The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama

Ilenia Anneth Forero

University of South Florida, iforero25@yahoo.com

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The Water Culture Beliefs of Embera Communities and Maternal and Child Health

in the Republic of Panama

by

Ilenia Forero

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Public Health
Department of Community and Family Health
College of Public Health
University of South Florida

Major Professor: Russell Kirby, Ph.D., M.S.
Ricardo Izurieta, Dr.PH., M.D., M.P.H.
Xavier Sáez-Llorens, M.D.

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Dedication

This final work is dedicated to my whole family who supported me during this new and challenging adventure—without them I would not have had the courage to go away for a long time. To my son, Anibal, who waited for me and my husband, Anibal, who gave him the tools to understand the distance. To my parents, Alina and Rogelio, who helped them during my absence.
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Abstract

Water has cultural and spiritual values to indigenous people. These beliefs expose them to unsafe water sources and make them vulnerable to waterborne diseases. This background is not taken into account when countries write their water legislations, therefore imposing a management of water not readily accepted by them. The Embera group is one of the indigenous groups from the Republic of Panama, who have strong water beliefs. They live along the shore of rivers in houses built on high stilts away from urban areas. The purpose of this cross-sectional community based study is to describe through a survey the relation between the water beliefs of Embera communities living inside the Chagres National Park and the health of women and children. A house to house visit was performed in two of the five Embera communities that reside inside the Chagres National Park to enroll them and complete the survey. Sixteen Embera households with 71 family members agreed to participate. Results showed that 18.5% were children under 5 years of age and 14.1% their corresponding mothers. One hundred percent of the households rely on rural aqueduct as their source of water, with no treatment performed to this water. Women that completed elementary school or had higher education level accounted for 53.4%. Analysis of frequency of more than three diarrheal episodes in children under 5 years of age with mother’s education level and months of breastfeeding had no statistical
significance ($\chi^2$ of 1.935, $p$-value of $>0.05$; $\chi^2$ of 0.258, $p$-value of $>0.05$). When the frequency of diarrheal episodes in women and their education level was analyzed a statistically significant association was found ($\chi^2$ of 6.429, $p$-value of 0.011). Five (38.5%) out of 13 children under 5 years of age in these communities had complete immunization calendar for their ages, but 10 (76.9%) have completed immunization for Rotavirus. No deaths due to diarrhea were reported in any member of the household. Marginalization in this type of communities is frequent since they settle in vast areas far from access to safe roads, safe water, basic sanitation and health services. A similar study can be applied to the 5 communities living in the area to have a clear view of their water beliefs, diseases and needs in order to concentrate efforts to close any gaps.
Chapter 1: Introduction

Statement of the Problem

**Water as a source of health.** As stated once by Kofi Annan, former United Nations (UN) Secretary General from 1997 to 2006 “Access to safe water is a fundamental human need and therefore a basic human right” (United Nations [UN], 2001). Based on this, countries around the world must guarantee through laws that this vital liquid reaches all of their population.

In September 8th 2000 the UN General Assembly made a resolution called the UN Millennium Declaration which was later known as the Millennium Developmental Goals (MDG). The MDG are composed of 8 goals adopted by the UN members that must be achieved by 2015. Goal 7, target 7c, is to halve, by 2015, the proportion of the population without sustainable access to safe drinking water and basic sanitation (UN, n.d.). According to the Progress on Sanitation and Drinking Water 2013 update from the Joint Monitoring Programme (JMP) for Water Supply and Sanitation, on 2011 improved drinking water sources were used by 89% of the world population, 2/3 live in urban areas. Eighty-three percent of the population that has not gained access to improved drinking water comes from rural areas. An improved drinking water source, as defined by JMP in the latest 2013 update, is one that because of the way it is constructed protects the source of water from outside contamination, like fecal material. In this case, improved water reflects the aspiration of reaching a higher number of people with access to water at their households, as well as in their schools and health centers. This definition was
expanded to include after the revision of 2015 MDG a classification of basic, intermediate and adequate drinking water supplies, to describe the closeness to households; a description of acceptable quantities; a description of quality, referring to < 10 cfu (colony-forming units) of Escherichia coli/100ml (JMP, 2013).

Water that is safe, reliable, affordable and easy to access is essential for good health (Hunter, MacDonald & Carter, 2010). Safe drinking water is water with microbial, chemical and physical characteristics that meet the World Health Organization (WHO) guidelines or national standards on drinking water quality. This safe water should not represent a significant risk to health when consumption is over a long period of time. To assure this safety, WHO recommends using a multiple barrier approach. This includes a proper selection of the source, protecting it, having an adequate treatment and distribution system taking in consideration that microbial water quality varies rapidly and widely. For this purpose, reference pathogens have been thoroughly described in the guidelines giving each country the option to choose the most relevant to their local conditions, incidence of waterborne diseases and source water characteristics. Nevertheless, E. coli still remains as the indicator microorganism for water pollution and efficacy of treatment processes when monitoring drinking water, expecting no detectable microbes in a sample of 100 ml from the source or the water distribution system (WHO, 2011).

According to the Global Water, Sanitation and Hygiene (WASH) initiative from the Centers for Disease Control and Prevention (CDC) access to safe water, adequate sanitation, and proper hygiene education are key in reducing illness and death from diseases. In return, this leads to better health, decrease poverty levels and progress in the socio-economic area. Throughout the world, an estimated 2.5 billion people lack basic
sanitation (more than 35% of the world's population) (CDC, 2013). Basic sanitation is described as having access to facilities for the safe disposal of human waste (feces and urine), as well as having the ability to maintain hygienic conditions, through services such as garbage collection, industrial/hazardous waste management, and wastewater treatment and disposal (CDC, 2013).

In areas where access to safe water, appropriate wastewater management, and adequate sewer systems is not feasible, certain programs, such as CDC's Safe Water System, can empower people to improve and protect the quality of their drinking water through simple, inexpensive technologies to treat and safely store water in their homes (CDC, 2013).

One consequence of not having access to safe water is waterborne diseases or water related diseases. Waterborne diseases are caused by pathogenic microbes that can be directly spread through contaminated water. Most waterborne diseases cause diarrheal illness. Eighty-eight percent of diarrhea cases worldwide are linked to unsafe water, inadequate sanitation or insufficient hygiene. These cases result in 1.5 million deaths each year, mostly in young children (Prüss-Üstün, Bos, Gore & Bartram, 2008). According to the words of UN Secretary-General, Ban Ki-moon at a UN unveiling that highlights safe water in 2007:

“Safe drinking water and adequate sanitation are crucial for poverty reduction, crucial for sustainable development, and crucial for achieving any and every one of the Millennium Development Goals” (UN, 2007).
Water Culture

It is important to note first that there are many definitions of culture. According to Vargas (2006), in his publication for United Nations Educational Scientific and Cultural Organization (UNESCO) “La Cultura del Agua: Lecciones de la America Indigena”, ultimately culture refers to the way certain populations are, what they do, how they live, that also includes ways to satisfy their needs. In other words, how they develop life strategies. Water culture is the sum of all beliefs, conducts or strategies that a community determines for the use of water based on their knowledge and practices through generations (Vargas, 2006).

Several important facts are emphasized by Vargas (2006) about the water culture. Among the most relevant we can mention that water culture: is linked to a group (ethnic or cultural); is often considered in programs built by countries as a component of the program and not its central axis; imposition of forms of organization and management of water coming from power groups to the rest of the population may originate cultural and social clashes, especially when the cultural background of the populations are not taken into account (Vargas, 2006).

In March 2003, The World Water Forum in Kyoto made a revolutionary change when indigenous peoples were invited and this resulted in The Indigenous Peoples’ Kyoto Water Declaration (2003). This declaration included the following statement:

"Indigenous Peoples interests on water and customary uses must be recognized by governments, ensuring that Indigenous rights are enshrined in national legislation and policy. Such rights cover both water quantity and quality and extend to water as part of a healthy environment and to its
cultural and spiritual values. Indigenous interests and rights must be respected by international agreements on trade and investment, and all plans for new water uses and allocations” (Water World Forum [WWF], 2003).

The next World Water Forums of 2006 in Mexico City and 2009 in Istanbul continued to invite indigenous inputs, although there were small concrete outcomes.

General Aspects of the Republic of Panama

The Republic of Panama started as a republic after its independence from Colombia in 1903. That same year, the Panama Canal construction, previously stopped, restarted in the hands of the United States of America, with whom the republic shared its administration until 1999 when it was finally reverted to national control (Loteria Nacional de Beneficencia [LNB], 2003).

The republic has a strategic location in the American continent, is a narrow isthmus with the shape of an “S” divided by a stream of water that connects the Caribbean Sea with the Pacific Ocean. The geographical boundaries are: to the North with the Caribbean Sea, to the South with the Pacific Ocean, to the East with the Republic of Colombia, and to the West with the Republic of Costa Rica. According to the latest National Census on Population and Housing in 2010, the republic has a total extension of 75,517.0 km², is made up of 9 provinces, 75 districts, 3 comarcas that function as provinces (Kuna Yala, Embera, Ngäbe-Bugle), and 623 corregimientos (smallest political division or township) that include 2 comarcas, Wargandi in Pinogana, and Madugandi in Chepo. Its climate is tropical and is characterized by having 2 seasons:
dry season, from December to April, and a rainy season, from May to November (Contraloria General de la Republica [CGR], 2010).

According to the republic’s Constitution and Law 19 from June 11, 1997, the Panama Canal Authority (Autoridad del Canal de Panama [ACP]) is responsible for the administration, maintenance, utilization and conservation of the water resources in the Panama Canal watershed (CHCP); the geographical area whose waters, superficial and underground, flow into the Canal as well as into its reservoir/dams and lakes, covering 339,650 hectares. The CHCP has lands in different provinces such as Panama and Colon, and is made up of 7 districts, 40 corregimientos and around 429 communities (ACP, n.d.). This is the most important watershed in the country because of its multiple uses: water collection and storage for the Panama Canal function, raw water source for later processing in different water treatment plants and distribution to Panama, Colon, La Chorrera and Arraijan cities, and electrical energy generation (ACP, 2012).

