justice is given to their interpretation of reality, instead of obscuring this outlook with the author's own world-view[1]. After all, the goal of the constructivist position is to liberate voices, or at least not contribute to intellectual colonization (Coates, Gray, and Hetherington 2006; Golinski 2005). While the role of the sociologist is to interpret and contextualize, the analysis presented below attempts to do so from a standpoint that stays close to the reality of the participants.

The focus of the analysis hinges on interpreting the ways in which people speak about factors in their lives have impact on their health. Some of these elements relate to direct healthcare decisions, such as deciding if and when to see a doctor. Others are about broader aspects of life, and have both intentional and unintentional consequences for health, but are, nonetheless, health-relevant. Indeed, identifying and interpreting the health-relevant choices and motivations of persons is done within these decision-making

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[1] In this vein, all quotations are left in the original language of participants, this is Spanish, Haitian Creole, or a mixture of the two. When translated into English, grammatical informalities were standardized to increase understandability to the reader.

environments that encompass many aspects of their lives. The answers of participants are not evasive when they answer questions in a broad way. Through dialogue in the interview process and in daily life, these people are evaluating sincerely health issues, not redirecting inquiries about health to a different topic. The interviews were very clearly focused on individual, family, and community health and health-related problems, motivations, and aspirations. Within this interview context, participants often led the discussion toward elements of life that are seemingly beyond the scope of health from a typical epidemiological standpoint, but were deemed important from the perspective of the participants.

Through the course of the interviews, and time spent in the community, health is identified as a common preoccupation and is defined very broadly. In fact, through the course of people's lives, their lived biographies, experiences, and explanations of these experiences, they have created and accumulated a "stock of knowledge" from which they draw while living their lives (Schutz and Luckmann 1973). This information forms the base of experience tapped into during these interviews about health, and clearly inform the ways that they explain health. In other words, this cumulative stock of knowledge that is collected about life experiences forms a decision-making environment that participants use to make sense of their health.

Demographics

A summary of basic demographic characteristics of the study participants is shown in Table 1. This description is offered to contextualize the participants, rather than provide a comprehensive description of their lived realities. The sample consists of thirty-five (35) interviewees, thirteen (13) men and twenty-two (22) women. They all live in

rural poverty, although some people are materially better off than others. Because race and ethnic issues in the Dominican Republic (DR) are different from the U.S., in this particular context the most crucial factor is that fifteen (15) participants were born in Haiti and immigrated, all without legal documentation, in search of work to the Dominican Republic (Grasmuck 1982; Martínez 1999). The remaining twenty (20) participants were born in the Dominican Republic, but many of them, despite being born in the DR, do not have citizenship. Nearly everyone in the community speaks both Spanish and Haitian Creole.

Many of the women in the sample were born in other batey communities and moved to Batey Algodón upon marriage. Several participants are still finishing high school, and one graduated from a university (in medicine) and is completing an internship (*pasantía*) nearby. The younger participants, namely, those under thirty, who were Dominican-born, tend to have achieved some early high school education, while many of the youngest women in the sample with children continue to study in high school. Those who immigrated from Haiti tend to have, at best, only basic primary education, which is cited often as a reason to why they left Haiti. In short, their families were too poor to send them to school or give them other resources. A roadblock to higher education levels that many reported, both Dominican-born and Haitian-born, is that documentation of citizenship is needed to enter the upper levels of secondary education that neither group can produce.

The women in the sample range in age from eighteen to sixty (18- 60) and have a mean age of thirty-three (33) years. The men in the sample range from twenty to eighty (20- 80), and have a mean age of thirty-four (34). Female participants have an average

number of 4.4 children (with a range of 0- 12). The men in the sample have an average of

2.5 children (with a range of 0- 8). Formal marriage is not a common practice in rural

areas in general in the DR, and nobody in the sample was legally married. Conceiving

children is generally how long-term, more or less monogamous partnerships are formed.

Of the twenty-one (21) women with children, sixteen (16) reported being in stable

relationships, although many of the male partners lived elsewhere to work in order to

send money home. Of the nine (9) men with children in the sample, eight (8) reported

being in stable relationships with a partner. Only one man with a child reported his child

being raised by his mother in the capital. Several of the participants in the sample are

raising grandchildren, while their grown children are working or pursuing education

elsewhere in the country.

Figure 1: Demographic characteristics of the sample

	Women (n=22)		Men (n= 13)		Total (n=35)	
	Frequency	Percentage	Frequency	Percentage	Frequency	Percentage
Education Level						
None	3	13.6%	5	38.5%	8	22.9%
Some primary	16	72.7%	4	30.8%	20	57.1%
Some secondary	3	13.6%	2	15.4%	5	14.3%
Completed hs and above	0	0%	2	15.4%	2	5.7%
Place of Birth						
Dominican-born	17	77.3%	5	38.5%	22	62.9%
Haitian-born	5	22.7%	8	61.5%	13	37.1%
Mean Number of Children	4.4	-	2.5	N/A	3.7	-
Mean Age	**33**	-	**34**	N/A	**33**	-
18-30	13	59.1%	7	53.9%	20	57.1%
31-50	6	27.3%	5	38.5%	11	31.4%
51-80	3	13.6%	1	7.7%	4	11.4%
In Stable Partnership	16	72.7%	8	61.5%	24	68.6%

An analysis of these interviews revealed many themes regarding health and decision-making processes in the community. Themes are discussed using quotations from the participants to stay true to how these people explain and define themselves, but are also interpreted through a sociological lens. Additionally, these themes are linked to broader social processes and tied to relevant literature that can help frame pertinent issues, while still giving authority on a given health or decision-making matter to the participants. The themes that emerged are discussed under five overarching concepts: Re-definitions of Health, Normalization of Hardship, Resource Availability, Life Decisions, and Gender Roles and Norms. Under these broad concepts, more specific themes are dissected. Figure 1 shows the conceptual map of how these themes came to be organized in the mind of the researcher, and presented in the rest of the chapter.

Figure 2: Conceptual web of themes
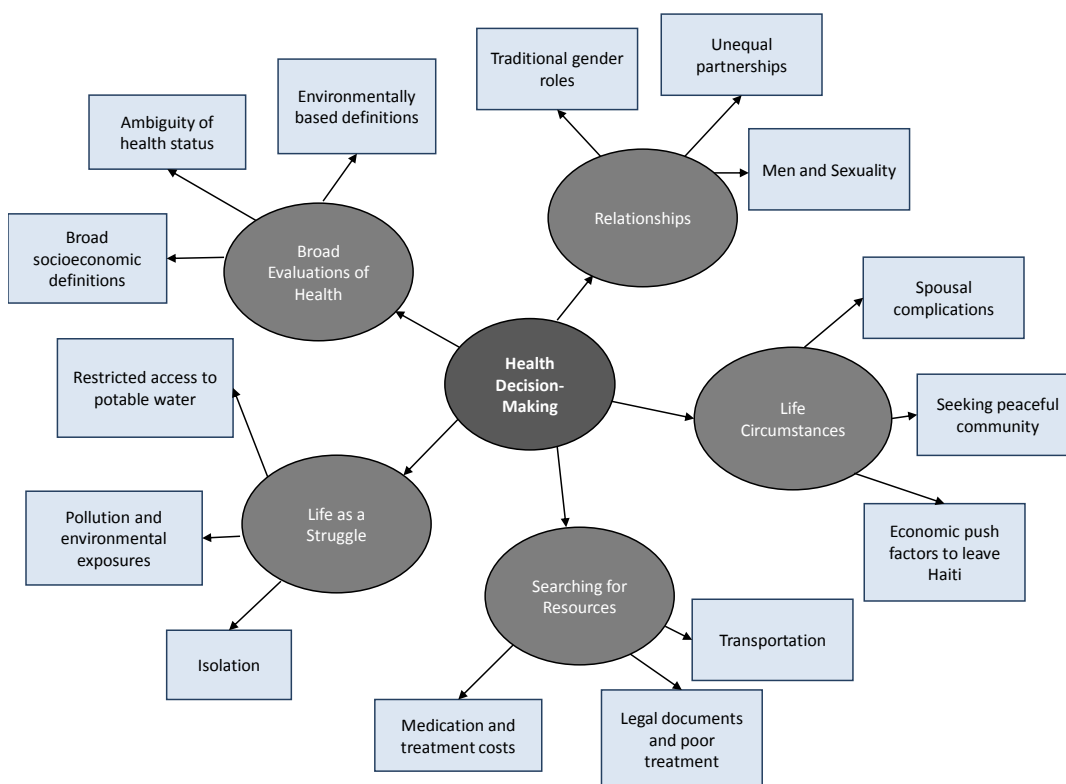
Broad Evaluation of Health

Most important is to understand the decision-making environment in which
people act that have impact on their health, both within the medical system and through
decisions in daily life, how they construct definitions of health and illness is very
important (Kleinmann 1995). In this study, participants explained health in ways that
would not be captured by a traditional epidemiological survey, and, in fact, included
many more broad and holistic aspects of life. Many participants responded to questions
about their health and that of their families by reporting physical ailments, such as high
blood pressure, skin infections among children, fevers, minor injuries, chronic stomach
pain, parasitic infections, headaches, dizziness, respiratory problems, and the common
cold. These responses are health problems defined within the biomedical model, but
were often addressed in ways that may be missed by an epidemiological survey, such as
home remedies, prayer, waiting, and making teas designed to address specific problems.

In addition to focusing directly on health problems, alternative ways of answering
health questions surfaced repeatedly, and these consisted of reframing and constructing
new definitions of health. These were not evasive maneuvers, but constructions of health
that persons deemed relevant. These components are recognized commonly in holistic
approaches to health research and are important with regard to how people make
decisions about their health (Link and Phelan 1995; Freund, McGuire, and Podhurst
2003). The overarching theme of these redefinitions is that a broader socioeconomic view
of health was constructed by respondents. Interestingly, the way many respondents
constructed health aligns remarkably with the World Health Organization's definition of
health, whereby this construct is described as "a state of complete physical, mental, and

social well-being and not merely the absence of disease or infirmity" (WHO 1948 p. 2).

First, many people broadened the definition of health by including other social issues in

their answers to explicit health questions, such as employment concerns, food insecurity,

and financial instability. Second, they often cited environmental issues and immediate

living conditions in response to health questions. And third, people often used language

that evokes ambiguity about their health status, oftentimes because they are functional on

a day to day basis, even if they do not feel completely healthy or are not free of stressors,

such as worrying constantly about the source of their next meal.

Theme: Broad socioeconomic definition of health

One common way of expressing definitions of health came about when people

responded to the general questions, "How is your health?" **(¿Cómo está su salud?)** or

"How is your family's health?" **(¿Cómo está la salud de su familia?)** In effect, the

question was often co-opted by the respondent with an answer that evaded the direct

question of health and, in turn, reframed health in terms of socioeconomic well-being.

This response was common particularly in the interviews conducted with parents of

young children when they responded to questions about the health of their families.

Instead of discussing an affliction or infirmity, they focused on the material necessities

that they struggle to provide for their families. This rejection of a narrow definition of

health reflects the ways in which these people see health as integrated into their lives,

general well-being, and security, particularly in terms of their economic struggles

(Freund, McGuire, and Podhurst 2003).

When asked about any preventive measures taken against illness and injury in her

own family, Elvida, a forty (40) year old mother of six (6), talks about the informal work

she pieces together to provide for the basic needs of her children. In her answer, she

defines clearly what she considers to be relevant to a question about health: money and

her ability to provide food for her children. In answering the very direct question about

how she keeps her children healthy, she answers by stating that she is always hustling in

the informal economy to protect their health. As Elvida stated:

H: ¿Qué hacen en la familia para prevenir enfermedades o daños?
E: Bueno, cuando yo estoy negociando, vendiendo ropita, reguero, vaina. ¡Imagínate!
H: ¿Para tener dinero?
E: Buscando pesitos para los muchachos, la comida.

H: What do you do in your family to prevent illness and injuries?
E: Well, when I am in business, selling clothes, crap, things. Imagine it!
H: To have money?
E: Looking for money for the kids, for food.

In two instances, persons respond to general health questions by framing this

issue as a constant battle that encompasses many aspects of life. The combative imagery

that they evoke shows the constant health-related hardships that people face. When asked

about the health of her family, Nicaura answers:

N: Bueno, luchando. Luchando para tener su dinerito nada más. Luchando para trabajar. A veces halla [trabajo] un día, a veces no. Un mes se sienta en la casa no halla nada.

N: Well, struggling. Struggling to have a little money, nothing more. Struggling to work. Sometimes you find [work] sometimes you don't. For a month you can sit in your house and not find anything.

She explains health in terms of a constant battle of searching for work and a job.

In this way, she constructs a definition of health that encompasses these pressures and

includes having money and food for her family. Effectively, she directs her answer to a

broad definition of what she considers to be health. This construction includes money and

work and goes beyond traditional health assessments. This imagery of a constant battle

for health is also evoked by Luisa, a primary school educated, partnered, twenty-eight

(28) year old mother of four children. She describes a battle that she constantly wages to keep disease out of her home:

H: ¿Que hacen a propósito para prevenir enfermedades o danos en la casa tuya? **L: Bueno, si está jodiendo en la calle pataleando por ahí, esto solamente puede llegar ahí. Pero si yo estoy allí yo no estoy haciendo eso en la calle. ¡Esa vaina puede venir para acá! ¿Qué busca? ¿Para dónde que va esa enfermedad? ¡Para ninguna parte!**	*H: What do you do intentionally to prevent illness or injury in your home?* *L: Well, if it is messing around in the street, kicking it around here, then it can come here. But if I am here and not engaging with it in the street. That thing can come here! What is it looking for? Where is this illness going? Nowhere!*

This anthropomorphism of disease helps explain her decision-making vis-à-vis health. She later continues to explain that her infant daughter has had a cold for a month, a fact that is stated matter of factly. But she is not being treated for her cold. If health is viewed as something that enters the house, like a natural and constant occurrence from the outside, she and her partner's decision not to seek medical care for their severely congested infant reflects this inevitability. If something sneaks through, there is not much that anyone can do.

Similar views that invoke the inevitability of difficult living situations and health problems are brought up by others through the course of interviews and may reflect a religiously-based cultural norm that God is in control of the situation,. Some exclamations that participants used in interviews are: "After God, nobody can control anything!" ("**Después de Dios, nadie puede controlar nada.**"), "God knows what he is doing for us poor folk!" ("**¡Dios sabe lo que hace para los pobres!**"), referring to a sick person, "He is God's love." ("**Él está en el amor de Dios.**") , and lastly, "I have faith that God has to send a medicine that can cure the boy. It just is." ("**Yo tengo fe que Dios tiene que mandar una medicina que se puede curar al muchacho. Es así. "**).

Throughout the interviews, the references to God being in control resurfaces regularly

and are considered throughout the analysis. References to God are relevant in this theme

of broad socioeconomic conceptualizations of health because persons refer to God's role

in finding work and inventing medicines.

When asked about what she does to prevent illness and injury to her children

Genia exclaims:

G: Bueno, para mí, nadie está preparado pa' esto. Lo que sabe es Dios. Porque si viene enfermedad, uno no sabe que va a hacer. ¿Llevarlo pa' los hospitales? Después ora para esto. ¿Qué va a hacer? Nada más. Yo no sé, la gente que no eran cristiano, que van a decir, pero para mí, hay que orar primero y llevarlo al hospital. Dios sabe lo que va a hacer.

G: Well, for me, nobody is prepared for that. The only one who knows is God. Because if a disease comes, one doesn't know what to do. Take them to the hospital? And then pray. What are you going to do? Nothing else. I don't know, the people who aren't Christians, what they would say, but for me, you must pray first and take them to the hospital. God knows what he is going to do.

A common way of negotiating the definition of health, and what is relevant to

perceived health status in this study, was to respond with answers about economic

opportunities. Instead of answering strictly about community health, Luisito, a thirty (30)

year old father of four (4) young children, redirects the answer to express a daily concern

over providing basic sustenance for his children.

