



Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency



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Nicaragua

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www.cao-ombudsman.org

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About the CAO

The CAO (Office of the Compliance Advisor/Ombudsman) is an independent post that reports directly to the President of the World Bank Group. The CAO reviews complaints from Communities affected by development projects undertaken by the private sector lending and insurance members of the World Bank Group, the International Finance Corporation (IFC) and the Multilateral Investment Guarantee Agency (MIGA). The CAO works to respond quickly and effectively to complaints through mediated settlements headed by the CAO Ombudsman, or through compliance audits that ensure adherence with relevant policies. The CAO also offers advice and guidance to IFC and MIGA, and to the World Bank Group President, about improving the social and environmental outcomes of IFC and MIGA projects.

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About this Report

The information in this report does not necessarily reflect the opinion of the authors nor of the CAO, nor is it primarily based on an evaluation conducted as part of the framework agreement presented before the CAO. The analysis of this information was in the context of identifying the medical needs of CRI patients in Chichigalpa. The issue of CRI prevalence will be addressed under an independent epidemiological study.

Key stakeholders (ASOCHIVIDA, NSEL, MINSA) have had the opportunity to review the preliminary report and make commentaries and corrections. Their input was analyzed and integrated into the final report.

Front cover photo

The focus group of ASOCHIVIDA CRI widows vote to prioritize their recommendations for improving health care for CRI patients.

Photographs in this report were taken by David Silver

TABLE OF CONTENTS

TABLE OF CONTENTS	i
List of Acronyms	ii
1. Background	1
2. Objectives of the health needs assessment	1
3. Methodology of the Assessment	2
3.1 Literature Review.....	2
3.2 Participatory process.....	3
3.3 Tools.....	3
3.4 Data collection and analysis.....	4
4. Summary of Key Findings	5
4.1 Standardized diagnosis and treatment guidelines for CRI.....	5
4.2 Laboratory monitoring of critical renal function and disease progression.....	6
4.2.1 Availability of laboratory reagents for renal function tests.....	6
4.2.2 Reliability of laboratory values for renal function tests.....	7
4.2.3 Availability of Ultrasound for renal evaluation.....	7
4.3 Medications: Appropriateness, Efficacy and Access.....	8
4.3.1 Appropriateness of CRI medications.....	8
4.3.2 Efficacy of essential CRI medications.....	9
4.3.3 Access to uninterrupted supply of essential CRI medications.....	10
4.4 Medical facilities.....	13
4.5 Medical attention.....	14
4.6 CRI Information for Patients and the Community.....	16
4.7 Access to recommended CRI diet (Seguridad alimentaria).....	18
4.8 Psychological needs of CRI patients and their families.....	19
4.9 Stage 4-5 treatment: Access to ESRD (end-stage renal disease) treatment.....	20
4.10 End of life Care for CRI patients and psychological support for their families.....	23
4.11 Improving early diagnosis of CRI.....	24
5. Summary of options from focus groups and key informants	25
6. CRI Medical Needs: Summary of Options identified by Dialogue Table participants to Improve Care	30
7. Next Steps	35
Annexes	36
Annex A. Key Informant Interviews List.....	36
Annex B. Clinical Capacity Assessment: Topic Guide Questions for Doctors addressing CRI	37
Annex C. La Evaluación Clínica de la Capacidad Médica para tratar a los pacientes con IRC: Preguntas Guía para discusión con Médicos que trabajan con pacientes que sufren de IRC....	40
Annex D. Focus Group Participants.....	43
Annex E. Medical Literature Review of CRI: Bibliography.....	44

List of Acronyms

ASOCHIVIDA....	Asociación Chichigalpa por la Vida (Association Chichigalpa for Life)
CAO.....	Office of the Compliance Advisor/ Ombudsman
CRI.....	Chronic renal insufficiency
FFLA.....	Fundación Futuro Latinoamericano
INSS.....	Instituto Nicaraguense de Seguridad Social (Social Security Agency of Nicaragua)
ISA.....	Ingenio San Antonio (San Antonio Sugar Mill)
MINSA.....	Ministerio de Salud (Ministry of Health)
NKF KDOQI....	National Kidney Foundation Kidney Disease Outcomes Quality Initiative
NSAIDs.....	Non-steroidal anti-inflammatory drugs
SILAIS.....	Sistemas de Atención Integral de Salud (Comprehensive Health Care System)
ToRs	Terms of Reference
UNAN.....	Universidad Nacional Autónoma de Nicaragua (National Autonomous University of Nicaragua)

1. Background

Although recognized as a global health problem, chronic renal insufficiency (CRI) has been sweeping through the Pacific coast of Central America in epidemic proportions. From 1996 to 2002, national mortality rates from CRI in Nicaragua increased by about one third (33%).¹ In contrast, in the Pacific Departments of León and Chinandega, the most affected regions, some studies estimate that the CRI mortality rate has nearly tripled from 1992 to 2002, with a male to female ratio of 5:1.² The high prevalence of CRI in this region is multiple times higher than rates for U.S. men and women and is not explained by usual etiologies like hypertension and diabetes.

Currently, about 1500 patients with CRI at all stages receive their ongoing medical care at the Centro de Salud, Chichigalpa, an agricultural municipality in the Department of Chinandega. In the face of this developing CRI epidemic, there are a total of only 12 nephrologists in Nicaragua, for a population of 5.4 million, most of whom work in Managua; in the most affected Pacific region, one nephrologist is based in León, another works in a private clinic in Chinandega, and a third nephrologist who attends in the public health clinic in Chichigalpa (Centro de Salud).

We would like to note that estimations of CRI prevalence that appear in this document are based on information compiled from interviews and from studies that already exist in Nicaragua. The information presented in this report does not necessarily reflect the opinion neither of the authors nor of the CAO, nor is it primarily based on an evaluation conducted as part of the framework agreement presented before the CAO. The analysis of this information was in the context of identifying the medical needs of CRI patients in Chichigalpa.

CRI is a progressively fatal disease with no cure. Most all CRI patients progress to end-stage renal disease (ESRD) and require either transplantation or ongoing kidney dialysis for survival. Both treatments are very costly and pose a substantial challenge to provision of care for patients. This is especially true in Nicaragua, a country where the national annual per capita health expenditure is \$251.³ At present in Nicaragua, there is no access to any treatments for ESRD for the vast majority of CRI patients.

Because the definitive etiology remains unsolved, the only preventive strategies address general measures to slow the progression of the disease such as antihypertensive medications, a specialized diet, and avoiding smoking, alcohol ingestion, heat exposure, and NSAIDs (non-steroidal anti-inflammatory medications).

2. Objectives of the health needs assessment

From March 9-14, a team sponsored by the CAO conducted a health needs assessment in the Departments of León and Chinandega. The overall purpose of the assessment was to identify short and long term options that could improve the health care people living with CRI

¹ Unpublished study by the Ministry of Health of Nicaragua and the Universidad Nacional Autónoma de Nicaragua (CRI mortality in 1996 was 6.8 per 100,000, reaching 9 per 100,000 in 2002)

² From 10 and 16 deaths per 100,000 inhabitants in 1992 up to 37 and 36 in 2002; Marín Ruiz, J., & Berroterán, J. Insuficiencia renal crónica: Cuadro clínico y situación epidemiológica en Nicaragua. Managua: Ministerio de Salud Nicaragua. 2002. In Cuadra S. Jakobsson K., Hogstedt C., Wesseling C. Chronic kidney disease: Assessment of current knowledge and feasibility for regional research collaboration in Central America. SALTRA; Work and Health Series ; 2006; 2, Section I: 11-42.

³ 2007/2008 Human Development Report, UNDP.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

are currently receiving and how to improve its accessibility. An additional purpose was to identify further options for collaboration from public health institutions to improve current health services for the affected communities.

The specific objectives of the medical consultant's work were to:

- *Conduct a 'needs assessment' that will be useful to inform the participants of the CAO dialogue table of options that could improve the immediate and long-term care for people suffering from CRI.*
- *Identify the different treatments available from public and private health institutions in departments of León and Chinandega for people suffering from CRI, and the accessibility impacted community members have to those treatments.*
- *Make suggestions of how further collaboration from public health agencies, NSEL and affected community members could be helpful to ensure better services for the communities affected with this chronic illness.*

3. Methodology of the Assessment

To accomplish these objectives, the CAO team sought to identify and map medical treatments provided by local health institutions for people suffering from CRI. In addition, the team met with members of the affected community to better understand their experiences and concerns regarding health treatments for CRI available to them in the Department of Chinandega.

The principle qualitative data gathering methods consisted of focus groups of CRI affected ASOCHIVIDA members and widows, and individual interviews with key medical personnel involved either in direct care or planning of health services for CRI patients. A participatory approach to evaluation was pursued to better incorporate local knowledge from CRI patients and widows. The assessment was predominantly qualitative, though the validity of the findings was enhanced by triangulation of multiple voices and points of view.

Data was analyzed to identify and prioritize common themes expressed. Our intention is not to provide a critical voice of the dire challenges surrounding adequate provision of care to patients affected with CRI. Rather, we are largely confirming most of what is already well acknowledged by physicians and public health professionals working on CRI in the Departments of León and Chinandega; our purpose is to provide a framework from which to move forward in improving care for CRI patients.

This report offers a group of preliminary recommendations arising out of the common issues expressed. These recommendations have been developed in regard to existing best practices for CRI through a medical and public health lens. A holistic approach toward addressing the challenging medical needs of CRI patients was intentionally taken in order to more directly include some of the root causes underlying these challenges.

3.1 Literature Review

To better evaluate current medical practices around CRI in Nicaragua, a literature review of best clinical practice guidelines in the diagnosis, treatment, management and prevention of chronic kidney disease was conducted. Documents reviewed are listed in the attached annex.⁴

⁴ See Annex E, *Literature Review: Chronic Kidney Disease*.

3.4 Data collection and analysis



Alexandra Perez facilitating focus group with CRI patients.

The principle source of both primary and specialty healthcare for CRI patients in Chichigalpa is the MINSA-run Centro de Salud (Public Health Clinic). The Centro de Salud has a designated CRI Clinic staffed by two doctors, a nephrologist and an internal medicine physician, who together provide ongoing clinical care to a group of about 1500 CRI patients in Chichigalpa. If they require hospitalization, Centro de Salud patients can only be transferred to Hospital España (half an hour away in Chinandega) because it is in the same Province. Patients currently have no access to UNAN Hospital in León.

In general, sugar cane workers who develop CRI do not have access to medical attention provided by the Hospital of the *Ingenio San Antonio* (ISA). The Company conducts periodic creatinine level monitoring of their employees. If elevated levels are found, the workers are prescribed up to 12 weeks of rest (*i.e.*, for cane cutters, the physical effort required in their work activities may be a factor associated with CRI). If after the rest period creatinine levels have not returned to normal, as in accordance with Nicaraguan law, a referral is made for the sick worker to follow up with INSS to request disability pension.

There are a few cases of CRI patients who work at ISA and who receive medical attention at the ISA Hospital; however these cases are primarily a result of chronic illnesses such as diabetes and hypertension. The nature of their work-related activities (basically administrative positions) does not increase their risk of exacerbating their CRI condition.