**Population composition.** The total population of the republic is 3,405,813, according to the 2010 national census. Due to certain historical circumstances the population is diverse and classified as non-indigenous and indigenous groups. The non-indigenous group is made of: Hispanic-indigenous, African colonial, West Indies, and other ethnic groups. The indigenous group is made of: Kuna, Embera, Wouna’an, Ngäbe, Bügle, Bokota, Naso/Teribe, and Bri Bri (Instituto Nacional de Estadística y Censo [INEC], 2010). Each of these groups has its own legislations recognized by the country’s laws and also recognizes their geographical areas known as Comarcas (Coba, Adames & Margarita, 2005).
The last Living Standards Measurement Survey (LSMS, 2008), reported that: 7.1% of the population of Panama is of indigenous composition; poverty in the urban areas of the republic account for 17.7%, rural 50.7% and indigenous 96.3%; of the 7.1% total indigenous population, 20.9% live in poverty and 41.8% in extreme poverty; the provinces with the highest poverty level are Bocas del Toro 53%, Darien 52.7% and Veraguas 52% and the comarcas 96%; and literacy of the indigenous population over 15 years old is 60.3% (INEC, 2008). The LSMS also reports that from the total republic population, around one million and ninety thousand people live in poverty, and from this around 481 thousand are in extreme poverty, representing 32.7% and 14.4% of the total population respectively. The indigenous community is 96.3% of this population (INEC, 2008). Not all the indigenous people live in comarcas. In fact, it is calculated that 43 percent of the indigenous live outside the comarcas. Seven indigenous languages are spoken in Panama: Spanish, Ngabere, Buglere, Embera, Wouna’an, Teribe and Bri Bri.

Characteristics of Embera-Wouna’an groups. The Embera groups are natives of the Colombian Choco indigenous culture that came into the republic at the end of the seventeenth century and start of the eighteenth. They settled at the pacific slope of the province of Darien, frontier with Colombia, along the shores of the rivers Jaque, Sambu and Balsas as dispersed communities. Law Nº22 of November 8, 1983 recognizes the Comarca Embera-Wouna’an of the province of Darien. Those that do not live inside the Comarca settled in other parts of the republic as tierras colectivas or collective lands which are still not legally recognized (Coba, Adames & Margarita, 2005). Due to their migratory customs, they have continued their movement year after year, now entering
areas in the province of Panama such as Chepo, Chiman and the Chagres river (Torres, 1999a).

According to the Census on Population and Housing of 2010, the comarca was made up of 10,001 inhabitants. Nonetheless, the rest of the country houses 12,924 persons that identify themselves as belonging to the Embera group. From the latter, 5,825 live in the district of Panama (INEC, 2010), and several non-defined groups live inside the PNCH (Autoridad Nacional del Ambiente [ANAM], 2005).

Aside from Spanish as the official language of the republic, the Choco group divides into Choco Embera and Choco Wouna’an. With two recognized languages, Embera and Wouna’an respectively (Torres, 1999a). The Embera group has 9 other dialects depending on the area they live in (Torres, 1999b). Embera stands for gente or people.

They live semi-nomadic lives, in constant movement through the rainforest in small social groups. Migration of agricultural colonists into Darien who utilize land differently from Embera and armed outlaw groups in the border between Panama and Colombia are situations that stimulate migration of this group, but they mostly do it in a rural to rural way since they feel the need to continue their customs and take advantage of natural resources (Unidad Tecnica del Proyecto Panama - Darien [Unidad Tecnica], 1978).

The Embera people live traditionally from agriculture, hunting and fishing. Traditional housing is built alongside rivers at considerable distances from each other, very high on stilts, up to 3 meters, usually for protection against wild animals such as the jaguar called locally tigre or tiger, wild boar, rodents etc. and without walls. This type of
construction also offers protection from flooding. Given that they live in tropical rain forest areas and their houses are very close to river streams, for means of transportation they build *piraguas* which are boats made of different types of woods like cedar or pine (Torres, 1999a).

This group uses what is called covering-sex clothing which is very common among populations living in tropical rain forests and that they decided to maintain as part of their tradition. For men, it consists of a piece of cloth covering only genitalia and reaching down up to the knees, held on its place by a thread wrapped around the waist. For women it is very simple, just a piece of colorful cloth at least 1½ meter in length wrapped around the waist with no covering of their chests except for necklaces made of *chaquira* or beads. They also adorn their bodies with paintings from different fruits which will last up to 8 days (Torres, 1999a).

**Embera Communities in the Chagres National Park**

The Chagres National Park (PNCH) has an extension of 125,491 hectares; is located in the provinces of Panama and Colon, made up of the districts of Panama, Chepo, Colon, Portobelo, Nombre de Dios and Santa Isabel (See Figure 1). There are 34 communities inside the PNCH. According to the 2000 census, these communities shelter a total of 2,737 inhabitants. The Embera Drua community reported the highest growth rate, 50%, during the 1990 to 2000 decade (ANAM, 2005).
Fig. 1. Administrative borders of the Republic of Panama with an inset of the Chagres National Park. Map created by author, 2012.

In the last two decades the increasing number of different population group settlements inside the PNCH has come to national attention, in particular the fact that 87% of them live in extreme poverty. Among these groups are a few indigenous migratory groups that belong to the Comarca Embera located in the province of Darien, which is one of the poorest provinces in the country. These Embera group settlements are: Tusipono, Parara Puru, Embera Drua and San Juan de Pequeni. Since 1984 some of their daily activities have been restricted, such as hunting and agriculture, because of the preserved area in which they are living. This is why they have sought, through tourism, a new way of generating income and improving their quality of life. These communities are
mostly rural. They also lack of a proper sewer for human waste. There are 16 multilevel classroom schools, but the assistance to these installations is decreasing (ANAM, 2005).

The family is made of a monogamous marriage and their children. The laws of marriage include: incest is forbidden, marriage among relatives is forbidden up to second cousin, and some mixed marriages are allowed although endogamy is preferred. The head of house is the father. He makes the decisions of the family and domestic life. This does not mean the women have an inferior standing in the house chain of command (Torres, 1999a).

Their income is made up mainly from the services they provide to tourist/visitors or tourist enterprises regarding payment for transportation across the river, rent for temporary housing inside the communities, selling of crafts, and hiking through natural settings (Ministerio de Salud [MINSA] & World Bank [WB], 2008).

The Management plan for the PNCH has different programs designed and directed to the diverse group of populations inside the park, and are focused on helping them to be self-sustainable by avoiding damage to nature and promoting tourism. This nature conservation affects specifically indigenous groups settled here, such as the Embera, since they cannot cultivate lands and have to turn to tourism and crafts selling as a source of income. This plan does not include determination of the communities’ needs in health and education matters (ANAM, 2005).

**Water Sanitation Structure in the Republic of Panama**

The first aqueducts in the republic were built in 1905 as a consequence of the modernization of water distribution and sanitation the country was undergoing due to the
Panama Canal construction. In 1956, a commission was created to design and build the aqueduct distribution system. Today this commission is known as the National Institute of Water and Sewerage (Instituto de Acueductos y Alcantarillados Nacionales [IDAAN]) and is composed of 47 treatment plants providing potable water to over 2.2 million people through a system of 5 thousand km of water networks and 1300 km of sewerage (IDAAN, n.d.).

According to the IDAAN’s Statistics Report No.26 of 2010-2012 (IDAAN, 2012), in the year 2012, 75% of the country’s total population had access to potable water. The indigenous populations living in the comarcas have 0% access to potable water where IDAAN only provides technical assistance. Potable water is defined by IDAAN as the one delivered to a population through aqueducts managed by IDAAN and who have a contract with IDAAN (IDAAN, 2012). In rural areas where there are no aqueducts there is collaboration between the Ministry of Health (MINSA) and IDAAN to give technical assistance to these communities through rural aqueducts, where water does not go through a purification treatment. Juntas de agua or rural water boards are established, managed and monitored by MINSA in these areas (MINSA, n.d.).

According to the latest national census the sources of water to drink and for other purposes is classified as follows: IDAAN aqueduct, rural aqueduct (individual or from the community), sanitary well, unprotected well, surface water, rainfall, river or stream, tank truck, bottled water. The first two sources of water could either have the pipelines and final water tap inside or outside the households (INEC, 2010).
**Water tradition in Embera communities.** The Embera people believe water is the work of almighty God in heaven. They pray through their chaman to different spirits and one is the mother of water or Antomia. Because of these believes no special artifacts or machinery are used to handle water. Water comes from the rain for use on surfaces and from the river for general use. To contain water they use the *totuma* or *jiado*. Water does not undergo treatment; it is used directly from the rain or river. There is no technical handling of feces, other human wastes, or garbage. They generally use the river for these matters, as they believe that the river takes all things that are not good away and everything that is thrown or poured into the river is cleaned and bad odors are removed (UNESCO, n.d.). The *Junta de agua* is in charge of the water supply for the community (ANAM, 2005).
Chapter 2: Review of Literature

Water Legislations Worldwide

The World Water Forum was created in 1994 and established in 1996 as an initiative of the UN to “promote awareness, build political commitment and trigger action on critical water issues at all levels” (WWC, n.d.). They recognized the access entitlement every person has to safe water. This became more inclusive after the Indigenous Peoples’ Kyoto Water Declaration of 2003, where they demanded that governments should recognize their interests on water and customary uses (WWF, 2003).

According to Panama’s constitution there are several articles that stress the responsibility of the government towards certain activities that involve healthy environment and ensuring water supply and quality for the population. For example, article 110 refers to the responsibility to develop accessible drinking water and sanitation in order to prevent communicable diseases; article 118 addresses the need to ensure healthy environment and water quality in order to meet appropriate standards of human life; article 258 stresses that certain waters in the republic, including those destined for public services are not subject to private appropriation (Asamblea Nacional de la Republica de Panama [AN], 2004).

