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Addressing CKDu – an Ongoing Challenge for Sri Lanka

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Contents

Editor's Note

Chronic Kidney Disease (CKD) is currently among Sri Lanka's most prevalent non-communicable diseases. Many CKDs have identifiable causes and are preventable, or have curative solutions for their treatment. Chronic Kidney Disease of an unknown etiology or 'aetiology' (CKDu), or in other words CKD for which a cause or the manner of causation of the disease or condition cannot be identified, has emerged as a fatal disease for which a certain method of prevention and control eludes both the medical and non-medical experts.

This edition of the LST Review attempts to capture, among other things, the history of its prevalence, its current impact and effect on the population, the health system's response to the disease, and whether sufficient policy and regulatory priorities have been identified and implemented with respect to the control and prevention of CKDu.

Since it was first identified in the 1990s, the evidence, as highlighted in the articles, suggests that CKDu is now prevalent in 6 of the 9 provinces of Sri Lanka; the Western, Southern and Sabaragamuwa provinces are currently free of CKDu. With a death toll exceeding 1000 persons a year, Sri Lanka has been hard pressed to find the etiology of the disease. The numbers affected are much larger, with far reaching consequences including – deteriorating health conditions, low productivity in agricultural livelihoods, economic loss, and psycho-social problems, to name a few.

CKDu has been diagnosed around the world among rural and impoverished communities that are most often engaged in agriculture. Also, in light of empirical evidence that indicates damage to the kidneys by toxic substances among patients, there is a strong association between CKDu, and the excessive and unregulated use of fertilizer, pesticides and herbicides. However, the extent of this association and whether it is the main causal factor of the disease is uncertain, as apparent in the discussions of this Review. In-fact, undue speculation of an association between fertilizer and the disease, it is argued, is potentially damaging to efficient agriculture production. Other hypotheses include kidney damage due to high concentration of minerals in ground water; however, CKDu is not always prevalent in areas with a high mineral concentration in ground water.

The response of the health sector and the academic community of Sri Lanka, in attempting to contain and prevent the incidence of CKDu have been impressive. A study commissioned by the World Health Organisation (WHO) in conjunction with the Ministry of Health has been instrumental in consolidating findings, with reference to case studies of CKDu affected persons, and prescribes immediate measures to address its adverse effects. In the meantime a number of inter-disciplinary research studies have been conducted, exploring the multi-dimensional effects of CKDu, including it social and economic effects.

Community consultations reveal however, that the different strands of findings have been arrived at in isolation from each other. There has been little effort to engage in a

collaborative and systematic strategy among different entities, in finding a holistic solution to the socio-economic and health problems arising from CKDu. Hence, communities are often left feeling unduly burdened by being forever the subjects of research and studies that do not produce much in the way of relief and redress.

Despite the recommendations of the various studies, there has been little discourse on the nature and scope of regulation and policy reform that is needed to fully address the potential causes of CKDu and to implement adequate preventive measures. For instance, there has been an apparent lack of regulation in the use of fertilizer and pesticides, though it considered a potential source of harm. Also, concerted effort is needed to factor in the socio-economic condition of those who suffer from CKDu; most often the poorest of the poor are most vulnerable. Intervention for their protection and care needs to consider other avenues of support, such as social and welfare support that are warranted in view of their vulnerability.

It is evident that addressing CKDu in Sri Lanka is an ongoing challenge that requires innovative and urgent solutions beyond curative and preventive interventions in health care. A way forward would necessarily have to encompass adequate regulatory, policy and social support for vulnerable and impoverished rural agriculture communities.

Rasika Mendis

Editor

Chronic Kidney Disease of uncertain Aetiology (CKDu); Policy Perspectives

Professor Shanthi Mendis*

Introduction

This article focuses on chronic kidney disease of uncertain origin (aetiology), a condition which has emerged in some developing countries in recent years. It outlines what is known about this condition and highlights the sustainable multi-sectoral policies required to prevent this disease in Sri Lanka.

What is Chronic Kidney Disease?

Kidneys are vital organs in the human body whose main function is to continuously filter and purify blood. Once the blood is filtered, kidney tubules reabsorb water and important organic and inorganic substances from the filtrate and excrete unneeded substances in the urine.

Worldwide, the commonest causes of chronic kidney disease are diabetes and hypertension[1]. A type of kidney disease which cannot be attributed to diabetes, hypertension or other known aetiology, has emerged in several parts of the developing world. Various terms have been used to refer to this type of kidney disease including Chronic Kidney Disease of Uncertain aetiology (CKDu), agricultural nephropathy, chronic kidney disease of nontraditional causes, chronic agrochemical nephropathy and mesoamerican epidemic nephropathy[2,3,4,5,6]. The disease has thus far been reported from El Salvador, Nicaragua,

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[1] Couser WG1, Remuzzi G, Mendis S, Tonelli M.The contribution of chronic kidney disease to the global burden of major non communicable diseases. Kidney Int. 2011 Dec;80(12):1258-70. doi: 10.1038/ki.2011.368. Epub 2011 Oct 12.

[2] Lebov JF, Valladares E, Peña R, Peña EM, Sanoff SL, Cisneros EC, Colindres RE, Morgan DR, Hogan SL. A population-based study of prevalence and risk factors of chronic kidney disease in León, Nicaragua. Am J Kidney Health Dis. 2015 Feb 24;2:6. doi: 10.1186/s40697-015-0041-1. eCollection 2015

[3] Wesseling C, van Wendel de Joode B, Crowe J, Rittner R, Sanati NA, Hogstedt C, Jakobsson K. Mesoamerican nephropathy: geographical distribution and time trends of chronic kidney disease mortality between 1970 and 2012 in Costa Rica. Occup Environ Med. 2015 Jul 21. pii: oemed-2014-102799. doi: 10.1136/oemed-2014-102799. [Epub ahead of print]

[4] Orantes Navarro CM, Herrera Valdés R, López MA, Calero DJ, Fuentes de Morales J, Alvarado

Costa Rica, Mexico, Sri Lanka, Egypt and India. Wherever CKDu occurs, the key ingredients are deep-rooted poverty combined with exposure to environment and occupational toxins, working synergistically with lack of safe drinking water, poor nutrition and harsh living and working conditions. Most of those who are affected have suboptimal access to health care. As a result CKDu is often diagnosed late when kidney damage already requires dialysis. Death within a few years is inevitable. Given these features, it would not be inappropriate to add `chronic kidney disease of the poisoned poor` to the list of terms which refer to this disease. In some settings, as is the case in Sri Lanka, governments are taking action to address the condition within available resources. In others, authorities conveniently postpone action demanding conclusive proof of causation which is unlikely to be produced for years. In some countries, the demands of the poor affected by CKDu, for more humane working and living conditions have been even repressed by authorities.

CKDu is slowly progressive, is asymptomatic until advanced and usually presents later in life[7]. The main histopathological features include atrophy of the kidney tubules, interstitial cell infiltration and fibrosis[8]. These histological features strongly suggest that nephrotoxins play a key role in the aetiology of CKDu.

In the mid 1950s, a chronic kidney disease which runs in families was reported from Serbia, Bulgaria, Romania, Croatia and Bosnia and Herzegovina. It is now known as Balkan endemic nephropathy [9]. It has a long incubation period and is also associated with cancer of the urinary tract. The cause of Balkan endemic nephropathy has been extensively studied over the last fifty years, fostering the publication of various hypotheses. Studies conducted over the last 10 years have provided particularly strong arguments that Balkan endemic nephropathy is caused by chronic poisoning with aristolochic acids.

CKDu in Sri Lanka

Hospital statistics suggest that CKDu is an important cause of clinic attendance, hospital admissions and premature death. As part of a collaborative research study between the

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Ascencio NP, Vela Parada XF, Zelaya Quezada SM, Granados Castro DV, Orellana de Figueroa P. Epidemiological characteristics of chronic kidney disease of non-traditional causes in women of agricultural communities of El Salvador. Clin Nephrol. 2015;83(7 Suppl 1):24-31.

[5] Said S, Hernandez GT. Environmental exposures, socioeconomics, disparities, and the kidneys. Adv Chronic Kidney Dis. 2015 Jan;22(1):39-45. doi: 10.1053/j.ackd.2014.09.003.

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[7] *Ibid*

[8] Nanayakkara S, Komiya T, Ratnatunga N, Senevirathna ST, Harada KH, Hitomi T, Gobe G, Muso E, Abeysekera T, Koizumi A. Tubulointerstitial damage as the major pathological lesion in endemic chronic kidney disease among farmers in North Central Province of Sri Lanka. Environ Health Prev Med. 2012 May;17(3):213-21. doi: 10.1007/s12199-011-0243-9. Epub 2011 Oct 13.

[9] Stefanovic V, Toncheva D, Polenakovic M. Balkan nephropathy. Clin Nephrol. 2015;83(7 Suppl 1):64-9

Ministry of Health (MoH) and World Health Organization (WHO) a hospital based registry was established using data of patients with chronic kidney disease attending the renal clinics at Teaching Hospital Anuradhapura, District General Hospital Polonnaruwa, Base Hospital Medirigiriya and Base Hospital Medawachchiya. Out of the 1997 cases included in the registry, 775 (39%) could be identified as CKDu.

Results of the MoH/WHO study showed that in the 15-70 year age group, the age standardized prevalence of CKDu is 16.9% in females and 12.9% in males. Severe stages of CKDu are more frequently seen in males and the prevalence of CKDu increases with age.

Cost of CKDu on the health care budget of Sri Lanka is very high. The mean cost of a haemodialysis session in Sri Lanka has been estimated to be LKR 6,377 (US$ 56)[10]. The annual cost of haemodialysis for a patient with chronic kidney disease undergoing 2-3 dialysis session of four hours duration per week has been estimated to be LKR 663,208 to LKR 994,812 (US$ 5,869-8,804). If prevention strategies are not strengthened, the limited health care budget will not be sufficient to keep pace with dialysis needs of patients affected by CKDu.

The MoH/WHO research study and policy recommendations

CKDu had been recognized in Sri Lanka since the late 1990's. However, in 2010 when the MoH/WHO study was launched, there were no reliable data on the prevalence of CKDu. Up to that time, a valid case definition had never been used to study CKDu. This made interpretation of any available data futile. As little was known about the aetiology of CKDu, the MoH/WHO study had to investigate the potential role of a very wide range of nephrotoxic agents. Further, since findings of hospital based studies are subject to selection bias, in addition to other limitations, a time consuming population based study had to be conducted. The MoH/WHO study quantified the magnitude of CKDu and investigated the potential aetiological role of 8 elements, 10 pesticide residues, nephrotoxic western medicines, aristolochic acid containing Ayurveda medicines and genetic predisposition. Water, food, soil, fertilizer, urine, blood, hair, nails and body tissues were analysed for nephrotoxins both from endemic and non-endemic areas.

The MoH/WHO study published in 2013 is the only population based study which used a clear case definition and disease grades for CKDu. The study was funded by the National Science Foundation and the WHO. The study results showed that urine cadmium and arsenic concentrations in individuals with CKDu were at levels known to cause kidney damage. The mean concentration of cadmium in urine was significantly higher in those with CKDu compared with people who were healthy. A significant dose–effect relationship was seen between urine cadmium concentration and severity of CKDu. Certain food items from the endemic area contained cadmium and lead above reference levels. Pesticides

[10] Ranasinghe P, Perera YS, Makarim MF, Wijesinghe A, Wanigasuriya K; the costs in provision of haemodialysis in a developing country: a multi-centered study. BMC Nephrol. 2011 Sep 6;12:42. doi: 10.1186/1471-2369-12-42

residues in urine were above reference levels in CKDu. These results indicate chronic exposure of people in the endemic area to nephrotoxic heavy metals through the food chain and also to pesticides. Deficiency of selenium and genetic susceptibility were also seen in individuals with CKDu, suggesting that they may be important predisposing factors for the development of CKDu.

