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

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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.[1][2]

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 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

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[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

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.

References

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