Water Related Diseases

Water related diseases, also known as waterborne diseases or diseases transmissible through water encompass a group of diseases due to microorganisms or
chemicals in water people drink, or injuries due to drowning (WHO, n.d.). This type of disease can affect any person who is exposed to contaminated sources of water, especially vulnerable populations such as indigenous groups, children and women.

According to UNICEF, diarrhea is an important public health problem and one of the most frequent diseases associated to poor water supply and sanitation. It can be either waterborne, transmissible through water, or water-washed, transmissible through unclean hands because of lack of safe water (UNICEF, 2013). Simple measures like handwashing with clean water and soap have proven to be cost-effective and can help decrease the burden of disease.

**Rotavirus.** Is the leading cause of severe diarrhea in children worldwide since the 1980’s, especially under 5 years of age. This is an RNA virus first identified as a cause of diarrhea in 1973. Usually has a short incubation period of 1 to 3 days and its first infection does not lead to permanent immunity. Transmission occurs through fecal-oral spread, fecal contamination of food and water and by fomites and respiratory droplets. Shedding of the virus is high in stools of infected persons starting 2 days previous to onset of symptoms until 10 days after onset, which makes it highly contagious within family members and in settings such as hospital and child care institutions (CDC, 2012; WHO, 2013a).

WHO reported 453,000 deaths in children under 5 years of age from Rotavirus for the year 2008 which accounted for 5% of all deaths in this same group. Most of these deaths come from low income countries. In order to prevent and decrease the number of deaths, many recommendations such as early and exclusive breastfeeding, handwashing,
improved water supply and sanitation, and treatment measures, such as the oral rehydrating salts, are to be taught and put into practice by the involved population. The most recent preventive measure is the oral Rotavirus vaccine. Two vaccines, Rotarix® (GlaxoSmithKline Biologicals) and Rotateq® (Merck), have been approved and introduced since 2006. They are still under surveillance for quality, safety and efficacy, and have proven to reduce the cases and deaths when the full course of either is given, but some protection is achieved following an incomplete course. In order to have a high impact, immunization must be administered before any case of gastroenteritis due to rotavirus is presented in a person or natural infection occurs in the target population (WHO, 2013a).

Risk factors for water transmissible diseases in children. There are various factors associated with the development of a water related disease such as diarrhea in children with potential death outcome. According to WHO, the passage of three or more loose or liquid stools per day as a consequence of contaminated food and drinking water, or from person to person infection due to poor hygiene is diarrhea. In developing countries children are exposed to an average of 3 diarrheal episodes per year which may lead to malnutrition (WHO, 2013b).

The following are relevant and measurable factors that protect or increase the chance of diarrheal episodes:

- Young age, especially under 12 months of age. This is described as a risk factor as well as a component of the socioeconomic variable of the affected population (Al-Saady, et al, 2006; Strand, et al, 2012).
• Not breastfeeding for at least 5 to 6 months. Breastfeeding is considered a protective factor and children lacking this exposure during their first year of age are more prone to developing diarrheal events that lead to death (Lamberti, et al, 2011; Strand, et al, 2012; WHO, 2013b). Several non-nutritional benefits have been attributed to the immunologic factors included in this milk such as: carbohydrates that inhibit binding of pathogens; nitrogen containing sugars that promote lactobacilli and bifidobacteria in the gastrointestinal tract; antibodies such as IgA and IgG that prevent binding and proliferation of pathogens; and promotion of neutrophils and macrophages. These factors help protect the gastrointestinal tract and most likely against recurrent episodes of diarrhea (Heining & Dewey, 1996; Haemer, Primak & Krebs, 2012).

• Living in rural areas. A number of authors agree that this is an important consideration when making distinctions between affected children, because it involves not only the infrastructure of housing, but also accessibility to potable water as well as healthcare facilities (Al-Saady, et al, 2006; Stanton & Clemens, 1987; Castillo, et al, 2000).

• Low maternal education and low economic status. There is a preset belief that women are in charge of the care of their children especially when they are sick. A low economic status is mostly related to a low education level. Low education level among mothers is what determines timing to seek for medical evaluation. (Stanton & Clemens, 1987; Castillo, et al, 2000; Fischer, et al, 2012; Caruso, et al, 2010).
Handwashing with soap, improved water quality, and excreta disposal. The opposite, no handwashing, lack of proper safe water access and excreta disposal, are the risk factors as a propagation or perpetuation of disease (Cairncross, et al, 2010; Stanton & Clemens, 1987; WHO, 2013b).

In summary, all of the authors cited above highlight the importance of dealing with these known risk factors in order to decrease the burden of disease and fatalities due to diarrheal episodes.

**Health Indicators for the Republic of Panama**

The institution responsible for managing and delivering health in the Republic of Panama is the Ministry of Health (MINSA). The latest report of health indicators was delivered by MINSA for the years 2007-2009. This report consists of data for population at the province level as well as the Comarcas (MINSA, 2010).

Relevant data from this report for the whole republic are:

- Life expectancy at birth 75.8 years for 2009, almost similar to 2005 where it was 75.2 years.
- Infant mortality 12.2 / 1000 which has decreased from 15.4 / 1000 in 2005.
- Maternal mortality 0.4 / 1000 which has decreased from 0.6 / 1000 in 2005.
- The three major causes of death in the republic were: diseases of the circulatory system, malignant tumors and diseases of external causes. These data was stratified by sex.

According to the national census of 2010, major causes of death for under 1 year of age were: certain diseases of the perinatal period, congenital malformations, and
pneumonia. For under 5 years of age were: pneumonia, diarrhea and gastroenteritis of infectious origin, and accidents, assaults and other types of violence (INEC, 2010).

Diarrhea and gastroenteritis cases as well as their consequences such as hospitalizations and deaths have been a reason for efforts worldwide in the introduction of a vaccine to help decrease these numbers. The republic of Panama’s government approved the introduction of Rotarix® in March 14th, 2006 as a vaccine part of the free immunization calendar given to population. In the case of this vaccine, two doses are programmed for children at 2 and 4 months of age. During this first period of introduction, in a study by Nieto, Lopez & Gonzalez (2008) no significant reduction in hospitalization rate, morbidity and mortality were found, but the study was performed at one year of the introduction of the vaccine and the reported coverage for the republic was 66.5% for the first dose with a decline to 57.9% for the second dose (Nieto, Lopez & Gonzalez, 2008).

In a more recent ecological study by Bayard et al (2012), an analysis of all causes of gastroenteritis related (GER) deaths and hospitalizations was performed pre and post introduction of Rotarix® in Panama. Comparison periods were 2000-2005 with 2007 and 2008. Although it was not specific for rotavirus, it did showed a decrease in overall GER deaths in children under 5 years of age from 31.1 per 100 000 in the 2000-2005 period to 15.5 per 100 000 in 2008; and in overall GER hospitalizations in children under 5 years of age from a mean of 3004 per year in the 2000-2005 period to 2109 in 2008 (Bayard et al, 2012). These results demonstrate the impact of the vaccine introduction in reducing deaths and hospitalizations due to gastroenteritis of any cause.
Health of Indigenous Populations in Panama

Health indicators for the country reveal data for the comarcas that can be compared with the overall republic for the year 2009 (See Table 1). By looking at this table we can see that the comarcas have higher mortality rates in general, but seem to have a good pregnancy control coverage and under 5 years of age follow-up, which sometimes translates in good community health. It is important to point out that population density in these areas is lower than in the rest of the republic.

Infant mortality is a clear indicator to evaluate the living conditions of this community and the gaps in terms of access to care providers and other sanitation practices that they lack (Davis, 2009). As we can see in Table 1, for Darien, the poorest province in the republic, this rate is the highest and reflects deficiencies for the comarca Embera that lies within it.

Table 1. Comparison of some health indicators among the Republic of Panama and the three Comarcas. 2009.

<table>
<thead>
<tr>
<th></th>
<th>Republic of Panama</th>
<th>Comarca Guna-Yala</th>
<th>Comarca Embera</th>
<th>Comarca Ngäbe-Bugle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy at birth</td>
<td>75.8</td>
<td>71.3</td>
<td>66.9</td>
<td>68.6</td>
</tr>
<tr>
<td>Population &lt; 1 year of age (%)</td>
<td>2.0</td>
<td>2.6</td>
<td>3.4</td>
<td>3.6</td>
</tr>
<tr>
<td>General population mortality (per 1000 inhabitants)</td>
<td>4.5</td>
<td>6.8</td>
<td>N/A</td>
<td>3.51</td>
</tr>
<tr>
<td>Infant mortality (per 1000 births)</td>
<td>12.2</td>
<td>22.3</td>
<td>22.6*</td>
<td>19.15</td>
</tr>
<tr>
<td>Maternal mortality (per 1000 births)</td>
<td>0.4</td>
<td>3.3</td>
<td>0.8*</td>
<td>1.83</td>
</tr>
<tr>
<td>Pregnancy control (%)</td>
<td>78.0</td>
<td>84.9</td>
<td>94.3*</td>
<td>71.9</td>
</tr>
<tr>
<td>Follow-up for &lt;5 years of age</td>
<td>59.0</td>
<td>91.0</td>
<td>N/A</td>
<td>94.0</td>
</tr>
</tbody>
</table>

Note: N/A = Data not available.
*Data includes the province of Darien and comarca Embera.
From Table 2 we can point out that diarrheas and gastroenteritis are among the 5 major consultation causes for children under 5 years of age for all the comarcas, as well as the province of Panama. As with other health indicators, information from the comarca Embera is not available separately from data collected and presented for the province of Darien by the Ministry of health.

Table 2. Comparison of the five principal causes of morbidity in children under 5 years of age among the province of Panama and the three comarcas. 2009.