The MoH/WHO sponsored study, for the first time provided data on the magnitude and aetiology of CKDu and identified important leads to preventive strategies. The final report submitted by WHO contained the following specific recommendations based on the results of the study and other scientific evidence[11].

1. Supply drinking water to households in the endemic area to mitigate the potential effects of high fluoride and high calcium in water, heat stress and dehydration which may aggravate the effect of kidney damage caused by nephrotoxins such as cadmium.

2. Strengthen the regulatory framework to improve quality control of imported fertilizer, particularly cadmium, arsenic and lead levels in phosphate fertilizer and curtail the indiscriminate use of synthetic fertilizer.

3. Regulate the quality of imported pesticides/weedicides to prevent contamination of the environment with heavy metals. Ban the use of diazinon, propanil, paraquat, chlorpyriphos and carbaryl which have been shown to be nephrotoxic in vivo and vitro experiments.

4. Implement comprehensive public health measures to safeguard the health of the general population including farmers through i) education on the appropriate use of fertilizers, weedicides and pesticides ii) compulsory provision of safety clothing, gloves and masks at the point of sale of agrochemicals, iii) control of the sale of agrochemicals which are known to be nephrotoxic e.g., diazinon, propanil, paraquat, chlorpyriphos and carbaryl, iv) creating awareness of the importance of adequate fluid intake and nonsmoking. v) education on cooking practices i.e. avoid the use of water from irrigation canals for cooking and drinking vi) advice to avoid the use of lotus yams from the endemic area as their content of cadmium is above stipulated levels vii) Advise on appropriate disposal of nickel Cd batteries, bottle lids etc

5. Strengthen tobacco control measures to protect people, from the harmful effects of tobacco use including potential health damaging effects due to high cadmium content in tobacco grown in this area.

6. Regulate the use of herbal medicines containing aristolochic acid as it is an established nephrotoxin which has been shown to cause kidney disease. Create awareness among the public and medical personnel regarding the ill effects of indiscriminate use of certain western medicines such as nonsteroid analgesics on the kidney.

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[11] Final Mission Report: *Research on Kidney Disease of Uncertain Aetiology (CKDu) in Sri Lanka; National CKDu Project.* Geneva: World Health Organization; 2013

7. Facilitate early diagnosis and treatment at the level of primary health care institutions including through scheduled clinic visits, access to laboratory tests and treatment with 'enalapril'.

8. Provide social welfare support to affected families and an allowance to patients diagnosed with CKDu to prevent them from getting more impoverished and malnourished. Inability to purchase food can cause iron, folate, antioxidant and trace metal deficiency which will increase susceptibility to harmful effects of nephrotoxins.

9. Facilitate research giving priority to research in actionable areas which can provide affordable and pragmatic solutions for addressing this public health issue

10. Monitor implementation of the above multisectoral measures through time bound targets.

The above recommendations were also presented and discussed at the high level meeting on CKDu held in September 2013, in Colombo, Sri Lanka, in which several cabinet ministers participated. The Government has already implemented some of these recommendations[12]. There have been efforts to improve the drinking water supply to the affected area, regulate the use of nephrotoxic pesticides, reduce the use of chemical fertilizer and increase the financial assistance provided to affected families.

While this is commendable, a great deal more needs to be done particularly for prevention of CKDu. While providing necessary health care for the affected people is important, it is even more important to take every action possible to prevent the development of CKDu in the first place. If this is not done, more new cases will continue to emerge and the costs that need to be incurred to provide health care for them will consume a significant proportion of the health care budget of Sri Lanka.

Human face of CKDu – addressing vulnerability

Worldwide, CKDu is closely associated with poverty. This relationship is particularly strong for chronic kidney disease caused by environmental and occupational causes. The poor are more vulnerable to develop chronic kidney disease due to several reasons. They include increased exposure to nephrotoxins, biological vulnerability, low health literacy and lack of access to health care. The poor often lack safe drinking water and sanitation and are more exposed to environmental pollutants and infectious agents. They may also be biologically vulnerable due to inadequate nutrition, genetic predisposition and other comorbidities. They lack knowledge on how best to prevent exposure to risk and disease. Further, because of their poor access to health care and inadequate financial resources, the disease is diagnosed in advanced stages. The relationship between poverty and CKDu is of course bi-

[12] Leading news from Sri Lanka; Sri Lanka implements measures to prevent kidney disease, bans import of agrochemicals. http://www.colombopage.com/archive_13A/Apr08_1365421309CH.php post-content

directional. While poverty contributes to the high kidney disease burden, CKDu entrenches people in poverty due to catastrophic expenditure on drug treatment and dialysis.

As a part of the MoH/WHO research project, a team of researchers from the Department of Sociology, University of Colombo undertook a study in Madawachchiya and Padaviya to gain insight into the psychosocial and economic impact of CKDu. Their findings, summarized below reveal the enormous suffering of patients and families and destruction of the social fabric of communities due to CKDu.

Results of this study show that the illness adversely affects the daily life of patients and their families including livelihood, consumption patterns and domestic and social life. Despite the serious nature of the illness, the majority of patients are compelled to continue working to support their families until late stages of the illness. Social and emotional costs of CKDu are devastating to affected families and communities. Patients and their families perceive that the illness is incurable and that death is inevitable. To cope with the situation and improve mental wellbeing they often resort to traditional rituals. Performing such rituals is expensive and contributes even more to impoverishment.

The fear of getting the illness and the stigma associated with CKDu, grip entire communities. Patients recognise the incurable nature of the illness. Drastic changes are made within family units in the domains of resource allocation, consumption patterns, setting family priorities, social relationships and participation in community activities. There are long-term adverse consequences particularly on the education of children and marriage prospects of young females in affected families. Entire communities suffer due to loss of valuable human capital and material resources.

Majority of CKDu patients use public health facilities. Most of them cannot afford to use private sector facilities. It is used only for certain health care services and for seeking a second medical opinion. The mental wellbeing of patients does not receive adequate attention in the public health service and there are significant communication gaps between the users and the providers. The strength of the family unit is critical to withstand the burden that results from CKDu. However, few social structures are in place to support affected families. People feel that decisions and research related to CKDu are centrally driven with no community participation and little benefit to them. These findings highlight the urgent need to alleviate human suffering by providing more financial assistance, strengthening the social capital and empowering communities.

Do we know enough to take action?

Since the publication of the MoH/WHO study, it has been widely referenced and sometimes even misquoted and misinterpreted. Additional studies have also been conducted more recently, some of which further explore the potential role of water quality, fertilizer and genetics.[13,14,15,16] As explained in the MoH/WHO report, multi-factorial aetiology is the best

[13] Dharma-Wardana MW, Amarasiri SL, Dharmawardene N, Panabokke CR. Chronic kidney disease

match with regard to the causation and pathophysiology of CKDu. This means that it will be arduous to determine the exact configuration of the risk factors and finally decipher the trigger of CKDu definitively.

There have been suggestions that more studies are required before taking any action to prevent CKDu[17]. Some of these claims can be traced to sources which have covert links to enterprises funded by agrochemical business[18]. In this context, as work on CKDu progresses many vested interests will be touched upon and full disclosure by researchers, policy makers and journalists becomes an ethical imperative.

Certain reports have attributed unspecified chronic kidney disease in agricultural workers to heat stress and dehydration. Although dehydration may contribute to kidney damage, it is very unlikely to be the sole aetiological factor causing CKDu.[19] Manual labour and even slave labour have sustained agriculture in tropical climates for centuries. Working conditions whether in sugar cane plantations, cotton fields or paddy fields in developing countries have always been harsh, exposing workers to high temperatures and even dehydration. However, CKDu became an increasingly common illness among agricultural workers only after the Green Revolution a few decades ago. Introduction of hybrid seeds, fossil fuel-based fertilizer and pesticides, and intensified irrigation, brought in the Green Revolution. It boosted agricultural output, which was welcome. In the long term however, these Green Revolution techniques have also stressed irrigation systems, depleted soil health and decreased biodiversity. Farmers have now become unduly dependent on costly agricultural techniques that profit multinational companies. As a result, traditional

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of unknown aetiology and ground-water ionicity: study based on Sri Lanka. Environ Geochem Health. 2015 Apr;37(2):221-31. doi: 10.1007/s10653-014-9641-4. Epub 2014 Aug 14.

[14] Jayasumana C, Fonseka S, Fernando A, Jayalath K, Amarasinghe M, Siribaddana S, Gunatilake S, Paranagama P. Phosphate fertilizer is a main source of arsenic in areas affected with chronic kidney disease of unknown etiology in Sri Lanka. Springerplus. 2015 Feb 24;4:90. doi: 10.1186/s40064-015-0868-z. eCollection 2015.

[15] Wasana HM, Aluthpatabendi D, Kularatne WM, Wijekoon P, Weerasooriya R, Bandara J. Drinking water quality and chronic kidney disease of unknown etiology (CKDu): synergic effects of fluoride, cadmium and hardness of water. Environ Geochem Health. 2015 Apr 10. [Epub ahead of print]

[16] Nanayakkara S, Senevirathna S, Parahitiyawa NB, Abeysekera T, Chandrajith R, Ratnatunga N, Hitomi T, Kobayashi H, Harada KH, Koizumi A. Whole-exome sequencing reveals genetic variants associated with chronic kidney disease characterized by tubulointerstitial damages in North Central Region, Sri Lanka. Environ Health Prev Med. 2015 Jun 25.

[17] Redmon JH1, Elledge MF, Womack DS, Wickremashinghe R, Wanigasuriya KP, Peiris-John RJ, Lunyera J, Smith K, Raymer JH, Levine KE
Additional perspectives on chronic kidney disease of unknown aetiology (CKDu) in Sri Lanka--lessons learned from the WHO CKDu population prevalence study. BMC Nephrol. 2014 Jul 28;15:125. doi: 10.1186/1471-2369-15-125.

[18] The permanent peoples tribunal session on agrochemical transnational corporations http://www.multiwatch.ch/cm_data/Anklaggeschrift_TPPBangalore_2011.pdf

[19] Jayasinghe S. Chronic Kidney Disease of Unknown Etiology Should Be Renamed Chronic Agrochemical Nephropathy. *MEDICC Review* 2014; 16: 72-4.
19. A/68/970 - Open Working Group of the General Assembly on Sustainable Development Goals https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals

agriculture practices which are environment sensitive have been abandoned. Fortunately, there is a growing interest in bio-farming and more sustainable agriculture practices. However, for now, agriculture workers will continue to douse sugar cane plantations, cotton fields and paddy fields with mixtures of pesticides with little regard to personal safety and environment pollution. There is scientific evidence for nephrotoxicity of diazinon, propanil, paraquat, chlorpyriphos, carbaryl, atrazine, 2-4 D and terbutryn. Strict regulatory measures are essential to balance the benefit of these agrochemicals on crop harvests, with risks to human health and pollution of the environment. It is unethical to argue that implementation of such measures should be postponed until there is conclusive scientific evidence.

Significant scientific understanding and interpretation is required to understand the extent to which chemicals in the environment pose a threat to health and the ecosystem. The ability to detect nephrotoxins in the environment surpasses our capability to unravel the impact of such findings on the pathophysiology of CKDu. Science therefore needs to evolve and there is no question that further research needs to be done. Research in actionable areas which can provide affordable and pragmatic solutions for addressing CKDu is of particular importance. However, planning and executing such research should not in anyway delay immediate policy, legislative and regulatory actions to protect workers, people and the environment from potential nephrotoxons.