H: ¿Cómo está la salud en la comunidad en general?
L: Faltamos a veces combustible pero comoquiera a Dios nos ayuda buscarla. [*Riéndose*]
H: El combustible, ¿eh?
L: Sí. Esto es la comida. Sí porque a veces uno se levanta al día y no sabe de donde viene y con Dios adelante a veces uno salga y pasa el día bien. Porque no tenemos empleo ni nada.

H: How is the health in the community in general?
L: Sometimes we lack fuel but somehow God helps us to look for it. [laughing]
H: Fuel, huh?
L: Yes. This is the food. Yes because sometimes one gets up for the day and you don't know where it is coming from, and with God's guidance you get through the day. Because we do not have employment or anything.

Again, the invocation of God as a kind of coping mechanism to reassure that

some kind of answer will be figured out is poignant in Luisito's description of

community health. This cultural imagery of God as having a plan is one way that Luisito

frames his response about community health. Luisito also includes economic viability in his definitions of his own health. When asked directly about his health, he says, **"Good because I am working, thank God, even though it is just watering plantain trees."** (***"Bien, porque estoy trabajando, gracias a Dios, aunque echando río en los plátanos."***) His definitions of health for both himself and the community as a whole are partially, if not primarily, defined by income and availability of sustenance.

Ismael, a twenty-one (21) year old recent immigrant who works in security at the sugar processing plant, describes health as tightly linked to economics and employment opportunities in a very succinct way during follow-up questions pertaining to an earlier statement about his good health. He equates directly health and money:

H: ¿No tienes ninguna queja de salud?
I: Sí, yo tengo algunas [*sic*] problemas.
H: ¿De qué?
I: Problemas de cuarto. [*Riéndose*]
H: Y ¿ésto tiene que ver con tu salud?
I: Sí.

H: You don't have any complaints about your health?
I: Yes, I have some problems.
H: Such as?
I: Money problems. [Laughing]
H: And this relates to your health?
I: Yes.

Shortly thereafter, when asked about how he and his brother do, in fact, maintain good physical health, Ismael replies that the reason is that they "work and stay strong" ("**Trabajamos. Mantenemos Fuertes.**"). In this regard, health is equated essentially with the earning of regular income for many participants, whether they are providing for others or not. Ismael views his good health as related to having employment, is proud of being able to work, and explains his good health as a result of this work. Pride is revealed in the way he speaks about being employed. Likely, this feeling stems from both the physical and psychological significance that he attributes to his job and that together this satisfaction keeps him healthy.

Luis, an eighty-something year old who has lived his whole life in the region and has worked both cutting sugarcane and in the factory, was asked how he views the health of the community. His response illustrates further the broad definition of health that relates to economic conditions:

L: Mala. Mala. Mala. Hay a veces que no halla trabajo. Hay a veces los viejos no pueden trabajar ya. No puede trabajar. Con estos chilitos que dan a uno no se gana nada (de seguridad social)! Los chelitos a mí, con cinco (5) muchachos que tiene que darle comida (sus nietos). Las cosas están caras ahora.	*L: Bad. Bad. Bad. There are sometimes when one cannot find work. Sometimes the old folks cannot work anymore. They cannot work. With these pittances they pay one doesn't earn anything! (From social security) These pittances I get with these five (5) boys I have to feed. Things are expensive now.* \

Similar to other participants presented here, unemployed, formally employed and informally employed, Luis, a retiree who receives basic government social security still holds a vision of health that is broader than most definitions used by epidemiologists. In his case, health is portrayed as basic securities and his ability to care for his grandchildren.

Theme: Environmentally based definitions of health

The physical environment in Batey Algodón provides challenges to residents. As in many societies, women bear the brunt of housework and household responsibilities, and therefore must contend daily with the physical environment. For example, the roads in the community are unpaved and when it rains houses can flood and roads become impassable from the mud. And when the weather is hot and dry, dust from the roads permeates everything in the community. Houses must be maintained constantly to keep the dirt and dust outside, because if closed up these homes become swelteringly hot.

There is also a drainage canal that runs through the center of the community that is necessary agriculturally to eliminate runoff water from the sugarcane. But people throw garbage in there and everything gets backed up. In addition, many pigs are kept

near the edge of the water, children sometimes play in the canal, and in the summer the stagnant water becomes a breeding ground for mosquitoes.

The community is also along the edge of the sugarcane, and when the cane is high people complain of rats, mice, and mosquitoes that come into the houses from the fields. Additionally, the community is located on the edge of the highway, with one row of houses about five feet away and below this road. Such proximity can create a danger for young children who must be watched carefully. All of these environmental issues provide the context where health-related decisions are made.

Nelcida is a twenty-four (24) year old single mother of four (4) children, the eldest of whom is seven (7) years old. Nelcida is one of the few people, especially among women, who has a relatively stable job, although in the informal sector. Six days a week she works as a housekeeper for a family that lives in nearby Barahona. She leaves her children with her mother while she works, but the oldest three are often found running around the batey all day long in bands of young children. Nelcida constructs the possibility of health for herself and her family as contingent on her physical environment and living situation. When asked what she would do differently to protect her health and that of her family, she responds:

¡Oh! Si yo pudiera, me mudara a otro lugar. Sí. Que sea más cómoda. Que no sea un bateycito como lleno de tierra así. Haría una casita mejor para yo poder vivir donde que no hay, como te digo, como muchas cosas que crían como animales. Sí, porque allí crían también y el mal olor viene allí también. Todo el [*sic*] charco de agua también. Si yo pudiera, me mudara para Barahona, o La Capital, porque allí se ve más cosa, más limpio.	*Oh! If I could I would move somewhere else. Yes. Somewhere more comfortable. Somewhere that is not a little batey full of dirt like this one. I would build a better little house where there aren't, how do I say this, like so many people raising animals. Yes, because from the pens comes a bad smell. All of the puddles full of water also. If I could, I would move to Barahona or the Capital because there everything appears cleaner.*

Essentially, she views the fact of living in Batey Algodón as detrimental to her health and that of her children. She responds to a direct health question by linking health to broader social and environmental concerns. Nelcida and her children live in a one bedroom barrack that was built originally for migrant sugarcane workers and does not have a bathroom or access to a community latrine. From her perspective, as the sole financial provider for her children, the living situation she is able to provide is central to the way she views her family's health.

The drainage ditch from the sugar cane field is a particular concern to residents, and nearly all respondents mentioned that they worry about the potential for disease transmission as a result of the sludgy consistency of the contaminated water or the slow flow that supplies a breeding ground for mosquitoes. Almost all of the participants talked about the nuisance of mosquitoes, particularly during the wet season when these insects are rampant. Although they have the knowledge that standing water leads to breeding, with the community built around this drainage ditch everyone must cooperate to keep this facet of the community clean. An individual or family's decisions about maintaining their house, and not leaving standing water in their own patio, means absolutely nothing when the drainage ditch is in such close proximity. Angela, an eighteen (18) year old mother of one who is in high school, expresses a common sentiment of concern about the disease producing possibilities of the ditch:

H: ¿Cuáles cambios en la comunidad en general ayudaría la gente ser más saludable?
A: Bueno, ¿cuáles cambios? Ninguno porque… Ah! Sí. Como que el drenaje que está allí, como limpiarlo y sacarle la basura para que no produzca dengue.
H: ¿Esta cañada que sale de la caña?
A: Sí, el agua negra, y todo eso. Para que no produzca dengue. Para que no produzca enfermedades.

H: What changes in the community in general would help people to be more healthy?
A: Well, what changes? None because…. Oh! Yes. Like that drainage ditch there, like to clean it and take the garbage out of it so it doesn't produce dengue.
H: The canal that comes out of the cane field?
A: Yes, the black waters and all that. So it doesn't produce dengue. So it doesn't produce illnesses.

In answering a direct question about how to improve the health in the community, Angela proposes a solution whereby health is defined at the community level and based on environmental issues and the risks that the local environment poses to all Batey Algodón residents (Dunlap and Catton 1994; Obrist, Van Eeuwijk, and Weiss 2003).

During a joint interview with Genia and Emilia, their definitions of health encompass clearly environmental issues, as well as an explanation of health depending on God's will:

H: ¿Cómo está la salud de la comunidad?
G: Bueno, la salud de la comunidad, cuando está lloviendo, nosotros tenemos problemas.
E: Esto es malo.
G: ¡Allí no hay camino para poner los pies! Ay mi madre, está acabando a uno.
E: Por allí hay un charco que tiene agua sucia.
G: Esto se da enfermedad a los muchachos, verdad. Cuando uno huele esto. Tiene un bajo. Yo no sé para otros, pero para mí, esto no está bien.
H: Y Ud., ¿cómo se ve la salud en la comunidad?
E: La salud de la comunidad, como dijo ella, así mismo. Uno levanta hoy. Hoy tu hallas algo pa' comer. Mañana tu no hallas nada. Entonces, uno da gracias a Dios que uno se siente ahí hablando. Si tu estas acostado allí, hay gente que le están poniendo cuchara en la boca. Esto es peor. Bueno, estamos bien. Gracias a Dios. Si uno halla comida, hay que decir, Gracias a Dios. Cuando Dios quiere. Y si no halla, ¿qué va a hacer?

H: How is health of this community?
G: Well, the health of this community, when it is raining, we have problems.
E: This is when it is bad.
G: There is no path to put your feet! Oh my goodness, it finishes you off!
E: Over there is a ditch that has dirty water.
G: This makes the kids sick, it is true. When you smell that. It stinks. I don't know about others, but for me that is not good..
H: And you, what things do you see in the community?
E: Health in the community, like she said, the same. One gets up today. Today you find something to eat. Tomorrow you find nothing. So, you give thanks to God that you are sitting here and talking. If you are laying down there, There are people with some one spoon-feeding them. That is worse. So, we are good. Thank God. If you find food you need to say, Thank God. When God wants. And if you don't find it, what are you going to do?

The way Emilia explains her references to God in this context seem to be a resignation of fact and a recognition that the difficulties one faces are the product of God's wisdom. In particular, Genia demonstrates the way that community health questions were broadened by some participants to capture environmental issues. She says that the rain is bad because, afterward, she cannot visit with people, attend church, or interact with others. Therefore, environmental factors contribute to one's health,

Ambiguity of health status

For most, there is a constant battle with dirt, microbes, mosquitoes, illness, waters, and hunger. At the same time, life goes on. Participants commonly answered the question, "How is your health?," by saying "in between" ("**entre dos**"). Through follow up questions about what they meant by "in between", participants often explained health in terms of functional well-being. Even if they did not feel confident that they were completely healthy medically, or felt that they had the potential to feel better and have more energy, they were able to function on a day to day basis.

Lisa, an eighteen (18) year old woman pregnant with her first child, constructs health in terms of what she considers appropriate and desirable social functioning. When responding to a general question about the health of the community as a whole, she stated:

L: Bueno, la salud está bien. Todos están bien, sí. Porque caminan, corren, aquí paran, están embarazadas, y todos están marchando a la profesión.

L: Well, health is good. Everybody is good, yes. Because they walk, run, here they stop and chat, they are pregnant, and everyone is working towards becoming professionals.

She describes health in terms of appropriate physical functioning for someone her age, in terms of educational and professional aspirations. During the course of the study, Lisa gave birth to a healthy baby girl, and with the financial support of the father who

works in the capital and sends money, along with the childcare assistance of her mother and sisters, was able to continue her high school education. From Lisa's perspective, becoming a mother was not mutually exclusive with continuing her studies, and in fact her pregnancy contributed to a holistic sense for her of being healthy and strong.

Others conceptualize health in terms of the superficial side that they show to the world, which demonstrates this "entre dos" duality of health, or what you see is not necessarily indicative of what is happening on the inside. Alicia, a forty-four (44) year old mother of twelve (12), and caretaker of six (6) young grandchildren, has been battling with a severe pain in her left ribcage. She has undergone multiple examinations and has been told varying things, such as her heart is inflamed and she has a fatty liver, but is in the process of a three month wait for the actual biopsy results. She explains how she functions on a day to day basis, and walks and talks, but that nobody knows what is going on inside her body unless she imparts this information:

A: [Y]o misma estoy bregando con mi dolor y si no explico a nadie, no se van a dar cuenta. Porque me ven hablando, caminando, y nadie sabe lo mío. ¿Ves?

A: I myself am battling with my pain and if I do not explain it to anybody, they are not going to realize this. Because they see my talking, walking, and nobody knows what I am dealing with, you see?

In an alternate construction of health, Dominic Pierre, a thirty-one (31) year old father of four (4), explains how he looks healthy from the outside, but he has no idea if anything bad is happening internally. He exudes a *joie de vivre* if he doesn't notice functional limitations or external manifestations of ill health, and thus is not ill for all practical purposes:

DP: Bueno, yo estoy bien porque no estoy enfermo. Se ve por el superficial que no estoy enfermo. ¡No sé por dentro!

DP: Well, I am good because I am not sick. You can see superficially that I am not sick. I don't know about on the inside!

Others engage frankly with the hardships of life on the batey and have an air of practicality when discussing health and illness, life and death. Many people have led lives of material hardship and reality is stark and honest. Roberta is a thirty (30) year old mother of seven (7) children. During the interview, her four youngest sat nearby with knives and machetes chewing on sugar cane, and this was the only food the family would eat that day. When asked about health in the community, Roberta answers without mincing words:

R: Aquí, yo puedo decir que está [salud] bien porque una gente que estaba enfermo ya se murió.

R: Here, I can say that it [health] is good because one person who was sick has already died.

Lively, boisterous conversationalists, Berta and Emilia define their health also in terms of what they deem appropriate daily functioning for two middle aged women:

H: ¿Cómo está su salud?
G: Bien.
E: Bien. ¡Está bien porque nosotros estamos aquí!
G: ¡No estamos acostadas, estamos sentadas! Estamos hablando.

H: How is your health?
G: Good.
E: Good. It is good because we are here!
G: We aren't laid up, we are sitting up! We are talking.

As is illustrated, the participants often began with the broad characterization of their health status as "in between", but then continue on to express the ways that they function. There is a sense that one should not complain, or express ungratefulness to be able to engage in life's daily tasks. Even if a person is not sure they are healthy, or does not feel completely healthy on the inside, the physical day to day functioning seems to outweigh this alternative designation of being ill.

Life as a Struggle

The ways that people make decisions, and what they consider to be relevant for health, are not universal but contingent on the world that they construct (Bordieu 1990; Kleinman 1995). Clearly human beings are unique in the sense that they can imagine other possibilities, and extrapolate from the experiences of others. However, there are often limitations to the world one can imagine based on the reality in which one lives; there can be limitations on both imaginative and physical capacities. Living in sheer poverty, where one is concerned with daily necessities, extending beyond the immediate reality can appear impossible. In Batey Algodón, three themes about hardships in daily life stood out as participants discussed their health. These themes relate to the relativism that characterizes normal experience and what is possible, and how these interpretations influence decisions about health. These themes coalesce around the issue of access to resources: the lack of access to potable water, the accepted nuisances of environmental exposures, and the physical isolation of the community, along with a paucity of ideas, media, and social exchanges.

Additionally, many of these daily hardships that community members face were discussed in the context of the belief that struggle is part of God's plan. This fact may be a coping mechanism in the face of hardship, or a straightforward acceptance of life. Many participants invoked God regardless of religious affiliation, and thus this type of imagery seems to be a generalized cultural phenomenon, and not solely a religious one. The use of God to explain struggles is a recurring thread throughout interviews. For example, Elvida states in her interview, when asked what she would different for her family health-wise if

anything were possible, *"This is it. God gives us our life. [laughing]. Easy."* ("**Esto. Dios nos da nuestra vida. [riéndose] Tranquilo.**").

Theme: Restricted access to potable water

Briefly, issues related to potable water provide the context for this theme. Several years ago, the Dominican government laid water pipes through the center of Batey Algodón to provide running water to a larger Dominican community several kilometers away, but did not open a pump in Algodón. So, community leaders in Batey Algodón solicited collaboration with an NGO and the Dominican government to gain access to this water, according to the pastor. They tapped into the pipes directly under the community, installed a chlorination treatment plant, and placed several pumps around the area. The water is not safe to drink (without boiling first) and is not tested or maintained for potability, but is acceptable for cooking, cleaning, washing, and bathing.