To obtain a more in depth picture of the current medical care provision for CRI patients in the Department of Chinandega, nine key informant interviews were conducted. These included a health official from the national MINSA, Managua, SILAIS director of the Department of Chinandega, director of Hospital España Dialysis Unit, directors of the Epidemiology Department and medical school dean of UNAN, ISA Hospital physicians, and both the general director and the nephrologist of the Chichigalpa Centro de Salud.⁶ Three focus group discussions were conducted with ASOCHIVIDA members. These included a group of 10 male ASOCHIVIDA members with CRI chosen by the board, 13 male self-selected

⁶ See Annex A. Key Informant Interview List.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

(volunteer) ASOCHIVIDA members with CRI, and 11 ASOCHIVIDA widows chosen by board.

Data analysis consisted of reviewing all focus group and key interview notes to identify a list of themes, indicators and emerging issues. Direct quotations from all focus groups and interviews were next sorted into several main categories that included several sub-categories as well. Agreement on interpretation and representativeness of the key findings was reviewed with assessment team members.

All focus group and key informant interviews were conducted in Spanish by assessment team members. English translation assistance was received for the focus groups so that discussions could be captured in their entirety and transcribed concurrently.

4. Summary of Key Findings

4.1 Standardized diagnosis and treatment guidelines for CRI



Blood chemistry (creatinine) protocol record (ISA Hospital)

One of the hallmarks of providing a consistent standard of quality care to a population is the utilization of standardized diagnosis and treatment guidelines. A set of protocols based on current medical knowledge and best practices assures that CRI patients are receiving the most appropriate means of early diagnosis, staging, management and prevention for their illness.

By defining chronic kidney disease and classifying the stages of severity, a CRI protocol would provide a common language for communication among providers, patients and their families, investigators, and policy-makers and a framework for developing a public health approach to affect care and improve outcomes of chronic kidney disease.⁷ A uniform terminology would permit:

1. *More reliable estimates of the prevalence of earlier stages of disease and of the population at increased risk for development of chronic kidney disease.*
2. *Recommendations for laboratory testing to detect earlier stages and progression to later stages.*
3. *Associations of stages with clinical manifestations of disease.*
4. *Evaluation of factors associated with a high risk of progression from one stage to the next or of development of other adverse outcomes.*
5. *Evaluation of treatments to slow progression or prevent other adverse outcomes.*⁸

⁷ The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI).

⁸ *Ibid.*

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Guidelines for CRI are not currently utilized in Nicaragua. However, the Nicaraguan Association of Nephrologists (Asociación Nicaragüense de Nefrología- ANINEF) has recently submitted a set of national guidelines for CRI (*Norma y Protocolo para el Abordaje de la Enfermedad Renal Crónica*). These protocols are currently awaiting the approval of MINSa (Ministerio de Salud) before they can be implemented on a national basis. The National Autonomous University of Nicaragua (Universidad Nacional Autónoma de Nicaragua or UNAN), Center for investigation of occupational health and environment (Centro de Investigación Salud Trabajo or CISTA) has also developed a protocol for early preventive screening of CRI.

Until these protocols are adopted and practitioners are trained to use them, diagnosis, management and prevention practices for CRI will continue to vary among medical practitioners caring for CRI patients or at risk agricultural workers in Nicaragua. Protocols for monitoring creatinine levels are already in place at the ISA Hospital. Existence and utilization of such guidelines, though, is not routine among clinics treating CRI patients in Nicaragua.

Estimates of glomerular filtration rate (GFR) are the best overall indices of the level of kidney function and thus are included in the U.S. National Kidney Foundation's *Kidney Disease Outcomes Quality Initiative (KDOQI)*. These universally accepted practice guidelines also state that the serum creatinine concentration alone should not be used to assess the level of kidney function. For this reason if creatinine levels alone are utilized, the potential exists for some CRI patients to be erroneously classified as to the level or stage of their illness.

The lack of guidelines for CRI diagnosis may also be contributing to the late diagnosis and mismanagement of certain patients. For example, some patients with anemia, proteinuria, or high blood pressure might be treated without determining the underlying cause.

Perhaps one of the most compelling reasons to utilize standardized protocols on a national level is the fact that there are a scant 12 nephrologists to serve Nicaragua's population of 5.4 million, with the country facing an impending CRI epidemic. A set of treatment guidelines will help ensure that the majority of CRI patients, who most likely will be managed by internal medicine physicians, will receive a current, appropriate standard of care for this complex chronic illness.

4.2 Laboratory monitoring of critical renal function and disease progression

Accurate staging and ongoing clinical management of CRI relies on precise laboratory monitoring of renal function.

4.2.1 Availability of laboratory reagents for renal function tests

Renal function testing requires an uninterrupted supply of laboratory reagents (reactants) to measure creatinine, uric acid, calcium, phosphorus, and electrolytes. INSS along with MINSa have been unable to secure the provision of essential reagents for the Centro de

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Salud in Chichigalpa (see 3. *Medications*, below for a discussion of institutional impediments to securing a continual supply).

A commonly shared theme among all focus group members that was confirmed by several key medical professional we consulted was ***the ongoing lack of reagents to test renal function at the Centro de Salud***. It is not unusual for CRI patients to have to wait for 4 months or longer to have their kidney function evaluated.

This is the way it is. Sometimes we get to the appointment 2 days beforehand for the lab tests, but they tell us they don't have enough reagents. So 2 days later we have our examination without lab tests. So the doctor bases our current diagnosis on lab tests from 2 months ago. (CRI patient)

In my case, I went to 3 appointments and haven't received any treatment because there weren't any reagents. Then, in what way are we able to survive if they are the ones who aren't complying? (CRI patient)

Ongoing lack of reagents is a critical issue that undermines the ability of physicians caring for CRI patients to adequately manage their patients. CRI patients sometimes have no other recourse than to pay the high out of pocket costs for obtaining these essential tests to monitor their renal function.

4.2.2 Reliability of laboratory values for renal function tests

Accurate calibration of laboratory equipment is another essential requirement for reliable renal function testing. Several medical personnel expressed doubt that some of the laboratory equipment in medical facilities in the Department of Chinandega is adequately calibrated and suggested ongoing monitoring.

The Centro de Salud in Chichigalpa conducts between 6-7,000 tests per month on CRI and general clinic patients. The equipment is currently working satisfactorily, but it is old and will have to be replaced soon. MINSA typically does not have the resources to replace the equipment, but sometimes they are able to get additional resources from INSS. In addition, the Centro de Salud requires more than the 2 microscopes it currently has for the current case load.

4.2.3 Availability of Ultrasound for renal evaluation

Another important need for CRI patients is to have periodic renal ultrasound testing to determine the size of their kidneys, which indicates the progression of their disease. When the CRI Clinic first opened at the Centro de Salud, a radiologist with ultrasound equipment was contracted to conduct tests for CRI patients. INSS funding subsequently stopped, and all patients needing an ultrasound currently have to travel to private physicians' offices in Chinandega to obtain an ultrasound. Both the cost of testing and travel expenses have provided substantial obstacles for most CRI patients in Chichigalpa. Ultrasound testing is supposed to be provided as a free service to ex-workers with CRI patients on the part of INSS. ***Accessible (local, free of cost) ultrasound examination to evaluate the extent of renal pathology for CRI patients in Chichigalpa is thus sorely needed.***

4.3 Medications: Appropriateness, Efficacy and Access



Pharmacy at the Centro de Salud, Chichigalpa

In evaluating the larger picture of CRI medical needs around medications, the issues of appropriateness, efficacy and access must each be taken into consideration.

4.3.1 Appropriateness of CRI medications

After establishing an accurate diagnosis, good clinical management of CRI next requires the utilization of appropriate medications. As previously mentioned, a set of protocols based on current medical knowledge and best practices helps assure that CRI patients are receiving the most appropriate means of treatment for their illness.

Although medicine cannot reverse chronic kidney disease, it is often used to help treat symptoms and complications and to slow further kidney damage. The principal class of medications indicated for patients with decreased kidney function is anti-hypertensives (blood pressure lowering) called ACE (angiotensin converting enzyme) inhibitors and ARBs (angiotensin receptor blockers). Enalapril, a medication in this category, is widely used for CRI patients in the Depts. of Chinandega and León. Hypoglycemic agents (for diabetes) are also commonly and appropriately prescribed to delay the progression of chronic kidney disease of CRI patients locally. Alupurinol, a medication utilized to reduce acid uric levels in gout patients, is administered to most all CRI patients in this region.

Other medications indicated to treat the pathologic manifestations of CRI include erythropoietin and iron (for anemia), calcium supplements (for hypocalcemia), and loop diuretics (for fluid overload). All of these medications are typically prescribed for CRI patients in this geographic region.

One instance of departure of local prescription practice from international standardized treatment guidelines for CRI was identified. Allopurinol, a drug used to lower uric acid levels in patients with gout, is commonly given to almost all CRI patients in this region. The National Kidney Foundation *KDOQI* guidelines⁹ do not include the use of allopurinol for routine management of CRI. However, the recently drafted Nicaraguan national guidelines for CRI (*Norma y Protocolo para el Abordaje de la Enfermedad Renal Crónica*) specifically call for the use of this medication. This disparity in medication indicated for CRI patients needs to be further investigated and addressed to assure that CRI patients are receiving the appropriate treatment for their disease.

⁹ The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI).

4.3.2 Efficacy of essential CRI medications

Determining the efficacy or pharmacological potency of medications is another key factor in adequate treatment. Generic formulations are more commonly used by the Centro de Salud, Chichigalpa, because they are relatively inexpensive and are produced in the region. Several local physicians have questioned the efficacy of these generic formulations; however claims are circumstantial and as yet remain unsubstantiated.

All three focus groups also widely expressed concern about the medications commonly given to manage CRI. For example, many were suspicious that medications provided were of poor quality.

The Allopurinol we are given is low quality. It says on the box that it's produced by the MINSA. It causes many side effects- decreased sexual appetite, decreased memory. (CRI patient)

We have a problem with Enalapril. If it's not already expired, it's just about to expire. (CRI patient)

Related to these suspicions about medication quality were many complaints about the numerous symptoms CRI patients were experiencing that were perceived as medication side effects.

Our medications are bad, very bad. I don't feel any better. In fact I feel worse. (CRI patient)

The medications didn't work- they just caused vomiting, diarrhea, and inflammation of the legs. (Widow)

Interestingly, many CRI patients and widows felt that the generic medications supplied by the Centro de Salud produced both more side effects and were less effective than the more expensive pharmaceutical brands purchased at the private pharmacy or private physicians' offices.

The medication they give us at the Centro de Salud keeps giving us stomach aches. The other brand that they don't give you at the clinic- yes, that one works. (CRI patient)

...they give us the free medication that's no good. The good medication they write you a prescription to buy. (CRI patient)

They give you a pill that costs 6 cordobas- the good ones cost 50 cordobas, from a good pharmacy. But they give you the stuff from El Salvador. (CRI patient)

Centro de Salud clinic physicians indicated that they felt that the generic medications were of good quality.

A couple of CRI patients mentioned that a pain shot (diclofenac) that they received at the clinic was temporarily helpful. Ultimately, most of all participants in each of the three focus groups complained that there were just no medications or treatments available to them that improved their disease in any perceivable way. In addition, a commonly shared experience for CRI patients is that the doctors at both the clinic and hospitals tell them that there is nothing to do when they feel ill.