Sustainable development and Prevention of CKDu

Sustainable development is development that meets the needs of the present without compromising the ability of future generations to meet their own needs. The world will adopt the post 2015 development agenda and time bound sustainable development goals at the United Nations Summit in September 2015.[20]Prevention of CKDu is closely linked with the need for sustainable development, especially pertaining to the protection of the environment. Pollution of the environmental and its impact may not be immediately obvious but can have far- reaching consequences on people and future generations. The results of the MoH/WHO study and other studies have shown that simultaneous exposure of people to nephrotoxic heavy metals and nephrotoxic pesticides are contributory factors in the pathogenesis and progression of CKDu and other diseases. The main source of exposure is a polluted environment. Many factors contribute to the pollution and degradation of the environment. They include inappropriate use of chemicals including agrochemicals, destruction due to industrial activities, weak enforcement of environmental laws due to political patronage and corruption.

In this context, there are three important action points with reference to CKDu. First, among other measures to prevent CKDu, people of the North Central Region must be provided safe drinking water. It is long overdue. Access to safe drinking water is a basic human right and is also one of the sustainable development goals. The exact mechanism

[20] A/68/970 - Open Working Group of the General Assembly on Sustainable Development Goals https://sustainabledevelopment.un.org/topics/sustainabledevelopmentgoals

how water plays a role in the aetiology of CKDu is of secondary importance. The MoH/WHO study did not find heavy metals above stipulated levels in water. However, provision of safe drinking water was one of the key recommendations of the WHO report in 2013, because water is likely to play a role in the development of CKDu through several other mechanisms (10). They include, aggravation of nephrotoxic damage due to limited availability of safe drinking water, contamination of the ground water with agrochemicals and nephrotoxins and synergistic interaction of nephrotoxins with other factors in the ground water in the North central region (such as fluoride, calcium, carbonate and other ions).

Second, Sri Lanka could take advantage of the current global dialogue on sustainable development and the related political atmosphere to strengthen existing policy and regulatory framework for the prevention of CKDu. According to Article 27(14) of the Sri Lank Constitution (1978), 'The State shall protect, preserve and improve the environment for the benefit of the community.' Every person in Sri Lanka also has a corresponding fundamental duty 'to protect nature and conserve its riches' (Article 28 (f). The National Environmental Act No. 47, enacted in 1980, has been the source of many important regulations to preserve the environment[21]. By making use of the operative legal framework the judiciary also can make an important contribution to protection of the environment and the prevention of CKDu[22].

In this regard, it is also important to take note of the precautionary principle in the Rio Declaration on Environment and Development of 1992[23], which states:

> *'Where there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation'*

Third, it is necessary to realize the scope of research evidence that is required to inform national policies, to transform `agribusiness` to `environment -friendly agriculture. Such research would need to encompass health, agriculture, environment and sustainable development. In addition, a strong legislative and regulatory framework would be essential to withstand the pressure of powerful vested interests against such change. All of us have a responsibility to support the restoration of the agro-ecological balance, because as articulated in an ancient proverb, "we do not inherit the environment from our forefathers; we borrow it for future generations".

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[21] National Environmental Act 1980 (No. 47 of 1980); Ecolex www.ecolex.org/ecolex/ledge/view/RecordDetails;...?id...

[22] Judges and environmental law. A handbook for the Sri Lankan Judiciary. United Nations Environment Programme 2009.

[23] Rio Declaration on Environment and Development 1992. Report of the United Nations Conference on Environment and Development, Rio de Janeiro, 3-14 June 1992

Conclusion

In conclusion, research evidence gathered so far suggest that the factors which contribute to the causation of CKDu in Sri Lanka include lack of access to safe drinking water, misuse of agrochemicals and the resulting environment pollution. While provision of health care and socioeconomic support for those already affected by the disease is important, they will not be sustainable without efforts to prevent the development of CKDu in the first place. While further research continues, more proactive efforts need to be made to ensure access to safe drinking water and prevent the misuse of agrochemicals and the resulting environment pollution through the implementation of multi-sectoral policies encompassing health, agriculture, environment and sustainable development.

Policy Aspects in Addressing Chronic Kidney Disease of an unknown/uncertain Etiology (CKDu)

Dr Chandani Liyanage*

Introduction

The issues associated with the prevalence of CKDu points to the need for re-visiting social policies, which are concerned with the several dimensions of the problem. It is necessary to examine whether policy priorities are sufficient to respond, not just to the health consequences of CKDu, but also to the psycho-social and cultural dimensions of the problem. The focus of this paper is to explain the ways in which CKDu impact on everyday life of people who live in affected communities and their discourse with regards to etiology and the origin of CKDu in their locality, and to revisit relevant social policies and assess their competency and limitations in responding effectively to the burning issues related to CKDu.[12]

Health hazards can occur in circumstances that may create extreme emergencies and life-threatening conditions. Chronic Kidney Disease of an unknown/ uncertain etiology (CKDu) has emerged as a health hazard in the North Western, North Central and Uva Provinces in Sri Lanka since late 1980s, and has now reached catastrophic proportions leading to the deterioration of health conditions, low productivity of livelihoods, and psycho-social problems in affected communities. Initially, CKDu was identified as a health hazard by local healthcare providers after investigating a considerable number of patients who visited them seeking treatment for symptoms such as continuing fever, back pain, swollen legs, headache, body-ache, kidney stones, urine infections and loss of appetite etc. While investigating patients with the above symptoms, the local healthcare providers were able to diagnose the disease as CKD but the etiology is yet to be determined as it goes beyond existing knowledge and a biomedical explanatory model with regard to renal failure. The

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[1] The author would like to acknowledge the contribution made by Prof. Ramani Jayathilaka for both Sociological Study on CKDu and Community Based Study on the Impact of CKDu and the contribution made by Prof. Amala de Silva for the Community based study on the impact of CKDu. I would like to acknowledge Disaster Management Center and WHO for providing necessary financial assistance to carry out the above two studies respectively.

[2] The analysis of this paper mainly is based on two community based ethnographic studies (Liyanage and Jayathilake 2009; Liyanage, Jayathilaka and Amala de Silva 2012) that supplements with relevant secondary information

local healthcare providers have also noticed that a number of patients visiting them with the above symptoms have been gradually increasing and therefore they conducted a series of screening programs at community level to identify CKDu patients. As a result, they were able to confirm that the high prevalence of CKDu in the North Central Province and surrounding areas where CKDu has become one of the main causes of death. It is significant to note that CKDu is prevalent among farming communities in the above areas, and includes both men and women across diverse social settings. It has had a devastating impact on the economy of these areas in many ways, especially among those who were anyway surviving in a subsistence economy.

In responding to CKDu, various interventions have been implemented during last few decades by the local communities themselves, healthcare and other service providers, the government, non-governmental and civil society organizations, since the beginning of the identification of CKDu as a public health concern. The health sector has taken immediate action to provide treatment to CKDu patients and established specific clinics in local hospitals to provide continuous treatment for CKDu patients. At the same time, the research community with diverse expertise has commenced a variety of research studies to determine the etiology of CKDu. Some of the studies explore the impact of CKDu in affected communities and identify appropriate mechanisms to mitigate the adverse effect of CKDu. The government has initiated a program to provide a monthly allowance for the patients who are in a critical condition. In addition to interventions by the government, kidney patients' associations and civil society organizations are involved with self-help and voluntary activities to assist CKDu patients and their families to face with financial and other difficulties. However, most of the above interventions have been implemented in an ad-hoc manner and they do not sufficiently address the real issues that are associated with CKDu.

CKDu has become a tragedy in affected communities and the government faces a greater challenge in responding to the continued prevalence of CKDu. The health sector of the country is already over burdened by CKDu and there are indications of cutting-back on services such as dialysis, kidney transplantation which may prove to be unethical.

Considerations for policy

The following discussions relate to the process of discovering and dealing with CKDu, and related policy implications.

The role of professionals in investigating etiology of CKDu

Health professionals have responded towards CKDu mainly in two ways, identifying CKDu patients and discovering the etiology of CKDu. Initially, health care providers attempted to identify CKDu patients in localities of concern. A number of screening programms were conducted by health care providers at the community level to identify CKDu patients, during the period 2003 -2005. As a result they were able to identify large number of patients and were able to map areas with a high prevalence of CKDu.

Health care providers have also taken necessary action to provide treatment for identified CKDu patients. The identified patients have been categorised into five groups, based on the severity and disease progression. Clinics in local hospitals have been set-up to provide necessary treatment for them. Patients at "stages 1 and 2" are instructed to attend the clinic once a year, and for those who are in "stage 3", they are requested to attend the clinic once in 6 months. The "stage 4 and 5" are considered critical, and patients who are at this stage are instructed to attend monthly clinic on regular basis.

Discovering etiology of CKD has become a critical challenge for all experts, irrespective of their discipline. There have been several efforts to identify the causes of CKDu without concrete conclusions. In addition to the studies carried out by individual researchers and research teams, the National Science Foundation(NSF) together with the collaboration of the World Health Organization (WHO) have initiated a National Research Program on CKDu with the emphasis of discovering unknown etiology that included population prevalence studies, case control studies, environmental studies, study on nephrotoxic herbal remedies, postmortem studies, hospital based chronic kidney disease registry, randomized clinical trial and also socioeconomic and productivity impact studies to assess the impact of CKDu on everyday life of people in affected communities (WHO 2011). Some of those studies were metal analysis of urine, analysis of hair and nail samples of patients for arsenic and renal biopsy studies (WHO 2011). Postmortem study focuses on analysing postmortem specimens of CKDu patients (kidney, liver and bone tissues). CKDu is considered as a geo-environmental issue and therefore, there are number of studies from this perspective where drinking water samples were tested for cadmium and arsenic, environmental samples such as irrigation water, agro-well water, soil of agricultural and non-agricultural lands, rice, vegetable, freshwater fish and some other food items from CKDu high prevalence areas were tested by experts from relevant disciplines. Soil and fertilizer samples were also tested (WHO 2011).

Though there is no concrete conclusion that has emerged from the variety of investigation undertaken since the 1990s, the research was able to identify some risk factors that are associated with the etiology of CKDu. Unsafe agricultural practices with heavy usage of chemical fertilisers and pesticides and poor quality of drinking water in CKDu affected areas have been identified as some of the key factors that contribute to the high prevalence of CKDu in the dry zone. Accordingly, it is concluded that exposure to a combination of factors that are toxic to the kidney contributes to the development of CKDu. However, there have been some limitations of the above investigation process.

Limitations in the investigation of CKDu

Among the issues and limitations of the process in discovering etiology of CKDu, are the gaps in the interactions between lay people and professionals. As verified by community based sociological studies mentioned above, the villagers who have firsthand experience of CKDu have been marginalised in the process of scientific investigation. Their involvement was limited to providing professionals the support to carry out their studies on local health hazards (by providing water samples, soil and hair, nail of patients ect). From time to time

different experts come to the village and established rather ambiguous judgments on the etiology of CKDu. The villagers have been increasingly confused as most of these explanations and conclusions appear to contradict each other.

Initially, the villagers were compelled to follow the instructions of various experts but latterly were confused with the contradictory opinions that they received from different groups of experts. Among the ethical issues of concern was that in the process of investigation, the privacy of villagers was neglected. Not only individual patients but also the entire community has been labeled either as CKD patients or as a locality that has high prevalence of CKDu, leading to stigma and discrimination while creating negative social consequences.

