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SUSTAINABLE MEASURES TO SAFEGUARD THE FAMILIES OF CKDU, ELEHARA DIVISIONAL SECRETARIAT IN THE POLONNARUWA DISTRICT, SRI LANKA.

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Abstract: Chronic Kidney Disease of Unknown Etiology(CKDu) is known as a kidney disease in patients who do not exhibit common causative factors such as diabetes or hypertension. There appears to be a link to people working in the soil and as agricultural workers. A large and growing number of Sri Lankans suffer from CKDu since the early 1990s. Since then, there has been a rapid increase of CKDu cases with a cluster of cases occurring in five endemic areas of the country. The CKDu positive population increased from around 21,000 in 2011 to over 25,000 by the end of 2013 based on 20.6% prevalence rate (Presidential Task Force in Chronic Kidney Disease Prevention, 2017). The majority of patients are lower income male farm workers in the age range of 30 to 60 years. The impact of the disease is traumatic on patients and their families where they are often unable to pay the high cost required for medical treatments.

CKDu occurs in areas where groundwater is the main source of drinking water due to the high concentration of fluoride in ground water. Furthermore, Sri Lanka- being a country of heavy rice consumption is therefore the second highest among the countries due to the high levels of toxic heavy metal cadmium found in rice. Both factors found to be creating a positive environment to spread the disease in endemic areas of the country. This study was conducted in Elehara DS area of the Polonnaruwa district, which is one of the areas having highest concentration of CKDu in the North Central Province.

Research objectives of this study include the investigation of environmental and socio-economic factors affecting the prevalence of the disease, identifying the socio-economic and cultural problems confronted by affected families, assessing the effectiveness of welfare strategies carried out by specific institutions in the area on sustainable basis to overcome the problem. This study revealed that the main reasons to develop the illness of the area are mainly; high concentration chemicals that entered ground water due to excessive use of fertilizer and insecticides, existing higher fluoride levels of the soil due to environmental reasons, using groundwater as the main source of drinking water and lastly, the consumption of rice and fresh water fish grown in this soil.

Among the problems confronted by CKDu patients, the declining ability to work and loosing employments, social isolation and marginalization, dependency upon the other family members for living and future uncertainty have been predominant. In the case of affected families, it was discovered that the collapse of the economic situation and poverty, interruption to children's education, collapsing social and kinship relationships, and labelling as vulnerable groups have been significant. Several government sponsored welfare programs implemented in the area seems to be targeted at enhancing the socio-economic situations of the affected families. Therefore, it is apparent that empowerment programs to find sustainable and long term solution to the problem should be implemented.

Key words: CKDu, Labelling, empowerment Marginalization, family welfare and

INTRODUCTION

Social problems may vary from time to time and society to another based on unfavourable conditions developed within. However, a common situation witnessed globally was that they affect the smooth functioning of livelihood among people in these communities. Chronic Kidney Disease of Unknown Etiologic (CKDu) is also one of the social problems found to be recently developed among several developing nations including Sri Lanka during the recent past.

Chronic kidney disease (CKD) is known as the progressive loss in kidney function over a period of months or years. It has been internationally recognized as a public health issue affecting 5–10% of the world population (Eknoyan, Lameire, Barsoum et al. 2004). Medical investigations have identified that diabetes and high blood pressure are common causes of chronic kidney disease. However, CKDu is known as a kidney disease in patients who do not exhibit common causative factors such as diabetes or hypertension.(Elledge et al. 2014) Many of the affected communities of CKDu being agricultural workers and farmers, scientists are commonly sharing a view that it has a link to the environmental conditions of those particular areas.

A large and growing number of Sri Lankans suffer from CKDu since the early 1990s. Since then, there has been a rapid increase of CKDu cases with a cluster of cases occurring in five endemic areas of the country. The CKDu positive population increased from around 21,000 in 2011 to over 25,000 by the end of 2013 based on the 20.6% prevalence rate. The majority of patients are lower income male farm workers in the age range of 30 to 60 years. The impact of the disease is traumatic on patients and their families where they are often unable to afford the high cost required for medical treatments (Presidential Task Force in Chronic Kidney Disease Prevention, 2017).

Among the problems confronted by CKDu patients, the declining ability to work and unemployment, social isolation and marginalization, dependency upon the other family members for living and future uncertainty have been predominant. In the case of affected families, it was discovered that the collapse of the economic situation and poverty, interruption to children's education, collapsing social and kinship relationships, and labelling as vulnerable groups have been significant.