Why should I go to a private doctor? They don't offer anything that can really make me better... (CRI patient)

When viewed together, many ***medication concerns seem to arise from a lack of understanding of CRI and its course, CRI medication efficacy and side effects.***

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

They use the same few medications for everyone and they don't work. (CRI widow)

The medicines are not good because we continue to get worse, because our disease is always progressing. (CRI patient)

Thus, the issue perceived by CRI patients as lack of efficacy of their medications might also be addressed through educational efforts (See 6. *Lack of Information for CRI Patients and the Community*).

4.3.3 Access to uninterrupted supply of essential CRI medications

According to national law, MINSAs is responsible for the Nicaraguan National Health System, and accordingly, provides medical attention to all Nicaraguans. Similarly, INSS is responsible for providing social security benefits to beneficiaries that include ex-workers affected by CRI.

A continued supply of medications necessary for the clinical management of CRI is another cornerstone of good care. Current lack of access to an ongoing supply of essential CRI medications represents one of the direst medical needs for Centro de Salud patients.

An agreement between MINSAs and INSS determining the responsibilities of medication procurement has not as yet been reached. As a consequence, essential medications, supplements (iron, calcium), vitamins, and laboratory reagents for the treatment of CRI have not been available on a regular basis.

ASOCHIVIDA members and widows of CRI patients consistently and emphatically reiterated the ***consistent lack of availability of essential CRI medications at the Centro de Salud.***

When we tell them what's bothering us, they hand us a prescription and tell us to go buy it... We speak with one voice about this. (CRI patient)

We had no choice but to try and buy pills because there were none in the Health Center (CRI widow)

The national CRI plan includes 3 sectors- public (*Ministerio de Salud- MINSAs*), social security (*Intituto Nicaraguenze de Seguridad Social- INSS*), and the private sector. INSS provides partial payment of health care to CRI patients with pensions or social security benefits, but funds are extremely limited. Medical personnel caring for CRI patients confirmed the inability of the public health system to provide an ongoing supply of essential medications. The reason is attributed to procurement problems in Managua with both MINSAs and INSS.

There is a law that dictates the procedures for public buying that was left by the last government. You need to comply with certain steps and it takes a long time. If we don't follow the procedures we risk problems with the law. (Health official)

I am really worried because of the new CRI case projections of the UNAN study. There is no way that INSS and MINSAs can keep up with the medication needs. (Health official)

The lack of available medications was compounded by the fact that appointments for CRI patients are only every 2-3 months.

With appointments every 2 months, if they tell you there are no medications, then you have to wait another 2 months. (CRI patient)

In addition to essential CRI medications, supplements such as vitamins were also frequently unavailable, considered inferior quality, or unaffordable.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

I was sick 6 months ago. I was sick, very sick. I went to the clinic and they said there was no cure, but the doc sold me vitamins for 800 cordobas. How come they have to sell those? So I sold my TV and everything in my home to buy the treatment. (CRI patient)

Several health officials indicated that MINSAs have many crises to which they must attend—trying to mitigate the aftermath of hurricanes, for example, or rushing to improve levels of immunization. Some even believe that the government doesn't really want to know the extent of the CRI problem because they are unable to address it, anyway. It is clear that some form of assistance to MINSAs and INSSs will be necessary to assure the ongoing procurement of medications essential for the clinical management of CRI patients at Centros de Salud in Chichigalpa and Hospital España.

The main issue at hand, though, is ***the inability for CRI patients to pay for prescriptions at private pharmacies***. This was one of the key concerns consistently raised in each of the focus groups.

My pension gives me \$50/month, and that's what the medication costs alone. (CRI patient)

Having to buy expensive medications means death for us- we have wives and children and can't afford this. It's another nail in the coffin. (CRI patient)

We had to decide whether or not to feed the children or buy the medicines. (Widow)

In my case, I have a little plot of land, but I lack enough money to plant it. Everything returns to the same miserable pension we receive from social security, which we need to use to buy our medications and the money is gone. (CRI patient)

Although the Nicaraguan National Assembly has voted¹⁰ to classify CRI as an occupationally related disease, it seems like there are still some difficulties for INSS to agree on providing social security pensions to ex-agricultural workers with CRI. Currently, workers are required to have worked for 104 consecutive weeks before they are eligible for compensation.¹¹ Because the *zafra*s (sugar cane harvests) only last 6 months, it is impossible for cane workers as well as other seasonal agricultural workers to reach the 104 consecutive-week threshold to be eligible for social security. As a result, few receive pensions even though they are disabled from CRI— and those qualifying for social security benefits receive \$50 per month, an amount insufficient to meet all their household expenses.

Some of us receive pensions, and if we don't, we sacrifice paying household expenses just to live a few more days. (CRI patient)

.... They are not only hurting me, but my whole family, that is the difficulty we are facing. We have been fighting for more than 5 years, and we have hope that God and all the organizations can do something. But it won't be for us, but our families. I am here talking to you today, but that doesn't mean that I am well. (CRI patient)

¹⁰ Since July 8, 2004 CRI has been considered a professional illness in Nicaragua. Law No. 456 – Law of Additional Risks and Professional Illnesses to Law No. 185 – Labor Code. For further information see: <http://www.mitrab.gob.ni/index/Ley456Nic.pdf>

¹¹ For further information see Article 81, General Rules of Procedure for the Social Security Law, Decree No. 975, February 11, 1982. Published on Gaceta No. 49, March 1, 1982.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

And we can't take care of other family members either. I have a daughter with leukemia. Sometimes she has so much pain she cries. And since I can't do anything at all for her, I just sit down and cry with her. (CRI patient)

After this last hurricane, it blew my house down. We spent 2 months living under plastic, and little by little we have a shack, but as soon as it starts raining it will leak. We can't take out a loan. How can we pay for that? We can't even pay for our food.

CRI patients face the untenable combination of needing an income to supplement their meager pension (if they have one at all), and knowing that hard work and sun exposure directly compromises their health.

But the other problem we have with this disease is that the doctor tells us that we need enough rest. The doctor has been very clear about this. You have to stay out of the sun. You can't be a guard who is up all night. So we're condemned no matter what we do... However you look at it, we're lost. (CRI patient)

Let's get to the nitty gritty of the problem. I'd venture to say that 80% of those affected are poor, and because of our poverty we have high mortality- because we have to work. For example, with a pension of \$50/month, 1 person eating 2 meals a day can eat for 2 weeks- but what about our wife and kids? We have to work to support our families. And the first thing the doctor tells us is not to be out in the sun. What are we to do? That is the reason why we have a high mortality rate. But it would be worse if we just crossed our arms and did nothing for 2 weeks a month.

To add to this difficult situation, workers have already made regular payments to INSS for all the years they have worked.

I think all the money that our husbands paid while working at the mill is being kept by the mill (or by social security). They say I can't have any of it until I'm 60- but I don't know if I will live that long. (CRI widows)

A step in a positive direction, though, is the current opportunity that INSS now offers to review pension status again after a 3-year period. In the past, INSS would only make a final determination and not offer an opportunity for a second hearing. INSS also provides eyeglasses to CRI patients at a lower cost.

CRI patients and widows often slighted the Ingenio for depriving them of benefits they felt they deserved.

We worked, we left our youth there, we gave them our best years. They only give the basket (of food) to those who retired because of age.

With insufficient or no pensions, lack of available work, and inability to work in the hot sun, CRI patients remain in an irresolvable dilemma.

Our salary is not enough- and if we work, we die sooner. (CRI patient)

Similarly, widows of CRI patients are left in a very tenuous position with the survival of their families.

Living requires working and we have no work (CRI widows)

When I became a widow I was a little younger and I looked for work at the hospital or the Ingenio and they couldn't help me. And of course, we know now that if you're over 60, no one gives you work. Here in Nicaragua, we are automatically eliminated. And even for the younger ones, there is no work. There are no jobs. (CRI widows)

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Lack of access to adequate financial resources remains a key life-threatening challenge for CRI patients and their families.

4.4 Medical facilities



Centro de Salud, Chichigalpa



CRI Clinic in the Centro de Salud

The Centro de Salud is the MINSA-run public health clinic in Chichigalpa. Although functional, it is a basic environment with barely enough space to provide its full complement of primary health care services. Attached to the Centro de Salud is the small CRI Clinic. It consists of a very modest waiting room with two adjoining small exam/counseling rooms where 2 physicians see 40-50 patients for 1.5 hours during 5 mornings a week. It was built by INSS just to take care of CRI patients, almost all of whom are ex-sugar cane workers and currently the numbers of patients are 1500.

ISA states that it provides some of the CRI clinic's equipment including a computer and air conditioning for the clinic and lab, among other donated items. The Ingenio indicates that it pays about \$200 a month to the center to cover basic supplies like paper goods and prescription pads. Aside from the lack of medicines, reagents and ultrasound essential for CRI management as mentioned above, the clinic also lacks critical equipment like an EKG machine. In addition, for the whole Centro de Salud, it is currently not possible to maintain an updated database because there is not enough computer capacity.

Although many components of the Centro de Salud are in substantial need of repair, the clinic lacks a budget for either maintenance or remodeling. For example, one of the bathrooms is not working, and there is also a problem with the air-conditioning in the lab.

CRI patients complain that the waiting room lacks chairs, is very hot, and is not comfortable. They are especially critical of the lack of an entirely independent CRI clinic. The CRI clinic shares a pharmacy, laboratory, supply room and scales with the general clinic. CRI patients state that they prefer not to have to wait in the crowded general clinic along with children and pregnant women before appointments or when they wait to receive medications or basic monitoring such as weighing. Despite complaints about medication shortages and facility problems, many CRI patients were grateful to have a clean, centrally located health facility where they could go for their illness.

As an extension of the Centro de Salud, there are 10 peripheral health posts scattered strategically around Chichigalpa. These remote posts are staffed by volunteer "brigadistas," community health workers who provide basic health information and initial basic health screening (vital signs, *e.g.*). Nevertheless, ex-workers with CRI are of the opinion that these peripheral posts are not able to manage their illness.

4.5 Medical attention

Adequate medical attention by competent and caring health care providers forms a cornerstone of good care for any illness. Toward this end, the Centro de Salud has a designated CRI Clinic staffed by two doctors, a nephrologist and an internal medicine physician. Together, they provide ongoing clinical care to a group of about 1500 CRI patients in Chichigalpa. Patients with a creatinine level under 3 are seen every 2 months, and every month if their creatinine level is greater than 3. This equates to a very demanding daily load of 40-50 patients between 2 physicians who see patients for 1.5 hours 5 mornings a week; appointment time is thus limited to less than about 5 minutes of physician contact on average.

CRI patients are not seen at the ISA Hospital, where only current workers receive medical care. Though when elevated creatinine levels are discovered, ISA Hospital physicians write a referral note to the Centro de Salud for the worker.

There are no nutritionists or social workers staffed at the Centro de Salud to provide dietary and counseling services important for CRI patients. Patients must travel to Hospital España in Chinandega to receive these supplemental services, but rarely do so because of travel expenses and time involved.

Despite the valuable resource that Centro de Salud provides for CRI, some CRI patients expressed their dissatisfaction with their care. Concerns that CRI progresses despite medication contribute to CRI patients having an underlying sense of mistrust of physicians that treat them. Accordingly, some CRI patients expressed **dissatisfaction with the way in which their physicians treated them**. This view is also shared by most of the widows of CRI patients.

So what I want to say, then, is you know when a medication is working. I talk with the doctor and say that I'm taking the med for high blood pressure but I'm worse. But they are not interested- they fill your meds and tell you to just come back.