Further, some of the CKDu patients were asked to participate in biopsy tests without giving adequate information about the investigation process and the outcome of their involvement. At the clinical setting only some patients were identified as 'research patients' and they receive special attention whereas the other patients are quite confused as to why they are not included into that category. The other important issue is that most of the experts have done their particular investigation in isolation from each other rather than engage in multidisciplinary team work. They meet briefly at scientific forums to share basic findings but hardly meet at other forums to discuss relevant issues in detail.

It is apparent that effort is required on the part of policy makers to mobilise a multi-disciplinary investigation with respect to the causes and consequences of CKDu. The lack of a streamlined process, adds to the stress that local level communities are subject to.

Community Discourse on CKDu

It is essential to consider the discourse among the villages when addressing issues related to CKDu. The community discourse on CKDu has been emerging since late 1990s after identification of CKDu as one of the main health problems in concerned localities. It is a dilemma within the community discourse, whether CKDu is a new phenomenon or an old issue. The village discourse with regard to the historical background of the prevalence of CKDu and its etiology is quite complicated. However, some of the villagers were aware of patients with similar symptoms in the area as far back as the 1960s, though the numbers were small, and diagnosis was not known to be CKD. According to narratives of villagers, symptoms of body swelling, anemia and disfigurement of face were identified locally as "pipihaluwa" or "pitthapanduwa". Some of the villagers connect their past experience with regard to pipihaluwa/ pitthapanduwa along with the symptoms of CKDu and view that the same has been prevailing in their locality for a long time, even though it was not recognized as CKDu and the numbers were relatively less.

However, most of the villagers view CKDu as a recent phenomenon in their locality due to adverse effects of contemporary agriculture transformation with modernisation of agriculture processes. Thus, the villagers view that CKD is clearly a recent phenomenon as a result of mismanagement of the natural and social environment during the last few decades. CKD may thus be considered a man-made disaster, and previous generations had

never experienced such a situation as they were capable enough to manage a harmonic balance between the natural environments with their social environment.

The villagers also view CKDu as an outcome of unplanned livelihood activities. In the past, livelihood activities were well planned in keeping with seasonal variations in weather patterns. Equal attention was given to both paddy and chena cultivation which provided them a balanced diet and a healthy lifestyle. The chena cultivation provided a variety of food items which were healthy as well as suitable for the ecological conditions of the dry zone. However, the chena cultivation had to be abandoned due to the conflict situation and with the problem of wild elephants. The result was that the villagers started cultivating in their home gardens that require chemical fertilisers and pesticides. Gradually they started using chemical fertilisers and pesticides not only for highland cultivation but also for paddy cultivation that leads to pollution of all water sources in the area. Hence, the assumption is that an increase in the use of fertilizer has led to an increased incidence of CKDu.

Agricultural policy in Sri Lanka

It is apparent that the spread of CKDu is a new phenomenon that goes parallel with agricultural modernisation in Sri Lanka. Modern agriculture requires as standard, the use of chemical fertilisers and pesticides. Empirical evidence of both the sociological studies on which this paper is based, reveals that the farmers are involved in risky agricultural practices. Those who cultivate paddy, vegetable, chili and tobacco are heavily reliant on chemical fertilizers/pesticides in their cultivation in both *Maha and Yala* seasons. Thus, the farmers hardly follow required instructions when they apply those fertilizers/pesticides. There is little instruction from relevant agriculture officers, and instructions are most often from persons who sell pesticides in local markets. As one of the participants pointed out in a focus group discussion, people receive instructions from what they refer to as "*vasa kade nona*" (the madam from the boutique of poison). Thus, the farmers are most often without access, and unable to read and understand instructions. Some of the younger farmers are willing to use masks or hand- gloves, which are not available in the local markets.

The farmers are compelled to use different pesticides for weeding as there is labor shortage in the locality. The farmers mix different varieties of pesticides expecting a better outcome. The danger of this practice is that nobody knows the final outcome of the combination that they make after mixing different pesticides. It is also observed that the farmers have easy access to different chemical fertilizers and pesticides as they are available in the local markets. Farmers who are diagnosed as CKDu patients are associated with such agricultural practices, as evident in the research. The majority of the patients has been completely separated from agricultural activities and is reliant on family support for their survival. Some of them are continuing with agricultural activities with alternative strategies such as hiring a person to spray pesticides and other activities. Thus, there are some farmers who continue with the perceived risks to their health, as they have no other alternatives for survival.

The evidence clearly suggests that the incidence of CKDu requires a revisiting of agricultural policy in Sri Lanka. Understanding among the community (as outlined in the previous section) is that the origin and spread of CKDu is in parallel with agricultural modernisation in Sri Lanka. Open economic policies of the past have further enhanced easy access to chemical fertilizers/pesticides, while the government has failed to regulate and maintain standards for safe practices in agriculture. It's a timely to re-visit agricultural policy and review its strengths and limitations, to ensure the food security of the country and to minimize harmful practices in agriculture.

It would be quite a challenge to change risk behavioural patterns of farmers and encourage them to move forward towards healthy practices in agriculture. Behaviour change communication mechanisms are required for community mobilisation while strengthening agricultural policy with appropriate recommendations for the use of fertilizer/ pesticides, and suitable monitoring mechanisms. Proper coordination between the Ministry of Agriculture and other relevant Ministries and institutions is also important while taking action for necessary institutional change. The empirical evidence suggests that the villagers are quite ready to adjust to good practices as they have been experiencing the negative consequences of harmful practices in agriculture.

Impact of CKDu and social protection systems for farming communities

The disease impact assessment studies clearly show that the economic and psycho-social consequences of CKDu on everyday life of people who are affected, where they are rapidly being marginalised. The economic burden of CKD is serious due to four factors: firstly, these rural households are often poor; secondly, their livelihoods are agricultural, with uncertain and low incomes; thirdly, the patients are mainly in the age group 41 to 60, with a majority of them being the chief householder; and fourthly, there is a large dependent population, with the result that any loss of income and labour has major adverse impacts on the household budget including the educational activities of children. Analysis of incomes and livelihoods clearly indicates that these poor households require as a priority, government intervention in the provision of appropriate, timely, close to client healthcare services. Action by social welfare services is imperative, in addition to the current allowance paid only in the last stages of the illness. Welfare programs targeting the family, particularly geared to ensure that the educational opportunities of children are safeguarded, should be implemented.

The majority of patients depend on free government healthcare. This has contributed to the government's economic burden of the illness considerably; though sporadic drug shortages result in fluctuating costs to the household. Private healthcare in the area is limited, but is accessed by some patients, but even this seems to be only when needed rather than as a regular practice.

Given that regular clinic visits are an important part of safeguarding the health of CKDu patients, steps need to be taken to reduce time costs involved in clinic visits, improve

transport facilities for accessing hospitals, provide close to client care through equipping smaller hospitals and ensure drug availability.

Issues related to communication gaps between the patient and the healthcare providers is identified as one factor that should be given priority in this context. The patient is treated in the clinical setting as a passive object where he/she receives only instructions to follow but hardly gets any explanation with regard to his/her ill-health and relevant treatment which contributes in further deterioration of the mental wellbeing of the patients concerned. It is important to locate the individual patients at the centre when evaluating his/her mental wellbeing. However, the empirical evidence of the above two community based studies strongly suggests the importance of considering family as a unit when examining the psychological/emotional impact of ill-health related to CKDu.

The emotional wellbeing of not only the patient and his/her family, but the entire community has been gradually deteriorating due to illness where there is hardly any significant distinctions among different social categories based on their individual or social characteristics such as age, gender, social class, level of income, and ethnicity. The findings of the two community based studies suggest that the entire community needs to be considered as a vulnerable group when designing any intervention with regard to mitigating the adverse effect of CKDu.

The empirical evidence of the above two community based studies further suggests that there is a need for organising and strengthening the community in order to mobilise its resources to face the challenge where the illness has already become a stigma and patients are discriminated due to illness. The evidence strongly suggests that there is an urgent need for integrating community social workers to the local context who are capable of organising such communities to mobilise their various resources at different levels to mitigate the disaster.

The findings strongly suggest that CKDu has a severe impact on the emotional wellbeing of both patients and their family members. However, the emotional dimension has been totally neglected by the healthcare delivery system, and this requires urgent action to incorporate clinical social workers in to the local healthcare delivery system. The family has given its foremost priority to manage ill-health of CKDu patients by allocating most of its material and human resources while neglecting most of the needs of other members in the family. The support given by family is extremely helpful to patients. However, the family should be considered as a unit of collective suffering bearing both emotional and social cost of CKDu that needs to be strengthened with regular counseling and other supportive mechanisms.

Conclusion

There is no systematic social security system for those who are involved in the informal sector of the economy that includes the vast majority of farming community in Sri Lanka. Chronic kidney disease has added further uncertainty into the lives of farmers as it negatively impacts on their productivity while requiring more recourse to manage the ill-

health that is associated with CKDu. Already the health services are burdened by the illness and there are indications of an implicit rationing of healthcare provision. While Sri Lanka lacks a comprehensive formal social support system, the loss of productivity, the costs of care and prevention all have cumulative impacts and the potential to push families and communities towards poverty. CKDu needs to be addressed not only as merely a health issue but also as an economic, socio- cultural, and political issue in contemporary Sri Lanka. Re-visiting the agricultural policy in Sri Lanka is crucial at this juncture, in order to maintain a balance between food security of the country and a healthy life to its citizens. It is also important to re-visit and review current policies for health and social protection, which have their strengths with respect to marginalised sections of the society.

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2.Liyanage, C., Jayathilaka, R. & De Silva, A., 2012, *Community based study on economic, social and psychological impact of Chronic Kidney Disease in the North Central Province and Interventions to support the affected Households*, Research report submitted to Ministry of Health/ World Health Organization under the National research programe on CKDu.

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Understanding Chronic Kidney Disease; its Global Prevalence and Implications for Regulation

Shashika L. Bandara*

The conversation on Chronic Kidney Disease of unknown or non-traditional aetiology (CKDu or CKDnt) is a seasonal one. The attention span usually limits itself to election campaigns or surge of media interests which dies down usually to make way for 'stronger' headlines such as the war crimes inquiry or a mega development project. The scattered coverage in the media and the lacklustre approach from the officials cannot be ignored any further as the disease shows no signs of slowing down.

Additionally, in a global climate where non-communicable diseases (chronic kidney disease, heart disease or diabetes) are overtaking communicable diseases (such as AIDS or malaria) as a contributor to mortality, Chronic Kidney Disease - with known and unknown aetiology - is considered a serious public health concern. Currently, including all forms of chronic kidney disease over 2 million people need dialysis or a kidney transplant to stay alive.[1] Additionally, as evident in many developing countries, millions die unable to afford access to proper treatment.[2]

In the Sri Lankan context, conditions are much worse due to the fact that the aetiology of the disease remains highly contested in the scientific community thereby making it untreatable unless through dialysis or kidney transplant. This is an important distinction to make over other patients with **Common Chronic Kidney Disease** (CKD) who remain treatable. Many of these patients can nurse themselves back to good health through healthy habits and proper medication though they cannot be completely cured in most cases.[3] Unfortunately, that luxury does not extend to the rural farming communities of Sri Lanka whose chronic kidney disease of unknown aetiology remains largely untreatable since the 1990s.

In 2012, it was reported that over 400,000 people were suffering from the disease and approximately 22,000 lost their lives to this disease in Sri Lanka.[4] In 2013, it was noted

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1 "Global Facts: About Kidney Disease", The National Kidney Foundation, January 8, 2015. Accessed September 9, 2015 at https://www.kidney.org/kidneydisease/global-facts-about-kidney-disease

2 "Chronic Kidney Disease." World Kidney Day. Accessed September 9, 2015.at http://www.worldkidneyday.org/faqs/chronic-kidney-disease/.