The community also, through collaboration with a faith-based organization, built and maintains a water filtration system for refilling large water bottles for drinking purposes. In DR, people typically purchase refills for *botellones*, 5 gallon plastic water containers, for household water consumption. Community members are charged only 10 pesos (approximately $0.25 USD) to refill these *botellones*, while the going rate from water trucks that sporadically pass by the community was reported by participants to be 50 (approximately $1.23 USD). This water system had been in place for over a year, but in November, 2012 this system was locked up by the Dominican water company because this facility was not registered with the government, even though a licensed hydrological engineer visited once a month to maintain this operation.

Filing the paperwork to become registered with the water company, according to the pastor, is on the order of $1000 USD. He also explains that the process is not straightforward and bribes must be paid. So, the potable water that people had grown accustomed to at an affordable price is no longer available, and the 50 pesos price is too high for many impoverished households. However, people are no longer used to boiling the water that comes from the pump, and feel somewhat safe that this water is chlorinated. This behavior has led to a perilous public health situation, since they drink from the pump regularly with little concern for their well-being. Since the water treatment facility closed during the course of the fieldwork, some interviews occurred under both circumstances.

Mothers, who tend to be the primary caregivers, noted regularly that children are mischievous, and even if you have bottled water in the house, as soon as no-one is looking they will drink tap water. The decision not to discipline children for drinking pump water appears to be a combination of not believing that the water is impure (although several respondents complain of stomach problems resulting from the water) and fatalism about leaving things up to God. Genia and Emilia talk about the habits of their young children:

H: Y para practicas más cotidianas, como agua y si los niños toman de la llave…
G: Bueno, para esto, Ud. sabe que los muchachos son… cuando uno compre agua del botellón, ¡siempre los muchachos salen a la calle y beben agua de la llave! De esto yo no puedo contestar, porque Ud. sabe los muchachos…. ¡De balde!
H: Por lo menos el agua de la llave viene clorificado.
G: Exactamente, aquí hay agua bueno.
E: Ellos andando jugando y beben agua mala.
G: Ellos beben comoquiera.
H: ¿Aunque tú tienes del botellón en la casa?
G: ¡Está ligado! ¡Está ligado!
E: ¡Hay que llamar a Dios!
G: ¡Exactamente! ¡Dios sabe lo que hace para los pobres!

H: And for more daily practices, like water and whether the children drink from the tap…
G: Well, for this, you know how kids are… when you buy bottled water, and the kids always go out to the streets and drink tap water! That I can't speak to that because you know how kids are…. It is in vain!
H: At least the tap water is chlorinated.
G: Exactly, here there is good water.
E: They run around playing and drink bad water.
G: They drink it no matter what.
H: Even though you have bottled water in the house?
G: It is mixed! It is mixed!
E: You have to pray to God!
G: Exactly, God knows what he is doing for the poor!

Genia and Emilia know clearly that drinking tap water is not ideal for their children, but they leave this problem in God's hands. They decided not to enforce water issues in their households because they feel as if they do not have control of the situation and they do not know whether children are basically difficult or whether God has an unknown plan.

Another hindrance to decision-making vis-à-vis water consumption was the need to be attentive to the arrival of water trucks in the community, which sometimes simply does not happen. A family's living situation may limit access, especially in households where there is not an adult at home all day to wait for the arrival of the truck. Teny explains that since the closing of the filtration system, he buys from the truck when he has money to do so; however, this strategy is not always an option:

H: ¿Cuál agua toman en la casa? ¿Entiendo que el envasador de agua buena no está funcionando?
T: No. No está funcionando. Por ahora, cuando las guaguas no pasen, nosotros bebemos agua de la llave. Siempre me da dolor de barriga también.
H: ¿Te da dolor de la barriga? ¿Aunque viene con cloro?
T: Sí. Me da dolor de la barriga.

H: What water do you drink in the house? I understand the water system is no longer working.
T: No. It is not working. For now, when the trucks don't come by, we drink water from the tap. And it always hurts my stomach.
H: It makes your stomach hurt? Even though it is chlorinated?
T: Yes. It gives me a stomach ache.

Even before the water treatment plant closed, however, there were still major issues related to potable water. Many people made the decisions to drink tap water, either because this option did not pose a perceived risk, or because they decided to allocate the little money that was available to other things. Ismael, frustrated by financial restrictions, explains he prefers good water, but has no money:

H: ¿Qué es el agua que toman para beber?
I: El agua, ¡cualquier agua yo me bebo!
H: Oh ¿sí?
I: Sí. Ya tu sabes las cosas están mal.
H: ¿Es por falta de dinero?
I: Falta de dinero para comprar agua, agua buena para beber.
H: ¿Así que te tomas agua de la llave?
I: Sí.

H: Which water do you guys drink?
I: Water? I drink any water!
H: Oh yeah?
I: Yes. You already know things are bad.
H: It is because you don't have money?
I: There is no money to buy water, good drinking water.
H: So you drink from the tap?
I: Yes.

Only two (2) participants out of thirty-five (35) reported that they boiled water from the tap. The vast majority bought bottled water while the filtration system functioned, but those who drank tap water before the system closed seem to be most knowledgeable about proper treatment. None of the people who reported switching from bottled water to tap water after the closure of the treatment facility boiled their water for consumption, even for children.

Rafael and his wife have eight (8) children, all of whom are school aged or younger. Neither parent has steady work, and with that many children in the household the purchase of water is not feasible. They used tap water even while the more affordable

filtered refills were available in the community. They talk with their children about these

issues and teach them about water and hygiene as part of an active parenting style. Rafael

and his wife make conscious decisions regarding water consumption and health. Since

they cannot afford to purchase water, they must take the necessary steps to protect their

children from acquiring a water-borne illness:

R: Nosotros compramos esta agua buena y cuando no hay, hervimos agua con cloro, y lo ponemos a enfriar para nosotros usar.	*R: We buy good water and when we don't have [money], we boil water with chlorine and we leave it to chill for us to use.*
H: ¡Te puede salir muy caro comprando agua con 8 muchachos en la casa!	*H: It can get very expensive buying water with 8 kids in the house!*
R: ¡Sí! Y para proteger [sic], hay que comprarlo. Si no lo compramos, las enfermedades se entran y se pone peor. Es mejor uno comprar agua para cuidar la salud.	*R: Yes! And to protect, one must buy it. If we don't buy it, sicknesses come in and it gets worse. It is better for one's health to buy water.*

Access to potable water is a major concern in many parts of the world (Sullivan et

al. 2003). Women often bear the brunt of the labor associated with collecting and treating

water. Due to this division of labor, this means they may be exposed to water-borne

illnesses more than others (Cannon 2002). Access to water in Batey Algodón has

improved greatly in recent years. Indeed, people used to fetch stream water some distance

from the community for all their needs. Now that people are accustomed to having access

to bottled water, and even chlorinated tap water, they seem to be out of practice with

respect to taking the precautionary measures they would have done previously as second

nature. There are certainly nuisances to boiling water, especially since many people in the

community do not have gas stoves and cook over an open fire, but these problems are

common to many people in rural areas in the DR. The recommendation in the country as

a whole, which is usually followed at least for small children in areas where purchasing

water is not an option, is to boil and cool all water prior to consumption. Theoretically,

all people should do this when drinking tap water, but this process is especially important for young children (McLennan 2000).

Theme: Environmental exposures/ pollution

The immediate physical environment also proves challenging and informs residents' perceived possibilities. This theme overlaps in some ways with the previous one of people defining health in terms of environmental factors, but here the focus is more on the behavioral culture, which ultimately is about how persons care for their community space. In some ways, environmental problems in the community seem bigger than any one person, but collective maintenance of the common space is important. Although many people act responsibly toward their community with their decisions on how to treat the environment, there are also many negative decisions that are made on a daily basis. For example, there is no refuse pickup in Algodón, so residents must figure out what to do with the garbage they produce. And because the drainage ditch that passes through the center of the community is filled with refuse, many of the people who live along the edges of this canal throw their garbage in the ravine.

Among the people who live along the canal, the sense of communal responsibility was not expressed as frequently as among those who live further away but also tend to be a little better off financially. For example, they live in houses with cement floors instead of dirt. Paradoxically, the people who live along the canal report disposing garbage in the canal. Perhaps the decision to pollute the canal reflects a difference in social consciousness, or perhaps the people who live nearby throw their garbage in the canal because of convenience or apathy, since others are already polluting their backyard.

The Public Health Department does not send regular garbage collection service to the community, and community members do not know if and when they may come. The available options for disposing of garbage are described by Charinson, a twenty-six (26) year old local resident who recently completed medical school, and is very interested in health aspects of his own community:

C: [H]ay muchas personas que recogen [la basura], la tiran aún en la cañada. Y hay otras que la recogen y la tiran en la misma calle. Y muchas personas que la entierran y otras personas que la queman.

C: There are many people who pick [garbage] up, then throw it in the canal anyway. And there are others who pick it up and just throw it in the street. Many people bury it and other people burn it.

Each household must decide what to do and these decisions cumulatively impact the environmental health of everyone. Some people, usually those who are relatively better off materially, and express a sense of connectedness with others in the community, report that they collect their garbage and take it to the edge of the sugarcane to burn it where the smoke will not bother their neighbors. Others report throwing their garbage in the canal because they do not have anywhere else to put this refuse. This kind of decision-making to pollute the common spaces of the community frustrates those who are trying to maintain cleanliness around their homes. Rafael, forty-three (43) year old father of eight (8), explains this frustration:

R: Bueno, nosotros preferimos que todo el mundo se cuida la salud pero todo el mundo no entender [*sic*]. Hay muchos que no entender [*sic*] que no tira la basura allí, que no entender. Que siempre la tiren allí. Cuando dice no tira el agua sucia allí, que no entiendan y tiranla [*sic*]. Cuando dice no deja en pozo el agua allí, hay muchos que no entender [*sic*] y siempre lo dejaban. Entones entender [*sic*] que esto pase al lado y 'cuídate la vida para que me la protege a mi.'

R: Well, we prefer that everyone takes care of their health but not everyone understands. Many do not understand they shouldn't throw garbage there, they don't understand. They always throw it there. When you say don't throw dirty water there, they don't understand and they throw it. When you say don't leave standing water there, there are many who don't understand and always leave it. But then, understand that this is next to us all and 'take care of your life to protect me.'

The decision-making of other community members has significant impact on the people around them. Some are frustrated by the poor health choices of others because these decisions affect themselves and their families. When one household disposes of garbage irresponsibly, the community is now dirty. Once a few people begin to abuse the common space, a sense of community responsibility tends to diminish rapidly (McKean 1992). Seemingly small things like litter can undermine a sense of community and lead to more and more deleterious action, because people often repeat these behaviors in common spaces (Kelling and Coles 1996).

Rosa's assessment of the health of children in the community has to do with environmental exposures. She also criticizes parents who do not act when their children are hurt. This criticism likely comes out of her loss of a twelve (12) year old daughter in 2004 to dengue fever. Environmental issues and the way they impact health are areas where parents could be making different decisions that would better protect the health of their children:

R: Bueno, te digo que la salud aquí no es tan…. es decir, no está estable, porque los muchachos padecen de hongos. Hay niños que tienen heridas y sus padres no los llevan al médico. Y que te digo, los niños por salud yo creo que por aquí hay poca salud. Porque tenemos aguas negras como lava, y los niños se meten. Muchos mosquitos. Pueda que aparezca dengue. Porque yo tuve una niña que se murió de dengue.

R: Well, let me say that health here is not….. let's say, it is not stable, because the children suffer from fungal infections. There are children that have injuries and their parents don't take them to the doctor. And how do I tell you, children's health around here, there is not much health. Because we have black waters like lava, and the children jump in. A lot of mosquitoes. It is possible to see dengue appear. Because I had a daughter who died of dengue.

Mosquitoes are a main concern of the canal and the puddles around the community. When there is a lot of garbage in the canal this waterway gets backed up and the stagnant water can breed mosquitoes. There have been cases of dengue reported in the community. Some people use mosquito nets, but many do not. For those that do use

them, the issue is not when they are sleeping but in the evening hours (when the dengue

and malaria carrying mosquitoes are at their peak activity). As Rosa says jokingly, "Well,

I have a mosquito net, but the mosquito net doesn't work except for when you are in

bed!" ("**Pues, yo tengo mosquitero, ¡pero el mosquitero no sirve nada más para**

cuando uno está acostado!") Others complain that they do not like to use the nets

because the weather is so hot; what little breeze would be reaching them in their beds is

blocked by the net. Indeed, the weather is hot in Algodón for much of the year. So, the

practicality of the mosquito net does not always fit into people's lives.

Theme: Isolation

The physical and social isolation of the community provides challenges to health-

relevant decision making (Whiteford 1990). When severe health events occur, parents

have to make hard decisions that sometimes involve commandeering a neighbor's

motorcycle to rush their children to the hospital or clinic. Rosa lost her twelve year old

daughter to dengue in 2004. This case, with extreme health consequences, can shed light

on some of the difficulties faced by community members and the importance of the

choices that people make. At the time, Rosa and her husband made the most informed

decisions that they could. They took very aggressive actions toward seeking treatment for

their daughter.

Anyone might imagine others in their situation taking a less proactive approach

because of financial barriers, lack of understanding the severity of an illness, or deferring

to an incorrect diagnosis by a doctor. As it was, Rosa and her husband made aggressive

decisions and advocated hard for their daughter to receive the care she needed, and still

she did not survive the illness. The Americas has seen a resurgence of dengue

hemorrhagic fever since that time, and this problem has become even more prevalent with highest regional levels occurring in 2010 (Phillips 2008; Guzman et al. 2011). Most likely this problem was not on health care practitioners' radar, as it would be now after several years of resurgence. Nonetheless, Rosa's daughter presented with flu-like symptoms, and thus when they took her to the hospital they were sent home. When her daughter did not get better, Rosa describes the dramatic decision to force their way again into seeing a doctor:

H: ¿En cuál momento decidiste llevarla a Barahona? ¿Cómo diste cuenta que era algo más que una gripe?
R: No pasaron 3 días. No pasé 3 días de que la llevé. Y entonces la llevé, me la chequearon, y ella se sintió mal otra vez, y el vecino tiene un motor allí, el papá vino y la agarro, 'préstame el motor'...
H: Ah, ¿la llevaste una vez y te mandaron para la casa?
R: Sí, y otra vez. Y la llevamos en el motor del vecino, de donde Berta, y él [papá] tuvo que empujar la puerta y al portero. Para que pudieran dejar. Porque la niña se sentía muy mal. Hasta que tuvieron discusiones y todo.

R: At what moment did you decide to take her to Barahona? How did you realize it was more than the flu? It wasn't even three days. I didn't let 3 days pass since I last took her. And then I took her, they checked her for me, and she felt bad again, and the neighbor there has a motorcycle, her father went, grabbed it, 'lend me the motorcycle'…
H: Oh, you took her once and then they sent you back home?
R: Yes, and another time. And we took her in the neighbor's motorcycle, from Berta's, and he[r dad] had to push past the door and the doorman. So that they would let him. Because the girl felt really bad. They even argued and everything.

She continues the story to explain that the doctor could not diagnose her daughter, so Rosa and her husband decided to leave the hospital in Barahona and went directly to Santo Domingo (approximately a three hour trip) and took her into the emergency room at La Angelita, the state run children's hospital. Finally, they got a proper diagnosis of dengue hemorrhagic fever, but by that time treatment was too late and she died that night. Rosa and her husband, at every point of making a decision about the health of their daughter, decided in favor of

acting. At no point did they wait to see the natural course of illness. In fact, they

had to advocate vocally and even physically to get doctors to listen to them and

act, and regardless, in the end, the intervention was too late. Rosa has an

incredibly strong-willed personality, in addition to being confident and informed.

Not many people act with the confidence that she exudes, and even this woman,

who is able to confront medical professionals, and challenge their diagnoses, was

unable to save her daughter.