The perception of mistreatment sometimes seems to stem from CRI patients' experience of being told there was no adequate treatment for their condition.

My problem is that they never were able to control my high blood pressure, I think because they never gave me the best or adequate medication.

The doctor is always giving me the same thing. I think that this is of concern. I don't see any result. I just don't think she's interested in each of us. That's what I think.

Some focus group participants also shared the notion that they receive better care from private physicians than Centro de Salud doctors.

At the public clinic they tell me to take 3 pills (Allopurinol) a day. But the private Cuban doctor tells me to only take 1 pill because it affects your sight. Already I'm having trouble with my vision. (CRI patient)

Many CRI patients consistently feel that their doctors don't spend sufficient time with them.

We like the doctors, but they have to see so many patients- they don't have the time. (CRI patient)

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

One doctor arrives about 10:30am and people are all waiting for him. He's the last to get there and the first to leave. And when he arrives, he's super quick with everyone. It seems like he's not concerned with your disease or what your problems are. He's there to just pick up his pay check. (CRI patient)

Given that there are only two part-time physicians providing care for 1500 CRI patients in Chichigalpa at the Centro de Salud working 5 days a week, this commentary is understandable. In case of an acute problem, CRI patients are not able to be seen without a previous appointment. A calculation of physician hours and patient load indicates that CRI physicians have only about 5 minutes or so per patient.

Infrequent appointments were another common theme shared by most focus group members. This long gap most likely reflects the lack of capacity of the Centro de Salud to handle this sizeable patient load with only 2 part-time physicians.

Other patient complaints about care centered on the fact that problems other than CRI are not addressed in the health center.

We are not prescribed other medications for all the other complaints we have- pain in hip, shoulder, decreased eyesight. (CRI patient)

All they give is allopurinol and the pill for high blood pressure. (CRI patient)

Some CRI patients said that they liked the care they received from their CRI doctors at the Centro de Salud, and did not blame them for the situation regarding medication and reagent shortages.

We IRC patients get good care from Dr. Reyes and Dr. Rugama. It's not their fault that we don't have medications.

Lastly, several CRI patients had an unanticipated observation regarding their care at the Centro de Salud.

After the World Bank visit, the clinic has improved.

The distrust of many focus group participants extended beyond the treatment they receive at the clinic to the health and social security systems at large.

At the public clinic, I had a creatinine of 1.8. At the private doctor, I had 2.1. It's as if the INSS is paying the clinic for coming up with a good result. (CRI patient)

And just imagine my surprise. My last creatinine test was 1.5. But since there are no reagents, I had to go to the private doctor- he told me 2.3. You can see what the difference is. The social security is doing these tricks so it seems that you're doing fine. (CRI patient)

A treating physician explained another difficulty with differences the change in creatinine levels between clinic visits or labs:

Sometimes patients become really angry at us because we recheck their creatinine and it goes down, and they still want a certificate that they are sick so they can receive their pensions. It's a terrible problem because they are so poor. (Health official)

Several voices spoke to their perception of the unfairness of the social security system.

My father-in-law died 3 weeks ago... If you paid (social security) for 26 of the last 52 weeks, then INSS is supposed to pay a pension. He worked 15 years, and just because he worked only 25 instead of 26 consecutive weeks, he didn't receive any pension.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Even though the Centro de Salud is supposed to provide 24-hour care, several focus group participants complained of **difficulties that they experienced after hours**.

The first cause of death in Chichigalpa is CRI. And during the night the doctors are sleeping and the pharmacies are closed. (CRI patient)

Access is an essential component of a patient's ability to receive medical care. Transfer of Centro de Salud CRI patients can only be within the Department of Chinandega to Hospital España; they do not know how to access Hospital Escuela Danilo Rosales Arguello in León. Each focus group mentioned the **lack of affordable ambulance transport to the Hospital España**. Contrary to social security laws that assure free hospital transport for very ill CRI patients, some payment seems to always be required for this essential emergency service.

And if I arrive at the clinic and I'm dying, they say "reach into your pocket and pull out 100 cordobas for a ride to the hospital." (CRI patient)

Sometimes there's an ambulance, but there's no gas. You have to give them money to pay for gas. (CRI patient)

Local health officials believe that the economic problem is not so much the transportation issue, but the family having to pay for 3 meals a day for 7-8 days of hospitalization of their head of household in Chinandega.

Many patients therefore select to remain at home and leave it up to God. (Health official)

Many of the issues surrounding gaps in medical attention reflect **challenges of the public health system at the national level** (MINSa). Several health officials explained that on occasion, qualifications and professional experience play a secondary role to political decisions. Besides, in general terms, they should be able to improve the technical capacity of those officials to allow more adequate planning.

Another commonly acknowledged system challenge expressed by key informants is the lack of motivation of physicians employed by MINSa. Because of very low salaries, many have to look for alternative sources of income, which can prevail over needed medical attention for CRI patients. This issue is not at all unique to Nicaragua, but represents an international problem in many developing nations.

4.6 CRI Information for Patients and the Community



Sign in CRI Clinic, Centro de Salud
(Personal hygiene practices for CRI)

Adequate management of CRI also requires knowledge of the course of the disease, potential complications, and treatments available (including medications and their side effects, and preventive methods).

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Basic information about CRI must be accessible to patients and their families. Armed with information about their illness, CRI patients will be better able to improve their attitudes toward medications, physicians, and treatment approaches, and increase the level of medication compliance and knowledge of preventive practices such as proper diet.

Both CRI patients and widows alike expressed a great interest to learn more about the disease of CRI, including how to best treat it, what medication side effects are, and how the disease advances.

I'd like to know what are the symptoms of the disease. What's said is that when you're in the last stages of the diseases, you loose your appetite, you start vomiting, get high fever, and when you get the hiccups, you know you're ready to die. (CRI patient)

I think we're almost dead because we lack understanding about our illness and medications (CRI patient)

You know..., it's like the doctor saying take 1 allopurinol- it's good for your uric acid- but she doesn't tell you about the side effects – how it will affect you. Sure it will help one thing, but our health worsens because of the side effects of the medicines. We don't have any type of information about side effects. (CRI patient)

As mentioned in the above section on medication problems, lack of knowledge about CRI among patients and families clearly contributes to their sense of powerlessness, mistrust, and fear about the natural progression of the disease.

Currently, the CRI Clinic at the Centro de Salud lacks a dietician, who most often provides necessary nutritional counseling and ongoing support to CRI patients and their families. There are also no social workers at the public health clinic. The dental team at the Centro de Salud is currently responsible for general health promotion and prevention. Hospital España, though, has a mobile team that provides care to some CRI patients and includes a nutritionist, psychologist and social workers.

I think the patients who are already in the program are OK. They know their disease and about the meds they need to take as well as the measures necessary to slow down the progression of CRI. We have the social workers and the psychologists talking to them all the time, so I think we have improved their information and knowledge of the disease quite a bit. (Health official)

To help slow the rising tide of the current CRI epidemic in Nicaragua, it is also essential to increase the knowledge about CRI and CRI preventive practices for the Community. It would be convenient that a committee at a departmental level would function to coordinate with the National Commission on Public Health (la Comisión Nacional de Salud Publica), and that involved governmental organizations at a departmental level, as well as private sector institutions, church, academic, and community service organizations. There is a great opportunity to build on this existing coordination, and there is willingness from the sugar mills to participate and support the work of the committee.

We are beginning to address what to do for preventive measures. It's not only prevention for those without CRI, but for how to stabilize CRI for those who have it. This includes encouraging the avoidance of alcohol, excessive heat exposure and smoking, for example. (Health official)

Pursuit of a formal national public health campaign on CRI will be a component of the set of protocols awaiting official endorsement by MINSa.

4.7 Access to recommended CRI diet (Seguridad alimentaria)



Sign outside CRI Clinic,
Centro de Salud, Chichigalpa

A specialized diet is one of the primary foundations in maintaining health and slowing the progression of CRI. Although most all CRI patients are aware of their recommended diet, lack of access to adequate financial resources to buy food remains a key life-threatening challenge for CRI patients.

Beyond limiting their ability to pay for essential renal medications and testing, **CRI patients are unable to afford the fresh vegetables, fruits and fish prescribed as part of their specialized diet.**

Mostly, they recommend eating vegetables. But we're poor- how can we afford to buy vegetables. (CRI patient)

... the \$20 I have to pay for a private doctor means 20 days of food for my family. (CRI patient)

Furthermore, CRI patients and their families face the threat of starvation on an ongoing basis. This is a commonly shared experience.

And of course I have a bad diet because I can't afford to buy good and enough food. I send my children to school hungry, and I'm ashamed of it. I'll do anything I can if I could work, but I just can't find work. (CRI patient)

I think the truth is that people are dying from hunger, from not eating all the foods that are recommended by the doctors to avoid. (CRI patient)

I had no other choice but to beg for money to help my husband. (CRI widow)

And it shames me to admit that I didn't have anything to feed my children. The children don't understand and they ask why. (CRI widow)

Like many Nicaraguans, CRI patients and their families also lack the practice of including fresh vegetables and fruits in their diet.

4.8 Psychological needs of CRI patients and their families



CRI widow, Chichigalpa

“The situation is difficult with a patient with this type of disease. How they cry for help and there’s nothing we can do! They don’t sleep at night, and of course, then we don’t sleep either. If they suffer, we suffer. Those are the experiences we had to live through.”

(CRI widow)

One of the most pervasive and perhaps most damaging issues facing CRI patients and their families is the serious psychological effects that accompany living with a chronic disease.

You have to psychologically overcome this when you know you have a fatal disease that affects you. I tell myself “don’t think about this!” I use to be like that. I would pee in a Coke bottle and check it. Psychologically, you start worrying. (CRI patient)

It’s a sad day for us to discuss what we’ve lost. (CRI widow)

It’s suffering to have such a sick husband. They don’t want to die. They kept saying, give me something for the pain. I wish we had like a magic pill to give them. We suffered a lot with them. (CRI widow)

In the midst of this dire need for emotional support, no psychological services of any kind have been available to CRI patients or their families.

God is the only one who gives us help. No one else can help us. (CRI widow)

Children are especially affected by having to witness the slow, painful death of a parent.

With parents dealing with CRI, the children feel abandoned. (CRI widow)

And yet still able to look at the positive side of their sad lives, the widows of deceased CRI patients expressed a bittersweet resolve about having learned to become stronger people through their traumatic experience.

We had to find inner strength for ourselves as well as our husbands. (widows)

CRI widows also shared a common view that “CRI brought families together because we shared suffering.”

They’re friends, they bring you bread and sugar when you don’t have any, and some came with money to help bury my husband. (CRI widow)

Psychological and social services are sorely needed to address the high level of mental stress resulting from living with a terminal illness, which will also improve physical health and ability to live with CRI for both CRI patients and their families.

4.9 Stage 4-5 treatment: Access to ESRD (end-stage renal disease) treatment



Peritoneal dialysis patient,
Hospital España, Chinandega

Most all CRI patients will advance to end-stage renal disease (ESRD) in time. Treatments including peritoneal dialysis, hemodialysis and renal transplantation are essential for ESRD patients to survive- and they are extremely costly. At present, access to such treatment options for end-stage renal disease is extremely limited and essentially non-existent for the vast majority of CRI patients in Nicaragua.