3 *Ibid*

4 Perera, Amantha. "Study Links Kidney Disease in Sri Lanka's Farm Belt to Agrochemicals." Study Links Kidney Disease in Sri Lanka's Farm Belt to Agrochemicals. August 21, 2012. Accessed September 9, 2015. http://www.ipsnews.net/2012/08/study-links-kidney-disease-in-sri-lankas-farm-belt-to-agrochemicals/.

that CKDu takes at least two lives a day in North Central and Uva Provinces of Sri Lanka.[5] A World Health Organisation (WHO) report compiled in collaboration with the Ministry of Health cited heavy metals such as cadmium, arsenic to be high in those affected by the disease concluding along with other research that heavy metal is one of the reasons for the disease.[6] Another theory is that glyphosate, a chemical that can be found in *"Round up"* weed killer manufactured by Monsanto is related to the disease. The chemical forming a compound when combined with heavy metals such as cadmium or arsenic can cause the disease, researchers argue.[7,8] Although the parent company vehemently denies these research findings, recent findings linking the chemical glyphosate to cancer has rekindled debates about the safety of agro-chemicals such as glyphosate and their market brands such as *Round Up.*[9] Based on these findings, the Environment Protection Agency of the State of California is considering labelling *Round Up* as a possible carcinogen.[10] More research is stacking up against Glyphosate highlighting that long term exposure to the chemical can damage kidney and liver in humans.[11,12]

Table 1 provides key differences between Common Chronic Kidney Disease (CKD) and Chronic Kidney Disease of unknown or non-traditional Aetiology. [13]

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[6] "Investigation and Evaluation of Chronic Kidney Disease of Uncertain Aetiology in Sri Lanka." December 31, 2012. Accessed September 9, 2015. https://www.documentcloud.org/documents/693945-who-final-report-on-ckdu.html

[7] Jayasumana, Channa, Sarath Gunatilake, and Priyantha Senanayake. "Glyphosate, Hard Water and Nephrotoxic Metals: Are They the Culprits Behind the Epidemic of Chronic Kidney Disease of Unknown Etiology in Sri Lanka?" *International Journal of Environmental Research and Public Health IJERPH*, 2014, 2125-147.

[8] Chavkin, Sasha. "Herbicide Ban on Hold in Sri Lanka, as Source of Deadly Kidney Disease Remains Elusive." Center for Public Integrity. April 11, 2014.

[9] Wylie, Ian. "Glyphosate Is a 'probably Carcinogenic' Pesticide. Why Do Cities Still Use It?" Theguardian.com. April 21, 2015.

[10] "California EPA Mulls Labeling Monsanto's Roundup as Being 'known to Cause Cancer'" RT English. September 6, 2015. Accessed September 9, 2015.

[11] Mesnage, Robin, Matthew Arno, Manuela Costanzo, Manuela Malatesta, Gilles-Eric Séralini, and Michael N. Antoniou. "Transcriptome Profile Analysis Reflects Rat Liver and Kidney Damage following Chronic Ultra-low Dose Roundup Exposure." *Environmental Health* 14 (2015).

[12] "Heavy Use of Herbicide Roundup Linked to Health Dangers-U.S. Study." Reuters. April 25, 2013. Accessed September 9, 2015.

[13] Chavkin, Sasha. "As Kidney Disease Kills Thousands across Continents, Scientists Scramble for Answers." Center for Public Integrity. September 17, 2012.

Table1: Key differences between Common Chronic Kidney Disease and Chronic Kidney Disease of Unknown or Non-traditional Aetiology.

Common Chronic Kidney Disease	CKDu/CKDnt
Prevalent worldwide but high in wealthy nations in older communities; both genders	Prevalent in working males in rural farming communities in developing nations
Obesity, Hypertension, Diabetes are considered as risk factors	Heat, Strenuous labour, exposure to toxic chemicals are considered as risk factors
Proteins in Urine: High	Proteins in Urine: Low
Affects Glomerulus similar to high blood pressure or sugar	Affects Tubules and Interstitial tissues similar to dehydration or toxic poisoning
Aetiology known	Uncertain Aetiology

Global Presence of the Disease

In order to understand that uncertain aetiology for this disease is not an isolated factor to Sri Lanka, it is important to look at the global context of CKDu or CKDnt. The chronic kidney disease with known aetiology (CKD) is related to hypertension and diabetes which is usually associated with ageing and/or obesity in developed countries.[14] However, the trend of unknown aetiology (CKDu/CKDnt) among rural farming communities in developing nations is much worse. The disease not only becomes a burden on saturated public health systems such as the Sri Lankan system, which is buckling under pressure but it also reduces the workforce especially in the agricultural sector. Lack of income and stigma attached to the disease results in low quality of life, social ostracism and contributes to human rights violations, such as the right to safe and sufficient drinking water.

As epidemiological researches reveal a very similar disease if not the very same could be found in India, Egypt, and Central America.[15] In Central America the disease is widespread in countries such as Nicaragua, El Salvador, Costa Rica, Guatemala and neighbouring countries. In Nicaragua itself the disease is so prevalent that an area previously known as 'The Isle' (La Isla) is now known as the 'Island of Widows' (La Isla de las Viudas) where men aged between 20-40 years die from the kidney disease that originate from unknown causes. In El Salvador, by 2011 CKDu has become the second largest killer of men in the

[14] Please refer to Table 1: Key differences between Common Chronic Kidney Disease and Chronic Kidney Disease of Unknown or Non-traditional Etiology.

[15] Almaguer, M., R. Herrera, and CM Orantes CM. "Chronic Kidney Disease of Unknown Etiology in Agricultural Communities." *MEDLINE*, 2014. Accessed September 9, 2015. http://www.ncbi.nlm.nih.gov/pubmed/24878644.

country.[16] CKDu/CKDnt is so widespread and deadly in Central America that it is being referred to as the 'Mesoamerican nephropathy'.

The sugarcane farm owners however, remain quiet about the disease preferring to discuss the bio-fuel opportunities as opposed to the prevailing disease; the workers tend to get fired if the owners realise that they have chronic kidney disease. Health workers are also not allowed to the farms to investigate the mysterious chemical causative factors in addition to recognised factors such as dehydration and heat. Even the World Bank seemed to have overlooked this as they approved loans over 100 million U.S. dollars for sugar cane farming without considering the workers who are prone to be affected by CKDu/CKDnt.[17]

In India, a similar story unfolds as the affected paddy farmers do not have the ability to afford treatment due to financial constraints. Therefore, unable to receive dialysis treatment or kidney transplant some patients have resigned to their fate. Harvard University led research have connected the disease to high levels of silica in the soil which again are related to use of pesticides that contain these chemicals.[18]

All these conditions exist in Sri Lanka, at different levels, contributing to disintegration of normal lives of these villagers. Government, up until very recent times continued to increase the agro-chemical subsidy while there is well-founded concerns of their effect on the kidney disease. Subsidies encourage the culture of dependency on agro-chemicals, despite documented and vocal opposition against it by researchers and environmentalists. Patients are increasing beyond the North Central Province where the disease was initially prevalent. Patients in rural Sri Lanka, in many instances, have to travel long distances merely to visit a clinic and is put under immense pressure due to the exorbitant cost of the treatments required.[19]

These trends unfold globally, with similar results, and with many of the families losing the bread-winner of the family. In the meantime, big businesses refute claims of agro-chemical harm and counter punch with research that favours their product. For instance, Monsanto amidst growing opposition, recently countered scientific research by the International Agency for Research on Cancer (IARC), a research arm of WHO that links glyphosate to cancer, by referring to the approvals of many risk assessment or control bodies around the world. Monsanto even went further to ask WHO to retract the report, which the WHO has not done.[20]

The pattern of these diseases, unregulated use of agro-chemicals where there is no conclusive evidence of their safety, and continued ignorance of the problem, together with

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[16] Chavkin, Sasha. "Thousands of Sugar Cane Workers Die as Wealthy Nations Stall on Solutions." Center for Public Integrity. December 12, 2011.

[17] *Ibid*

[18] Chavkin, Sasha. "Countries Target Pesticides as Suspected Link to Rare Kidney Disease."International Consortium of Investigative Journalists. September 19, 2013.

[19] Sunil, W.A. "World Socialist Web Site." Chronic Kidney Disease Spreads in Rural Sri Lanka. March 5, 2014.

[20] "Monsanto Seeks Retraction for Report Linking Herbicide to Cancer." Reuters. March 24, 2015. Accessed September 9, 2015.

heavy marketing by the companies, creates a picture reminiscent of the "Big Tobacco" versus public health officials of many countries that challenged them; for years big tobacco companies claimed that their products are not harmful to the human body.

As CKDu or CKDnt is an obvious public health concern, both locally and globally, it is crucial to understand a way to deter at least the possible causative factors. Consistent to this crisis are - the use of agro-chemicals that are potentially harmful, their unregulated sale, overuse and application of agro-chemicals and lack of attention towards farmers' health, either by farm owners or by individual farmers. The demographics of these farmers, most often located in poor rural communities, is also a prominent factor that allows them little choice but to engage in farming despite the fear of CKDu or CKDnt.

In Sri Lanka, bans on agro-chemicals come and go without any establishment of a long standing policy or reinvention of farming methods. In March 2013, a ban was imposed on glyphosate which was then lifted in May 2013, due to the lack of a "justifiable reason to impose the ban." The pesticides registrar at the time Mr. Anura Wijesekara was a vocal opponent of the ban choosing to question definitive science behind the ban as well as the effect of it on the agriculture in the island, which incidentally was similar to the stance of the parent company Monsanto.[21] A Presidential Task Force was constituted in 2014, under the former President of Sri Lanka, Mahinda Rajapakse, which identified contaminated drinking water content as a possible causative factor, due to contamination by agro-chemicals or presence of heavy metals, as cited in the WHO report.[22]

The present government under President Maithripala Sirisena, whose electorate in Polonnaruwa is severely affected by the disease, has vowed to find solutions to the issue. Yet, the government is only able to focus on damage control by increasing proper healthcare and support for those who are suffering due to uncertain aetiology. To this end they have recently set up the "Kind Project" to raise funds for the National Kidney Fund.[23]

Legal Aspect: International[24]

To find lasting solutions in a climate where medical solutions seem few, legal intervention is important, to minimise the damage and to enhance the lives of those who are affected. Legal interventions or approaches could also be used as starting point to trigger policy change in relation to agro-chemical regulation. If suspected chemicals cannot be banned outright at least increased regulatory efforts could lead to better health conditions of the

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21 "Herbicide Ban on Hold in Sri Lanka, as Source of Deadly Kidney Disease Remains Elusive." Center for Public Integrity. April 11, 2014.

22 Hettiarachchi, Kumudini. "Tackling Kidney Disease in NCP." Sundaytimes.lk. April 27, 2014.

23 "President Appoints Muralitharan, Dilshan Brand Ambassadors for National Kidney Fund." Nation.lk. August 1, 2015.

24 Legal analysis of the Chronic Kidney Disease was done in consultation with *Vishakha Wijenayake,* also based on the data from the chapter 'Development and Human Rights' to be published in *State of Human Rights 2015* by the Law & Society Trust.

users. This approach can be supported through both international and local laws on the basis of safeguarding fundamental human rights.