In light of the isolation, why do people decide to stay? For many people, they

have lived there for so long that other choices are not likely. For others, who are more

recent arrivals, who know a different life and are struggling to make a living in Algodón,

one major factor driving the decision to stay is the belief that children should be raised in

their hometown. Rafael, father of 8, explains this sentiment:

H: Estoy escuchando mucho que no hay trabajo aquí, pero la gente se quedan. ¿Por qué no se mudan a donde halla más trabajo?
R: Bueno, y lo que veo es que uno a veces sale a buscar lo que pueden para la familia hasta que se mejoran las cosas. Pero yo no veo esto así, de mi parte, no veo esto así. Porque, bueno, que aquí nacieron los muchachos, se crían aquí, allí se sabe mejor porque todo el mundo conoce. Y hasta mañana que quizás llegan a la Universidad, ellos quieren vivir en otro sitio. Pero a donde ellos nacen, deben de criarlos a ellos. Entonces, pero es duro esto de recursos. Pero todo que está en la mano de Dios está favorable.

H: I hear often that there is not work here, but people stay. Why don't they move to where they can find more work?
R: Well, and what I see is that one sometimes leaves to search for whatever they can for their family until things get better. But I don't see it like that, for my part, I don't see it like this. Because, well, here is where the kids were born, they are being raised here, they know it better here because everyone knows them. And maybe tomorrow they will make it to university, they want to live in another place. But where they are born is where they should grow up. Then, but it is tough in terms of resources. But everything is favorable in God's hands.

Rafael and his wife immigrated from Haiti before their children were born.

Interestingly, the beliefs he expresses in raising their children where they were born

reflects some traditional Haitian beliefs about death, home, and community (Miller

2000). In traditional Haiti, people believe that at death the soul lives on and remains

involved in the family and community, which is reflected by the practice of constructing

tombs in front yards in rural Haiti in close proximity to the soul's descendants (Miller

2000). The ideas that Rafael has about children and the need to grow up in the place that

they are from reflect similar themes of a spiritual home. These cultural beliefs influence

his and his wife's decision to stay in Algodón, despite the difficulty they both have

finding work.

The isolation of the community also impacts teenagers, since they have a thirty

minute walk along a highway to arrive at the high school. While this situation has not led

to any incidences yet, the potential seems to be there for two main reasons that are

described by Nairobi.:

H: ¿Vas al liceo en Palo Alto?	**H: Do you go to high school in Palo Alto?**
N: Sí.	**N: Yes.**
H: ¿Te vas a pie?	**H: Do you go on foot?**
N: Sí. A pie a veces. Hay una guagua que nos lleve, pero a veces no aparece y nos toca ir a pie.	**N: Yes. On foot sometimes. There is a truck that takes us but sometimes it doesn't come and we have to go on foot.**
H: ¿Siempre caminas con amigos?	**H: Do you always walk with friends?**
N: No. Yo voy sola de vez en…. Siempre van en grupos, sí.	**N: No. I go alone sometimes…… they always go in groups. Yes.**
H: ¿No es peligroso?	**H: It isn't dangerous?**
N: No tanto. No tanto. Hay muchas veces que salen de Barahona que nos encuentra en camino, y nos da bolas.	**N: Not that much. Not that much. There are many times when people coming from Barahona stop and give us a ride.**

Nairobi does not present this condition as problematic. The reality she faces is

taken for granted. However, observing the walk to school makes one nervous about the

possibilities of children getting hit by cars and the potential for bad things to happen

while hitchhiking. So, while viewed as normal from the point of view of high school

students, this scenario is observed to be a potentially dangerous situation, and, in

addition, is a context that would not necessarily be assessed by an epidemiological survey.

Material and Legal Resources

Access to health services is always a major component of analyzing health system utilization. This issue is no different in Batey Algodón. Some of the main barriers that people perceive to seeking health interventions or preventive care in this specific context are closely linked to financial restrictions. An overarching theme that participants discussed about decisions related to health often were based on money.

In the first place, transportation is costly and a common barrier to health system utilization and treatment seeking behavior in the developing world (Mukherjee, Ivers, Fernet, Farmer, and Behforouz 2006). Another commonly mentioned barrier, which was particularly important to people who were not eligible to enroll in the state social welfare system, was the cost of medicines that they would have to pay for out of pocket. People explained that they often made their decisions to get treatment based on how much they thought they would end up spending to address their ailment. This decision was often based on what they anticipated the cost of a medication to be and if they were eligible for the state insurance, *Seguro Nacional de Salud* (SENASA).

Related to the issue of having SENASA insurance, emerged the issue of justice that influenced several participants' perceptions and utilization of the formal medical system. Those without a SENASA card, which signals to health practitioners that a person is undocumented[2], expressed great concern about being treated as second class

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[2] The word "undocumented" is used for both political reasons and for better accuracy. Politically, "undocumented immigrant" is preferred to the term "illegal alien" because a person is not being labeled as something outside of the law. Furthermore, in the particular

citizens. These financial and legal issues influence greatly the way people view the health

care system, the people who staff positions in that infrastructure, and how they make

decisions regarding their and their family's interactions with the medical system

(Andrulis 1998).

Theme: Transportation

Transportation costs are a kind of first-line barrier to seeking care, and a major

influence in the decision-making process of whether people pursue care, especially

among the very poor (Peters et al. 2008). When transportation costs are paid by a third

party, rural Haitians are much more successful at seeking follow-up HIV therapies and

treatments, thereby illustrating how much of a barrier transportation costs are to the poor

(Mukherjee, Ivers, Fernet, Farmer, and Behforouz 2006). There are two main components

to the transportation decision for residents of Batey Algodón. The first is the type of care

needed. If the problem is something simple that can be treated at the rural clinic, this trek

requires a long walk that is especially daunting if someone is not feeling well or is

bringing young children. For more serious ailments, medical tests, and follow-up care

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case of the population of people living on bateyes, many people who do not have papers
were actually born on Dominican soil and have lived all their life there. Some are even
third generation. The laws as to who has rights to citizenship have vacillated with
different Dominican presidencies and social movements over the years. As it stands
currently, children born to undocumented "temporary workers" do not have rights to
claim Dominican citizenship. However, children born to diplomats and visitors "in
transit" are eligible for citizenship namely, non- Haitians. The government has even
retroactively revoked citizenship from people who were born to undocumented workers
under previous law and had been issued birth certificates. This has created a situation in
which many people living in *bateyes*, in particular, do not have an official nationality.
Being denied both Haitian (one must reside at least five years in Haiti to qualify) and
Dominican citizenship, as is the case for many Haitian descendants born and raised in the
Dominican Republic, is a violation of the United Nations Universal Declaration of
Human Rights article, 15, part 1 (United Nations 1948), in addition to violating the
Organization of American States human rights agreements.

people must go to the nearest city, that is, Barahona. To get there, one must hire a

motorcycle taxi, catch a passing bus, or hitchhike.

Tatiana, a twenty-one (21) year old mother of three (3), explains the various

things that influence her decisions about how to get to Fundación when she needs to get

to the clinic. This trip can be an extra challenge with young children, especially when

they are sick and cannot walk the long distances.

H: ¿Te hace difícil llegar a Fundación cuando tienes que ir?	*H: Is it difficult to get to Fundación when you need to?*
T: Sí. Si uno no tiene dinero, uno tiene que ir a pie. Si no, bajamos allá abajo, si no hay concho aquí y tenemos dinero, pagamos un concho para irnos. Es mejor si pusieron una clínica aquí.	*T: Yes. If you don't have money, you have to go on foot. If not, we go down there, if there isn't a motorcycle and we have money, we pay a motorcycle taxi to take us. It is better if they would put a clinic here.*

Luisito, a married thirty (30) year old who never received any schooling, explains

the costs and the necessary personal connections required to get to the clinic. He has a

cousin who has a motorcycle, and he must both pay him for use of the motorcycle and

gasoline. Not to mention that, with four (4) young children, the decision to go to the

clinic on the motorcycle also means that the other children must be left with someone,

which influences the decision-making:

H: ¿Quién toma las decisiones en la familia de cosas de salud? Como, si se enferma un niño, ¿Quién dice que "ya, tenemos que ir al médico?"
L: Bueno, yo tengo un primo que tiene un motor. Tengo que buscar y echarle su gasolina y pagarle el pasaje para llevarlo pero por aquí no tenemos ninguna persona para llevarlo así gratis. Tenemos que pagarle y pagar el pasaje. Sí.
H: ¿Y esto a veces hace que no puede llevarlos cuando crees que debes?
L: Sí.
H: ¿Ha pasado esto? ¿Como que querrían llevar un niño pero no hay en qué?
L: Exactamente. No hay en que llevarle.

H: Who makes health related decisions in your family? Like, if one of the children gets sick, who says, 'now we need to go to the doctor'?
L: Well, I have a cousin who has a motorcycle. I have to go look for him, put gas in his motorcycle, and pay him to take us because there is nobody here who will take you for free. We have to pay him and pay for passage. Yes.
H: Sometimes does this mean that you can't go when you believe you should?
L: Yes.
H: Has that happened? Like, you wanted to take one of the children but didn't have a way to get there?
L: Exactly. There was no mode of transportation.

Pastor Jaquie, the pastor of the evangelical church in Batey Algodón, when brainstorming the types of interventions that would improve community health, identifies the need for a community vehicle that could be used by anyone who has an emergency:

P: Cuarto, tener un vehículo para transportar en cualquier caso de emergencia de una persona que de repente aparece una enfermedad rápido. Entonces no poner esa persona a través [atrás] de un motor, entonces que es un peligro, está lloviendo, no. Le cargo y le pone en una guagua con 3 o 4 personas a acompañando esa persona hasta el hospital o a donde van.

P: Fourth, to have a vehicle to transport any emergency case for a person who suddenly falls ill rapidly. So as not to put this person on the back of a motorcycle, which is dangerous, it is raining, no. We take them and put them in a truck with 3 or 4 people accompanying them to the hospital or wherever they are going.

The Pastor recognizes the dangers associated with lacking transportation, especially in emergency situations. This finding is common in health research in marginalized or impoverished areas (Mukherjee 2006), yet still something that can be overlooked easily by outsiders.

Theme: Medication and treatment costs

Medical affordability, as a factor in people's pathways to treatment of a medical issue, is embedded in deeper societal issues (Andrulis 1998). The state sponsored medical

insurance and infrastructure SENASA is only available to Dominican citizens. To enroll, one must show a Dominican identity card, or in the case of children a Dominican birth certificate. With enrollment in SENASA, basic medications are provided free of cost, or at deeply reduced prices. So, inequality in access to health care becomes contingent on one's immigration status. The people who spoke about making decisions based on the price of potential prescriptions or analyses were all undocumented immigrants. Those who were eligible for, and report using, SENASA benefits have been generally happy with their access to medications and tests.

Nelcida, a twenty-four (24) year old mother of four (4), is discussing a bump on her infant daughter's head. Since she is undocumented, neither she nor her children have access to the state health system. Even though her children were all born in the DR, Nelcida has not taken them to be declared. Nelcida herself was born in the DR, but was never declared. There are several reasons why people do not take this step: a.) laws frequently change with respect to who has rights to citizenship, b.) although children are eligible for citizenship by birthright, parents who came illegally are afraid of deportations, and c.) a great amount of questionable information is passed through word of mouth about campaigns to get people to declare their children. All of this ambiguity leads to many parents not feeling comfortable declaring their children, even the ones who do qualify for citizenship.

Nelcida, despite the fact that she was actually born and raised in the DR, has not declared any of her four children, and therefore they cannot utilize the SENASA system. The bump is abnormal and she does not know the cause, but she is unable yet to go to the doctor. Yet, there is no point in seeking treatment until a diagnosis is made, and even the

diagnosis is a financial strain on this young mother. When asked about any health

problems with her children, she points to the baby she is holding and says:

N: Nada más gripe y ella que tiene una cosa en la cabeza.
H: Y ¿qué es?
N: Hay que tirarle una placa en la cabeza. Ella nació así y así se le está creciendo la bola como si fuera un líquido allí. Como blandito.
H: Y ¿no sabe qué es?
N: No. Que me mandaron a tirar la placa primero….
H: ¿Es como una biopsia?
N: Sí. Hay que chequearlo en papel. Sí. Esto es con dinero yo tengo que…..
H: Y ¿Cuándo lo vas a hacer?
N: En estos días que yo consiga dinero lo voy a hacer.
H: ¿Es muy costoso?
N: No. Algun 500 pesos así.

N: Nothing more than colds and she has a thing on her head.
  H: And what is it?
  N: She needs an x-ray of her head. She was born like that and the bump is growing as if there were liquid there. It is like really soft.
  H: And you don't know what it is?
  N: No. They sent me to take the x-ray first…
  H: Is that like a biopsy?
  N: Yes. They have to check it on paper. Yes. This is with money that I need…
  H: When will you do that?
  N: When of these days when I find the money I will do it.
  H: Is it very expensive?
  N: No. Something like 500 pesos (~$12 USD).

When the interviewer did not understand the phrase "tirar la placa" (which

indicates some kind of x-ray or MRI- like scan) and asked if she was talking about having

a biopsy of the lump done, Nelcida did not seem to understand what exactly she was

supposed to be doing to seek follow-up care. Since she is undocumented, and has to pay

out of pocket, the doctors who helped to deliver her baby were not providing quality

follow up care. This lump is something that was present since birth, yet, as a mother,

Nelcida is expected to have understood (and be able to remember) what the doctors told

her postpartum, save money, and eventually find a private lab that will do the correct test,

take the test back to the doctors (likely paying another consultation fee), and from there

do what is medically necessary for her daughter.

These steps would be necessary for anyone, but if someone has the SENASA

insurance card the examination would have likely been done, or at least referred, at the

hospital originally and the additional burden of money would have been eliminated. Nelcida is a single mother of young children who works six days a week cleaning a family home. In effect, she cannot imagine how she will be able to complete these steps and do what is medically advisable for her baby. Inequality in access to the health care system is furthered by her (and her child's) lack of access to state support. Her decision-making process of seeking a diagnosis, and then, potentially, treatment for her child, is contingent on many factors that are tied both to the management of her life and influenced by factors that she cannot control.

Many families without access to SENASA have faced a similar situation, most commonly the inability to purchase medications. For example, anyone documented or undocumented is entitled legally to receive primary care. However, follow-up care is not guaranteed, for example, in the purchase of prescriptions. Imireyna, an eighteen (18) year old mother of one, explains that this situation is something that pains her in terms of not being able to provide for her children. When asked what she would do differently to protect her health and that of her children, she responds:

I: Si yo podría, nunca le faltaría un médico. Nunca le faltaría la medicina. Siempre voy a cubrir los gastos de mi familia, pero no tengo. La salud- a veces está bien, a veces está mal.
H: Y ¿qué ha pasado alguna vez que no has podido cubrirlos?
I: Algunas veces no hemos podido comprar la medicina. El dinero no nos alcanza.
H: Tenías que esperar y esperar?
I: Esperar y esperar a ver de donde viene el dinero. Y algunas veces se pasa la receta, pasa el día en que se puede comprar.

I: If I could, they would never lack for a doctor. They would never lack for medicine. I will always cover the expenses of my family, but I don't have. Health- sometimes it is good, sometimes it is bad.
H: Has it happened before that you couldn't cover them?
I: Sometimes we haven't been able to buy medicine. The money doesn't stretch.
H: You had to wait and wait?
I: Wait and wait to see where the money would come from. And sometimes the prescription expires, the day in which you can buy it passes.

While Imireyna and her husband decided to take the children to the doctor when they were sick, they did not have the resources to seek treatment every time. In this sense, they decided to get illnesses checked out by a doctor, but could not afford the treatments. Clearly the issue is not that people in this community decide not to allocate the money they *do* have to medical care. The reality is that they do not have the money at all. Decision-making about health, in this sense, is rendered moot.