Need and capacity issues

The extent of need of CRI patients for dialysis is vast. In the Dept. of Chinandega alone, over 3,000 CRI patients have been identified that require ongoing treatment and monitoring. Although an estimated 3-5% now needs dialysis, the majority of these patients will continue to develop end-stage renal disease requiring dialysis or transplant for survival. No dialysis services presently exist in Chichigalpa, and ESRD patients must be referred to Hospital España in Chinandega. There are currently 20 patients on chronic ambulatory peritoneal dialysis (CAPD) in Hospital España, and 80 who are waiting to start in the dialysis program. In Chichigalpa, there are another 81 patients also awaiting the opportunity to start dialysis. UNAN estimates that the actual present need for dialysis in Chichigalpa is closer to 200.

We have serious lack of capacity to provide service to all who need it. (Health official)

Peritoneal Dialysis

In the Dept. of Chinandega, peritoneal dialysis (PD) is currently being offered at Hospital España, but it is essentially not a viable program at present for several reasons. Although there are sufficient staff with the technical capacity to insert PD catheters and oversee PD patients, the very high expense (about \$3-4,000/month/patient) and uncertain availability of essential supplies are primary limiting factors. At this time, the 20 patients on PD at Hospital España face an uncertain fate, as no supplies are available to them after the end of this March.

Another major obstacle to the widespread implementation of PD for CRI patients is the requirement for homes to be hygienic. Some CRI patients knew some of the criteria required for home peritoneal dialysis.

When you do PD, you need a clean home- not a dirt floor with all those bacteria. You can't have a dirty home with that thing sticking out of you. And that's just to survive a few more years. (CRI patient)

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

PD patients also require access to a high protein diet, which is too expensive for most CRI patients to afford. PD patients require a certain educational level and training as well to be able to properly and safely perform PD in their homes. As a result of these criteria, poor patients living in rural areas are not especially suited as candidates for PD.

Deep fears by CRI patients about peritoneal dialysis also represent a significant obstacle, and were expressed by many focus group participants and echoed by treating physicians.

Dialysis kills us. Everyone who has had it dies. (CRI widow)

Here we have offered them HD (hemodialysis), PD, and even transplant- but all refused. Patient and families alike are resistant. (Health official)

Nevertheless, some CRI patients said that they would be immediately willing to undergo dialysis if it became available to them. It will clearly take a concerted effort to overcome local fears and misconceptions around PD.

Hemodialysis

Hemodialysis (HD) is a highly technical method for removing waste products such as potassium and urea, as well as free water from the blood for end stage (Stage 5) renal disease (ESRD). Hemodialysis utilizes sophisticated medical equipment and expensive reagents and is conducted in a dialysis outpatient facility, either a purpose built room in a hospital or a dedicated, stand alone clinic. A specialized staff made up of nurses and technicians are necessary to initiate and manage hemodialysis treatments. Typically, 3-4 hour treatments are required 3 times a week for patients with ESRD.

In Nicaragua, HD costs about \$9,000 per patient per year. In a country where the national annual per capita health expenditure is \$251,¹² this expense is a far reach from the current budget of the social security program (INSS). Even if INSS could somehow pay, the INSS system would still exclude all the sick patients without pensions or social security benefits. And it is unlikely that MINSAs would be able to cover the exorbitant ongoing costs of HD supplies.

In Managua, there are 10 new hemodialysis machines for 40 patients, but they lack sufficient chemicals to begin and maintain treatment. Hospital España received a donation of 8 new HD machines from Baxter International last year, but they currently lack a cold storage room for supplies so they cannot provide any treatment. Ingenio Monte Rosa originally offered to cover the cost of the room, but they reneged when they found out it would cost \$80,000.

National financing of expensive CRI treatments may be more an issue of prioritization. With national and global health priorities focusing on the considerably higher cost/benefit ratio of investing in mitigation of preventable diseases (vaccine preventable illnesses, diarrheal and respiratory disease in infants and children, e.g.), CRI, a chronic, fatal disease, is often relegated to taking the back seat.

Renal Transplantation

Renal transplantation demands a highly skilled team, is a very expensive procedure, and requires a lifetime of relatively expensive anti-rejection medications post-transplant. The cost to private patients is about \$52,000 in Nicaragua. Because of an agreement between private hospitals and INSS, the cost to CRI patients is about half (\$26,000) of this amount.

¹² 2007/2008 Human Development Report, UNDP.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Two Managua Hospitals have the capacity to perform renal transplant surgery- Mascota and Hospital Militar. Adult and pediatric renal transplant teams have been trained in Italy. Mascota is a public hospital that only does pediatric transplants. In total, Mascota has done 17 transplants, and we understand that 2 have failed. Hospital Militar is a private facility performing only adult renal transplantation. In the past 2 years, they have done a total of 14 transplants with 1 rejection. A different Italian NGO has offered to train another transplant team under the condition that MINSa provide the operating and recovery rooms. As yet, MINSa has not accepted their offer.

Another obstacle facing the option of renal transplant is the lack of a law that permits the use of cadaver kidneys for donors. Although living donor kidney transplants are more often successful, cadaver kidneys provide a much larger pool of potential organs available for transplant.

CRI patients were quite familiar with the high costs associated with treatments such as dialysis and renal transplant.

At Hospital España they said a transfusion and kidney transplant was necessary in order to live. Where can we find \$70,000 (dollars)!?...and a donor as well? (CRI patient)

They also express an interest in earlier intervention to maintain their quality of life.

It would be good if the health center could send you for dialysis if you were only half sick. Why wait until we are almost dead? By the time they do give you the treatment, it's not going to extend my life. I wish they would place more importance and have more will to help us when we need it, when we can still put up with the treatment. We have orphans- we leave them without their father and there is no need for this. (CRI patient)

In the context of the limited annual per capita health budget in Nicaragua, and established national and global priorities for public health issues, maternal and child health has been prioritized. With this priority, the possibility of access to costly ESRD seems remote indeed for the vast majority of CRI patients.

It is very difficult to budget our limited financial resources for a chronic treatment with no cure or end-point in sight except for death. (Health official)

A renal transplant center is not feasible at this time. And now with the economic crisis, they're even cutting our current budget for health expenditures. I don't know what's going to happen. (Health official)

In order to begin to address this unfortunate situation, it will be necessary to know the comparative costs and capacity requirements of each treatment. In the meantime, it remains essential that all CRI patients have access to their maintenance medications to better control disease progression and hopefully slow down the potential avalanche of CRI patients who will eventually need dialysis or renal transplant.

This reflects a systemic problem. I think it's going to become big political issue very soon. (Health official)

4.10 End of life Care for CRI patients and psychological support for their families



End of life care is an essential component in the continuum of care for patients with CRI. Palliative care assistance provides both physical and emotional comfort through the dying process for patients and their families.

In developed nations, palliative care is typically offered in both the home as well as a palliative care center setting.

There are currently no psychologists or social workers based at the Centro de Salud. In addition to no access to treatment of their end-stage disease, CRI patients and their families also lack access to any palliative care.

...They (Centro de Salud) order us to go to Hospital España- there they only put in needles and patients leave in a box. (CRI widows)

He would call me to his bed and tell me "I'm afraid, I'm going to die." I would tell him "no," but he would say, "Yes, I'm going to die. The doctor told me." He would have headaches, and didn't have the strength to stand up. He was like a child because he was so disabled. He would tell me, "I'm going to die, and I feel really bad about our children, because they are all so small." I would tell him, "No, you're not going to die; we'll take you to the hospital." He said "But they'll just take me to the hospital and do dialysis." He wouldn't sleep at night. He would call me and tell me "I don't want you to leave me, because I'm going to die." The doctor told us that dialysis wouldn't even help. He said, "Just go home and let him die. You will only have him another 8 days." I paid that doctor, Fidel, he told me to take him home and let him die in peace. Imagine, he was a big man, and from the road to our house is a long way, and I took him slowly to return to the house. (CRI widow)

At present, CRI patients and their families are seriously preoccupied with their ever-approaching death. To make matters worse, their fears are intensified by having witnessed the extremely painful and dramatic death of their friends and co-workers. Currently, they see their only option for terminal support from Hospital España. As such, they focus on the need to have improved access available through free ambulance transport from their homes to the hospital. Even still, they realize that their hospitalization is likely to be the way they spend their last days. And the cost of food for the rest of the family staying at the patient's bedside in Chinandega is unaffordable.

Increasing the understanding of the course and treatment for CRI is an immediate necessity in helping CRI patients and their families make better plans and choices around how to handle the illness, especially in its terminal phase. But what is also lacking is a hospice program that can provide both relief of suffering from physical symptoms as well as offer emotional support to both CRI patients and their families. A hospice program could also address the gap in preparing families to live without their head of household and to help them investigate other potential sources of economic support.

4.11 Improving early diagnosis of CRI



Former sugarcane worker,
Chichigalpa

The need for the prevention of additional CRI cases is an essential component necessary to help slow the rising tide of the CRI epidemic as swiftly as possible. Part of an effective prevention strategy includes methods to diagnose CRI at the earliest stage possible of the disease.

To best achieve an early diagnosis of CRI, it will be necessary to more accurately determine the underlying cause or causes of this disease. A pending epidemiological study will be evaluating the possible causes of CRI. Although the focus of this current medical assessment is not to address causality issues, the matter of improving early diagnosis of CRI is nevertheless an important current consideration of this assessment.

Previous sections of this report discussed components of a health system that would more adequately address CRI, including accurate laboratory equipment and a ready supply of reagents. These components are also essential for a health center or hospital to conduct early laboratory screening for CRI. Other useful diagnostic measures like urine dipsticks that are not being utilized regularly will require standardized guidelines to promote their use.

There is another issue facing the sugar mills that puts some cane workers at higher risk. Workers identified with elevated creatinine levels are not hired by most sugar mills. Some of these workers will go to the city registry and reapply for a new ID. They then reapply at the same or another sugar mill under a new ID. Apparently, corruption issues within the national registry allow this to transpire.

Several participants in each focus group, especially the CRI widows, expressed a deep concern for doing everything possible to prevent additional family and community members from developing CRI.

At least, I feel that we have to be more careful now with our children, our grandchildren who are working cutting can, that they have the right foods, medicines to be preventive. (CRI widows)

ISA doctors explain that workers now receive encouragement to drink ample amounts of a chilled electrolyte drink provided to them throughout the day in the fields, along with nutritional cookies. Although initially screened for creatinine at the beginning and middle of the *zafra*, workers are refusing to obtain a creatinine recheck after the end of the harvest. The workers just leave after their contract, and are not checked again until the beginning of the next harvest year. This represents a lost opportunity for early detection of CRI in sugar cane cutters.

The critical element in mounting a national public health CRI prevention campaign, though, is awareness of the principle underlying causes of the disease. A large-scale, in depth study is indispensable, but sadly, in actuality necessary financial resources are not available.

5. Summary of options from focus groups and key informants

Participants in all three focus groups proposed a strong set of recommendations that closely reflected their expressed concerns about their health care situation, including the broader context of their dire living conditions. Their recommendations are listed in order of priority determined by the number of votes given to each issue. Informal recommendations of key informant health officials are also woven into each corresponding theme.

All the people sick with CRI, especially those who are too poor to pay for treatment, should receive assistance

This recommendation addressing their desperate need for resources was the most strongly and consistently voiced issue throughout all focus group participants. Assistance was seen most often in the form of receiving their deserved pensions from INSS.