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the right to health. Article 12.2 acknowledges that the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such *inter alia* healthy working conditions.[25] The Special Rapporteur for the Right to Health specified that especially in the context of agricultural work, the right to health also requires States to address the prevention and reduction of the population's exposure to harmful substances, such as pesticides given that exposure to pesticides has been linked to various acute and chronic toxic illnesses, including a number of cancers. Where there is a real and confirmed hazard, the obligation to protect the right to occupational health requires States to prohibit production, sale and use of these substances; States also have a duty to take appropriate measures to reduce or prevent exposure, taking into consideration both the likelihood that harm will result and the extent of that harm. However, the special rapporteur notes that there are strong indications that efforts to regulate the distribution, application and disposure of such pesticides have been ineffective in reducing exposure and that regulation have been deficient in scope and under-enforced in both the developed and the developing world.

It is challenging however, to enforce legal regulation, where scientific data does not reveal a definitive cause. On a global scale it is not for the lack of trying that legal regulations have not panned out. In Central America, where the disease has hit the hardest, apart from Sri Lanka, many legal avenues have been approached.

In April 2013, both high level medical personnel as well as regional ministers held a conference in El Salvador where the Pan American Health Organisation (PAHO) declared the disease as an extremely serious health issue, which is associated with toxic occupational and environmental factors in addition to dehydration and other factors. The San Salvador declaration which had the support of regional health ministers of each country was adopted by the regional committee of the WHO on October 2013.[26] The declaration was considered a victory as the same effort to recognise this disease earlier in 2011 was not successful.

El Salvador's legislative committee, in 2013, following Sri Lanka's glyphosate ban, approved a ban on 53 agro-chemicals including glyphosate of Monsanto's *Round Up* as well

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[25] Committee on Economic, Social and Cultural Rights, General Comment 14, The right to the highest attainable standard of health (Twenty-second session, 2000), U.N. Doc. E/C.12/2000/4 (2000), reprinted in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, U.N. Doc. HRI/GEN/1/Rev.6 at 85 (2003).

[26] Pan American Health Organization, World Health Organization; "Chronic Kidney Disease in Agricultural Communities in Central America." In *152nd Session of the Executive Committee, Provisional Agenda Item 4.7; CE152/25.*

as 2,4, D produced by Dow Chemicals that are linked to CKDU/CKDnt.[27] However, it was not signed into law by the President of El Salvador.

Most recently, The California Environmental Protection Agency's Office of Environmental Health Hazard Assessment (OEHHA) intends to list the chemicals tetrachlorvinphos, parathion, malathion, glyphosate as known to the state to cause cancer under the Safe Drinking Water and Toxic Enforcement Act of 1986. [28,29]

Failed attempts at regulation, have led to frustration and disappointment among affected communities. In March 18, 2013, in an area called Chichiglapha of Nicaragua the adverse effects of the disease and the continued inaction became so unbearable that it resulted in a riot. Over 180 workers, widows, children were involved who were swiftly subdued by the law enforcement agencies by the extreme use of force.[30]

Although, Central American countries as a region have come together to find a solution the same cannot be said of the South Asian region. India and Sri Lanka are affected by the CKDu/CKDnt but the impact is not the same for the two countries. In India, the disease is affecting Andhra Pradesh where as in Sri Lanka which has relatively low land mass and a significantly lesser population has a non-communicable disease at hand which is spreading out to many regions of the country.

Legal and Policy Aspects: Sri Lanka

Therefore, it would be vital for lawmakers, affected farmers, their families, and organisations that aim to find legal solutions, to review and assess implications for the legal intervention in Sri Lanka.

The Constitution of Sri Lanka of 1978 provides a framework within which to address the growing incidence of CKDu within the country. Article 27(14) of the Constitution states that the "State shall protect, preserve and improve the environment for the benefit of the community." This is coupled with duties of every person as enshrined in Article 28 (f), which states that the exercise and enjoyment of rights and freedoms "is inseparable from the performance of duties and obligations and requires every person to conserve nature in addition to ensuring that the rights and freedoms of others are respected. However, Articles 27 and 28 are 'directives of State policy' and do not fall within provisions that are

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[27] "Countries Target Pesticides as Suspected Link to Rare Kidney Disease." Center for Public Integrity. September 20, 2013. Accessed September 9, 2015.

[28] "OEHHA Proposition 65 Intent to List: tetrachlorvinphos, parathion, malathion, glyphosate." Office of Environmental Health Hazard Assessment. September 4, 2015. Accessed September 9, 2015.

[29] Guyton, Kathryn Z, Dana Loomis, Yann Grosse, Fatiha El Ghissassi, Lamia Benbrahim-Tallaa, Neela Guha, Chiara Scoccianti, Heidi Mattock, and Kurt Straif. "Carcinogenicity of Tetrachlorvinphos, parathion, malathion, diazinon, and glyphosate." *The Lancet Oncology*, 2015, 490-91. Accessed September 9, 2015. http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(15)70134-8/fulltext.

[30] "Anatomy of a Riot." La Isla Foundation. April 26, 2013.

justiciable or enforceable. However, these Articles have been used in certain court cases for interpretive guidance of the Constitution.

Clearly, the right to health of individuals has been compromised and as a result of muddled government policy with regard to CKDu. Such failure to take action may be indicative in the best case of negligence, and in the worst case of white-collar thuggery by powerful Multi-national Corporations. What exacerbates the situation is that the Sri Lankan Constitution does not explicitly recognise social cultural and economic rights. However, it is worthwhile exploring whether a remedy can be found in the fundamental rights jurisdiction of the Sri Lankan Constitution.

Human rights advocates are constantly required when litigating in domestic courts to look into creative processes through which they can appeal to existing judicial practice and explore avenues most appealing to the courts; in realising socio-economic rights, such as the right to health. One such approach has been to embrace the idea of interdependence and interrelatedness of human rights. The Human Rights Committee in General Comment No. 6 has noted that the protection of the right to life requires that States adopt positive measures. Accordingly, States must take all possible measures to increase life expectancy, especially in adopting measures to eliminate epidemics. This implies that the right to life (ICCPR) and the right to health (ICESR) are intrinsically intertwined. The Indian Constitution has utilised this rationale to overcome the lack of social cultural and economic rights in its Constitution accepting in one instance that water is one of the bare necessities of life and therefore 'that which alone makes it possible to live becomes part of right to life'. This acknowledges that while right to health and right to water are independent rights on their own, often the effects of their violation affect other rights such as the right to life.

Unlike its Indian counterpart, the Sri Lankan Constitution does not recognise the right to life. However, the courts in a case dealing with unlawful detention interpreted the right not to be deprived of life and, by necessary implication, to mean recognition of a right to life. The court of appeal commenting on public nuisance in *Singalanka Standard Chemicals v Thalangama*, a case on aluminium factory, furthered this negative obligation of the state to a positive right. Accordingly, the right to life would take within its sweep the right to a decent environment. This was under the rationale that rights must be interpreted broadly, and the purpose of protecting fundamental rights must be deemed to have conferred all that is reasonably necessary for this Court to protect those rights effectively. This opens the door for those aggrieved by Chronic Kidney Disease to seek remedy in the Fundamental Rights Jurisdiction, in the highest court of the land.

In addition to these Constitutional guidelines, Sri Lanka in 2009 set out a National Policy on Prevention and Control of Non-Communicable Diseases (NCD) which identifies chronic renal diseases as a major cause for concern. The Policy considers the right to health as one of its key guiding principles, and highlighted that chronic renal diseases of unknown aetiology are emerging public health issues which have been reported from the North Central and North Western provinces. It goes on to say that the specific causes are still being investigated and appropriate specific interventions may be required in the future. It

is also important to note that the National NCD Policy was to be reviewed in response to changing needs and updated in 5 years from 2009.

With reference to Sri Lanka's regulatory provisions that are relevant to the control of CKDu, the Control of Pesticides Act No.33 of 1980 does not expressly deal with issues of cumulative effects of having used pesticides over a long time. Regulations that have been developed by the Sri Lanka Standards Institute to measure the content of pesticides in food or water, but there are no enforcement mechanisms for such standards. In July 2014, a parliamentary debate was conducted on the regulation of pesticides in Sri Lanka. The then Health Minister Maithripala Sirisena stated that the harmful agro-chemicals have led to health hazards such as kidney ailments and that various research conducted by prominent institutions have proved this fact.[31] However, no concrete action has resulted from this debate.

Certain legal remedies may be available to those affected by CKDu by the provisions of the Consumer Affairs Authority Act No. 9 of 2003. The Authority is able to entertain complaints concerning "unfair trade practices". The Authority can impose a fine on manufacturers/ traders and order compensation to be paid to the consumer where it determines that the goods fail to meet a standard/specification/warranty/guarantee, under section 13(4) of the Act. Where goods do not conform to the standards set by the Authority it can apply to the High Court to forfeit and destroy such goods (section 61 and 62).

The possibility also exists of pursuing a product liability claim in the District Court under the common law (Roman Dutch law) where it is possible to claim for damages through a delictual action. This legal action however, will need to prove that the either products/goods do not conform to a standard which has been difficult prove in the instance of agro-chemicals.

A brief overview of the following cases is presented chronologically to provide insight into the nature of legal intervention in matters of 'agro-chemicals vs public health'. [32]

August, 2011:

The Centre for Environmental Justice filed action on 5th August 2011 in the Court of Appeal against the Registrar of Pesticides, the Central Environmental Authority, and the Commissioner General of Agrarian Development, Consumer Affairs Authority and the Attorney General - *Centre for Environmental Justice (Guarantee) Ltd. V. Registrar of Pesticides and 4 others* (CA Application No. 531/2011)

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[31] Marasinghe, Sandasen, and Disna Mudalige. "Moves to Control Use of Pesticides." Dailymirror.lk. July 23, 2014.

[32] This section of the article contains data from the presentation prepared by Shashika Bandara and Dinushika Dissanayake on behalf of the Law & Society Trust, which was disseminated at a regional conference organised by European Center for Constitutional and Human Rights.

The Petition was filed requesting the Court to make an order investigating the importation of pesticides containing significant amounts of arsenic into the country, and to inquire from the authorities, as to what remedial action they would take. The Petition alleged that 9 pesticides were found with significant amounts of arsenic, including insecticide accurator (carbofuran 3%), and Herbicide powermet 36% and 7% of other pesticides.

January, 2012:

In 2012, a case was filed in the Court of Appeal by several petitioners including Dr. Channa Jayasumana of Rajarata University based on research findings on the link between glyphosate and kidney disease - *Green Party v. The Registrar of Pesticides and Others.* Petitioners sought an enjoining order against the permission granted by the Pesticides Registrar to import pesticides with arsenic. Defendants included the Registrar of Pesticides and 5 companies that import pesticides into Sri Lanka. According to counsel representing the Petitioners, the case was withdrawn in November 2014, and the Attorney General (State counsel) had stated that regulations would be formulated. LST is informed that the Court had seemed reluctant to intervene in what it deemed as state policy.

May, 2014: Public Health Ruling:

The Court of Appeal in 2014 denied a tobacco company's request to delay implementation of regulations on public warnings on cigarette packages. Anil Gooneratne J. in *Ceylon Tobacco Co. v. Minister of Health* recognised that the right to health of citizens is paramount and must be balanced with the commercial interests of companies.[33]

Based on the above ruling the Supreme Court ordered Ceylon Tobacco Company to abide by health ministry regulation starting first of January, 2015.[34] Further there is an effort to amend the National Authority on Tobacco and Alcohol Act.[35]

The above principle, of promoting public health, mirrors that which is recognised in Article 15 (7); that exercise and operation of fundamental rights enshrined in Articles 12, 13(1), 13(2) and 14 are subject to such restrictions as may be prescribed by law in the interests of the protection of public health. Accordingly, since a citizen's fundamental right to engage in lawful trade is guaranteed by the Sri Lankan Constitution as per Art.14(1)(g), it is subject

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[33] (*Ceylon Tobacco Co. v. Minister of Health*, C.A. (Writ) 336/2012, C.A Minutes 12.5.2014)

[34] "Supreme Court Orders Manufacturer to Include Graphic Health Warnings." Supreme Court Orders Manufacturer to Include Graphic Health Warnings. July 11, 2014. http://www.tobaccojournal.com/Supreme_Court_orders_manufacturer_to_include_graphic_health_warnings.52504.0.html.