Theme: Legal Documents and poor treatment

A secondary, long lasting result of not having SENASA is that people in the study felt they were treated poorly in the clinical setting. The public health system has been shown to have many problems in quality of care and in equality of care (Ugalde 1984; Whiteford 1990; Miller, Cordero, Coleman et al. 2003). Past clinical experiences of being attended to poorly, or looked down on for not having SENASA (an immediate identifier of undocumented status), along with stories that abound about other people being denied care for not having legal papers, deter people from seeking health care immediately. Several people discuss how their own or others' past experiences influence their decisions to seek care. Teny, a young twenty-two (22) year old, the day he was interviewed had thought about going to the clinic in the morning because he was feeling lethargic and not quite right. Instead, he decided to rest around home. His decision to not seek care when something was slightly but not completely wrong was influenced by his past experiences. Feeling kind of lethargic and depressed, he did not want to put himself at risk for being treated poorly at the clinic. When asked how he has been treated in the past at the clinic and hospital, he responds:

T: Sí, cuando uno va así pa' la clinica, por ejemplo, si uno no tiene documentales [*sic*], te dejan un par de minutos sin atender a uno. A veces te miran a uno como cualquiera así (en forma negativa).
H: ¿Te ha pasado esto? ¿Qué te tratan como segunda clase?
T: Sí. Como segunda clase. Y ese chin a mí no me gusta. Somos personas. Tú me cortas, sale sangre. Y te sale sangre también. ¡Atiende uno como gente!

T: Yes. When you go to the clinic, for example, if you don't have documents, they leave you a few minutes without attending to you. Sometimes they look at you like you are just nobody like that (in a negative way).
H: Has this happened to you? They treated you like second class?
T: Yes. Like second class. And that bit I don't like. We are people. You cut me, I bleed. And you bleed also. Attend to people as people!

Teny incorporated his past negative experiences as an undocumented patient into his decision to not seek help that day. The stress that he experienced in the past tainted his view of the kind of help that is often provided at the clinic, and instead he opts to stay home and relax. This thinking speaks to the way that health decision-making is not always thought about in a rational choice framework, because for Teny the importance of being treated poorly greatly outweighed any physical ailment (Boudon 1998). Nonetheless, like Dreyfus and Dreyfus' expert decision-makers, Teny incorporated past experiences and the humiliation he was subjected to at the clinic, representative or not, into his decision-making.

Similarly, Emilia has heard stories from others about their poor treatment by doctors, and this discovery changes her view of the medical system. The key is that this story is spreading throughout the community, no matter the level of truth and how much the motivation of racism attributed to the doctor is accurate in the story. Indeed, rumors often become part of the landscape of how people in the community come to view the formal medical system. Emilia tells the story she heard about a man denied treatment because he did not have documents to be in the country:

E: Así me estaba diciendo *Nombre de Hombre* hoy. Me dijo a mí a él, los americanos lo llevaron grave a Barahona. ¿Tú sabes lo que hace? A las 12, ¡los tiraron a el a fuera! Así me dijo el hombre.
H: ¿Por qué lo tiraron pa' afuera?
E: ¡Parece que no tenia ninguno papel! Bueno los tiraron pa' afuera. Él durmió afuera.

E: This is what <u>Man's Name</u> *was saying today. He told me that the Americans took him gravely ill to Barahona. You know what they did? They threw them out! That's what the man told me.*
H: Why did they throw him out?
E: Apparently he didn't have legal papers! Well they threw them out! He slept outside.

Juliana has had direct experiences with doctors that she felt treated her poorly because she did not have SENASA. She speaks of the spotty care that depends on the doctor. Her perceptions of the doctors, and the way they have treated her, makes her wary of seeking treatment in the future:

H: ¿Pero te atiendan? ¿Los médicos te revisan por lo menos o como que te dicen que no?
J: Sííí [con ambivalencia]. A veces se atiende. Pero a veces tú sabes que Satanás esta siempre cerca de uno, a veces tú hallas uno que es un demonio que se ha portado mal contigo.
H: ¿De los médicos?
J: Exactamente. A veces tu hallas de los buenos porque si Dios esta con uno se habla bien con uno, pero si Satanás esta atrás de uno siempre hablan mal con uno. Pero siempre me dice, "si fulano hablando mal conmigo es porque Satanás está encima de ella." Porque si Satanás está encima de ella te va a hablar malo. Bueno, uno tiene que sufrir. Porque yo no me gusta hablando malo conmigo tampoco. ¡A veces hasta yo me puse a llorar!
H: ¿En el hospital?
J: ¡Sí! Yo soy así. [riéndose].

H: But do they attend to you? Do the doctors at least give you a checkup or do they just refuse?
J: Yesss [ambivalently].
Sometimes they treat you. But sometimes you know that Satan is always nearby, sometimes you find one that is a demon and that behaves badly with you.
H: The doctors?
J: Exactly. Sometimes you get the good ones because God is with you and they speak nicely with you, but Satan is behind you and you get one that speaks poorly with you. But I always tell myself, "If so and so is speaking badly with me it is because Satan is with him." Because Satan is with her she is going to speak badly to you. Well, one must suffer. Because I don't like people talking poor with me either. Sometimes I have even cried!
H: In the hospital?
J: Yes! I am like that! [laughing]

These personal experiences with medical personnel, and the stories lived through others, shape the way in which the participants perceive the medical system and assess the type of care they will get, and whether this treatment is worth seeking (Larkey et al. 2001). This condition is particularly salient for people without Dominican citizenship

because they are made vulnerable to abuse by not holding a SENASA card, in addition to

having to pay out of pocket for any medical expenses or treatments.

Life Circumstances

Health is influenced by the types of environmental and physical exposures

persons are subject to in the course of daily life, in this case pesticides, cooking smoke,

dust, and mosquitoes. Participants have decided to reside in Algodón, exposing

themselves to a specific set of health challenges. Different persons decided to live in

Algodón for different reasons, some positive and others negative. Many just landed,

usually coming from Haiti and left there by a *buscón* (smuggler), had family living there,

or simply ran out of money and never left. So, these decisions about where to live have

everything to do with health, and reflect environmental factors, living conditions, and

possibilities for earning a basic living.

Theme: Economic push factors to leave Haiti

Because living in Batey Algodón entails so much hardship, the reasons why

people moved to the community in the first place and their reasons for staying there were

of great interest. Because the environment is so harsh, specifically the isolation from

employment opportunities other than the most difficult of manual/ agricultural jobs,

movement out of the community seems only logical. Nonetheless, such out migration

does not seem to be the case. The group that has left consists mostly of young people who

are pursuing college in Santo Domingo, exactly because of the limited opportunities in

the community. The people who have stayed are primarily parents, elderly, and families

with young children. A few similar reasons for coming to live in Batey Algodón in the

first place were given by most people.

Ashlina is a twenty-four (24) year old woman who is in a partnered relationship and has a one (1) year old daughter. Her decision to move to Algodón had everything to do with so-called push factors from an even more difficult environment. She came from a very poor family in Haiti and decided to come across the border to look for a job in Santo Domingo. However, she used the money she had to pay the *buscón*, and did not have enough to continue to the capital. In survival mode, she found someone who she could partner with and moved in with him, and now they have a child together:

A: Co-contado/ traducido por Nicaura- Ella estaba trabajando en casa de familia y su mamá vive afuera. No estados unidos, no, como afuera en un pueblo. Su mama vivía en una loma. Su mama no tenía ayuda para ayudarla a ella. Su mamá no tenía dinero para ayudarla a ella, entonces ella salió de Haití y vino pa' acá. Ella no se iba a quedar aquí. Ella se iba para la capital. Pero, por falta de dinero ella se quedó allí. Y vino, halló un hombre, casó con el. Y allí mismo se quedan teniendo este niño allí.
H: Así que ¿tu pretendía llegar a la capital, se te acabó el dinero, y por aquí te quedaste?
A: Sí.
N: Y allí mismo se casó.

A: Co-told/translated by Nicaura: She was working in the home of a family and her mom lived outside. Not in the United States, no, but like in a Little own. Her mom lived in the rural mountains. Her mom didn't have help to help her. Her mom didn't have any money to help her, so she left Haiti and came here. She wasn't going to stay here. She was on her way to the capital. But, she ran out of money and stopped here. She came, found a man, and married him. And just like that they are here with this little boy here.
H: So, you intended to go to the capital but you ran out of money and that is why you stayed here?
A: Yes.
N: And just like that she got married.

For Ashlina, the series of decisions that led her to Algodón had everything to do with her poverty. Now in Algodón, she is okay but also struggles with basic hygiene/ infrastructure issues. In her interview, which was conducted jointly with her best friend/cultural broker, they described their biggest health challenge as not having access to a latrine. They live right next to the highway, and so when they need to go to the bathroom they cross this road and seek privacy in the sugarcane. Her neighbor and best friend, Nicaura, helps her navigate the health system and many aspects of daily life because Ashlina only speaks Haitian Creole. When she needed to go to the clinic or hospital for checkups during her pregnancy and to give birth, Nicaura was always at her

side explaining things to her and speaking to doctors and staff on her behalf. Ashlina's

series of life circumstances, particularly reacting to the sheer poverty from which she

came, have landed her in a living arrangement where she must rely on others to navigate

the health system for her.

Manón, a twenty-two (22) year old man with one child, left Haiti under similar

circumstances and explains that his decision to move to Algodón paid off. He left Haiti

"looking for life" ("**buscando vida**") and found more possibilities living in the *batey* than

he did on the other side of the border. He used to have somewhat consistent work in

construction, and although he is unemployed currently he finds the possibilities more

favorable than in Haiti:

MT: Yo viniendo [*sic*] aquí porque mi familia casimente no tiene como que puede mantener a mí. Yo salí de allí afuera en Haití y vine aquí buscando vida.
H: ¿Era lo que pensaste aquí?
MT: Sí, aquí yo hallo más algo de Haití, porque tú sabes en Haití casimente no hay nada. Cuando yo vengo [*sic*] de Haití, yo muy chiquito casimente mi familia no tiene cuarto para mantener a mi para pagar escuela. Tú sabes en Haití, uno tiene que pagar mucho cuarto. Y de allí, yo no puedo seguir más, y vengo [*sic*] aquí.

TM: I came here because my family nearly has no way to maintain me. I left over there in Haiti and came here looking for life.
H: Was it what you thought it would be here?
TM: Yes, here I find it more something that in Haiti, because you know in Haiti there is almost nothing. When I came from Haiti I, being very young my family had no money to maintain me and pay for school. You know that in Haiti, you have to pay a lot of money. And from there, I couldn't continue, and I came here.

Theme: Spousal complications

For several of the women in the study, the decision to move to Algodón was

because they got married and their husband planned to work in the sugar industry, or he

had family in Algodón. When asked why she decided to move to Algodón more than a

decade ago, Tatiana's mom, who is extremely unhappy with her living conditions,

expresses frustration with herself because she followed the father of her children to this place, and now she feels she has no escape:

H: ¿Por qué elegiste esta comunidad? **M: ¡Por mi sin vergüenza! ¡Por mi puta andando atrás de los hombres, del pai de los hijos míos!** **H: ¿Por un hombre que viniste aquí?** **M: Sí. Que me jala hasta por aquí pero si no fue así yo no vivo aquí. Yo no acostumbro de por aquí. Yo no soy de por aquí. Yo soy de por La Romana.**	*H: Why did you choose this community?* *TM: Because of my own shamelessness!* *Because of my whoredom following men,* *because of the father of my children!* *H: You came here for a man?* *TM: Yes. He dragged me all the way out here, if it weren't for that I wouldn't be here. I never got used to it here. I am not from here. I am from La Romana.*

Throughout her interview she explains how she hates living in Algodón and how her living conditions are atrocious and have a negative impact on her health. For example, she has a latrine that was built adjacent to her house by an NGO, which she has converted into an aviary (she raises birds to sell). When used as a latrine, the smell is too noxious to be so close to the house. She also complains of eye problems because she has to cook over an open fire. Her decision to move into these circumstances, and her feelings of helplessness that prevent her from leaving, clearly affect her health and quality of life. As a woman, she feels that she must stay in the area because the father of her youngest children is there.

Rosa has dealt with a lot in her life, having lost a child and kicked her husband out of the house for rampant infidelity. However, she is still affected by the things that he does, and the complicated ties that she has with her ex-husband still influence her life after years of separation. Her ex-husband is presently incarcerated, accused of battery. Currently, she is taking care of an adolescent boy who is the product of her ex-husband's infidelity. She explains the complex decisions involved, but nonetheless feels that she must help when she can:

R: El varón es hijo de mi marido. Con otra mujer. El viene aquí. Vivía aquí y se fue para donde su tía porque era muy travieso. No me hace caso cuando le hablo y cosa.
H: ¿Pero tú lo criaste cuando el ex-marido vino a vivir contigo?
R: Él estuvo hace poco aquí. El problema que yo no puedo tener un muchacho ya grande, y que no me oye. Y hablé con la mamá para que le lleva a la misma Tía allá. Yo nunca he tenido problemas con nadie, ahora nadie me va a meter en problemas.
H: ¿Llevas bien con la mamá de él?
R: Hablamos. Ella está trabajando en la capital.
H: Es una situación complicada.
R: No es fácil, no.

R: The boy is my husband's son. With another woman. He comes here. He used to live here and he left to live with his Aunt because he is real trouble. He doesn't listen to me when I speak and stuff.
H: But did you raise him when your ex-husband came to live with you?
R: He was here not too long ago. The problem is that I cannot have a boy here who is already so big who cannot hear me. And I spoke to his mother si she could take him back to his Aunt there. I have never had problems with anybody, and now nobody is going to get me involved in problems.
H: Do you get along well with his mother?
R: We speak. She is working in the capital.
H: It is a complicated situation.
R: It isn't easy, no.

Even though he is her ex-husband, she still feels responsible for some of the damages that he has caused, and has done her part in trying to help raise his child with another woman that was conceived while they were married. The stress of this situation on a very hardworking, confident woman are clear in her frustrations about the situation and illustrate how interpersonal relationships are constructed and managed, but not without difficulty.

Theme: Seeking peaceful community

On the other hand, some people made active decisions to move to Algodón, in search of a better life with more peace and less threat of violence. The community of Algodón was founded by a group of people who left a nearby community, Batey Altagracia, in the mid-1980's. Many of the original people who came report that the other batey was getting overcrowded and violence was beginning to be a frequent occurrence. Rosa tells a story that many of the first residents also report about the decision to come to the community in search of a peaceful life:

R: De Altagracia mi mamá vino por voluntad propia. Y entonces los demás vinieron porque hubo un problema allá. Vinieron de Altagracia pa' acá.

R: *From Altagracia, my mom came here of her own accord. And then, the rest came because there was a problem there. They came from Altagracia to here.*

H: ¿Qué fue el problema?

H: *What was the problem?*

R: Un problema que un muchacho tenía problema con una gente de Fundación. Y se armó como un pleito y la gente salieron viniendo pa' acá.

R: *A problem was a guy had problems with some people from Fundación. A big brawl ensued and people left there to come here.*

H: ¿Qué se empezó a poner como más caliente en Altagracia y la gente salieron?

H: *Things were like too heated in Altagracia and so people left?*

R: Exacto.

R: *Exactly.*

H: ¿Pero un pleito grande entonces?

H: *It must have been some fight!*

R: ¡Sí! Fue un pleito grande. Porque el muchacho como que fue a hacer como un atraco, y había una señora mayor, y entonces le tiró…. Como que era agua caliente, no me recuerdo bien. Creo que la mujer se murió. Y por esto la gente salieron corriendo de allá. Porque sabían que podía vengarse de cualquiera persona. Y vinieron a vivir pa' acá.

R: *Yes! It was a big fight. Because the guy went to like attack somebody, and it was an older woman, and he threw…. Like hot water on her, I don't really remember that well. I think the woman died. And because of this people left running from there. Because they knew that vengeance could be taken on anybody. And so they came here.*

H: La gente buscando tranquilidad.

H: *People looking for more tranquility.*

R: Sí.

R: *Yes.*

H: ¡Por esto es tan tranquila aquí!

H: *That is why things are so calm here.*

R: Exacto. Aquí es más tranquila que pa' allá.