...then there are others who have no access to social security payments that should receive them. I think that INSS should give a pension to everyone who paid or even those who didn't pay- and if not, give us back the money that we paid in. (CRI patient)

We need them to give us our pension. (CRI widows)

Several older CRI widows bemoaned the added vulnerability of old age.

We need financial aid for all the senior citizens because now we are not able to walk, so we are not able to sell in the street. (CRI widows)

A widely agreed-upon recommendation in this category was that the Ingenio provide ex-workers and CRI widows with the same food subsistence benefit given to retired workers.

Every retiree is given the value of a small food basket every 15 days. In our case, as ex-employees, we should also receive that benefit, because we all worked at the same place. (CRI patient)

Multiple participants suggested the idea of assistance in the form of more financial resources made available to them. The idea of having a microcredit loan, for example, was mentioned by both CRI patients and CRI widows alike as a specific way of addressing this need.

We need an organization to come and help us, not just to give, but to help us with a low-interest loan. (CRI patient)

If they give me a loan to help me start a business or plant a plot of land, we could live longer. (CRI patient)

Another form of assistance identified by each focus group was in the form of land made available to them along with some technical aid.

We don't really need a lot of land- just a plot. We also need technical support to learn a vocation and help with how to best plant our plots.

Some mentioned that even though some CRI patients might have a plot of land, they lacked decent, affordable housing.

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Lastly, under this recommendation heading, other CRI patients and widows requested help to find a source of work for themselves, or in the case of some elderly widows, for their children.

Public health officials recommended broadening the potential scope of support for CRI affected workers by involving other sugar mills and getting in touch with ATC (Asociación de Trabajadores de Campo).

We need better treatments and better medications for CRI

Another broadly expressed recommendation throughout all focus groups addressed the concern for the lack of adequate treatment for CRI.

Improve the treatment for CRI because now it doesn't help us.

We need the help of MINSA, INSS and the Empresa (Ingenio) to find solutions to the illness of CRI. (CRI patient)

One way in which CRI treatment inadequacy was very often seen was in the demand for different and higher quality medications for CRI.

Better medications will improve the medical care of those with CRI. (CRI patient)

That the expensive medications and good vitamins are provided for us at the health center

Taken together, these recommendations from all CRI focus groups seem to reflect a lack of understanding of the natural course of CRI, the limited efficacy of any medications to significantly alter the inevitable downward spiral of the disease, and the belief that some medications (“*the expensive ones that you have to buy from the private doctors*”) are more effective than the cheaper generic ones given out by the Centro de Salud.

Provide a regular supply of medications at the Centro de Salud for CRI patients

Another widely proposed recommendation was in response to the inadequate supply of CRI medications at the health center.

That there are medications available (in the Centro de Salud) because there is no money to buy them outside (CRI patient)

As discussed in the central themes section, most of all participants strongly voiced the urgent need to have their medications essential to managing CRI available in an uninterrupted supply. Dependable medication provision would help alleviate the untenable choice they have constantly faced between their health and ample food for their families. CRI patients and health officials shared the recommendation that ISA should provide these needed medications.

CRI patients need their own exclusive clinic in the Centro de Salud

A frequent and widely accepted recommendation among CRI patients was to have a medical clinic exclusively for CRI patients, including a separate pharmacy and laboratory.

The problem is that when we're there, there are pregnant women, children- you can't even get through. So we need a separate clinic- they make you sick, all those sick kids. If there's a pregnant woman there to be weighed, I'll have to wait to get weighed. (CRI patient)

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

The health center should have similar conditions as Hospital España or the Hospital in León, because Chichigalpa is big enough. (CRI patient)

And the women say all these old guys are going to die any way, so why are you spending so much time with them? (CRI patient)

CRI patients clearly feel that even the present separated CRI waiting and exam rooms are not meeting their needs for adequate space, privacy or special attention. Additionally, several key informants felt strongly that establishing a CRI clinic independent of the Centro de Salud is the only feasible way of assuring that equipment, medications and supplies targeted for CRI patients could be secured for their use.

Availability of free hospital transport for critically ill CRI patients

All focus groups responded that an ambulance should be available for free transport of very ill CRI patients, including no additional charge for fuel. This recommendation would help resolve the economic barrier limiting access to hospital care in Chinandega (Hospital España) for CRI patients in Chichigalpa.

We need to learn more about CRI, the medications prescribed, and how to prevent this disease

Another consistent recommendation expressed in all groups was the desire to learn more about CRI treatment and preventive measures.

We need to learn how to protect our children and grandchildren (all in strong agreement). (CRI widows)

I think we're almost dead because we lack understanding about our illness and medications.

We need a professional to help guide us. Then at least we'll be able to know if the medication is the right one for our disease. We've already had experiences that we've mentioned about pills that make us feel worse. I would like to know that if I'm given acetaminophen for fever that it will work. And at least then, if they don't have it at the health center, if I have a little bit of money, I would try to buy it.

Gaining greater understanding about CRI treatment and prevention was seen not only as a measure toward staying healthier, but also as a means of building the capacity to better prevent the illness from occurring.

The recommendation of closer monitoring of current sugar cane workers to prevent CRI came solely from CRI widows, and reflected a fairly widespread concern for the health and well being of their children.

We have sons who now work at the Ingenio, and want them monitored closely so that they don't develop CRI (CRI widows)

Beyond closer monitoring, a more radical recommendation was proposed by some CRI patients.

CRI has no cure and they need to declare it an epidemic because the water we drank while working at the Ingenio was contaminated and the chemicals and acids that they made us breathe. (CRI patient)

A study or report will help give us more solid information about causality and how to prevent CRI. (Health official)

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

There is an opportunity to build on the public health committee that already exists to develop a prevention campaign program. Additional efforts can be coordinated through the MOE to educate students more about CRI prevention. (Health official)

Both public and private sectors should become more involved with prevention. The Ingenios should especially take a leading financial role in prevention.
(Health official)

You have to take into consideration that when people start working at the Ingenio, they are not sick. When they leave, they have CRI. Other people are working hard- teachers, road maintenance, and other laborers- but only sugar cane and banana plantation workers are contracting CRI.

Doctors need to have more patience with the sick

Another widespread recommendation among the CRI widows group regarded the request that doctors treat CRI patients more compassionately.

That the doctors have more patience with their sick patients (CRI widows)

It is likely that this recommendation also reflects several other patient care issues previously raised, such as the lack of sufficient time to examine patients, the lack of sufficient treatments for CRI, and the inherent divisiveness of working in both public and private sectors.

The Director of the Centro de Salud believes that the clinic should also have beds in order to provide some level of inpatient treatment.

Improvements for Centro de Salud

A common theme expressed primarily among CRI patients is to improve conditions in the Centro de Salud. This list included improving the level of cleanliness, having functioning toilets and a cold water dispenser, and air-conditioning.

I mean the clinic itself is too small. It needs to be bigger with better conditions.
(CRI patient)

Provide ultrasound exams for CRI patients in the Centro de Salud

CRI patients shared that when the CRI Clinic opened in the Centro de Salud, a radiologist was contracted who provided on-site ultrasound exams for CRI patients. A sign on the CRI Clinic wall states that INSS provides free ultrasound exams, but since they are not currently provided, CRI patients recommend having ultrasound available to them locally in Chichigalpa. This would save considerable time and expense both of travel and of having to pay a private physician for an ultrasound exam. An EKG machine is also necessary at the clinic.

24-hour medical attention at the Centro de Salud

Although the Centro de Salud apparently offers 24-hour medical attention, several recommendations addressed the need for 24-hour availability of doctors.

That a doctor is available through the night to help with emergencies

Further investigation is necessary to tease out what specific gap needs to be addressed regarding this issue.

Desire for treatment options for end-stage CRI

While a substantial number of CRI patients expressed a desire for “a blood-cleaning machine,” many did not seem to realize that this was the same as hemodialysis.

Widespread fears exist about peritoneal dialysis, given the high amount of fatal complications of peritonitis that have occurred. As a result, there were no recommendations from CRI patients proposed for peritoneal dialysis. Nevertheless, a number of CRI patients indicated interest in having a renal transplant center in Chichigalpa.

Some local health officials believe that the Chichigalpa Centro de Salud should develop a dialysis center to accommodate the increasing numbers of CRI patients.

I would say with an internist and nephrologist working 4 days a week- and the rest of us doctors receiving training- we have the capacity for a renal dialysis unit. (Health official)

While some patients have an adverse reaction about undergoing dialysis, most would accept dialysis, although the acceptance rate has not been studied as yet.

Although most public health officials are skeptical about the feasibility of providing treatment for end-stage renal disease, they still recommend the need to study the feasibility of a transplant center.

Frequent periodic general examinations

A few participants made the recommendation for the Centro de Salud to provide a general check-up every 6 months. Currently, CRI patients receive a short visit limited to monitoring their CRI about every 2 months. This recommendation reflects the lack of sufficient physician coverage for the load of 1500 CRI patients attending the Centro de Salud in Chichigalpa.

We need a steady supply of reagents

There was considerably less emphasis on recommending a regular supply of laboratory reagents than was initially voiced during the discussions of health care weaknesses. It remains uncertain why this particular need was not more proportionally addressed. Nevertheless, on the basis of the extensive discussion and grievances about lack of reagents, it is a safe assumption that this issue would be considered more of a priority if reviewed with the groups.

We want to be checked as well for CRI

A commonly accepted recommendation that arose from the CRI widows group was that they all be examined for CRI at no cost. Comments seemed to indicate a lack of understanding about the nature of CRI.

For example, I'd like for all of us, all the widows, to be checked for CRI... I think it would be good because I feel that that disease can be passed from one person to another. (CRI widows)

It is not unusual for someone who has cared for a dying loved one to be concerned about having contracted even a non-contagious disease like renal failure or cancer. This

expressed desire to be checked may well reflect the level of unaddressed and buried fear and anxiety prevalent in CRI widows and patients alike.

Psychological support for stress from living with CRI (for patients and spouses)

Although this issue received a great deal of interest and emotional engagement among the CRI widows group, no specific recommendations were written. It was clear from all of the widows participating that they each had experienced a great deal of psychological stress from the process of caring for their slowly dying husbands. Furthermore, they had received no formal psychological help whatsoever to help them deal with their extensive emotional trauma. Thus, the option of addressing this critical unmet need should be included in considering the realm of possible recommendations to assist not only this particular group, but current CRI patients and their families as well.

Public health officials and medical doctors treating CRI patients recognized this important gap in provision of psychological support.

We don't have a social worker in the Centro de Salud. Of course, having a social worker would be very useful, especially for CRI patients. We also don't have a psychologist at the Centro, but that should also be considered for the new (proposed) hospital as well. (Health official)

Diabetic support groups exist. It's a process of empowerment of groups of people to inform them about diet and practices. Perhaps similar empowerment groups can be developed for CRI patients. (Health official)

6. Summary of Options identified by dialogue table participants to Improve Care

This list of proposed key options is offered as a further condensed and reorganized summary of the above recommendations from ASOCHIVIDA focus groups, health practitioners both from NSEL and the public sector, and health officials. The perspective and approach taken is through a medical and public health lens. Categories have been grouped to facilitate understanding and follow up actions, using objectives and options to enhance the development of a strategic plan as the next step.