[35] "In the Matter of Article 122(1)(b) of the Constitution." Tobaccocontrollaws.org. February 6, 2015. http://www.tobaccocontrollaws.org/litigation/decisions/lk-00000000-in-the-matter-of-article-1221b.

to restrictions as may be prescribed by law in the interest of public health (Art 15(7)).[36,37] In the case of CKDu, this may be a tool for the judiciary to use, in the event any governmental action regulating the use of agrochemicals is challenged by the companies on grounds of violating their fundamental right to engage in lawful trade.

Conclusion

Mere understanding of legal or medical avenues might not be sufficient for effective combating of CKDu in Sri Lanka. As per recent developments tracked in this essay, it is evident that CKDu/CKDnt has progressed a lot further over the years since the 1990s. However, the world has only just started to notice. In Sri Lanka especially, many initiatives to combat the disease turn into token initiatives that are not very effective. As the death toll rises, as in Nicaragua, people may take to extreme measures to find a solution. The demand for treatment is very high and the demand for dialysis machines is also increasing. However, it is important to note that addressing these demands alone is only as good as placing a Band-Aid over a festering wound. Money and effort is needed in the field of research, to move further beyond the WHO reports and also to remedy the negative social effects such as ostracism of patients in affected communities. Therefore, a sense of urgency is needed to be instilled; starting from media institutions to government officials, before the disease completely cripples the agricultural workforce as well as rural social structures.

At present glyphosate has been banned again from Sri Lanka by the current President Maithripala Sirisena. Despite the ban, tea plantations will continue to receive controlled amounts of the chemical according to government officials.[38] While such preventive and pro-active measures are important, it is also vital that livelihoods are also considered. Alternative farming strategies or proper training in pesticide usage could be considered as starting points in eradicating CKDu/CKDnt as well as other potential diseases caused by improper use. More importantly, it is vital that initiatives to combat Chronic Kidney Disease in Sri Lanka do not waiver with changing governments so that the efficiency of the efforts are maintained through continuity.

Additionally, CKDu/CKDnt has been recognised as more than a mere local crisis. Therefore, it is important to collaborate with international actors and other affected countries in terms of scientific research to find definitive answers as well as legal research to avoid exposing communities to potentially hazardous policies; since time is a factor as thousands remain sick collaborative efforts may be the fastest route to find an effective solution.

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[36] 'Sri Lankan Court of Appeals Balances Trademark Rights and Promotion of Public Health', Althaf Marsoof, Journal of Intellectual Property Law and Practice, 21st July 2014, accessible at http://jiplp.blogspot.com/2014/07/sri-lankan-court-of-appeal-balances.html.

[37] Marsoof, A. "Sri Lankan Court of Appeal Balances Tobacco Trade Mark Rights and the Promotion of Public Health." *Journal of Intellectual Property Law & Practice*, 2014, 708-10. http://jiplp.oxfordjournals.org/content/early/2014/07/16/jiplp.jpu131.abstract.

[38] Wijedasa, Namini. "It's Official: Glyphosate Import Is Banned." Sundaytimes.lk. June 14, 2015. Accessed September 9, 2015.

Chronic Kidney Disease: Clarifying Misconceptions and Assumptions and Outlining Essential Treatment and Preventive Measures

Ranjit Mulleriyawa*

Introduction

This paper attempts to discuss and clarify some misconceptions and assumptions pertaining to Chronic Kidney Disease (CKD) as well as outline essential treatment and preventive measures.

CKD is believed to be the second most prevalent non-communicable disease in Sri Lanka at the present time accounting for the death of over 1000 people each year. About 2000 new patients seek treatment for end stage renal disease each year. Many times that number may be developing clinical symptoms of the disease and progressing towards end stage renal failure.

The Ministry of Health spends over 400 million rupee annually in the management of renal disease (on dialysis, transplants etc). Costing the loss to the Nation's labour force, defies quantification.

CKD is defined as having some type of kidney abnormality, or "marker", such as protein in the urine and having decreased kidney function for three months or longer.

CKD is a worldwide public health problem accounting for about 10 per cent of the global population. Even with the best available treatment, CKD tends to be a slowly progressive disease resulting in 150 to 200 End Stage Renal Disease (ESRD) patients per annum per million population. *ESRD is a chronic irreversible condition that will ultimately lead to death within six to twelve months unless treated effectively.*

There are many causes of CKD. Some kidney conditions are inherited (run in the family.) Diabetes is known as the leading cause of kidney disease. High blood pressure (also known as hypertension) is another common cause of kidney disease. Some other factors which may lead to kidney damage are urinary tract infections, the over use of drugs and medication and pain relievers for a long time), hard drugs like heroin and 'crack', alcoholism, dehydration, snake bite and infectious diseases like leptospirosis ('rat fever'). Besides the

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above known causes, there are kidney diseases caused by hitherto unknown factors. One such disease is *Chronic Kidney Disease of Uncertain Aetiology (CKDu)* which is proving to be a serious health issue among farmers in several parts of Sri Lanka's dry zone.

Symptoms of the disease

Clinical symptoms of CKDu are: fatigue, panting, lack of appetite, nausea, anemia and swelling of feet and face (towards the later stages). The disease is said to be 'chronic' because it takes many years for symptoms to develop. A significant observation with respect to CKDu is that some patients afflicted with the disease do not manifest any abnormal symptoms until their kidneys have been seriously damaged.

The following case history narrated by Dr. Lishanthe Gunarathne, Medical Officer in Charge of the Renal Unit at Girandurukotte Hospital clearly illustrates this point:

> *"A 36 year old unmarried male patient came to me recently with a history of headache for five days. He appeared quite healthy. However a blood test revealed serious kidney damage – his GFR (Glomerular Filtration Rate) was 2ml/min/1.73 m2. (In a normal healthy adult,GFR is over 90) I helped him obtain immediate treatment at the nephrology unit of Kandy Hospital, but I heard that he had died after a few weeks."*

Kidney damage caused by diabetes and hypertension manifests similar clinical symptoms, but CKDu patients do not have a prior history of diabetes or hypertension.[1] Post mortem studies of kidneys (histo-pathological studies) of CKDu patients reveals damage to urinary 'tubules', whereas diabetes and hypertension induced kidney damage is said to mainly affect blood vessels. Damage to urinary tubules is frequently associated with nephro toxins (substances toxic to the kidneys).

History of the disease and its investigation

An Assistant Government Agent (AGA) working in Padaviya (North Central Province) around 1990-92, was alarmed by many mysterious deaths occurring in his area, and drew the attention of officers in the provincial health sector to the problem. Credit for the first detection and diagnosis of CKDu is attributed to Dr. Thilak Abeysekere, a nephrologist attached to Anuradhapura hospital at the time.

A few years later, the disease was also reported from villages in Medirigiriya in Polonnaruwa district. All the above areas fall within the North Central Province (NCP). As such, many persons began to refer to the disease as CKDu in the NCP. However, the same disease was also observed to occur among farmers in Girandurukotte and Mahiyangana (Uva Province) and Dehiattakandiya (Eastern Province). There were also reports from

Nikawewa (in the North-Western Province) of CKDu cases. All the above areas fall within the 'dry zone' of Sri Lanka.

From existing reports and records, it is apparently evident that prevalence of CKDu is in six out of the nine provinces in the country. Only the Western, Southern and Sabaragamuwa provinces appear to be free of CKDu.

Detection of the disease in areas outside the NCP may be due to improved diagnostic facilities, widespread countrywide screening of vulnerable populations, as well as increased and heightened awareness among the people prompting their active participation in screening programs.

Reliable countrywide statistics of confirmed CKDu patients are still unavailable. However, reliable and most recent statistics of CKDu patients currently afflicted by the disease in the NCP is 19,000. Total population in the NCP is around 1.3 million. Number of deaths due to CKDu in the NCP is estimated at 10-15 persons per month.

The disease is predominantly confined to male farmers over the age of 40. More males are affected by the disease, the ratio of male to females affected by the disease ranges from 3:1 to 2.4:1. CKDu has not been diagnosed in children below the age of 15.

Scientists have been researching the etiology of the disease for almost two decades, but they have still not been able to determine scientifically valid and convincing evidence as to the specific cause of CKDu. Many questions need to be asked in unraveling the mystery of this disease. Some such questions are enumerated below:

1. What is/are the nephro-toxic substance/s?
2. How does the toxic substance enter the human body?
3. Why is the disease confined to the dry zone and farmers?
4. Why is there no manifestation of the disease in some dry zone areas (eg. Ampara, Batticaloa, Kalpitiya and Hambantota)?
5. Why has CKDu emerged as a major health problem only during the past 20-25 years?
6. Why is the incidence of CKDu prevalent in older people (mostly among those in the age category of 55-60 years)
7. Why are more men (than women) affected by this disease?

Because biopsy of kidney tissue of confirmed CKDu patients clearly indicate damage caused by some toxic substance, it is necessary to investigate and identify the responsible toxin/s, and also, determine how they enter the human body.

Toxic substances (toxins) can enter the body through food, drinking water, air, or skin contact. However, the specific toxic substance/s causing CKDu is still unknown although it is widely believed that drinking water and/or the food chain may be the main mode of entry

of toxins. Several hypotheses have been suggested as possible causes of the disease. The main hypotheses advanced thus far are briefly discussed below.

Fluoride Hypothesis -2004

Professor Oliver Illeperuma, (Dept. of Chemistry, University of Peradeniya) and his research team consisting of Geologists and Chemists, attributed CKDu to high fluoride content (2-5 parts per million) in drinking water and the use of low quality aluminum utensils for cooking and storing water. They observed a close positive correlation between fluoride content in ground water (well water) and distribution of CKDu patients. The WHO permissible limit for fluoride in drinking water is said to be 0.6 parts per million (ppm).

Fluoride in water was believed to react with aluminum in utensils (cooking utensils and aluminum pots used for water storage) forming aluminum-fluoro complexes which enhances the entry of fluoride into the human body. High fluoride content has been shown to result in kidney damage in rats. However, the nephro-toxic effects of fluoride in humans do not seem to have been firmly established as yet.

If fluoride is indeed the main "culprit" responsible for CKDu, the question remains as to why CKDu has not been detected in other areas (Ampara and Hambantota) having even higher levels of fluoride in ground water. Illeperuma's contention is that people in these areas prefer to drink water from irrigation canals since well water tends to manifest high salinity. "Canal water has less fluoride and salt".

Heavy metals in drinking water (cadmium and arsenic)

According to the available evidence, none of the metals which have guideline values, including nephrotoxic metals such as cadmium (Cd), arsenic (As), and lead (Pb), are present at toxic concentrations in the drinking water consumed daily by people in CKDu areas.

It is also interesting to note that symptoms of arsenic toxicity – skin lesions and pigmentation, and cancers- are very different from CKDu. Likewise, medical specialists state that Cd toxicity results in Osteoporosis (ref. "itai itai' disease in Japan). CKDu patients manifest symptoms of bone sclerosis (thickening of bones).