<table>
<thead>
<tr>
<th></th>
<th>Province of Panama</th>
<th>Comarca Guna-Yala</th>
<th>Comarca Embera*</th>
<th>Comarca Ngäbe-Bugle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhinopharyngitis</td>
<td>49327</td>
<td>2730</td>
<td>5776</td>
<td>14588</td>
</tr>
<tr>
<td>Diarrhea and gastroenteritis of infectious origin</td>
<td>14560</td>
<td>2005</td>
<td>3122</td>
<td>4825</td>
</tr>
<tr>
<td>Influenza and other respiratory viruses</td>
<td>8450</td>
<td>1942</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Pyoderma</td>
<td>NR</td>
<td>1934</td>
<td>1960</td>
<td>4852</td>
</tr>
<tr>
<td>Malnourishment</td>
<td>5304</td>
<td>1268</td>
<td>NR</td>
<td>8798</td>
</tr>
<tr>
<td>Intestinal parasitosis</td>
<td>NR</td>
<td>NR</td>
<td>1250</td>
<td>5011</td>
</tr>
</tbody>
</table>

Note: NR = No report for the year 2009.
*Data comes from the province of Darien.
Adapted from: Health Indicators for the Republic of Panama 2004-2010, Ministry of Health of Panama.

In the corregimiento of Chilibre where the Caimitillo health center is located health statistics are stratified by dividing communities into 2 zones. Zone 1 includes all the communities living nearby the health center; Zone 2 includes the 5 communities from the PNCH which are Victoriano Lorenzo, Tusipono, Parara Puru, Embera Drua and San Juan de Pequeni. From the reported 20 major causes of morbidity in children under 5 years of age, the main infectious causes were rhinopharyngitis and diarrhea and
gastroenteritis of infectious origin. Table 3 summarizes the number of attentions according to the zones for the past 4 years. There seems to be a difference in the number of cases reported for these diseases among the zones, but Zone 1 has a larger population in all groups of ages including children under 5 years of age with over a 90% difference. When we look at the rate each of this diseases represent, then the proportion of cases is not that different for diarrhea and gastroenteritis among the zones.

Table 3. Comparison of the morbidity in children under 5 years of age for the communities in Zone 1 and Zone 2 from corregimiento of Chilibre.

<table>
<thead>
<tr>
<th>Year</th>
<th>Zone 1</th>
<th>Zone 2</th>
<th>Zone 1</th>
<th>Zone 2</th>
<th>Zone 1</th>
<th>Zone 2</th>
<th>Zone 1</th>
<th>Zone 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>n=1010</td>
<td>n=51</td>
<td>n=1008</td>
<td>n=91</td>
<td>n=1032</td>
<td>n=93</td>
<td>n=1056</td>
<td>n=95</td>
</tr>
<tr>
<td></td>
<td>(21%)</td>
<td>(10%)</td>
<td>(34%)</td>
<td>(2%)</td>
<td>(11%)</td>
<td>(19%)</td>
<td>(29%)</td>
<td>(8%)</td>
</tr>
<tr>
<td>Rhinopharyngitis</td>
<td>208</td>
<td>5</td>
<td>348</td>
<td>2</td>
<td>110</td>
<td>18</td>
<td>303</td>
<td>8</td>
</tr>
<tr>
<td>Diarrhea and gastroenteritis of infectious origin</td>
<td>44</td>
<td>1</td>
<td>96</td>
<td>NR</td>
<td>47</td>
<td>2</td>
<td>45</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(4%)</td>
<td>(2%)</td>
<td>(9%)</td>
<td>(5%)</td>
<td>(2%)</td>
<td>(4%)</td>
<td>(1%)</td>
<td></td>
</tr>
</tbody>
</table>

Note: NR = No report for the year 2009
Adapted from: Health Indicators for Caimitillo health center, Ministry of Health of Panama.

The Surveillance department from the Expanded program on immunization (PAI) of the Ministry of Health sends a yearly report of immunization coverage in the country. A compilation from reports of coverage for the Rotavirus vaccine for the San Miguelito Health Region to which the corregimiento of Chilibre belongs, is shown in Table 4.

From this information we can see that since the vaccine was introduced in the republic, coverage has increased in both, the first and second dose, but there is always some loss to follow up for the second dose regardless it is for free. Although effectiveness for incomplete doses of Rotarix® vaccine is not known, that is only 1 of the 2 recommended doses, there is always some protection achieved (WHO, 2013a). After
dose 1, shedding of 50% to 80% has been detected through ELISA test at day 7 post vaccination. Although there is a risk of transmission of the virus or in the case of antigens transmission of immunity, this data has not been assessed (CDC, 2012).

Table 4. Comparison of Rotavirus vaccine coverage in San Miguelito district for the years 2006-2012.

<table>
<thead>
<tr>
<th>Year of application</th>
<th>Target population</th>
<th>First dose Population</th>
<th>Coverage(%)</th>
<th>Second dose Population</th>
<th>Coverage(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>10166</td>
<td>6596</td>
<td>64.9</td>
<td>3312</td>
<td>30.1</td>
</tr>
<tr>
<td>2007</td>
<td>10205</td>
<td>8992</td>
<td>88.1</td>
<td>6447</td>
<td>58.5</td>
</tr>
<tr>
<td>2008</td>
<td>10152</td>
<td>8653</td>
<td>85.2</td>
<td>6969</td>
<td>64.3</td>
</tr>
<tr>
<td>2009</td>
<td>10745</td>
<td>8864</td>
<td>82.5</td>
<td>7382</td>
<td>68.7</td>
</tr>
<tr>
<td>2010</td>
<td>11011</td>
<td>9251</td>
<td>84.0</td>
<td>8131</td>
<td>90.6</td>
</tr>
<tr>
<td>2011</td>
<td>10745</td>
<td>9506</td>
<td>88.5</td>
<td>8277</td>
<td>77.3</td>
</tr>
<tr>
<td>2012</td>
<td>11049</td>
<td>10366</td>
<td>93.8</td>
<td>9506</td>
<td>92.1</td>
</tr>
</tbody>
</table>

Adapted from: Data provided by the Surveillance Department from the Expanded Program on Immunization, Ministry of Health of Panama.

For the year 2012, the Caimitillo healthcenter reports 88% immunization coverage for their area of responsibility which is an aggregate of data from all the vaccines administered in all of the communities in Zone 1 and Zone 2. The stratified information for this data is not available to determine the real coverage for the communities of Parara Puru and Victoriano Lorenzo.
Chapter 3: Methods

Design of the Study

This is a cross-sectional community-based study on the Embera indigenous community living near a watershed in the PNCH area, intended to reflect any relationship between their cultural water beliefs and any health problems in their women and children. This study began after the approval from the National Ethics Committee of Research (CNEI) from the Gorgas Memorial Institute in Panama City and the Institutional Review Board (IRB) of the University of South Florida.

A locked file cabinet was used in order to store all signed informed consents, completed surveys and a copy of the software database in a flash drive for a minimum of 5 years at the offices of the USF Foundation in Panama, Republic of Panama.

After 5 years of storage, data will be destroyed through services of a certified company in the presence of the principal investigator and a report of the process will be requested as proof.

Location of the Study

This study took place in the communities’ settlements in the PNCH in the province of Panama where 5 Embera communities reside. The communities chosen to represent the Embera groups were Parara Puru and Victoriano Lorenzo. Both of these communities are of Embera background, continue to have the same beliefs as before they migrated from the province of Darien. Parara Puru is made up entirely of Embera groups,
but in Victoriano Lorenzo the land is shared between Embera groups and mestizos or non-Embera, therefore house-to-house visits were made to determine which were Embera. They have an estimated population of about 104 and 276 inhabitants respectively according to Caimitillo health center. They are both located at different travel distances from the Corotu pier in the corregimiento of Chilibre (See Figure 2). Travel distance depends on the river flow and the season of the year.

Figure 2. View of Corotu pier at corregimiento of Chilibre and travel to communities on a *piragua*. Photographs taken by the author, 2012.

Figure 3. Households from the Parara Puru community (left) and Victoriano Lorenzo (right). Photographs taken by the author, 2012.
Population Recruitment

Meetings with members of the communities were held on April 2nd at Parara Puru and April 8th at Victoriano Lorenzo. Here we asked for the community’s involvement in the process and also established a preliminary schedule per house depending on their daily activities.

The Parana Puru and Victoriano Lorenzo communities within the corregimiento of Chilibre are mostly led by male head of the house, therefore a first approach was made with the cacique or noko (chief of the community) to ask for permission to enter the community and develop the study. In order to determine which households could participate in the study inclusion and exclusion criteria were applied.

Inclusion criteria. Households from Parara Puru and Victoriano Lorenzo communities that fulfilled these criteria were included in the study:

1) belongs to the Embera ethnic group;

2) whose head of the house had ≥ 18 years of age and read and agreed to participate by signing the informed consent.

Exclusion criteria. Any of the households from Parara Puru and Victoriano Lorenzo communities that fulfilled these criteria were not included in the study:

1) do not belong to the Embera ethnic group;

2) whose head of the house had ≥ 18 years of age, and read and did not agree to participate by signing the informed consent.
**Informed consent.** An informed consent was administered to the head of the household of the communities participating in the study in order to comply with all regulations concerning the handling of personal and confidential information given by the participants. This informed consent was signed by the head of the house. Because some of the head of houses might not speak Spanish, a translator was present at the interview in order to collect the desired information. The interview was held at the houses with the permission of the head of the house. Enough time was given to each person to fully read, understand and ask any questions regarding the study and the information stated in the informed consent form, even to talk to their family members about participating in the study. Households whose head of house decided not to participate were excluded from the study.

Two informed consents were signed per household by both the head of the house and the investigator. One was kept by the participating household and the other was properly stored by the principal investigator.