R: *Exactly. That is why it is much more calm here than there.*

Without the comparison to the old community, people seem to have decided to live in a very difficult place. The overcrowding of the original batey settlement, not to mention new job opportunities to work the sugarcane near Batey Algodón, were the real draws for coming to this community. Compared to where people were before, the new community was peaceful and the threat of physical violence greatly reduced. In addition, many people talk about the community as a community of Christians, and every night the church is filled with women, children, and some men. The search for a community that has a strong network, based in a religious belief system, has enriched many people's lives. Women, especially, refer to their fellow church members as their "church family" ("**familia de la iglesia**").

Gender Roles and Norms

Gender norms and gendered ways of thinking have impact on health decision-making in different ways (Varga 2003; Pulerwitz et al. 2002). Many of the decisions that people make are influenced by the way they view their societal and interpersonal roles. The gendered lens applied to this section is meant to expose some of the ways that these taken-for-granted norms and rules in the local culture influence the choices that people make vis-à-vis health (Garfinkel 1964). Themes that developed out of the interviews run the gamut of gender norms, ranging from men and women in partnerships where they feel immense solidarity to the aftermath of a rape of a young girl in the community and the responses that are elicited from community members. The sub-themes addressed here are categorized as unequal partnerships, men and sexuality, and gender roles.

Theme: Unequal partnerships

Several women, who complain about the quality of life and the difficulties of rural living, explain with frustration that they have stayed out of obligation to their romantic partner. These women are all transplants to the community who partnered with men who had some kind of familial connection in Algodón, and after having children insisted on moving there. Roberta is thirty (30) years old with seven (7) children. She lived most of her life and had her children in Haina, just outside of Santo Domingo. Because her husband wanted to be closer to his mother, they moved to Algodón about a year ago. Roberta hates living there, but she decided to stay because that is her role as wife, even though she feels that her situation is compromising her ability to be a good mother:

H: ¿Por qué están aquí todavía? ¿Por la familia de él?

R: Yo no sé porque! Cuando él me dijo, 'Vamos pa' acá' yo le dije que 'no'. Me dijo "¡Que sí! ¡Que sí! Vamos!" Bueno, yo soy su mujer, no puedo decir que no!

H: ¿Es así? ¿Y él no se ve que las cosas están difícil?

R: Está mal, malísimo.

H: ¿Por qué quiere quedar él?

R: Bueno, él nunca me diga así que va a salir. Pero yo tengo que salir. Porque yo no puedo criar mis hijos así como estamos.

H: Why are you still here? For his family?

R: I don't know why! When he told me, 'Let's come here' I told him 'no.' He said, "yes! Let's go!" Well, I am his woman, so I can't say no.

H: Is it like that? And he doesn't see that things are difficult?

R: It is bad, really bad.

H: Why does he want to stay?

R: Well, he never tells me that we are going to leave. But I have to leave. Because I cannot raise my children in the way we are.

Theme: Men and sexuality

The construction of sexuality is another social issue that has impact on decision-making and affects how persons view their possibilities. Several female participants reported having thrown out a male partner because he was a *mujeriego*, a womanizer. Younger women and older women both report having broken up with partners to protect themselves from contracting sexually transmitted infections (STIs), because they found that their partner was having relations with other women. Nelcida talks about her decision to break up with the father of her 3 youngest children:

N: Me dejé con el papá del niño y me casé con otro. Y ya estamos dejados. Estoy sola ahora.

H: ¿Por qué se dejaron?

N: Porque así. No me gusta ya. A veces hacen cosas que no me cae bien.

H: ¿Como qué?

N: Como son mujeriego, no se queda con una sola mujer. Busca una más pa' adelante, así… y hay muchas enfermedades.

N: I broke up with the father of the boy and I married another. Now we are broken up. I am alone now.

H: Why did you break up?

N: Because it is like that. I don't like him now. Sometimes he did things that didn't sit well with me.

H: Like what?

N: Like he was a womanizer, he doesn't stay with one woman. He looks for another one up ahead like that… and there are many diseases.

Another interesting way of constructing sexuality is found in the use of contraception and STI prevention. Nobody reported using condoms as their

current method, which indicates that decisions about safe sex are based primarily on contraception and not STI prevention (Severy and Newcomer 2005). The contraceptive methods reported by participants were birth control pills, birth control injections, and the rhythm method (calendar based methods). The one person who reported using the rhythm method with his partner was doing so incorrectly, biologically speaking. Both women and men discuss that they do not like using condoms, but for different reasons that reflect intriguing gendered influences on decision-making, based on the way that gender and sexuality are co-constructed in the community.

Several men reported that they do not use condoms with their sexual partner because they do not like the physical sensations. Dominic Pierre and his wife have two (2) children together, and he has two more from a previous relationship. He does not want more children, but she laughs and looks away when he makes this statement. He would like for her to get her tubes tied, a common form of contraception even for young women in the DR who have had all the children they want. So, even though he wants no more children, he decides against using condoms and creates a story for his own benefit about the negative health impacts of condoms on men, a tale that unravels with a little prodding and seems to be a thinly veiled justification of not liking the physical sensations:

D: Pero esto no es muy bueno porque también el condón hace daño. Esto hace daño porque una grasa que esto estira, y esta grasa no le conviene. Por eso uno no…. uno lo usa para prevenir pero no es muy bueno usarlo.
H: Es especialmente difícil pensar usarlo a lo largo plazo si uno no quiere tener más hijos por el resto de la vida.
D: Muy difícil sí. Y esto le hace daño también al hombre porque pone….fuerza demasiado. Y esto le para la respiración. Sí, porque esto no deja respirar porque esto está sellado y al estar así, hace que el hombre hace mucha fuerza.
H: ¿Por qué no se siente tanto las sensaciones?
D: No. ¡Esto es verdad! [*riéndose*]

D: But that is not very good because condoms also do damage. They hurt you because of the oils that they contain, and this oil isn't good for you. This is why people don't… people use them for prevention but it is not very good to use them.
H: It is especially difficult to think of using them long term if you do not want any more children for the rest of your life.
D: Yes, very difficult. And it also hurts the man because he puts…. He has to force himself too much. And this stops one's breathing. Yes, because this doesn't let you breathe because it is sealed and to be like that, the man must use too much energy.
H: Because you don't feel as much?
D: No. That is true! [laughing]

Tatiana, a twenty-one (21) year old mother of three (3), came to the same contraceptive decision not to use a condom with her husband, but the reasons she discusses are very different and reflect a gender norm of women showing their fidelity by not demanding condom use by their partner. For her, using a condom was not an option because such an act would signal that there was no trust between her and her husband as sexual partners. She discusses the thought process of how she made her decisions regarding contraception:

H: ¿Cómo hiciste la decisión de tener los 3 hijos? ¿Tú te planificaste?
T: Yo nunca he planificado. Lo que pasa es que cada vez que yo me quiero planificar, como que me da miedo porque dicen que hay inyecciones que no le llega la menstruación, otras que te ponen gorda, otras que te ponen flaca, y yo de negligencia siempre me quedé embarazada.
H: Pero no es negligencia porque estas pensando en las químicas que pones en el cuerpo.
T: Sí, sí. Pero por esto siempre me quedé embarazada.
H: ¿La probaste [planificación] alguna vez?
T: Nunca nunca nunca. Yo la voy a tomar ahora, la inyección.
H: ¿Ahora que tienes tres?
T: ¡Sí! Porque si no, ¡se va a llenar el mundo!
H: ¿Nunca hablaron de usar condones?
T: No, él no le gusta. A veces se lo digo que se lo ponga y dice que 'no', que no le gusta.
H: ¿Por qué no le gusta?
T: ¡Yo no sé! Que yo no soy una mujer de afuera, que yo soy su mujer. A veces se lo dijo que lo ponga, y el, 'no'.
H: ¿Cómo que se pone sospechoso o algo?
T: (riéndose) ¡Sí!
H: Así que la gente se usan condones más…
T: Con alguien de fuera. Sí.

H: How did you decide to have the three children? Did you use family planning?
T: I have never used contraception. What happened each time I wanted to go on contraception, i was like scared because they say that with the injections your period stops, others make you fat, others make you skinny, and me out of negligence always ended up pregnant.
H: It isn't negligence because you were thinking about the chemicals that you were putting in your body.
T: Yes, yes, But that is why I always ended up pregnant.
H: Did you ever try it [contraception]?
T: Never never never. I am going to do it now though, the injection.
H: Now that you have three?
T: Yes! Because if not, the world is going to fill up!
H: Did you ever discuss using condoms?
T: No, he doesn't like them. Sometimes I tell him to put one on, but he says, 'no' that he doesn't like them.
H: Why doesn't he like them?
T: I don't know! Because I am not a woman from the streets, I am his woman. Sometimes I tell him to put i ton, and him, 'no'.
H: Like he gets suspicious or something?
T: [laughing] Yes!
H: So, people who use condoms are like…
T: with someone from outside, yes.

In these examples, there are the interpersonal negotiations of sexuality and what using protection means. Additionally there is the issue of gender, power, and sex. Unfortunately, in the community, during the course of the study there were a couple incidences of rape. The incident most talked about was the rape of a 6 year old girl by a close family friend. This event was clearly tragic, and the researcher, as somebody embedded in the community, ended up taking one of the violated girls to the capital to receive psychological counseling through the host organization, CENISMI. Of sociological interest, however, are the ways that these incidences were interpreted by

community members. Nelcida attributes the responsibility of the rape to the parents and how they raised her. Clearly the girl is the victim, but Nelcida, in thinking about how something like this can be prevented, blames the parents (mothers in particular) and writes off the man's actions as natural male behavior:

N: En los campos, en los bateyes, siempre pasa algo de esto.
H: ¿Por qué crees?
N: Sí, porque hay muchas madres que son descuidado con sus hijas hembras. Por esto, cualquier que tiene hijas hembras tiene que cuidarlas. Decirle 'quieto'. Como te digo, si yo tengo hija hembra, tengo que decirle, "Mira mi hija, cualquier hombre que te viene a tocar- no deje que te toca el cuerpo ni nada. Porque esto es sagrado." Porque hay madres que dejan a sus hijos pidiendo 5 pesos, 2 pesos, entonces el hombre le puede engañar con esto, 'Mira, toma esto.' Y lo lleva por allí y hace cualquiera cosa. Sí.
H: Y ¿qué de los hombres que lo hacen?
N: ¡Lo hacen por su gusto! ¡Así!

N: Things like this always happen in rural areas, in bateyes.
H: Why do you think that is?
N: Because there are many mothers who don't care for their daughters well. That is why anyone who has a daughter has to take care of them. Tell them, 'be calm.' How do I say this, if I have a daughter, I have to tell her, "Look daughter, whatever man that wants to touch you, don't let him touch your body anywhere. Because this is sacred." Because there are mother who allow their children to beg in the streets for 5 pesos, 2 pesos, and men can can trick them with this, "here, take this." And he takes them away and does whatever he wants. Yes.
H: And what about the men who do this?
N: They do it because they want to! Like that!

In her reality, the onus is on the mother of girls to prevent rape. Because men's actions are deplorable, Nelcida believes that all she can do is protect her three girls and teach them how to defend themselves. This plan may not reflect directly decision-making about health, but is relevant to the way in which parents socialize their children and react to occurrences that are terrifying, especially to parents.

Theme: Traditional gender roles

Traditional gender norms of women caring for the house and men seeking work are expected in Algodón. However, forced by economic hardship, many younger couples with children have begun to share the burden of household duties and paid labor. There are also many female headed households in the community

where women do everything, while relying partially on their parents, usually without any financial assistance from absentee fathers. In the end, there is no monolithic gender structure in the community, but different individuals and small groups of people who carve out their relationship norms while working with harsh economic and family conditions. So, gender norms influence decision-making in different ways, depending on their social context.

Adela, for example, lives with her husband and is raising two grandchildren, while her grown children work in Santo Domingo. Adela is forty-eight (48) and, as an informal business, sells beer out of her house, usually on weekend nights. Her husband works cutting sugar cane during the *zafra* (the sugar season). Adela is overweight and suffers from high blood pressure, high blood sugar, and what is locally called *comezón*, which she describes as itchiness of the whole body.

Adela and her husband follow fairly traditional gender norms in their household, although she does run the informal business on the side. Adela is responsible for household chores, cooking, and taking care of the young grandchildren. She reports taking regular medication and monitors her high blood sugar and high blood pressure. She describes navigating the biomedical aspects of treatment with ease, ie. she goes to the doctor and follows orders. However, when asked if the doctor has ever discussed diet and exercise with her, her tone changes completely as she reveals her dislike of the behavioral changes that the doctors have suggested:

H: ¿Que te dijeron de cosas de dieta o de ejercicio? ¿Te hablaron de cosas así? A: Pero se lo dice a uno y no lleva su dieta como tiene que llevarlo. Como uno tiene que hacer ejercicio pero yo no voy. Para no dejar la casa sola. O el oficio que tu tienes en la casa… uno hace ejercicio. Es por eso. Entonces me dan los medicamentos, yo los tomo. ¡Así!	*H: What did they tell you about things like diet and exercise? Did they talk to you about things like that?* *A: They can tell you that but you don't follow their diet like you should. Like one has to do exercises but I do not go. I can't leave the house alone. Or all the chores that you have to do at home… that is exercise. That is why. So, they give me my medications, I take them. Like that!*

Adela's decisions to adhere to doctor recommendations are greatly shaped by her role in her family and how she constructs her possibilities. From the outside, her reluctance to lock up the house and go for a walk to exercise every day does not appear to be a big impediment. But in her mind such recreation is impossible to undertake during the day, not to mention that she has no energy for exercise after she does all the chores at home.

Eighteen (18) year old Angela has an increasingly common familial context, where she is finishing high school and is also a single mother of a daughter. She describes how gender norms are changing and that she has decided to continue her education:

A: Los hombres trabajan y las mujeres limpian y hacen de to'. Pero algunas también como yo, ¡ellas se fajan! Yo estaba embarazada e iba a la escuela, iba al liceo. También hay muchas que hicieron esto- embarazada y fueron al liceo, y estudiaban, terminaron su año, y después ir a la Universidad.	*A: Men work and women clean and do everything. But some women like me, we work hard! I was pregnant and I went to school, I went to high school. There are many who have done this- being pregnant and they went to school, and they studied, and they finished their year, and afterwards they go to university.*

Often gender norms are viewed as having negative impact on women, but there are influences on men as well (Courtenay 2000). Men both enact their masculinities and are involved in social interactions where their masculinity is being co-constructed, and this process can lead them into situations and decisions that place them at rish where the physical stakes are high, particularly related to their health (Courtenay 2000). For men

working as sugar cane cutters, these gendered roles and the resulting decisions they make to enact their masculinity can lead to serious injury and death. Luis is an eighty (80) year old man who cut cane for forty years, and subsequently worked in the sugar factory for seventeen years. He has had a lot of experience with the abuses and risks of that occupation. Currently he lives off a small pension and cares for his five grandsons while their parents work.

He tells stories of his own experiences and also how the father of one of his grandson's was killed in a fight between cane cutters over a disagreement over who owned some of the cane that had been cut. Altercations between workers, and between workers and overseers, are common and put men at risk for further injury in an already difficult occupation. He describes how things used to be for cane workers and the physical risks they were exposed to when he cut cane before moving into the factory side of the process:

L: Yo estaba trabajando picando caña y pues, yo tenía un hermano mio que estaba en el ingenio allá en Barahona, y me mandó a buscar. Los jefes me puso a trabajar. Si no fue por esto sería picando caña! Uno coge sol! Mojado! Antes nosotros amanecer en la finca trabajando mojado. Porque ahora no es como el tiempo aquel. Antes si te tocaba tú tenías que estar allí! Que venían con guardia que tú tenías que salir de la casa al corte de caña obligado. Cuenta que cuenta, tú puedas tú puedas, tú tienes que ir. Con guardia! Ya no. Ya uno pica caña si tú quieres. Y ahora no halla caña para picar aquí.

L: I was working cutting cane and then, I had a brother who worked in the processing plant there in Barahona and he sent for me. The bosses put me to work. If it weren't for that I would still be picking cane! You get sunburned! Drenched! Before we would work through the night working drenched. Because now it is not like those old times. Before if it was your turn you had to go! They came with the guards and you had to leave the house to cut cane obligatorily. Whatever happened, come on come on, you had to go. With guards! Now you cut cane if you want. And now you can't even find cane to cut.