The WHO study tested a wide variety of food (rice, vegetables, locally grown pulses, fresh water fish etc.) for cadmium, and arsenic. Cadmium levels in rice, in both CKDu endemic and non endemic areas were found to be less than the maximum permissible limit. They found only three items (viz. Lotus rhizomes, tobacco and tilapia fish) that contained Cd levels above the maximum permissible level. No mention is made of the arsenic content in food.

The Department of Agriculture tested 28 rice samples from CKDu endemic areas, and detected arsenic content of any significance only in three samples. In the light of the above findings, fears of arsenic poisoning through drinking water and locally grown food would

seem to be unwarranted, and the role of arsenic as a causative factor of CKDu would appear to be speculative.

Quality of Drinking Water and CKDu

Drinking water obtained from shallow dug wells in most CKDu endemic areas tends to contain high (over 1 ppm) concentrations of fluoride and dissolved calcium and magnesium salts contributing to the condition referred to as 'hard water' (*Kivula*). People drinking "tap water" (in Anuradhapura town) obtained from open reservoirs ('tanks') like Nuwara Wewa and Thuruvila do not appear to suffer from CKDu. Reservoir water in general contains less fluoride (less than 0.6 ppm) as well as lower concentrations of salts of calcium and magnesium.

Villagers drinking spring water ("*ulpath watura*") in areas like Kebithigollewa in Anuradhapura district do not seem to be affected by CKDu. This water has also been found to be of 'good quality' (low in fluoride and salts). These observations have contributed to the belief that improving the quality of drinking water may help mitigate the disease (CKDu).

Dehydration

Recent research indicates a spike in the number of CKDu patients reporting at hospitals during the dry season (June-September). This observation has heightened an interest in investigating the possibility of dehydration as a causative factor of CKDu.

Fertilizers, Pesticides and CKDu

The commonly held belief that inorganic fertilizers and pesticides associated with modern agricultural practices are causing CKDu appears to be an assumption. There is no convincing scientific evidence at present to prove that fertilizers and pesticides used by farmers are causing the disease. No pesticide residues of any significance have been found in either well water or reservoir water.

The only published evidence of a pesticide residue – the herbicide glyphosate in drinking water is by Jayasumana. They recorded 3.5 parts per billion (ppb) of glyphosate in an abandoned well in Padaviya, and 0.7 ppb in a well in use in the same area. These levels are 200 times lower than the maximum permissible contaminant level specified by the U.S. Environment Protection Agency standard (700ppb). There is no Sri Lanka standard for glyphosate in drinking water as yet.

In 1977, the Department of Agriculture permitted use of glyphosate for controlling weeds in non-cropped lands in the hill country and this was extended to all of Sri Lanka in 1994, again for only non-crop lands. Use in paddy fields was permitted only in 1998.

Glyphosate began to be used by some paddy farmers as a pre plant spray applied 10-14 days before ploughing their fields. However, its use by paddy farmers became popular only after the banning of the much cheaper herbicide paraquat in 2010. Price of glyphosate was more than ten times that of paraquat in the early days, and 'poor' paddy farmers could not have afforded it even if they wanted to. It was mainly used in the plantation sector (Coconut and Tea estates) on control of perennial weeds such as *'Illuk'* (Imperata cylindrica). The price of glyphosate plummeted after 2000, when the multinational corporation Monsanto's patent on GLyphosate"*Roundup"* expired, and China began to take over as the world's largest manufacturer of glyphosate. Tea Estates and Coconut plantations are major uses of glyphosate for weed control to this day.

The first cases of CKDu were diagnosed in the North Central Province (NCP) in the mid 1990s- long before the widespread use of the herbicide glyphosate by paddy farmers. CKDu has not been diagnosed in many other parts of the country (Batticaloa, Hambantota, Kalpitiya, Ampara etc) where glyphosate is widely used, and farming practices are similar to the NCP. CKDu has not surfaced in the plantation sector where glyphosate is widely used. Thus, glyphosate as a causative factor of CKDu is untenable and highly speculative.

In perspective, it would appear that none of the hypotheses discussed thus far in this paper provide a convincing answer towards unraveling the CKDu mystery.

Unraveling the 'mystery' and preventing CKDu

"From a hydro geological perspective, all areas where CKDu has been detected, fall within the 'shallow regolith aquifer' region", says Dr. C.R. Panabokke, elder statesman of Sri Lanka's Earth Science Community.

Ground water quality in these areas manifests high levels of fluoride and dissolved salts (mainly calcium and magnesium) contributing to the condition referred to as 'hard water', concurs Professor Oliver Illeperuma (Emeritus Professor in Chemistry, University of Peradeniya). Dr. Sarath Amarasiri (Soil chemist, and a Former Director General of Agriculture), has done detailed studies on the chemical composition of the ground water, especially in the North Central Province (NCP). His research points to increased electrical conductivity of well water, which in turn is indicative of high concentrations of dissolved salts. Underlying geology, climatic factors and land use systems influence the chemical quality of groundwater. Chlorides, fluorides magnesium and iron are the main constituents found to influence groundwater quality. High levels of fluoride in ground water have been reported in the districts of Anuradhapua, Polonnaruwa and Hambantota. It is estimated that approximately 40 per cent of tube wells constructed in dry zone districts during the last decade of the 20th century have had to be abandoned due to high levels of fluoride as well as iron and manganese. This chemical composition results in increased 'ionicity' of the water, and the specific minerals detected (fluoride, calcium and magnesium etc) may have a denaturing effect on proteins and could cause kidney damage in people who drink such water over a long period of time, claims Professor Chandre Dharmawardene, Sri Lankan born Scientist currently domiciled in Canada.

In a recent study initiated by the International Water Management Institute, Manthritillake ,(unpublished paper, presented at a Water Resources Board Seminar in September, 2015), seems to have tied up all the loose ends, and presented empirical evidence to substantiate the hypothesis that pockets of ground water in the 'regolithic aquifer' of the dry zone, contain high concentrations fluoride, chlorides, bicarbonates, sodium, calcium and magnesim ions, which could trigger a "Hofmeister type mechanism" contributing to protein denaturing and resultant kidney damage, as proposed by Chandre Dharmawardene.

Are the pieces in the 'jigsaw puzzle' finally fitting together? This fit does not seem to occur in other parts of the dry zone where CKDu has not been diagnosed (despite similar climatic conditions and farming practices).

Preventing CKDu

Most people living in CKDu endemic villages obtain their drinking water from open dug wells, where the water tends to contain high concentrations of Fluoride (2-4 ppm) and dissolved Calcium and Magnesium salts giving rise to the condition known as "hard water". There is widespread consensus among doctors and scientists that improving the quality of drinking water in these areas may prevent, or retard the progress of this kidney disease This was recognized more than two years ago, but obtaining the required potable wate continues to be an illusion for people in the affected areas.

Despite the above knowledge, our failure to effectively address this issue with a sense of urgency is causing the death of almost a thousand people each year island wide. Many times that number may be developing clinical symptoms of the disease and progressing towards end stage renal failure.

Context of CKDu affected areas

It is essential that the specific context of CKDu affected villages be considered in deciding the most appropriate method of providing clean drinking water to the resident population. People in the disease affected areas are desperately poor. Their houses are widely scattered. The roads are dilapidated. Public services - transport, healthcare, sanitation, education, extension services and communication facilities, are poorly developed. Rural institutions (farmer organizations, rural development societies) are mostly dysfunctional. Electricity is hard to come by; even where electricity is available, voltage fluctuations and interruptions to power supply are frequent.

These areas receive an annual rainfall of 1000-1200 mm. Over 75 per cent of this rainfall occurs within four months of the year (October, Nov. Dec. and January) giving rise to frequent floods. Total annual rainfall tends to be relatively consistent. However its distribution pattern has fluctuated widely in recent years.

Providing clean drinking water through rainwater harvesting

A possible and practical solution for the drinking water problem of these rural communities is the collection and storage of rainwater (one of the purest forms of water available to man) flowing down the roofs of houses during the rainy season. All that is required is a storage structure large enough to collect and store sufficient water to last through the 6-8 months of dry weather (February to September). It is estimated that a household consisting of 5 persons, would require approximately 20 liters of water per day for drinking and cooking purposes (4 liters per person per day). Thus, a storage tank capable of holding 5000 liters is adequate to cope with even a severe drought. This facility (complete with a gutter and down pipe) will cost Rupees 50,000 per household. It requires no maintenance cost (except replacement of the gutter every five years or so). It will last 10 -20 years, and provide households with independent access to potable water at an affordable price (25 cents/liter). Rainwater harvesting is thus the most rational, cost effective, socially acceptable and ecologically sustainable method of providing clean drinking water to widely scattered rural households in the dry zone. The technology involved is simple and easy for rural people to understand, implement and sustain, and its efficacy in providing potable water to rural households throughout the year has been proven by a rainwater harvesting project implemented by a local NGO (Lanka Rainwater Harvesting Forum) in the Vavuniya area. This project has been funded by The United States Agency for International Development (U.S. AID).750 households in Vavuniya district are said to benefit from this project which provides each family with independent access to clean drinking water at their door step.

Other necessary interventions

An effective community health education programme designed to inform rural households on the importance of drinking adequate quantities of water (at least 3liters/adult/day); refraining from smoking, intake of illicit brews (Kassippu), avoiding self medication by rushing to the nearest pharmacy or village *Kade* to purchase strong analgesics (pain killers) for relief of common body aches and pains, and overall improved nutrition is a vital need for residents in CKDu endemic areas. Educating school children on the above issues may help in getting the message across to their parents.

Serious shortcomings in the agricultural extension services (advisory services) of the Department of Agriculture have resulted in considerable misuse of both fertilizers and pesticides by farmers. It is therefore essential to ensure that effective strategies are developed to rectify this deficiency. One possible option is to train farmers to assist fellow farmers in correct application of pesticides. Such 'farmer to farmer extension' has proved very successful in Thailand and some Lain American countries.

Treatment of CKDu

_Kidney disease_can be treated successfully. Careful control of diseases like diabetes and high blood pressure can help prevent kidney disease or keep it from getting worse. Kidney

stones and urinary tract infections can also be treated successfully. Because the exact causes of some kidney diseases are still unknown, specific treatments are not yet available for them. Sometimes, chronic kidney disease may progress to kidney failure, requiring dialysis or kidney transplantation.

Kidney failure may be treated with haemodialysis, peritoneal dialysis or kidney transplantation. Treatment with haemodialysis (the artificial kidney) is usually performed in hospital (dialysis units). Such treatments are usually performed three times a week. Peritoneal dialysis is generally done daily at home. Continuous Cycling Peritoneal Dialysis requires the use of a machine while Continuous Ambulatory Peritoneal Dialysis (CAPD) does not. A kidney specialist (Nephrologist) can explain the different approaches and help individual patients make the best treatment choices for themselves and their families.

Kidney transplants

Kidney transplants have high success rates. The kidney may come from a brain dead person (cadaver) or from a living donor who may be a relative, friend or possibly a stranger, who donates a kidney to anyone in need of a transplant. Sri Lanka has made rapid progress in recent years in treatment of end stage renal patients by providing dialysis and transplants. Progress made by the Kidney Center at the Kandy Teaching Hospital is most impressive. This Center currently has the highest number of hemodialysis units (30) at any one place in the country and it also performs approximately three transplants per week at present. It has performed almost 850 kidney transplants during the past ten years, and actively follows up another 1,200 patients.

The Renal Center at the General Hospital, Kandy has also recently launched a Cadaver Transplant Programme. It has already performed 80 Cadaver Transplants. Many of these transplant patients are leading normal productive lives.

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