**Data Collection and Analysis**

Data for this study came from primary and secondary data sources. The primary data was collected through answers given to a semi-structured survey administered to the head of the households. The secondary data was gathered from the published vital statistics of the Ministry of Health, National Institute of Statistics and Census (INEC) and from the Caimitillo Healthcare center that is in charge of the health services for these populations.
The first two weeks of May 2013 were used to visit both Embera communities, Parara Puru and Victoriano Lorenzo, and recruit participants to the study. A total of 16 head of households, 10 in Parara Puru and 6 in Victoriano Lorenzo, agreed to participate and answered the survey. This corresponded to 36 household members in Parara Puru and 35 in Victoriano Lorenzo. Other households, 2 households in Parara Puru and 3 in Victoriano Lorenzo, were asked to participate but not included in the survey because the head of the household was not present.

**Instrument.** A semi-structured survey was designed to collect data through the administration by the principal investigator directly to the head of the household after signing the informed consent. Answers were written down and the interview was recorded for further examination of responses. No identifiers were used in the surveys in regards to names, personal identification numbers, passport numbers, or addresses.

The survey was organized into 4 sections to address the following topics:

1) General information to collect demographics of the family members

2) Information about water sources

3) Information about waste and stool disposal

4) Information about healthcare services and diseases

**Data analysis.** Data was collected in two weeks and entered in an Excel database for further analysis. Quantitative data was organized according to the information in different tables. Further analysis was performed through the program IBM SPSS
Statistics 21. Values of p less than or equal to 0.05 (p ≤ 0.05) were used to establish statistical significance of the descriptive analysis using chi square.

Quantitative variables were divided in the following categories for analysis:

1. General information: total household members with age and sex, level of education of parents, breastfeeding and immunizations for children under 5 years of age, years living in the community, and access to social security fund.

2. Water source, garbage and stool disposal: main source of water, closeness to household, treatment performed, household activities and water, garbage disposal and types of stool disposal.

3. Health services and treatment at home: preferences of health services for any illness according to family member, frequency of diarrheal episodes, preferred treatment for diarrheal episodes, consequences from diarrheal episodes.

Qualitative data was separated according to content, but was used as support for quantitative data analysis, specifically for preference of water source, choice to treat water and influencing factors to seek medical attention.
Chapter 4: Results

Demographics of Participants

Of the representative households from the Embera communities living inside the PNCH, 16 were surveyed with a total of 71 family members. The average number of years living in these communities was 19.9 years, ranging from 2 to 69 years. Children under 5 years of age represented 18.3% (13) of the total population and live in 62.5% (10) of the households. Literacy of parents showed that fathers with incomplete elementary school or no formal education were 31.2% and mothers were 46.7%. On the other hand, 68.8% of fathers and 53.4% of mothers reported complete elementary school or higher education. Families with access to social security fund account for only 12.5% of the households (See Table 5).

Sources of Water, Garbage and Stool Disposal

One hundred percent of the representative households trust and depend on rural aqueducts as their main source of water to drink and daily activities. Therefore, no treatment is performed in a regular basis to tap water; just 1 household boils this water for their child. Because of the household structure elevation over stilts, water taps located at the bottom of the household is considered to be inside or less than 5 minute walk. This accounts for 100% of the households (See Table 6).
Table 5. Demographic and economic characteristics of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Mean (SD)</th>
<th>%</th>
<th>Max</th>
<th>Min</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total house members</td>
<td>71</td>
<td>19.9 (14.35)</td>
<td>69</td>
<td>69</td>
<td>2</td>
</tr>
<tr>
<td>Years in community</td>
<td></td>
<td>19.9 (14.35)</td>
<td>69</td>
<td>69</td>
<td>2</td>
</tr>
<tr>
<td>Father’s age (years)</td>
<td>16</td>
<td>29.3 (8.9)</td>
<td>22.5</td>
<td>72</td>
<td>21</td>
</tr>
<tr>
<td>Mother’s age (years)*</td>
<td>15</td>
<td>24.6 (7.65)</td>
<td>21.1</td>
<td>73</td>
<td>15</td>
</tr>
<tr>
<td>Children &lt;5 years of age</td>
<td>13</td>
<td>18.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children &gt;5 years of age</td>
<td>20</td>
<td>28.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Households with children &lt;5 years of age</td>
<td>10</td>
<td>62.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Families with SSF (n=16)</td>
<td>2</td>
<td>12.5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Father’s education level | 16        |           |      |     |     |
| None                    | 2         | 12.5       |      |     |     |
| Incomplete elementary   | 3         | 18.7       |      |     |     |
| Complete Elementary     | 7         | 43.8       |      |     |     |
| Incomplete High school  | 3         | 18.7       |      |     |     |
| Complete High school    | 0         | 0          |      |     |     |
| Higher education        | 1         | 6.3        |      |     |     |

| Mother’s education level | 15        |           |      |     |     |
| None                    | 3         | 20         |      |     |     |
| Incomplete elementary   | 4         | 26.7       |      |     |     |
| Complete Elementary     | 4         | 26.7       |      |     |     |
| Incomplete High school  | 4         | 26.7       |      |     |     |
| Complete High school    | 0         | 0          |      |     |     |
| Higher education        | 0         | 0          |      |     |     |

*One household’s father is a widow.
Adapted from: answers to questions 1 through 5 of the survey.
Table 6. Characteristics of households’ source of water of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Main source of water</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDAAN aqueducts</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Rural aqueducts</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td>Other*</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source of water to drink and other activities</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDAAN aqueducts</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Rural aqueducts</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td>Bottled</td>
<td>1§</td>
<td>6.3</td>
</tr>
<tr>
<td>Other**</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Closeness of source to household</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inside or &lt;5 min walk</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td>Other***</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment to source of water</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boil</td>
<td>1§</td>
<td>6.3</td>
</tr>
<tr>
<td>Filter</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Chlorine</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>100</td>
</tr>
</tbody>
</table>

*Other: well, river, collected rain, tank truck, bottled  
**Other: sanitary well, unprotected well, river, collected rain, tank truck  
***Other: 5-30min walk, ≥ 1hour walk, Don’t know  
§This reflects a family who does a different thing for their daughter.  
Adapted from: answers to questions 6 through 11 of the survey.

The usual method to dispose of garbage for 14 (87.5%) of the households was to burn it, but 10 households perform a second activity between burying, transporting garbage across the river or other. A 100% of the households had pit latrine as the type of sanitary service for stool disposal (See Table 7).
Table 7. Garbage and stool disposal of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Total households (n=16)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Garbage disposal</strong>*</td>
<td></td>
</tr>
<tr>
<td>Burn it</td>
<td>14</td>
</tr>
<tr>
<td>Bury it</td>
<td>1</td>
</tr>
<tr>
<td>Dump in river</td>
<td>0</td>
</tr>
<tr>
<td>Transport across river</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

| **Type of stool disposal** |  |
| Pit latrine               | 16 | 100 |
| Flush toilet              | 0  | 0   |
| River                     | 0  | 0   |
| Ground                    | 0  | 0   |

*Some families reported more than 1 way for garbage disposal, therefore numbers may not sum.
Adapted from: answers to questions 14 and 15 of the survey.

Health Services Preferences and Treatment at Home

When asked about the health services that were readily available if any member of the household got sick, 62.5% preferred to go to the health center and 50% preferred a local healer. One family preferred a private clinic (See Table 8). These answers vary according to these representative households depending on several factors like the weather, money, distance and that most of the times they went to the health center and there are limited medical quotas for receiving health attention. Some of the opinions from the household members to question 18 “Factors that influence the decision of which healthcare service to attend”:

“Too much waiting time (in the health center) and they don’t understand why we are late sometimes. Besides, almost always we reach the health center there are no available medical quotas for attention.”
“Waiting time is the first reason (not to attend health center). Also it is too far and when winter comes (rainy season) the river is too risen and we cannot cross over.”

“The first problem is distance and that increases when the river is dry. Even if we want to be there (health center) early we cannot. Sometimes we need to sleep over in order to be there early. We have too many expenses, the piragua, the taxi and food. When we are finally there we are always last.”

When asked specifically if the sick person were a children under 5 years of age or a women during pregnancy, 53.8% and 80% preferred the health center respectively despite of any difficulty addressed before. Hospital (38.5%) and home remedies (30.8%) were the second choices for delivery of health for children under 5 years of age. For pregnant women, hospital (20%) was the second choice (See Table 8).

When asked specifically if the sick person were a children under 5 years of age or a women during pregnancy, 53.8% and 80% preferred the health center respectively despite of any difficulty addressed before. Hospital (38.5%) and home remedies (30.8%) were the second choices for delivery of health for children under 5 years of age. For pregnant women, hospital (20%) was the second choice (See Table 8).

<table>
<thead>
<tr>
<th></th>
<th>Anyone (n=16)</th>
<th>Child &lt;5 years of age (n=13)</th>
<th>Pregnant women (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Home remedies</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Local healer</td>
<td>8</td>
<td>50</td>
<td>0</td>
</tr>
<tr>
<td>Health care worker</td>
<td>2</td>
<td>12.5</td>
<td>0</td>
</tr>
<tr>
<td>Health center</td>
<td>10</td>
<td>62.5</td>
<td>7</td>
</tr>
<tr>
<td>Hospital</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Other*</td>
<td>1</td>
<td>6.3</td>
<td>0</td>
</tr>
</tbody>
</table>

Note: Data for pregnant women comes from households with children <5 years of age. Some families indicated more than one preference of health service, therefore numbers may not sum.

*Preference for private clinics.

Adapted from: answers to questions 17 through 22 of the survey.
According to the representative households, no deaths occurred to the family members due to diarrheal episodes. Nevertheless, hospitalizations due to diarrhea occurred in 30.8% (4) of children under 5 years of age and in 4.6% (2) of other family members (See Table 9).

Table 9. Consequences of diarrheal episodes of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th></th>
<th>Other members (n=43)</th>
<th>Children &lt;5 years of age (n=13)</th>
<th>Pregnant women (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>2</td>
<td>4.6</td>
<td>4</td>
</tr>
<tr>
<td>Deaths</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Adapted from: answers to questions 27 through 30 of the survey.