1. Improve the diagnosis, monitoring and treatment of CRI

1.1 Improved laboratory capacity to measure renal function and CRI disease process (availability of reagents and accurate equipment)

1.2 Medications: Access to an uninterrupted supply of essential CRI medications

1.3 Professional staff available at the Health Center for CRI patients (Physician, social workers, nutritionist)

1.4 Standardized guidelines for the diagnosis, classification, prevention and ongoing management of CRI

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

When considered as part of an integrated whole, the four components included in this options category will operate together to enhance the capacity of the public health infrastructure to diagnosis, monitor and provide ongoing treatment for CRI patients. Establishing a CRI clinic that could operate more independently of the Centro de Salud general public health clinic could potentially solve a number of the main challenges of assuring better overall care for CRI patients. Several health officials believe that it will be easier to more reliably procure and provide medications, reagents and equipment in the context of a separate CRI clinic.

Existence of standardized guidelines for CRI by themselves does not assure that they will be implemented and utilized fully and properly. Capacity building and ongoing encouragement of doctors treating CRI patients to adopt the guidelines will be necessary to improve and standardize the care of CRI patients.

Objective:

To assure the uninterrupted supply of medications, reagents, equipment and essential services for renal function testing and for clinical management of CRI patients in Chichigalpa

Options:

Short term

⇒Immediate assistance to the MOH (MINSA) and Social Security (INSS) with the continuous provision of medications, reagents, equipment (ultrasound) and essential services for clinical management of CRI patients in Chichigalpa

Intermediate-long term

⇒Assistance to MINSA and INSS for an exclusive CRI clinic in Chichigalpa

2. Access to treatment for end-stage CRI (Stages 4 and 5)

Although very costly, treatments including peritoneal dialysis, hemodialysis and renal transplantation are essential for patients with end-stage CRI to survive. In order to begin to address this ominous situation, it will be necessary to know the comparative costs and capacity requirements of each treatment.

In addition to treatment, end of life care is an essential component in the continuum of care for patients with CRI. Palliative care assistance provides both physical and emotional comfort through the dying process for patients and their families.

2.1 Improved access to treatment for Stages 4 and 5 (dialysis, renal transplant)

Objective:

To provide treatment options for CRI patients with end-stage renal disease

Options:

Short term

⇒A feasibility study of potential treatments for end-stage renal disease to consider peritoneal dialysis, hemodialysis and renal transplant.

Intermediate and long term

⇒Provision of dialysis and renal transplant for CRI patients

2.2 Provide end of life (Palliative) care for IRC patients and assistance for their families

A home-based end of life program in Chichigalpa could offer MINSA the opportunity for a palliative care pilot project for the country. In addition, a palliative care center with a half dozen beds or so could provide a higher level of technical support for patients in their last days of life and offer a dignified death (*una muerte digna*). Aside from the physical structure of a small building, equipment and supplies are basic and relatively inexpensive.

Objective:

To provide assistance and palliative care (physical and emotional for a dignified death) in the home and in a palliative care center for CRI patients in Chichigalpa

To prepare families how to live without their head of household

Options:

Short term

⇒A capacity building pilot project in palliative care for MINSA in Chichigalpa

Intermediate term

⇒A palliative care center for CRI patients in Chichigalpa

3. Provide for complimentary needs of CRI patients

Aside from access to good medical care for their illness, CRI patients require access to adequate nutrition in terms of the quantity and quality of foods necessary for their specialized diet. A specialized diet is one of the primary foundations for maintaining health and slowing the progression of CRI. Although most of all CRI patients are aware of their recommended diet, lack of access to financial resources necessary to secure their specialized diet remains a key life-threatening challenge for CRI patients.

Adequate management of CRI also requires knowledge of the course of their disease, potential complications, treatment (including medications and their side effects, and preventive methods) for CRI patients and their families. Armed with information about their illness, CRI patients will be better able to improve their attitudes toward medications, physicians, and treatment approaches, and increase the level of medication compliance and preventive practices. Furthermore, to help slow the rising tide of the current CRI epidemic in Nicaragua, it is also essential to increase the knowledge about CRI and CRI preventive practices for the Community at large.

3.1 Food security for CRI patients

Securing adequate food for CRI patients and their families on an ongoing basis is a key priority. While NSEL might be able to address this need on a short-intermediate term basis, sustainability remains the major challenge. CRI patients and their families must be given greater opportunities for income generation as well as producing some of their own food. These steps may only be possible by broadening the scope to include other Ingenios and potential target groups.

Objective:

To provide a direct means of getting fresh vegetables, fruits and protein necessary to improve the nutritional status of patients with CRI in a sustainable way.

Options:

Short term

⇒To provide aid in securing food for CRI patients

Intermediate term

⇒To investigate options for income generation (e.g., household garden projects, economic assistance through microcredit) for CRI patients and their families.

3.2 Increase knowledge and capacity about CRI for patients and the Community

An opportunity exists to take advantage of the existing National Public Health Commission (la Comisión Nacional de Salud Pública) to develop a more comprehensive CRI awareness and prevention campaign program.

Objective:

To improve the knowledge of CRI disease development, potential complications, treatment (including medication and side effects, and preventive measures) for patients with CRI and their families

Options:

Short term

⇒Public CRI information forums facilitated by MINSA, INSS, and academic institutions in the Department of Chinandega

Intermediate term

⇒Information campaigns in schools and in the community
⇒Capacity building in CRI knowledge for teachers, civic and religious leaders
⇒Incorporation of mass media to promote CRI awareness

4. Improve measures to better prevent CRI

The need for the prevention of additional CRI cases is an essential component necessary to help slow the rising tide of the CRI epidemic as swiftly as possible. Part of an effective prevention strategy includes improving measures to diagnose CRI at the earliest stage possible of the disease. An opportunity exists to more closely monitor the renal function of the at risk population of cane cutters in Ingenios throughout the Department of Chinandega.

Objective:

To provide additional means of assisting in the identification of CRI in its early stage

Options:

Short term

⇒To monitor creatinine levels of sugarcane cutters in the Department of Chinandega at the end of the harvest

7. Next Steps

Several important considerations for these proposed CRI options to improve care are essential to address at the onset of the strategic planning process. First, priorities will need to be established based on such criteria as relative costs versus potential impacts, feasibility and sustainability, and relative risks and chances for success of each recommendation. Potential opportunities lost and implications of choosing one recommendation over another must also be taken into consideration. Thus, as a first step in this prioritization process, all dialogue participants will need to be sufficiently informed about each recommendation so that they can make the best decisions possible.

Next, in order to promote feasibility, sustainability, and impact, an overall approach must be identified that integrates individual options into a cohesive strategic plan for CRI patients and their families. Finally, mechanisms will need to be put into place in order to monitor agreements and implementation plans both over the short and long term. A means of enforcement will also be necessary to assure compliance.

In developing a strategic plan to improve medical treatment of CRI in the Department of Chinandega, certain challenges for the public health system will specifically need addressing. These include lack of financial resources and budgetary allocation for CRI, insufficient personnel and capacity to provide CRI services, frequent medication and reagent stock-outs, and lack of protocols and information systems. In order to meet these difficult challenges, it will be necessary to build and maintain strong working partnerships with political will and commitment that maintain ongoing institutional coordination between public and private institutions at the local, national, and international level for the long term.

At present, a unique opportunity exists to build such partnerships between MINSA, INSS, academic institutions and sugar mill companies in the Department of Chinandega.

Annexes

Annex A. Key Informant Interviews List

Dr. Carlos Jarquín, MINSA Central Director of Medical Services, Managua

Dr. Roberto Jiménez, Nephrologist, former Director of Hospitals, Nicaragua

Dr. Marvin González, .Epidemiologist, Professor, Centro de Investigación Salud Trabajo (CISTA), Universidad Nacional Autónoma de Nicaragua (UNAN)

Dr. Luís Lindo, Director, SILAIS, Department of Chinandega

Dr. Francisco López, Director, Dialysis Center, Hospital España, Chinandega

Dr. Alejandro Marín, Director Hospital Ingenio San Antonio, with **Dr. Felix Zalaya**, Hematologist/Oncologist, Clinician, Hospital Ingenio San Antonio

Dr. Fermín Martínez Director, Centro de Salud de Chichigalpa

Dr. Rodolfo Peña, Dean of Medicine, UNAN, with **Dr. Aurora Aragón**, Epidemiologist, Director Centro de Investigación Salud Trabajo (CISTA),

Dr. Erwin Reyes, Nephrologist, CRI Clinic at the Centro de Salud de Chichigalpa

Annex B. Clinical Capacity Assessment- CRI **Topic Guide Questions for Doctors addressing CRI**

Clinical Level Questions

Current CRI services provision

Existing CRI services (Strengths)

*What kinds of clinical services do (your medical facility) currently provide for CRI patients?
What are their strengths?*

Are there any preventive services or screening currently provided to workers/patients at increased risk of developing CRI? Which?

Clinical evaluation of patients at increased risk of CRI

How do you evaluate workers/patients at increased risk of CRI?

Do you have specific guidelines/algorithms that everyone in the clinic follows?

What do the guidelines include? (for example, ROS, PMH, FH, Meds, PE, lab)

What markers do you use to detect kidney damage?

How do you calculate GFR?

What criteria do you use to diagnose and stage CRI?

Clinical treatment of CRI patients and those at increased risk of CRI

Do you offer any precautions or treatment for at risk patients (workers) with no signs of CRI?

How do you treat patients at each stage of CRI?

What medications are prescribed? (Why?)

What supplements are prescribed? (Why?)

Are there any changes in work assignments made?

Clinical monitoring and follow-up of CRI patients and those at increased risk of CRI

How are at risk workers and CRI patients followed up?

What markers are followed for each group? (symptoms, BP, labs)

How often are at risk workers and CRI patients monitored?

Clinical management of patients with CRI

What stages of CRI is your medical facility able to handle?

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

When would a referral be made to another facility? Which one? How easy or hard is it to obtain a referral?

Renal biopsies:

Are renal biopsies being done? If so, where?

When would you consider doing a renal biopsy?

What results have been obtained?

Administrative/Organizational Level CRI Capacity Questions

Unmet needs in existing CRI services

What unmet needs (gaps) do you see in existing clinical services for CRI patients?

Why do you think these unmet needs (gaps) exist?

Recommendations to improve CRI treatment

What recommendations do you have for short and long term options that could fill existing gaps and improve the health care that people living with CRI are currently receiving?

Are there any national efforts toward the standardization of CRI diagnosis, treatment and management?

What do you think about the capacity of CRI medical providers at each level and within levels? In your opinion, which kinds of staff are the most poorly prepared to provide CRI services? Why? What do you suggest to improve their capacity? And what is necessary to accomplish this?

What do you think about the capacity of national health care system to treat and manage ESRD (end-stage renal disease), specifically in regard to dialysis and renal transplantation? What do you suggest to improve the capacity?

Do you see any issues regarding accessibility of CRI patients to medical care? If not, how so? If so, what might you recommend to improve accessibility to care?

What are some of the areas that you would recommend for operational research to help in planning or assessing CRI service provision?

Do you see any further options for collaboration from public health agencies to improve services for the affected communities?

What do you think about the possibility of partnerships between public and private health agencies?

What cautions do you have about planning to fill unmet needs in existing CRI services?

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Who else would be good to talk to about these issues so that we can best understand the current challenge of CRI? (Why do you suggest them, and to discuss which issues in particular?)

Do you have any additional recommendations or suggestions?