Now the abuse is more subtle. There are no longer the middle of the night deportation round ups and semi-forced labor that Luis described. Now, the abuses are different. Quesnell, for example, reported having been cheated out of several days' pay, and this rip-off created a lot of stress and anger for him, which obviously influences his health. He describes that he liked having the work, but he cannot do it for free. The decision to leave a formalized job and move to the informal sector and work on other people's lands has also changed the family gender dynamic. He describes these changes and the shared responsibilities that parents have in a difficult economic climate:

Q: [E]lla (su esposa) estaba allí en las cruces. Trabajando en la casa ajena a ver si consigue algo porque yo como yo estoy yo soy hombre, ahora no, no es así. Porque ella puede, que nosotros podamos conseguir algo porque imagínate uno que tiene sus hijos tu no puede sentar todo el día en la casa no haciendo nada porque no hay nada para uno hacer.

Q: She (his wife) was at the crossroads. Working in someone's house to see if she could find something because how I am I am a man, now, no, it is not like that. Because she can, we can find something because imagine it, when one has children you can't sit all day in the house not doing anything just because there is nothing to do.

Conclusion

By analyzing interviews and drawing conclusions from the researcher's first hand experiences and field notes in the community, five main concepts emerged from this information. Clearly, decision-making about health is complex and cannot be summarized with a handful of neat variables. By using in-depth interviews, the messiness of people's existence becomes visible with respect to how they organize their lives. Decisions about health in this particular community were influenced by broad social issues, such as legality, citizenship, and gender identity. Furthermore, the perceived options of persons were shaped by day to day minutiae related to medication costs, environmental pollution, availability of water, and knowledge about disease prevention.

In the next chapter, interventions, solutions, and possibilities for future community improvement projects are discussed while using the themes identified in the interviews. Some of the insights gathered from this fieldwork, moreover, might be able to shape policies that are relevant to this community. In this way, some of the problems they face might be mitigated.

Chapter 6: Discussion and Conclusions

There are several ways to proceed with a discussion of findings at this juncture. One way would be to rehash each thematic finding and propose concrete epidemiological and social interventions. Clearly there are some projects that could be undertaken in the community that would improve overall health and well-being. They range from technical fixes (paving roads), addressing social inequalities (gender-based consciousness raising), and legal interventions (declaring youngsters), to name a few possible projects on different scales. These community needs are not very difficult to identify and would surely help improve living standards in the community. The focus here, however, will be on the epistemological lessons learned that can be applied more broadly to inform constructivist approaches in epidemiological fieldwork beyond the specific locale under study presently.

Several fields concerned with health research have shifted from an individual focus to broad environmental and community-based interventions to more appropriately address health needs (Stokols 1995). This study can contribute to this shift by focusing on the construction of health and the constitution of reality for a community. A challenging aspect of this epistemological shift to the health researcher is gaining access to the biographies and related narratives through which people arrive at their current understanding of their own health and that of their families. Simply stated, planners should understand what persons deem relevant to their well-being. Moving beyond seeing the human element as an obstruction, something subjective and unreliable, this factor is instead viewed as crucial in order to understand the real ways that people view the world

and act within this reality (Max-Neef 1998). By delving into the ways that certain aspects of a community are constructed, negotiated, and altered by the people living there, the possibilities available to persons in their "common sense" or everyday interpretive world become available to the researcher (Garfinkel 1964).

In casual conversation, walking up to somebody and asking how they are, one of the most common exchanges overheard in Batey Algodón is similar to the following:

¿Cómo estás?   *How are you?*

Ya tú sabes, buscando el moro.   *You know, searching for rice.*

This is not just a symbolic answer about food insecurity, and the pressing needs in people's lives, although this expression does convey this meaning. This is a phrase heard on a daily basis that demonstrates the construction of a person's well-being and way of seeing and existing in the world. In this case, the struggle for the next meal is experienced through the multiple lenses through which people experience everything that happens in their daily lives as mothers, fathers, friends, workers, cane cutters, and any other hats a person wears in a day. The answer to this most casual question is answered frequently with a version of reality that reflects a holistic construction of well-being in survival mode, living meal-to-meal and day-to-day. In addition to the participants constructing their realities, the researcher and readers will also inevitably provide a lens through which the construction of health in a community is understood (Pollner 1991; McAdams 2005).

During the interview process, topics ranged from broad health and well-being issues to very personal questions. Often these questions were answered in unique ways and spoke to themes that go beyond what is immediately understood as pertaining to

health. Often participants opened up their lives to the interviewer in ways that were

unexpected. Questions about health and hardship were responded to often with

biographical accounts of the ways in which people have struggled to provide for

themselves and their families.

In conversations during the interviews, participants often revealed their

motivations and thought processes about intimate health decisions. Both of these styles,

the biographical narratives and the revealing of personal information, suggested four

main conclusions. First, to understand epidemiology at the community level a planner

must have access to the epistemology that is operative. Second, this epistemology extends

well beyond immediate health, and therefore a truly holistic way of thinking and

integrating different facets of community and individual life is necessary to understand

correctly the issue. Third, in order to grasp the health related decision-making that is

meaningful to community members, the biographical narratives that persons adopt to

explain their health practices and concerns are of utmost importance (Charon 2001;

Stevenson 2004). And last, the meanings from these narratives must be tied back to the

sociological perspective, not in an *a priori* way that seeks empirical qualities in order to

infer causality, but to appreciate how the broader social environment is co-constructed

with the meanings of health. The unique ways that persons respond to health questions

and reveal their own biography draw the researcher along this path of understanding the

whole picture of health. In this regard, Zaner may be correct that health is the most

existential issue (Zaner 1988).

Need for an Active Epistemology

Planners and epidemiologists can use these findings to adjust the way they enter into working relationships with communities. The analytical findings from the previous chapter shed light on immediate health concerns of the community, but the big picture is that people construct their reality in a very active way. The "cosmos" of this community, and decisions that participants make, are based in their "substantive rationality" and conditioned by others with whom they interact (Weber 1971). This study sought to enter and comprehend the *lebenswelt* (life-world) of this community. This agreed on reality that provides a familiar backdrop to participants' lives is real for the people who live and make decisions in this context (Garfinkel 1964). Accessing this community's existence through qualitative sociological inquiry, and focusing on the narratives persons use to organize their world, is an appropriate method to understand the reality that is created from their activities (Richardson 1990). In this case, through the process of interviewing, the biographical context is revealed to be crucial to persons' experiences. The collaborative process of drawing out relevant narrative stories through the course of the interview resulted in rich contextualized pieces of information about how the participants made meaning of their lived health experiences (Guba and Lincoln 1989; Creswell 2013).

If an outsider enters a community such as this without the knowledge of how this reality is constructed, these persons might be viewed as evasive. But the reality is that people are engaging in a very active and in-depth epistemology, and the typical health and epidemiological questions do not begin to capture what is relevant to this population in terms of health, hygiene, and security. In addition, by essentially deconstructing the "natural facts" by which people live their lives, the issue became clear that participants

are not simply responding to questions, but are in fact reacting and creating an active

epistemology. This finding is consistent with an idealist epistemology whereby

participants are viewed as active constructors of a socially manufactured reality. The

webs of meaning they construct (their *sinnsuzammenhang*), in fact, are often much

broader than anticipated originally (Weber 1971).

Most participants set the tone for the entire interview by answering personally-

focused health questions with an active construction of health that incorporates very

expansive components of life. At first glance, this strategy could be seen as elusive, or

just a colloquially or poetic way of answering questions, but upon scrutiny and placed in

the context of a larger conversation and time spent in the community, this method

illustrates the complex construction of their world. For example, by answering "in

between two" (**entre dos**) when asked about health, people are not being intentionally

ambiguous, but defining for themselves the way that they view health. Rather than the

presence or absence of a pathogen, they focused on their ability to function in the ways

and roles that are important to their lives and society (Blaxter 1990). These meanings

would be difficult to express, let alone to understand in context, if this inquiry were

limited to easily circumscribed input. These persons viewed their health as tied to factors

that might not be part of a typical epidemiological survey (Leung, Yen, and Minkler

2004).

The active epistemology employed by community members is not only important

for understanding properly an issue, but also gives insight into more complex and

meaningful solutions that can address health problems in a holistic way. This seemingly

complex starting point for understanding should not, however, cause despair among

outsiders, because often social distance is helpful for making problematic the everyday backdrop that supports community knowledge. The non-dualist approach in this study allows persons to identify their own health reality, without having to adhere to the usual epidemiological survey scripts. The findings show the "primary concepts" that persons employ to construct their world vis-à-vis health, while their social, physical, and biographical contexts connect a wide range of factors (Schutz 1953).

The black box epidemiological paradigm of the past, whereby relationships between exposures and outcomes were noted but intervening factors were not elucidated, is stale and being replaced by an epidemiology that finds answers in understanding societal influences and local meanings in health outcomes (Susser and Susser 1996). In such a community-based environment, a willingness to view what may appear to be simple in complex terms is both crucial and necessary to understand how people make sense of their own experiences. Most important, however, is that this construction is interactive (Guba and Lincoln 1989). Instead of approaching the community in terms of traditional risk-factors, the subtleties, values, and beliefs that people used to describe their health-relevant biographies were elevated in priority for this research (Murphy 1992).

This active epistemology can only be accessed by a methodology that is constructivist, accompanied by an interpretive analysis. The researcher and the participants come to understand together the community context, and, in turn, this dialogue increases validity because meanings that are in line with participants' realities are communicated and understood (Richard, Gauvin, and Raine 2011). This community-based perspective provides a space to legitimize these more complex understandings and

interrelationships between health, functionality, gender, legal status, joblessness, food insecurity, and a host of other issues, big and small, that are present constantly in people's lives as they make decisions about health. The unique contribution of a community-based sociological approach to epidemiology is that these complex realities can be appreciated and engaged, instead of pared down to the simplest level of variables isolated and identified for points of intervention (Agar 2003). In this regard, planners must embrace the messiness of primary concepts and the locally constructed meanings of health as something situated in a broader context (Dixey et al. 2013). The way to do this is through understanding health as a holistic construct.

Search for Holism

As is noted in the previous section, following from an actively understood epistemology is the need for a holistic approach to health improvement in the community. This holism is not cursory, but one that understands health decisions to be integrated into every aspect of an individual's life and the community. Holistic approaches to health address physical, social, psychological, and spiritual aspects of health (Barrett et al. 2003). This holistic formula was revealed in the narratives that people provided when they redirected questions about personal health to broader socioeconomic processes. To understand this holism, in turn, planners need to understand the narratives that people are creating to explain and make sense of their lives (Sandelowski 1994). In this regard, the participants were hesitant to limit their answers to concrete health issues, because this reductionism is inconsistent with the way in which their reality is constructed. The biographies of people are intimate constructions of their lives and reveal how a planner or an outsider can enter the *lebenswelt* of the community.

The ecological perspective available from a community-based public health approach, and closely related to an ecosocial approach in social epidemiology, is relevant to these findings that people tie health directly to other elements of their lives, such as economic and formal educational opportunities (Franks, Gold, and Fiscella 2003; Cummins et al. 2005; Ahs and Westerling 2005). The ecological perspective has developed from many disciplines, and thus provides a familiar reference point to consider the complex context in which health decisions are made (Kelly 1966; Brofenbrenner 1986). Simply put, invoking the ecological perspective is useful because of the widespread familiarity with this viewpoint across academic disciplines.

From this perspective, health depends on individuals and their ecological or social context, such as family, community, physical environment, and culture. The basic idea is that persons exist in an environment, and that a host of factors are relevant to determine the health status of a person or community (Green, Richard, and Potvin 1996). In this regard, the ecological perspective is often used to assist in the conceptualization of models that bring in multiple layers of influence. Although the goal is not always to have a myriad of variables fill in all the gaps to predict human health behavior, one is often left with a sense of searching for missing factors. In part, this failing comes out of the positivist roots of this perspective in biology, sociology, psychology, and public health (Green, Richard, and Potvin 1996). Nonetheless, these assumptions are challenged by more postmodern ecological studies that reject the necessity of observable, causal chains of variables (Green, Richard, and Potvin 1996). The usefulness of the ecological perspective, however, remains relevant.

In line with the vision of the ecological perspective that seeks a deep understanding, and not a superficial search for new missing variables, the results from this study support an argument for a truly holistic approach to health. Specifically important is that people make sense of their health in ways that are not linear, and not defined in terms of strings of causality, but a true holism that views health in terms of the lived, imagined, and embodied experiences of people. In this study, for example, many of the people who had immigrated from Haiti as adults, as well as some Dominican-born participants, contextualized their current health in terms of the extreme poverty they faced as children. In fact, several respondents qualified their present life in contrast to their parents who simply could not provide for them or send them to school. In their biographies, the prospect of having left dire circumstances shaped greatly the way they think about their present lives and health. Listening to how important biographies are to the ways that people engage their health, their decisions are misrepresented if they are confined, for example, to rational choice models (Vernberg 1998). Indeed, their entire worldview is shaped by their early life experiences and all the other things that have happened in their life. But the holism that is helpful is not achieved by attempting simply to control for certain effects, as is often the case. When this method is followed, holism is achieved under *a priori* conditions that restrict how all additional factors are understood. This sort of holism is truly truncated.

A convention of research especially in public health, with the goal of providing actionable suggestions and solutions, is to create a real or figurative conceptual map that links together "layers" of reality from micro-level to macro-level, in order to fit them together and offer points of intervention (Sallis, Owen, and Fisher 2008). This naturalistic

version of the ecological model is contrary to the spirit of the perspective. Such

multilevel causal models are useful for their concreteness and interpretability, but do not

represent the truly holistic way in which health is integrated with all other facets of a

person's life (Green, Richard, and Potvin 1996). In the community-based sense, holism

can be approached only by listening to the narratives that people build to understand their

health and their lives. In short, holism is not the same as understanding a person's or a

community's narrative, since these stories shed light on how persons' lives are linked

together, and to a range of social, cultural, and environmental considerations.

Understanding Narratives and Biographies

People tell narratives that reflect how they understand of their lives. By accessing

these interpretations, a researcher can also get a sense of decision-making processes,

particularly the values that persons assign to the various facets of their lives. Specifically

noteworthy, life narratives are told by people whose beliefs and actions affect themselves

and others, and the contents have real world consequences (McAdams 2006). Various

approaches to discourse analysis have been used in sociology. Common approaches that

are particularly relevant here are those that aim to synthesize multiple viewpoints on a

single topic or construct, and others that have as a goal to understand both the person and

the society in which a narrative occurs (McAdams 1988).

A recurring example for many of the women in the study revolved around having

moved to Batey Algodón because their husbands had family connections there. However,

several of them felt unhappy with this decision because of the difficult economic climate,

and how this situation hindered their ability to be good mothers. A few women told

similar stories that demonstrate the ways in which their duties as wife and mother were

coming into conflict that leads to stress and affects their children's health. These recurring narratives help to contextualize both the family's decision about health-related issues, and also broader gendered social norms that are prevalent in the community.

In a sense, the analogy of a kaleidoscope is relevant to describe the ways that people understand their health. A community of individuals sees various aspects of life contributing to a vision of health that is often shifting and organized in novel ways, but still very coherent. Furthermore, people tilt the kaleidoscope differently based on things such as their values, social roles, beliefs, responsibilities, and material well-being. In the end, all of the facets of a kaleidoscope are related, and are hardly stale, but these connections should not be described as causal. The reason for this claim is quite simple: persons intervene and establish the strength of these relationships on the basis of values, beliefs, and commitments (Blumer 1986). The proper way to understand the twist of the kaleidoscope is through the story of why some roles and values, for example, are elevated over others when people construct their health biographies. What might appear to be a distal cause, accordingly, could be very important when considering the source of a problem or a health option.

