CDKu and the Island of Widows

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ABSTRACT
We recently had the opportunity to spend 3 months working with La Isla Foundation (LIF), a non-governmental organization that aims to raise awareness and combat the Chronic Kidney Disease of Unknown Etiology Epidemic (CKDu) ravaging regions of Nicaragua. This epidemic has not received the international coverage and awareness that it deserves, but recent research studies and news articles have been published which have drawn global attention. There have been multiple anecdotal reports of a high chronic kidney disease prevalence in rural parts of Nicaragua and El Salvador. We assisted La Isla Foundation in their work, contributing to a variety of community development, public health, and human rights projects which gave us exposure to the important cause for which they fight.

OUR PERSPECTIVE
“The Island of the Widows” is a small community in Northwestern Nicaragua devastated by a unique and rapidly progressing kidney disease epidemic. The men of the community die young, leaving behind widows, fatherless children, and lives unlived. The disease has left a sense of hopelessness amongst the people. However, we have learned first-hand of their great strength and perseverance in the face of uncertainty.

As third year Bachelor of Health Sciences students specializing in global health, we had the opportunity to complete an embedded learning experience and spend three months in Nicaragua working with La Isla Foundation (LIF). LIF is a non-governmental organization (NGO) that aims to raise awareness and combat the chronic kidney disease of unknown etiology (CKDu) epidemic. This epidemic is afflicting rural regions of Nicaragua as well as other areas throughout Central America. This epidemic has not previously received the international coverage and awareness that it deserves, but in recent months, research studies have been published that have drawn great global media attention. Reports of related epidemics have led many to believe that CKDu may be present amongst rice paddies workers for India and Sri Lanka. Since this disease is not as isolated as previously thought, international attention to the impacts of CKDu are rising and leading to increased awareness, funding, and treatment, ultimately working towards eventual abolition of the epidemic.

Contributing to a variety of community development, public health, and human rights projects provided us with a unique perspective on the important cause that LIF fights for. The LIF team’s passion, dedication, and unyielding pursuit of social justice was truly inspiring. During our time in Nicaragua, we witnessed the profound impact that this disease has on the local people.

UNDERSTANDING CKDU
CKDu seen in Nicaragua differs greatly from the traditional chronic kidney disease (CKD), despite the fact that both conditions present with a progressive degeneration of renal tissue. While traditional CKD is associated with hypertension, diabetes, and obesity, CKDu has been associated with grueling manual labour in hot temperatures. Recent research has demonstrated that fructokinase, a liver and kidney enzyme, plays a key role in regulating the disease. Using mouse models, Roncal Jiminez et al. showed that extreme heat, strenuous work, dehydration, and hydration using fructose-rich drinks causes the metabolism of fructose through the aldose reductase pathway with fructokinase. The activation of this particular metabolic pathway produces oxidants and other inflammatory mediators, resulting in renal damage.

Exposure to environmental toxins is also being investigated as a potential compounding cause of CKDu, but much of the research suggests chronic dehydration is a primary cause. Unfortunately, misconceptions regarding toxins in the water have resulted in some workers avoiding the hydration that their bodies so desperately need. In fact, it has been shown that patients with CKDu show damaged renal tubules and interstitial tissues consistent with chronic dehydration. Hydration with fructose-rich hydration packs provided by the sugar mills which employ the workers may exacerbate the problem.

THE COMMUNITY
The community of La Isla is one of five communities that constitute the larger Guanacastal-Sur in the rural sector of Chichigalpa, Nicaragua. It has become known as “La Isla de las Viudas”, or “The Island of the Widows”, due to the devastating effects of the CKDu epidemic on the community. The majority of working-age men are employed by local sugar production companies to perform various jobs in the fields or factories. In Chichigalpa, a small city near where La Isla is located, 75% of all male deaths in those aged 33-55 from 2002-2012 were due to CKDu. In the small community of La Isla itself, 40% of males 15 and older have stage 3 or higher CKDu. This leaves workers searching desperately for treatment.

While the Nicaraguan social security system covers certain medical services, kidney transplant is not included. Furthermore, there is a lack of capacity for a large-scale transplantation network. As a result, afflicted individuals must resort to dialysis as the only treatment option. In theory, two types of dialysis are feasible: hemodialysis and peritoneal dialysis. Hemodialysis involves blood being filtered outside the body in order to reintroduce clean blood into the system, while peritoneal dialysis involves fluid filtration across the peritoneal membrane in the abdomen through a catheter. In order to qualify for hemodialysis coverage, one must meet the strict requirement of having worked for 750 full weeks; it is almost impossible for the young workers to fulfill this before the disease itself prevents them from working. This leaves peritoneal dialysis (PD) as the only feasible option for the impoverished people of this community.

The CKD mortality rate in Chichigalpa is approximately
Aside from the significant lack of resources, a major impediment to the home dialysis program is the high rate of infection among patients. Although infection is a major complication of PD in any part of the world, the unsterile environments in rural areas further increase PD infection rates. The living conditions in the rural communities contribute to a lack of functional, sterile clean rooms, which the patients must pay for out-of-pocket at a cost of $2,000 USD. Once infected, the PD catheter should be removed, the patient treated with antibiotics, and the catheter replaced. However, the difficulties of travel and seeing a doctor mean that many choose to continue to use the old catheter, thus worsening the infection. Infections also cannot be controlled in most cases because of the nonspecific prescription of antibiotics and the inability to continue dialysis while the catheter is removed. As a result, the catheter remains and the patient is left in an extremely vulnerable condition, unable to fight off the infection.

**REFLECTIONS**

Measures must be taken in order to end the injustice that is occurring in Nicaragua and other areas affected by this epidemic. LIF’s multi-faceted approach to tackling the epidemic through a variety of initiatives including public health, law and human rights, community development, and scientific research will allow for a lucid appraisal of the problem and a holistic response. An example of a recent effort by LIF is their PD project, which attempts to evaluate, improve, and expand the current PD program at Hospital España. LIF attempts to take an integrated approach through lobbying, awareness campaigns, and grassroots partnerships with community organizations as well as academic research institutions and multilateral organizations. Corporate responsibility must also be encouraged through the sugar mills to create a safe working environment that respects basic human rights. Furthermore, since treatment is not feasible in many cases, focus must be placed on prevention through humane working conditions, information dissemination amongst community members, and improved access to medical care. To this day, we are moved by the magnitude of this situation and can only hope for change in sugarcane production. If these measures are implemented and the problem is addressed thoroughly and responsibly, we can build lasting partnerships and repair the damage done in this fractured community.