Thank you very much for your useful answers. As we mentioned at the beginning, the results of this interview will be very informative to the CAO. If requested, we will keep all of your answers confidential and share them only in aggregated analysis with other CAO key informants. We will ensure that a summary of the results is available to you. Finally, we would be glad to be provided any documents that you think could possibly be of relevance to our information gathering process on this issue.

Would you be available for any direct follow up if we have additional questions arising from your responses?

- a) phone call? Best number to use _____
 Best time/day to call _____
- b) Skype call? Address/number to use _____
 Best time/day to call _____
- c) e-mail? Address/es to use _____

Annex C. La Evaluación Clínica de la Capacidad Médica para tratar a los pacientes con IRC

Preguntas Guía para discusión con Médicos que trabajan con pacientes que sufren de IRC

Preguntas al Nivel Clínico

Provisión de Servicios Existente para IRC

Servicios Existentes para IRC (Fuerzas)

*¿Qué tipos de servicios clínicos proporcionan su facilidad médica a pacientes con IRC?
¿Cuáles son las fuerzas?*

¿Hay algunos servicios o investigaciones preventivos que proporcionaron a trabajadores/pacientes con alto riesgo de IRC? ¿Cuáles son?

La evaluación clínica de pacientes con alto riesgo de IRC

¿Cómo se evalúa a trabajadores/pacientes con alto riesgo de IRC?

¿Tiene usted pautas/algoritmos específicos que todos en la clínica siguen?

¿Qué incluyen las pautas? (por ejemplo, repaso de sistemas, historia médica pasada, historia familiar, medicaciones, examinación física, estudios de laboratorio)?

¿Qué marcadores utiliza usted discernir daño de riñón?

¿Cómo calcula usted RFG (el ratio de filtración glomerular)?

¿Qué criterios utiliza usted para diagnosticar y determinar el nivel de IRC?

El tratamiento clínico de pacientes con IRC y con alto riesgo de contraer IRC

¿Ofrecen ustedes alguna precaución o tratamiento para pacientes/trabajadores con alto riesgo de IRC, con algún signo o síntomas de IRC?

¿Cómo trata usted a pacientes en cada nivel de IRC?

¿Qué medicinas son prescritas? ¿Por qué?

¿Qué suplementos son prescritos? ¿Por qué?

¿Se hacen cambios en las tareas asignadas a los trabajadores?

El monitoreo clínico de pacientes con IRC con alto riesgo de contraer IRC

¿De qué manera se da seguimiento los trabajadores con riesgo y los pacientes con IRC?

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

¿De qué marcadores se hace seguimiento para cada grupo? (Síntomas, presión arterial, los estudios de laboratorio, por ejemplo)

¿Con qué frecuencia están chequeados los trabajadores con riesgo y los pacientes con IRC?

La gestión clínica de pacientes con IRC

¿Qué niveles de IRC puede manejar su centro médico?

¿Cuándo se hace una referencia a otro centro o facilidad médica? ¿Cuáles son estos otros centros? ¿Qué tan fácil o difícil es obtener una referencia?

Las biopsias renales:

¿Se hacen las biopsias renales?

¿Si eso es el caso, dónde?

¿Cuándo consideraría usted hacer una biopsia renal?

¿Qué resultados han sido obtenidos?

Preguntas sobre la capacidad Administrativo/Organizacional para reaccionar y atender pacientes con IRC

Necesidades inapropiadas (vacíos) en los servicios existentes con IRC

¿Qué vacíos ve usted en servicios clínicos existentes para pacientes con IRC?

¿Por qué piensa usted que existen estos vacíos?

Las recomendaciones para mejorar el tratamiento de IRC

¿Qué recomendaciones tiene usted para opciones de corto y largo plazo que podrían mejorar la asistencia médica a las personas viviendo con IRC?

¿Hay algunos esfuerzos nacionales hacia la estandarización del diagnóstico de IRC, el tratamiento y la gestión?

¿Qué piensa usted sobre la capacidad de provisión de servicios médicos para la IRC en los diferentes niveles del sistema nacional de salud en Nicaragua? ¿En su opinión, qué grupos del personal médico son lo menos preparados para proveer los servicios de IRC? ¿Por qué? ¿Qué recomienda usted para mejorar la capacidad de ellos? y qué se necesita para lograrlo?

¿Qué piensa usted de la capacidad del sistema nacional de asistencia médica para tratar y manejar ESRD (la enfermedad renal del nivel terminal), específicamente con respecto a diálisis y trasplante renal? ¿Qué recomienda usted para mejorar la capacidad?

Annex D. Focus Group Participants

Location of all focus groups: Chichigalpa

Facilitator: Alexandra Pérez

Co-facilitator: David Silver

Focus Group 1: 10 male ASOCHIVIDA members (all CRI patients)
Chosen by the ASOCHIVIDA board

Participant Ages: 37-59 years old

Years worked cutting sugarcane: 5-21 (median: 14 years)

Years diagnosed with CRI: 4-18 (median: 9)

Focus Group 2: 13 male ASOCHIVIDA members (all CRI patients)
Self-selected (volunteers)

Participant Ages: 39-64 years old

Years worked cutting sugarcane: 11-35 (median: 17 years)

Years diagnosed with CRI: 5-17 (median: 9)

Focus Group 3: 11 ASOCHIVIDA widows (including a former worker)
Chosen by board

Participant Ages: 43-75 years old

Years husbands worked cutting sugarcane: 7-50
(median: 24) years)

Age of husband when deceased from CRI: 35-81 (median: 59)

Annex E. Medical Literature Review of CRI: Bibliography

CKD, GENERAL

Chronic kidney disease, DynaMed, 2009 Feb 16

Chronic Renal Failure, eMedicine Nephrology, <http://emedicine.medscape.com/article/238798> University of Manitoba, Canada
Updated: Sep 4, 2008

De Broe, MD, PhD, Marc E, **General CKD Analgesic nephropathy**, UpToDate
Post, MD, Theodore W, Gibson, MS, MD, C Michael, Henrich, MD, MACP, William L;

Chronic kidney disease and coronary heart disease, UpToDate, 2009
Renal function - Wikipedia, http://en.wikipedia.org/wiki/Glomerular_filtration_rate
3/1/09

Sheridan, MD, Alice M; Rose, MD, Burton D, **Secondary factors and progression of chronic kidney disease**, October 17, 2008

CAUSES

Kelsh, Ph.D., M.P.H. Michael A., **Chronic Renal Insufficiency: A review of epidemiologic and toxicological information relevant to developing future health research**, Exponent report for CAO, March 25, 2009.

DIAGNOSIS CKD

Bleyer, MD, MS, Anthony, **Reciprocal serum creatinine concentration and chronic kidney disease**, UpToDate, May 30, 2008

den Hartog, Julia R. **The Costs and Benefits of Automatic Estimated Glomerular Filtration Rate**, Clinical Journal of the American Society of Nephrology, January 28, 2009

Obrador, MD, MPH, Gregorio T; Pereira, MD, Brian JG ; **Epidemiology of chronic kidney disease and screening recommendations**, UpToDate, October 6, 2008

Post, MD, Theodore W ; Rose, MD, Burton D ; **Diagnostic approach to the patient with acute or chronic kidney disease**, UpToDate, August 27, 2008

Post, MD, Theodore W ; Rose, MD, Burton D, **Urinalysis in the diagnosis of renal disease**, UpToDate, May 14, 2008

GUIDELINES

National Kidney Foundation KDOQI (Kidney Dialysis Outcome Quality Initiative) **Clinical Practice Guidelines for Chronic Kidney Disease**

National Kidney Foundation, **CKD: Management Calculators and Tables for Health Care Professionals** http://www.kidney.org/professionals/kdoqi/gfr_calculator.cfm

National Institutes of Health, **Healthy People 2010: Chronic Kidney Disease**

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

MANAGEMENT

Ohno, Iwao; Hosoya, Tatsuo; Rinsho, Nippon; **Measures against hyperuricemia**, Division of Kidney and Hypertension, Department of Internal Medicine, Jikei University School of Medicine, 2008 Sep; 66 (9):1779-85

Fox, MD, Chester H.; Swanson, BA, Andrew; Kahn, PhD, Linda S.; Glaser, BA, Kathryn; and Murray, MD, Brian M.; **Improving Chronic Kidney Disease Care in Primary Care Practices: An Upstate New York Practice based Research Network** (UNYNET) Study

Ismail, MD, Nuhad; **Indications for initiation of dialysis in chronic kidney disease**, *UpToDate*, 2008

Post, MD, Theodore W ; Rose, MD, Burton D, **Overview of the management of chronic kidney disease in adults**, *UpToDate*, October 1, 2008

Rose, MD, Burton D; Bakris, MD, George L; **Antihypertensive therapy and progression of nondiabetic chronic kidney disease**, *UpToDate*, 2008

Siu YP, Leung KT, Tong MK, Kwan TH., **Use of allopurinol in slowing the progression of renal disease through its ability to lower serum uric acid level**, Division of Nephrology, Department of Medicine, Tuen Mun Hospital, Hong Kong, China, 1: Am J Kidney Dis. 2006 Jan;47(1):51-9. PMID: 16377385 [PubMed - indexed for MEDLINE]

PERITONEAL DIALYSIS

AAKD (American Association of Kidney Patients), Understanding Your Peritoneal Dialysis Options, 2009

Cueto-Manzano, Alforonso M.; **Peritoneal dialysis in Mexico**, *Kidney International*, Vol. 63, Supplement 83 (2003), pp. S90–S92
Unidad de Investigación Médica en Epidemiología Clínica, Hospital de Especialidades, CMNO, IMSS, Guadalajara, Mexico

Dratwa, M; **Costs of home assistance for peritoneal dialysis: Results of a European survey**, Department of Internal Medicine, Clinique de Néphrologie-Dialyse, Centre Hospitalier Universitaire Brugmann, Université Libre de Bruxelles, Brussels, Belgium, *Kidney International* (2008) 73, S72–S75; doi:10.1038/sj.ki.5002605
<http://www.nature.com/ki/journal/v73/n108s/abs/5002605a.html>

MayoClinic.com, Peritoneal dialysis
<http://www.mayoclinic.com/health/peritonealdialysis/>

NIDDK, NIH, Treatment Methods for Kidney Failure: Peritoneal Dialysis, 3/6/09
<http://kidney.niddk.nih.gov/kudiseases/pubs/peritoneal/>

Sennfält K, Magnusson M, Carlsson P., **Comparison of hemodialysis and peritoneal dialysis--a cost-utility analysis**, Center for Medical Technology Assessment, Linköping University, Sweden. 1: Perit Dial Int. 2002 Jan-Feb;22(1):39-47.

PMID: 11929142 [PubMed - indexed for MEDLINE]

Sheridan, MD, Alice M; Rose, MD, Burton D; **Secondary factors and progression of chronic kidney disease**, *UpToDate*, 2009

Needs Assessment:

Options to improve immediate and long-term care for people suffering from Chronic Renal Insufficiency

Vikrant, S; ***Continuous ambulatory peritoneal dialysis: A viable modality of renal replacement therapy in a hilly state of India***, Department of Nephrology, Indira Gandhi Medical College, Shimla (Himachal Pradesh) - 171 001, India; Year: 2007 | Volume : 17 | Issue : 4 | Page : 165-169

Wikipedia, ***Peritoneal dialysis***