**Risk factors in children under 5 years of age and pregnant women.**

Frequencies of 2 diarrheal episodes a year were 46.1% in children under 5 years of age and 30% for pregnant women. A 38.5% of children under 5 years of age were reported as having one episode every 2-3 months. Sixty percent of pregnant women never had an episode. A small number of children and pregnant women were reported with high frequency of diarrheal episodes, 1 (7.7%) child with 2-3 times a month and 1 (10%) pregnant women with once a month (See Table 10).

Ten out of the 13 children under 5 years of age, 76.9%, received more than 6 months of breastfeeding. Among these, 4 (40%) had 1 diarrheal episode every 2 to 3 months; 4 (40%) had 2 diarrheal episodes per year; 1 (10%) had 2 to 3 diarrheal episodes per month; 1 (10%) had no diarrheal episodes (See Table 11).

From the information gathered and reported in Table 11, children under 5 years of age for the Embera households surveyed had an average of 2.67 to 3.5 diarrheal episodes
per year. This goes in accordance to the average 3 diarrheal episodes per year that children in developing countries experience (WHO, 2013b). This result came from the following calculations:

- 5 children with 1 episode every 2-3 months = 20 to 30 diarrheal episodes,
- 6 children with 2 episodes per year = 12 diarrheal episodes,
- 1 child with no episodes = 0 diarrheal episodes.

Taking in consideration the abnormality of having around 24 to 36 episodes of diarrheas per year, this child was excluded from this analysis.

Only 5 (38.5%) of the 13 children under 5 years of age have complete immunizations for their age, but 10 (76.9%) of the 13 children have completed their schedules passed the 4 months of age which includes the Rotavirus vaccine (See Table 11). Although the Caimitillo healthcenter reported 88% immunization coverage for their area of responsibility in the year 2012, this data was not stratified in zones to determine the real coverage for the communities being studied and the exact coverage for the Rotavirus vaccine.

Table 10. Diarrheal episodes in children under 5 years of age and pregnant women of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Frequency of episodes</th>
<th>Children &lt;5 years of age (n=13)</th>
<th>Pregnant women (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>2-3 times a month</td>
<td>1</td>
<td>7.7</td>
</tr>
<tr>
<td>Once a month</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Once every 2-3 months</td>
<td>5</td>
<td>38.5</td>
</tr>
<tr>
<td>2 times a year</td>
<td>6</td>
<td>46.1</td>
</tr>
<tr>
<td>Never</td>
<td>1</td>
<td>7.7</td>
</tr>
</tbody>
</table>

Note: Data for pregnant women reflect the opinion during pregnancies in the households with children under 5 years of age.
Adapted from: answers to questions 23 and 24 of the survey.
Table 11. Relation between time of breastfeeding, diarrheal episodes and immunizations in children <5 years of age of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Children &lt;5 years of age (n=13)</th>
<th>Months of breastfeeding</th>
<th>Number of diarrheal episodes</th>
<th>Immuniz.*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;6 months</td>
<td>&gt;6 months</td>
<td>2-3 times /month</td>
</tr>
<tr>
<td>1 year</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>4 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>3 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>1 year</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>10 months</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>4 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>9 months</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>5 months</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>2 years</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>1 year</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Note: The immunization calendar for the republic of Panama includes Rotavirus vaccine given at 2 and 4 months of age.

*Immuniz. = Immunization calendar for the country; N/A = Information not available.

**These children have not updated their schedule, meaning they lack the vaccines that correspond to the actual age.

Adapted from: answers to questions 3 and 23 of the survey.

By grouping the number of diarrheal episodes as more than 3 cases per year and less than 3 cases per year, according to WHO average diarrheal episodes for children in developing countries, a statistical analysis was performed having diarrhea as the outcome variable and months of breastfeeding as the exposure. Information used for this analysis was taken from Table 11. This resulted in an chi square ($\chi^2$) of 0.258 with a p-value of 0.612 or >0.05 for a non-statistically significant association.
With a 70% and 66.7% home remedies were the preferred choice of treatment at home for either children under or over 5 years of age respectively. Six (60%) out of ten households with children under 5 years of age offered oral rehydrating solutions during diarrheal episodes (See Table 12). From this households, 8 (80%) use water from the rural aqueduct to prepare the solution; 1 (10%) boiled water from the rural aqueduct prior to preparing the solution; 1 (10%) buy bottled water to prepare the solution.

Table 12. Choices of treatment at home during diarrheal episodes of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th></th>
<th>Houses with children &lt;5 years of age (n=10)</th>
<th>Houses without children &gt;5 years of age (n=6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Just water</td>
<td>Frequency 1</td>
<td>% 10</td>
</tr>
<tr>
<td>Home remedies</td>
<td>Frequency 7</td>
<td>% 70</td>
</tr>
<tr>
<td>Oral rehydrating solutions</td>
<td>Frequency 6</td>
<td>% 60</td>
</tr>
<tr>
<td>Medicines</td>
<td>Frequency 1</td>
<td>% 10</td>
</tr>
<tr>
<td>Nothing</td>
<td>Frequency 0</td>
<td>% 0</td>
</tr>
</tbody>
</table>

Note: Some families indicated more than one way of treatment of diarrhea at home, therefore numbers may not sum. Adapted from: answers to questions 1 and 25 of the survey.

One child of mother with incomplete high school was reported as having frequent diarrheal episodes, 2 to 3 times a month. This is a high frequency of diarrheal episodes per year for a 2 years of age child that received over 6 months of breastfeeding (as seen in Table 10). Other 6 (46.1%) children of mothers with complete elementary school or higher were reported as having only 2 episodes a year (See Table 13).

By grouping the number of diarrheal episodes as more than 3 cases per year and less than 3 cases per year, according to WHO average diarrheal episodes for children in developing countries, a statistical analysis was performed having diarrhea as the outcome
variable and mother’s level of education, none/incomplete elementary school, as the exposure. This resulted in an chi square ($X^2$) of 1.935 with a $p$-value of 0.164 or $>0.05$ for a non-statistically significant association.

Table 13. Mother’s formal education and frequency of diarrheal episodes in children under 5 years of age of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Mother’s education level</th>
<th>Frequency (%) of diarrheal episodes of children &lt;5 years of age (n=13)</th>
<th>$X^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>2-3 /months 1 /month 1 /2-3 months 2 /year Never</td>
<td>1.935</td>
<td>$&gt;0.05$</td>
</tr>
<tr>
<td>Incomplete elementary</td>
<td>0 0 3(23.1) 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete Elementary</td>
<td>0 0 1(7.7) 4(30.7) 1(7.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete High school</td>
<td>1(7.7) 0 1(7.7) 1(7.7) 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete High school or</td>
<td>0 0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>higher</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted from: answers to questions 1 and 23 of the survey.

Six mothers (60%) with complete elementary school or higher education reported to had never experienced a diarrheal episode during their pregnancies. One mother that completed elementary school reported one diarrheal episode per month of pregnancy. Two illiterate mothers, with no education or incomplete elementary school, reported only 2 episodes during their pregnancies (See Table 14).

By grouping the number of diarrheal episodes during the pregnancy period as more than 3 cases and less than 3 cases, a statistical analysis was performed having diarrhea as the outcome variable and mother’s level of education as the exposure. This resulted in an chi square ($X^2$) of 6.429 with a $p$-value of 0.011 for a statistically significant association.
Table 14. Mother’s formal education and frequency of diarrheal episodes in pregnant women of the representative households in the Embera communities inside the PNCH.

<table>
<thead>
<tr>
<th>Frequency (%) of diarrheal episodes in pregnant women (n=10)</th>
<th>2-3/months</th>
<th>1/month</th>
<th>1/2-3 months</th>
<th>2/year</th>
<th>Never</th>
<th>$X^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s education level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1(10)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete elementary</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2(20)</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete Elementary</td>
<td>0</td>
<td>1(10)</td>
<td>0</td>
<td>0</td>
<td>3(30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incomplete High school</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3(30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete High school or higher</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted from: answers to questions 1 and 24 of the survey.

Water Beliefs Questions

Survey questions addressing water beliefs and some of the answers are described below.

1. When they were asked “Do you believe all water sources are equal?” (question 10 from the survey), some of the answers were:

“No. Tap water from outside of here is the one that makes us sick, it upsets our stomach. Water from our aqueduct does not do that.”

“No. Streams may be contaminated, but the one that comes through the aqueduct is not. We were told by a teacher that samples were collected and everything was good.”

“Yes. We Embera learn from workshops that we need to add chlorine to water, but we are not used to these practices because we think all waters are equal.”
“No. The difference is that the water that comes from our small dam is fresh and healthy and we are historically used to drinking it like that. But water that comes purified from IDAAN aqueduct upset us and is hot”

2. When they were asked “Do you believe untreated water can cause diarrhea?” (question 13 from the survey) some of the answers were:

“Yes, because it (water) is not purified and that (diarrhea) is what happens in my house.”

“Yes. Sometimes it (diarrhea) can happen because of lack of maintenance (of aqueduct).”

“If I answer depending on what I learn on workshops I would say yes it can cause disease because we don’t know which animals can be where the water is collected. Diarrhea and vomits can happen because we drink raw water.”

“Yes. Children can get amoebas from water without chlorine.”
Chapter 5: Discussion

The main purpose of this cross-sectional study was to describe the perceptions Embera groups have about safe water, hygiene practices and any relation between unsafe water, their cultural beliefs and disease, especially among children under 5 years of age and pregnant women.

The 16 surveyed representative households from the Embera groups living inside the PNCH had a total of 71 family members with an average of 19.9 years (SD 14.35) living in these communities. Ten of the households had children under 5 years of age which accounted for 18.5% of the surveyed population. Only 2 (12.5%) households had access to social security fund.

Literacy among parents of the households was distributed as follows: high education level 68.8% and 53.4% of fathers and mothers respectively; low education level was 31.2% and 46.7% for fathers and mothers respectively. Mother’s education level was further analyzed with the frequency of diarrheal episodes that the 13 children under 5 years of age and the ten mothers of these household had.

