

CDKu and the Island of Widows

ARUN PARTRIDGE AND LOUISE CHONG

Bachelor of Health Sciences (Honours), Class of 2015

Correspondence: arun.partridge@learnlink.mcmaster.ca and louise.chong@learnlink.mcmaster.ca

GLOBAL PERSPECTIVE



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 un-lived. 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 paddy workers for India and Sri Lanka.¹ 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.² Recent research has demonstrated that fructokinase, a liver and kidney enzyme, plays a key role in regulating the disease. Using mouse models, Roncal Jimenez 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.⁴

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.⁵ Unfortunately, misconceptions regarding toxins in the water have resulted in some workers avoiding the hydration that their bodies so desperately need.⁶ 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.⁵

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.² In the small community of La Isla itself, 40% of males 15 and older have stage 3 or higher CKDu.² 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.² 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

“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.”

10 times higher than the national and international average, mainly due to the mortality caused by CKDu.³ La Isla is just one of many small communities across Nicaragua and Central America that are believed to be suffering quietly from this epidemic. As volunteers within this community, we spent our time managing an arts and sports club at the local school. We found that the majority of children we worked with had a father, uncle, or brother taken from their family much too early by CKDu. Tragically, the people of La Isla have come to expect this and have little ability to find other work to escape this cycle of death.

THE CHRONIC KIDNEY DISEASE MORTALITY RATE IN CHICHIGALPA IS APPROXIMATELY 10 TIMES HIGHER THAN THE NATIONAL AND INTERNATIONAL AVERAGE...³

BARRIERS TO CARE

Near the end of our time in Nicaragua, we had the opportunity to visit and talk with some of the staff at the local public hospital about the patients they receive. Hospital España is the nearest Ministry of Health hospital to the community and is the only one that offers PD in the department of Chinandega.⁷ There are 8 beds in 4 rooms of the Hospital España dialysis unit, with only 4 functional PD machines. Baxter, a pharmaceutical company, donates PD equipment to the Nicaraguan Ministry of Health, which in turn buys fluids and other supplies. This system theoretically allows for the provision of treatment to all without cost.² However, the lack of medical personnel and resources combined with the large demand makes this more difficult in practice.

At the hospital, there is an outpatient program and a home dialysis program, overseen by a nephrologist who is at the hospital for only 4 hours per week. The capacity of the outpatient program is limited because of the high demand, compounded with the lack of beds and requirement for each patient to have two sessions of 12-24 hours each per week. This outpatient program makes use of the PD machines through Automatic PD, which exchanges the renal fluids across the peritoneal membrane. In the hospital, there is also one training room devoted to the home dialysis program, which consists of 28 patients. A nurse or doctor teaches the patients the practices of home PD, which requires manual exchange of fluids every 6 hours throughout the day.²

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.⁸ 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. ■

REVIEWED BY NARMEEN HAIDER & ILANA WEISS

NARMEEN HAIDER graduated from the B.H.Sc. program at McMaster University and earned her M.Sc. in International Health Policy from the London School of Economics and Political Science. She is currently a manager for the Health Impact Fund and an instructor for the Department of Health Sciences at McMaster University. ILANA WEISS is the director of policy and public health at La Isla Foundation.

EDITED BY NICOLE FALZONE | PHOTO COURTESY OF LOUISE CHONG & ARUN PARTRIDGE

1. Countries target pesticides as suspected link to rare kidney disease [Internet]. International Consortium of Investigative Journalists. [cited 2014 Feb 1].
2. Weiss I, Glaser J. Improving Home PD for cane workers affected by CKDu. La Isla Foundation. 2013.
3. Wesseling C. Mesoamerican Nephropathy, Rapport from the first international research workshop on MeN. Page 40 table 1.
4. Brooks D. Final Scoping Study Report: Epidemiology of Chronic Kidney Disease in Nicaragua. Boston University; 2009. P 42 Table 5. Available at http://www.cao-ombudsman.org/cases/documentlinks/documents/03H_BU_FINAL_report_scopestudy-CRL18.Dec.2009.pdf last visited August 12, 2013.
5. Johnson RJ, Sánchez-Lozada LG. Chronic kidney disease: Mesoamerican nephropathy—new clues to the cause. *Nat Rev Nephrol*. 2013 Oct;9(10):560-1.
6. O'Donnell JK, Tobey M, Weiner DE, Stevens LA, Johnson S, Stringham P, et al. Prevalence of and risk factors for chronic kidney disease in rural Nicaragua. *Nephrol. Dial. Transplant*. 2011 Sep;26(9):2798-805.
7. Jain AK, Blake P, Cordy P, Garg AX. Global trends in rates of peritoneal dialysis. *J. Am. Soc. Nephrol*. 2012 Mar;23(3):533-44.
8. Li PK-T, Szeto CC, Piraino B, Bernardini J, Figueiredo AE, Gupta A, et al. Peritoneal Dialysis-Related Infections Recommendations: 2010 Update. *Perit Dial Int*. 2010 Jul 1;30(4):393-423.