Relevant to these different lived realities is that a community-based analysis tends to expose the "taken-for-granted" aspects of life (Schutz 1953; Berger and Luckmann 1966). An example is the way that men's and women's sexuality played different roles in decisions about condom (non)-use with primary partners. One woman explained that her husband would be suspicious of infidelity if she used condoms for contraception, while a man argued that condom use over-exerts him and thus is bad for his health. These very different social constructions of gender and sexuality had the same outcome of neither

person using condoms with their primary partner, despite the lack of other contraception and the desire to not have more children. Another way was how motherhood and partnership were interpreted by people to restrict their options about where to live. These seemingly "natural facts" can come to be embodied as health issues that have cumulative effects on people. Therefore, the need to understand health within the broader narratives of persons and communities is crucial to appreciate how these factors are related, along with their weight in making decisions about health.

Empirical qualities versus constructed reality

The final component of this understanding, and a partial way to link the constructivist approach to more applicable methods of intervention, is to understand how the empirical qualities of a community are related to the potential success of interventions. For example, a positivist will likely view these differences in terms of empirical variables, often referred to as "social indicators" (Gregoire 2002). In this regard, these differences could be operationalized as "class differences", or the result of environmental conditions related to housing, pollution, or overcrowding.

But the reduction of entire social worlds to indicator variables is inappropriate in community-based research. The dominance and legacy of the scientific method is such that often researchers feel the need to justify their work as scientific, even when, perhaps, this strategy is inappropriate to answer their research question. Demographic variables, which are intended to provide some semblance of context to epidemiological studies, are used to calculate odd and risk ratios of disease onset, but this method is not necessarily sensitive to how people engage with health and illness (Vernberg 1998). Statistics such as risk ratios are appropriate for generalized population-level descriptions of disease

prevalence, but are entirely foreign to how individuals conceive of their health, their risk for illness, and generally has no bearing on their decisions.

Although these empirical factors are relatively easy to identify, their social or cultural significance is overlooked in indicator analysis in traditional epidemiological studies (Weiss 2001). Variables such as economic status, educational level, gender, race, and age are used often without giving their meanings serious consideration. For example, using gender as a control variable to study a health outcome should be accompanied by a critical explanation of how gender norms in a society, for instance, may put women at greater or lesser risk for a particular health outcome because of their roles, societal position, and lack of power. These considerations, like other facets of community life that have meaning for participants, from the constructivist perspective, are embedded in narratives.

In Batey Algodón, for example, people living 50 yards away from each other used the barrier of the drainage ditch to construct an othering discourse. A young woman, who lives in the original part of the community, the old barracks, was asked about a sexual violence incident that had occurred previously on the opposite side of the drainage canal. Her response was, "That was in the upper part where the new arrivals live. The new arrivals from Haiti. That was between them." (**Esto fue en la parte arriba, de los que llegaron. De los que llegaron de Haití. Esto fue entre ellos mismos.**") Space, in this sense, is not as objective as indicators might suggest.

Another example from the study is the way in which one woman perceived her role as grandmother and wife. The doctor had told her to exercise for her obesity and resultant high blood sugar levels. However she believed that she could not leave the

house unattended with her two granddaughters residing there, in addition to feeling exhausted from her daily household chores which further reduced her motivation to go for walks for exercise. These reasons that were revealed through her narratives would not have been picked up by checking off a list of demographic and behavioral variables. In other words, the *why* of the "non-adherence" to medical advice would not have been captured.

Conclusion

Applicable health solutions were revealed through the analysis of participants' interview responses and discussed in the previous chapter. The focus was on the way that people build their understandings of health, and linkages were drawn between concrete health issues, social processes, and the ways in which people viewed all of these issues to be intertwined. By going into a deeper understanding of the community's *lebenswelt* (life-world), health came to be understood as embedded in every aspect of a person's life. The construct of health, accordingly, depended on how economic viability, gender roles, and household issues, for example, are embedded in their stories about community life and their biographies (Garro and Mattingly 2000). The real lesson learned here is that through this type of understanding, a multifaceted view of health was attained. In this regard, the so-called empirical traits of a community provide merely starting points to understand the multiple realities that are constructed on a daily basis.

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Appendix A: Informed Consent Forms

Community- based epidemiology: health- relevant practices in a Dominican batey

CONSENT FORM

You are being asked to take part in a study about health in this community. You will be asked to answer questions about yourself, your family, your health, and your living conditions. We will conduct the interview in a place and at a time that is comfortable for you; and if you would like to be interviewed with somebody else, that is fine. You can determine the length of the interview and stop this process at any moment. The interview may last up to an hour, and you may be contacted again in the future to discuss additional health questions.

The interview will be audio recorded. At any time during the interview you can ask me to turn off the recorder.

Your participation in this research is voluntary, and you will not be penalized if you refuse to participate or decide to stop the interview. I do not anticipate that you will encounter any risk or receive any direct benefits from your participation in this project. And you will not be paid for participating in this research study.

The recordings, documents and transcripts of the interviews will be kept on a password-protected computer and in a secure location that is accessible only to the study team. Additionally, the recording will be destroyed immediately after the transcripts have been completed.

The Investigators and their assistants will consider your records confidential to the extent permitted by law. The Department of Health and Human Services (DHHS) may review these research records. Your records may also be reviewed for auditing purposes by authorized University of Miami employees or other agents who will be bound by the same provisions of confidentiality.

The results of this research will be published as part of my doctoral thesis at the University of Miami. It is possible that the results may also be published in academic publications. When the results are reported, no individual will be identified in any way.

In case you have any questions about the project please contact me, Hilary Cook (h.cook@miami.edu) at (809) 533-5373/2873 o John Murphy (j.murphy@miami.edu) at

(305)284-6157. You may contact the Human Subject Research Office at the University of Miami at (305)243-3195, if you have questions about your rights as a research subject.

Participant Agreement

By signing this document means I affirm that I have read the information above, or that it has been read to me, and that I voluntarily agree to participate. Also, I have had the opportunity to ask questions about the project, and they have been answered satisfactorily. I understand that I have the right to a copy of this document.

_____
Signature of Participant

_____
Signature of Project Agent

Audio Recording
[ ] I do **not agree** to be audio recorded
[ ] I **agree** to be audio recorded

_____
Signature of Participant

_____
Signature of Project Agent

Epidemiología basada en la comunidad: Una investigación de factores complejos sobre decisiones relacionadas con salud en un batey dominicano.

FORMULARIO DE CONSENTIMIENTO

Se le pide a usted que participe en una investigación sobre la salud de su comunidad. Voy a pedirle que responda a algunas preguntas sobre su salud, y las condiciones de su vivienda. La entrevista se realizara en un lugar y hora conveniente para usted. Usted puede ser entrevistado/a en compañía de otra persona que sea de su confianza, como un familiar o amigo/a. Usted puede determinar la duración de la entrevista y terminar este proceso a cualquier momento. La entrevista durará una hora, y quizás yo le pida que me permita entrevistarla nueva vez en el futuro.

Su participación en esta investigación es voluntario/a, y no será sancionado/a si rehúsa participar o decide terminar la entrevista. No se anticipan riesgos ni beneficios directos por participar en esta investigación. Además, no existe ninguna remuneración económica relacionada con su participación en esta investigación.

La entrevista será grabada. En cualquier momento durante la entrevista puede pedirme que apague la grabadora, si no se siente comodo/a. La grabación, la transcripción, y los documentos de su entrevista serán guardados en una computadora y en un sitio seguro que será accesible solamente al equipo del estudio. Además, las grabaciones serán destruidas inmediatamente después de completar las transcripciones.

Los investigadores y sus ayudantes considerarán sus documentos confidenciales hasta lo permitido por la ley. El Departamento de la Salud y Servicios Humanos (DHHS, por sus siglas en ingles) de los EEUU podrá revisar los documentos utilizados en esta investigación. Sus documentos también podrían ser revisados por empleados autorizados de la Universidad de Miami quienes deberán observar los mismos criterios de confidencialidad.

Los resultados de esta investigación serán publicados como parte de la tesis doctoral de la investigadora principal y además en publicaciones académicas. Ningún individuo será identificado/a de ninguna forma, cuando los resultados estén reportados,

En caso que Ud. tenga alguna pregunta con respeto a este proyecto, por favor contacte a Hilary Cook (h.cook@miami.edu) al (809) 533-5373/2873 o a Dr. John Murphy (j.murphy@miami.edu) a (305)284-6157. Si tiene algunas preguntas relacionadas a sus derechos como un participante, por favor, llame a la Oficina de los Derechos de Participantes (Human Subjects Research Office) en la Universidad de Miami a (305)243-3195 o al Dr. Rodolfo Núñez Musa, Comité de Ética del Centro Nacional de Investigaciones en Salud Materno Infantil Dr. Hugo Mendoza (CENISMI) al 809533-5373.

Acuerdo con el Participante

He leído la información precedente, o me ha sido leída, por lo que acuerdo participar voluntariamente en esta investigación. También, he tenido la oportunidad de hacer preguntas sobre este proyecto de investigación, y han sido contestadas satisfactoriamente. Entiendo que tengo el derecho a una copia de este documento.

_____
Firma del Participante

_____
Firma de la entrevistadora

Audio Grabación
[ ] **No estoy** de acuerdo con el proceso de grabación.
[ ] **Estoy** de acuerdo con el proceso de grabación.

_____
Firma del Participante

_____
Firma del Agente del Proyecto

UNIVERSITY OF MIAMI

University of Miami
Human Subjects Research Office (M8
PO Box 016960, Miami, Florida 3310
1500 NW 12 Avenue, Suite 1002, Mia

Ph: 305-24
Fax: 305-24
www.hsro.n

EXPEDITED – APPROVAL

March 24, 2011

John Murphy, Ph.D.
University of Miami
Department of Sociology
Coral Gables Campus
Coral Gables, FL 33124

HSRO STUDY NUMBER:	**20101005**
STUDY TITLE:	**Community based epidemiology: A study of complex factors in health decision-making in a Dominican batey**
IRB ACTION DATE:	**3/22/2011**
STUDY APPROVAL EXPIRES:	**3/21/2012**
SPONSOR NAME:	There are no items to display
FWA:	**FWA00002247**

On 3/22/2011, an IRB Chair approved the following items under the expedited review process, with a waiver of Informed Consent for the Observational Portion only.

APPROVAL INCLUDES:

New Research Protocol
Research Materials *(English & Spanish Versions Only)*

- Informed Consent Form

- Interview Guide

NOTE: Translations of IRB approved study documents, including informed consent documents, into languages other than English must be submitted to HSRO for approval prior to use.

Sincerely,

[This is a representation of an electronic record that was signed electronically and this page is the manifestation of the electronic signature]

Amanda Coltes-Rojas, MPH, CIP
Director
Regulatory Affairs & Educational Initiatives

/vc

A request to continue this study must be submitted to the HSRO at least **45 days** before IRB approval expires. If this study does not receive continuing IRB approval prior to expiration, all research activities must cease, and it may be officially suspended or terminated.

cc: IRB File

Hilary Cook

**CENTRO NACIONAL
DE INVESTIGACIONES
EN SALUD MATERNO INFANTIL
DR. HUGO MENDOZA**

Hospital de Niños
Robert Reid Cabral
Abraham Lincoln No. 2
Santo Domingo, Rep. Dominicana

Miembro de la Red de Centros de
Investigación Asociados al CLAP
(Centro Latinoamericano de
Perinatología y Desarrollo Humano)

Santo Domingo, D.N.
11 de agosto del 2011

Miembro de la Red de
Centros de Investigación de la
Secretaría de Estado de Educación
Superior Ciencia y Tecnología
(SEESCYT)

Mstra. Hilary Cook
Estudiante del Doctorado en Sociología
Universidad de Miami

Estimada Mstra. Cook:

Por medio de la presente certificamos que el Comité de Ética de Investigación del Centro Nacional de Investigaciones en salud Materno Infantil Dr. Hugo Mendoza (CENISMI) aprobó mediante evaluación expedita la investigación denominada: *Epidemiologia basado en la Comunidad: Una investigación de factores complejos de las decisiones relacionadas con la salud en un batey dominicano".*

Esta aprobación le compromete a dar inicio efectivo al estudio, tomando todas las medidas necesarias para resguardar los derechos de los participantes, apegarse al protocolo presentado (cualquier cambio debe ser comunicado al comité para su aprobación), remitir los informes de evolución cada tres meses, reportar cualquier evento adverso en un plazo no mayor de 7 días (si es un evento adverso serio debe reportarse durante las primeras 24 hrs), avisar si por alguna razón el estudio es suspendido, notificar la finalización del estudio y remitir un informe final del mismo.

Sin otro particular, le saluda atentamente,

Dr. Rodolfo Nuñez-Musa
Presidente
Comité de ética del CENISMI

Habitación 424 Teléfonos (809) 533-5373 / 533-2873 Fax (809) 532-6450 E-Mail cenismi@yahoo.com
Página Web http://www.cenismi.org

Si esta carta no tiene el sello de la institución, no tiene validez

Appendix C: Interview Schedules

Interview Guideline

1. How is your health?

2. How is the health in your family?

3. How is the health in the community?

4. What things influence your health and the health of your family?

5. What things are beyond your control that influence your health, and what things are under your control?

6. Do you do things on purpose that help you (and your family) from getting sick or hurt?

7. Sometimes things are recommended to improve health. Do you do any such things.
    (probe examples: use mosquito nets, water preparation techniques, hand washing)

8. Some places make it easier to be healthy, and some places make it more difficult. Are there things in this community that impact health, for good or for bad?
    (probe examples: environmental, religious, community norms, recreation areas, animals, runoff standing water from fields, religion, alcohol use)

9. How have your experiences at the clinic or hospital been?
    (probe examples: doctor interaction, access to these places, language barriers, legal concerns with care seeking)

10. What things would you do differently to protect your health or that of your children, if you could?

11. Do you take care of anyone else or their children when they are sick?
    (probe examples: exposed to disease, stress, economic strain)

12. How do you do things in your family?
    (probe examples: who makes decisions about children health, money allocation, relationship quality, sexual practices)

13. What changes in your community would help you and your family to be healthier?

14. Collect demographic and biographical information
    Age
    Number of children
    Education level
    How came to community
    Languages spoken
    Employment

Guía de Entrevista

1. ¿Cómo está su salud?

2. ¿Cómo está la salud de su familia?

3. ¿Cómo está la salud de esta comunidad?

4. ¿Cuales cosas se influyen la salud de Ud. y la salud de su familia?

5. ¿Cuales cosas son más allá de su control que influyen su salud? y, ¿cuales cosas son bajo su control?

6. ¿Hace Ud. cosas a propósito que le ayudan a Ud. (y su familia) para prevenir enfermedades o daños?

7. A veces se recomienden cosas para mejorar la salud. ¿Ud. hace tales cosas?
    (ejemplos probativos: uso de mosquiteros, prácticas de preparar agua, práctica de lavarse las manos)

8. Algunos lugares se facilita ser saludable, y algunos sitios se lo hace más difícil. ¿Hay cosas en esta comunidad que se impactan la salud, por bueno o por malo?
    (ejemplos probativos: medio ambiental, religión, normas comunitarias, áreas de relajo, animales, agua estancado, uso del alcohol)

9. ¿Cómo han sido sus experiencias en la clínica o en el hospital?

    (ejemplos probativos: interacción con doctor, acceso a estos sitios, barreras de idioma, preocupaciones legales relacionado con visitar instituciones de salud)

10. ¿Qué haría Ud. diferente para proteger su salud, o la salud de su familia, si podría?

11. ¿Cuida Ud. a otra persona, u otros niños cuando se enfermen?
    (ejemplos probativos: exposición a enfermedad, estrés, dificultades económicas)

12. ¿Cómo se hace cosas en su familia?
    (ejemplos probativos: quien toma las decisiones sobre la salud de los niños, reparto de dinero, calidad de relación romántica, prácticas sexuales)

13. ¿Cuáles cambios en la comunidad le ayudaría a Ud. y su familia ser más saludable?

14. Recoge información demográfico y biográfico

    Edad
    Número de hijos
    Nivel de educación
    Cómo vino a la comunidad
    Idiomas
    Empleo