The representative households had no access to potable water; instead their water supply is based on rural aqueducts that are installed and under the supervision of MINSA and one chosen person from each community for continuous maintenance. From the 16 representative households, 100% rely on rural aqueducts for water to drink and other household activities. This is exactly as stated by IDAAN’s report (2012) were the
comarcas had 0% access to potable water, as well as rural areas where IDAAN’s aqueduct are not viable.

They strongly believe that water from the river is natural and clean, therefore the 16 households (100%) do not routinely perform treatments to the water from the rural aqueducts. Nevertheless, there are certain reasons why they decide to use an alternative source of water or treat the water from the rural aqueduct. In one case, two different families either bought bottled water (6.3%) or boiled water from the aqueduct (6.3%) to offer to their children as a routine to avoid diseases. A second reason was climate changes, that is when dry season comes and the river level is low the fact that water is not running makes it unclean and unsafe to drink.

In an 87.5% (14) of the households the usual method to dispose of garbage is burning it, and 100% of the households have pit latrine as the type of sanitary service for stool disposal.

The fact that these communities have rural aqueducts, pit latrines and disposal of garbage through burning, points out that these are rural areas which encompasses not only the infrastructure of the household, but also accessibility to sanitary and healthcare facilities (Al-Saady, 2006; Stanton & Clemens, 1987; Castillo, et al, 2000). This risk factor, living in rural area, could not be used to determine any association with frequency of diarrheal episodes in children under 5 years of age and pregnant women, since it was a constant among the sample and no stratification could be made in the sample for comparison.
In regards to infant and maternal mortality, the surveyed households did not have any deaths due to diarrhea in these two groups, even in older children or the rest of the adults that lived there.

Although family members have expressed that there are reasons not to attend a medical appointment at the health center like distance, expenses, waiting time or not finding an available medical quota, the health center still signifies for these representative households the first choice to deliver health service when a children under 5 years of age (53.8%) or a pregnant women (80%) is sick. Hospital was the second for both, with 38.5% and 20% respectively.

It is important to mention that one child reported a frequency of 2-3 diarrheal episodes per month. This child comes from a young family with both parents having incomplete high school education, a history of receiving over 6 months of breastfeeding and a complete immunization calendar for the age. They reported buying bottled water or boiling water from the rural aqueduct only for the child. This abnormal high frequency of diarrheal episodes per year, around 24 to 36 episodes, does not correlate with literature that supports breastfeeding and a high education level as protective factors against diarrhea (Lamberti, et al, 2011; Strand, et al, 2012; WHO, 2013b; Stanton & Clemens, 1987; Castillo, et al, 2000; Fischer, et al, 2012; Caruso, et al, 2010). This particular case must be studied separately to look for an underlying disease that may be causing these diarrheas.

Analysis were made to find associations between risk factors for frequency of diarrheal episodes (developing more than 3 episodes of diarrhea per year according to WHO) and the fact of being a child under 5 years of age or a pregnant women. The risk
factors analyzed were months of breastfeeding, described as more or less than 6 months, and mother’s education level. Both of these variables were considered exposures. Analysis for frequency of diarrheal episodes (outcome) and mother’s education level (exposure) in children under 5 years of age showed no significant association, therefor no difference between groups ($X^2$ of 1.935, $p$-value of >0.05). When the analysis for the same group of children was made for frequency of diarrheal episodes (outcome) and months of breastfeeding (exposure) again no significant association was found, that is no difference between groups ($X^2$ of 0.258, $p$-value of >0.05). Both cases could have been influenced by the fact of a small sample, only 13 children. This contrasts with literature that supports that breastfeeding for less than 6 months and having mothers with a low education level are associated with high frequency of diarrheal episodes and even death due to diarrhea (Lamberti, et al, 2011; Strand, et al, 2012; WHO, 2013b; Stanton & Clemens, 1987; Castillo, et al, 2000; Fischer, et al, 2012; Caruso, et al, 2010).

The same analysis was performed with the mothers of the households where children under 5 years of age lived which resulted on 10 women. For the analysis they recalled the frequency of diarrheal episodes during their pregnancy and reported their education level. This resulted with a significant association between outcome and exposure, $X^2$ of 6.429 with a $p$-value of 0.011, meaning that having a low education level is associated with a higher frequency of diarrheal episodes.

None of the protective factors for preventing diarrheal episodes, months of breastfeeding and mother’s high education level, could be verified in this studied sample through statistical analysis due to a small sample size. Nevertheless, other protective factor, complete immunization against Rotavirus, was reported in 76.9% (10) of the 13
children under 5 years of age. This information is important because by knowing their daily exposure to non-potable water and use of pit latrine does not correlate with a low average frequency of diarrheal episodes a year, 2.67 to 3.5, and they must be getting protection elsewhere, for example vaccines. It is known that the virus in infected children or antigens in vaccinated children are present in their stools, but no studies so far have assessed and prove this theory of passage of immunization (CDC, 2012).

Other important risk factors like living in rural areas or not having access to potable water could not be analyzed in this way since data was a constant among the population.

**Limitations**

It is important to state that results from this study are not generalizable to the entire Embera population in the republic of Panama. No communities from the comarca were visited. Only two of the five communities in the PNCH area were visited and the entire number of households did not participate in the study.

Time is another limitation that should be mentioned from this study. A timeframe was elaborated to conduct this study and obtain a larger sample size. Due to administrative issues the Panamanian ethics committee was going through, the approval of the study was delayed leaving a short period of time to collect and analyze the data. These communities are to be reached through the use of a piragua after getting to the pier and when the noko or chief of the community allows the entrance through a previous appointment without interfering with their daily activities.
Conclusions

Being a child under 5 years of age or a woman becomes a higher vulnerability risk when they belong to indigenous groups. A first approach to the analysis of the Embera group water culture and the way diseases behave among them, specifically water related, was put into practice through this study.

Information about these communities let us know that no matter where they settle, the comarca or other province, they honor their cultural beliefs and look for deep vast areas to settle which marginalize them from the rest of the countries populations and makes it difficult to have access to safe roads, safe water, basic sanitation and health services. This fact was seen when the surveyed households reported interest in having more access to the health center, but also described the access as climate dependent, too far from the communities that live in the PNCH, and sometimes influenced by the unavailable medical quotas due to population living nearby that always get there first.

It is important to point out that a high number of residents in these communities try to get educated and receive an occidental health service and this should call the attention of authorities to reduce the gap of access to these services. Education has always been a key to improvement, and health is linked to knowledge. Not only teaching about something, but being certain that the message got through, was accepted and was placed into practice is essential in order to meet any goal. For example, having rural aqueducts is convenient and enough for these communities, but it is not. Having rural aqueducts must come with the knowledge that the damn should stay clean and that water still needs treatment, without violating their beliefs.
A complete approach to the five communities in the PNCH area to assess their water beliefs, diseases and needs is still ahead since no study like this has come to our attention that concentrates efforts in determining the difficulties they experience. For a future study more time for planning and scheduling household visits to every household in each of the communities and inclusion of the mother in the interview, with permission of the head of the household, should be considered. From this information, a report to the responsible authorities is important in order to find joint short and long term solutions.
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http://www.minsa.gob.pa/direccion/direcci%C3%B3n-del-subsector-de-agua-potable-y-alcantarillado-sanitario


http://whqlibdoc.who.int/publications/2008/9789241596435_eng.pdf


Strand, T., Sharma, P., Gjessing, H., Ulak, M., Chandyo, R., & et al. (2012). Risk Factors for Extended Duration of Acute Diarrhea in Young Children. 7(5).
doi:doi:10.1371/journal.pone.0036436


Appendices
Appendix A: Institutional Review Board Approval

December 20, 2012

Ilenia Forero
Community and Family Health
4301 Shive Court, Apt. 306A
Tampa, FL 33613

RE: Expedited Approval for Initial Review
IRB#: Pro00010374
Title: The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama.

Dear Mrs. Forero:

On 12/20/2012 the Institutional Review Board (IRB) reviewed and APPROVED the above referenced protocol. Please note that your approval for this study will expire on 12/20/2013.

Approved Items:
Protocol Document:
Embera study protocol

Consent Documents:
Embera study IC translated to Spanish.pdf
Embera study IC.pdf

Please use only the official, IRB-stamped consent document(s) found under the "Attachment Tab" in the recruitment of participants. Please note that these documents are only valid during the approval period indicated on the stamped document.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review categories:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or...
Appendix A: Institutional Review Board Approval (Continued)

diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A. Schinka, Ph.D., Chairperson
USF Institutional Review Board
Appendix B: Informed Consent

Informed Consent to Participate in Research
Information to Consider Before Taking Part in this Research Study
IRB Study # _Pro00010374_

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called: The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama.

The person who is in charge of this research study is Ilenia Forero. This person is called the Principal Investigator. Ilenia Forero is being guided in this research by Dr. Russell Kirby from the Community and Family Health Department at the College of Public Health in the University of South Florida.

The research will be conducted at the communities of Parara Puru and Victoriano Lorenzo in the corregimiento (township) of Chilibre, District of San Miguelito, Republic of Panama.

Purpose of the study
The purpose of this study is to:

- Determine the relation between the water beliefs in two indigenous Embera groups living inside the Chagres National Park and their maternal and child health.
- This study is conducted by a degree seeking student as part of the coursework towards a Master of Science in Public Health.

Before you decide to participate in this study remember:

- Read carefully the entire form
- While you are reading you can ask questions regarding the study and information on this form
- Your participation in this study is voluntary
Appendix B: Informed Consent (Continued)

Study ID: Pro00010374 Date Approved: 12/20/2012 Expiration Date: 12/20/2013

Study Procedures
If you take part in this study, you will be asked to:

- Read this entire form and sign it.
- Take part in an interview that asks you questions through a survey about sources of water and waste disposal for your household, illnesses experienced by women and children in the household, and health services used by your household.

General Information about the study
- Duration. The interview to complete the survey will take around 2 hours. If you cannot complete the interview in one visit, the principal investigator will schedule a time convenient for you for a return visit.
- Location. This study is going to be performed in the communities of Parara Puri and Victoriano Lorenzo, corregimiento (township) of Chilibre, San Miguelito district. You will be interviewed at your home.
- With your permission your interview will be audiotaped by the principal investigator and only she will have access to these recordings. If you decide not to be audiotaped, this will not affect your participation in the study.

Total Number of Participants
All the households in the communities of Parara Puri and Victoriano Lorenzo, an estimate of 95 households, will be eligible to take part in this study. The investigator plans to interview a minimum of 52 households for this study.

Alternatives
You do not have to participate in this research study. If you decide not to participate, no records will be kept and no consequences will come from this decision. Nevertheless, by participating important information about the maternal and child diseases of the communities can be collected and the needs of the communities will be assessed.

Benefits
No direct benefits for individuals will come from the participation in this study.

Risks or Discomfort
This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who decide to take part in this study.

Compensation
You will receive no payment or other compensation for taking part in this study.

Cost
There will be no additional costs to you as a result of being in this study.
Appendix B: Informed Consent (Continued)

Privacy and Confidentiality
We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The Principal Investigator and other research staff.
- The National Bioethics Committee of Research (CNBI) from the National Secretariat of Science, Technology and Innovation and the staff responsible for the supervision of this type of studies.
- Other regulatory authorities.
- The San Miguelito Health Region, Caimitillo healthcare center and their personnel involved with the supervision of this study.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- The USF Institutional Review Board (IRB) and its related staff, who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

Voluntary Participation / Withdrawal
You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints
If you have any questions, concerns or complaints about this study, call Ilena Forero at (507) 6671-4810 or USF Panama at (507) 317-1822.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call:

- Dr. Ruben Berrocal, President of the National Bioethics Committee of Research (CNBI) from the National Secretariat of Science, Technology and Innovation at (507) 517-0014.
- USF Institutional Review Board at 813-974-5638.
Appendix B: Informed Consent (Continued)

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and authorize that my information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_________________________          ____________________
Signature of Person Taking Part in Study                   Date

_________________________
Printed Name of Person Taking Part in Study

_________________________          ____________________
Signature of Witness (if applicable)                   Date

_________________________
Printed Name of Witness (if applicable)

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands:

• What the study is about;
• What procedures will be used;
• What the potential benefits might be; and
• What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

_________________________          ____________________
Signature of Person Obtaining Informed Consent / Research Authorization                   Date
Appendix B: Informed Consent (Continued)

Study ID: Pro00010374 Date Approved: 12/20/2012 Expiration Date: 12/20/2013

Initials: __ __ __

Printed Name of Person Obtaining Informed Consent / Research Authorization
Appendix C: Survey

The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama. Pro00010374

ID#: ___ ___ ___ Date (dd/mm/yyyy): ___ ___ ___

The Principal Investigator of this study appreciates the time you are taking to answer the questions in this survey.

General Information

1. Community

<table>
<thead>
<tr>
<th>District</th>
<th>Corregimiento (township)</th>
<th>Name of Community</th>
<th>Check only one</th>
</tr>
</thead>
<tbody>
<tr>
<td>San Miguelito</td>
<td>Chilibre</td>
<td>Parara Puru</td>
<td>□</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Victoriano Lorenzo</td>
<td>□</td>
</tr>
</tbody>
</table>

2. Total Household members (number) __________

3. Description of the household members

<table>
<thead>
<tr>
<th>Family member (e.g. father, mother, son, daughter)</th>
<th>Sex¹</th>
<th>Age</th>
<th>Education Level²</th>
<th>Children under 5 years</th>
<th>Breastfed¹</th>
<th>Immunization card¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

¹ = F (Female) or M (Male)
² = N (No formal school), CE (Complete Elementary school), IE (Incomplete Elementary school), CH (Complete High school), IH (Incomplete High school), U (University)
³ = Months with exclusive breastfeeding, N (Was never breastfed)
⁴ = VC (Vaccines complete according to age), VI (Vaccines incomplete according to age), NB (Only newborn vaccines), N (No vaccines have been applied)

4. Do any of the parents have Social Security fund? (Y/N) ______

IC Version 01 English, 05Oct2012
Appendix C: Survey (Continued)

5. Total years living in this community __

Information about Water Sources

6. Which of the following is the main source of water for this household? (Check only one)
   □ IDAAN aqueduct
   □ Rural aqueduct
   □ Well
   □ River
   □ Collection of rainfall
   □ Tank truck
   □ Bottled water
   □ Other. Name it ____________________________

7. How close is this main source from the household?
   □ Inside the household
   □ Between 5-30 minutes walking
   □ One hour or more walking
   □ Don’t know

8. Do you perform any of the following treatments to water before using it? (Check all that apply)
   □ Boil
   □ Filter
   □ Chlorine
   □ None
   □ Don’t know

9. Which of the following is close to or surrounds your water source? (Check all that apply)
   □ Farm animals
   □ Farmlands
   □ Pesticides / Herbicides storage
Appendix C: Survey (Continued)

The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama. Pro00010374

☐ Septic tanks / Pit latrine  
☐ Garbage tanks  
☐ None  

10. Do you believe all water sources are equal? (Y/N) Explain

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

11. Sources of Water according to activity performed

<table>
<thead>
<tr>
<th>Activity performed</th>
<th>Sources of Water in the community*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>IDAN aqueduct</td>
</tr>
<tr>
<td></td>
<td>In</td>
</tr>
<tr>
<td>Drink</td>
<td></td>
</tr>
<tr>
<td>Wash / prepare food</td>
<td></td>
</tr>
<tr>
<td>Cook food</td>
<td></td>
</tr>
<tr>
<td>Bathe</td>
<td></td>
</tr>
<tr>
<td>Handwash</td>
<td></td>
</tr>
<tr>
<td>Brush</td>
<td></td>
</tr>
<tr>
<td>Clean house</td>
<td></td>
</tr>
<tr>
<td>Wash dishes</td>
<td></td>
</tr>
<tr>
<td>Wash clothes</td>
<td></td>
</tr>
</tbody>
</table>

*Sources of water according to the 2010 Census of Population and Households, National Institute of Statistics and Census – Panama.

12. Do you believe untreated water can cause diseases? (Y/N) Explain

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

IC Version 01 English, 05Oct2012

3
Appendix C: Survey (Continued)

13. Do you believe untreated water can cause diarrhea? (Y/N) Explain

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Information about Waste and Stool disposal

14. How do you dispose of garbage?
   □ Burn it
   □ Bury it
   □ Dump it in the river
   □ Transport it across the river
   □ Don’t know
   □ Other. Name it __________________________

15. What type of facilities you use for stool disposal?
   □ Pit latrine
   □ Flush toilet connected to sewer or septic tank
   □ Bedpan
   □ River
   □ Ground

16. Do you believe garbage or stools can contaminate your water sources? (Y/N) Explain

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Information about Healthcare Services and Diseases

17. Which are your available healthcare services? (Check all that apply)
   □ Local healer
Appendix C: Survey (Continued)

The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama. Pro00010374

ID#: __________ Date (dd/mm/yyyy): __________

18. Factors that influence the decision of which healthcare service to attend: (Check all that apply)
   □ Distance
   □ Money
   □ Waiting time
   □ Other. __________________________

19. To which service will you go first in case of disease in children under 5 years old?
   (Check only one)
   □ Homemade remedies
   □ Local healer
   □ Community Health worker / Health post
   □ Health center
   □ Hospital
   □ None

20. To which service will you go in case of disease in pregnant women? (Only one)
   □ Homemade remedies
   □ Local healer
   □ Community Health worker / Health post
   □ Health center
   □ Hospital
   □ None

21. Children under 5 years of age are taken to the health center: (Check all that apply)
   □ Once a year for follow-up / immunizations
   □ When they have a disease with no previous treatment
   □ When they have a disease that did not improve with the local healer
   □ You wait for medical tours
   □ Never
Appendix C: Survey (Continued)

22. Pregnant women are taken to the healthcare center: (Check all that apply)
   □ Once every month for follow-up during the pregnancy
   □ When they have a disease with no previous treatment
   □ When they have a disease that did not improve with the local healer
   □ You wait for medical tours
   □ Only for delivery
   □ Never

23. How common are diarrhea cases in your household in children under 5 years of age?
   □ Two to three times a month
   □ Once a month
   □ Once every 2 to 3 months
   □ Twice a year
   □ Never

24. How common are diarrhea cases in your household in pregnant women?
   □ Two to three times a month
   □ Once a month
   □ Once every 2 to 3 months
   □ Twice a year
   □ Never

25. How do you treat diarrheal cases at home? (Check all that apply)
   □ Just water
   □ Homemade remedies
   □ Oral rehydration solution
   □ Medicines
   □ Nothing

26. What type of water you use to prepare Oral rehydration solution?
   □ River water
   □ Rainfall water
   □ Treated river / rainfall water
Appendix C: Survey (Continued)

The Water Culture Beliefs of Embera Communities and Maternal and Child Health in the Republic of Panama. Pro00010374

ID#: __________ Date (dd/mm/yyyy): __________

☐ Well water
☐ Bottled water
☐ Do not know

27. Have any of the diarrheal cases led to hospitalization? (Y/N)____ Which of the following?: (Check all that apply)
☐ Children under 1 year of age
☐ Children under 5 years of age
☐ Pregnant women
☐ Other adults and children over 5 years of age
☐ All of the above
☐ None

28. Has any child under 1 year of age died in the past year due to diarrhea? (Y/N)____
29. Has any child under 5 years of age died in the past year due to diarrhea? (Y/N)____
30. Has any pregnant woman died in the past year due to diarrhea? (Y/N)____

Thanks for your participation!!!