Other than the medical treatments available to those patients in government hospitals, there are several welfare programs sponsored by government and non-government organizations implemented in those affected areas for enhancing the socio-economic situations of the affected families. This study is mainly aimed at investigating the type of welfare measures carried out by external agencies to uplift the living conditions of the affected families and their sustainability in a selected community of Sri Lanka.

CKDu and its implications in Sri Lanka

The geographical distribution of CKDu patients were found to be concentrated in dry zone regions of Sri Lanka where agriculture is the main economic activity of the majority of people. (Victorian, 2008) It includes North Central and North Western provinces, Uva, Eastern, and Northern Provinces in where the occupation is over 2.5 million. According to a news report following a December 2013 symposium on CKDu organized by the National Academy of Sciences of Sri Lanka, experts at the symposium estimated that the number of CKDu patients in the endemic areas was 20,336 (Victorian,2008).

Community screening of CKD/CKDu patients by the Ministry of Health has identified 38,000 patients by the end of December 2014. Anuradhapura and Polonnaruwa Districts reporting approximately 1,000 and 500 CKD/CKDu patients annually during the past four years (Ministry of Health 2015).

According to available health statistics there are approximately 20,000 admissions/ re-admissions of patients with renal failure to government hospitals with approximately 2,000 deaths annually (Presidential Task Force, 2017)

In Sri Lanka, the aetiology of CKDu is uncertain. However the disease is attributed to several causative factors including high use of agrochemicals, hard water which include high levels of Calcium and Fluoride, dehydration due to inadequate drinking of water and heat, and presence or absence of certain chemical compounds (eg. High levels of Arsenic and Cadmium, low levels of Selenium).

Research has revealed that the victims of CKDU in affected areas were subjected to this vulnerability due to several reasons. These studies uncovered that the main reasons to develop the illness was mainly; high concentration chemicals that entered ground water due to excessive use of fertilizer and insecticides, existing higher fluoride levels of the soil due to environmental reasons, using groundwater as the main source of drinking water and using metal utensils for food preparation (Wanigasuriya 2012). In addition, majority of these patients are lower income farm workers who frequently work in agricultural land where dehydration occurs due to excessive heat and also lack access to drinking water due to the dry zone climatic conditions. Furthermore, some socio-cultural factors were also found to be contributing to increase the vulnerability of these affected families. Among the victims, a majority is represented by poor agricultural workers who work with soil that is highly contaminated due to environmental reasons (Ranasinghe and Ranasinghe 2015). Also due to the low income situation and the malnutrition of many such agricultural workers, the daily food intake was insufficient to gain access to adequate levels of selenium to their bodies to improve the resistance to such sicknesses. Furthermore, several other cultural habits such as excessive tobacco and alcohol consumption have served as contributory factors to increasing vulnerability. Finally, taking into all this environmental and socio-cultural factors, it has been ensured that this illness was highly concentrated among men than women in affected communities (Victorian 2008)

In response to the higher increase of CKDU patients in affected communities, Sri Lanka's Ministry of Health (MOH) established CKDu disease registries at district hospitals in the dry zone provinces in 2009. However, it has been reported that many rural residents tend to self-treat their ailments or seek ayurvedic treatment, and they do not seek western medical care until symptoms are severe. Also in some endemic areas it has been reported that patients were having fear or stigma associated with a formal CKDu diagnosis. Combining, these factors- CKDU remained under estimated and unrecognized.

As far as the actions undertaken to assist the CKDU victims are concerned, the following strategies have been implemented under the sponsorship of the Sri Lankan government in collaboration with the Ministry of Health:

i. Screening for early detection of the disease through selected communities.
ii. Strengthening of the 04 curative sectors for management of the CKD patients

a. Primary Health Care Units
b. Nephrologists Visiting Centers
c. Hospitals with Dialysis Facilities
d. Nephrology Visiting Centers

iii. Introduction of CKD/CKDU surveillance and patient registries in high-risk areas
iv. Providing Financial Assistance to CKD/CKDU patients (Presidential Task Force, 2017).

Several government sponsored welfare programs implemented in the area seems to be targeted at enhancing the socio-economic situations of the affected families. Therefore, it is apparent that empowerment programs are requires to find sustainable and long term solutions to the problem.

The research problem of this study is to investigate the socio-economic and cultural problems confronted in the implementation of welfare programs by the governmental and non-governmental organizations to enhance the family welfare of the CKDu affected people.

OBJECTIVES OF THE STUDY

Research objectives of this study includes the investigation of environmental and socio-economic factors affecting the prevalence of the disease, identifying the socio-economic and cultural problems confronted by affected families, assessing the effectiveness of welfare strategies carried out by specific institutions in the area on sustainable basis to overcome the problem. Accordingly, this study is mainly targeting to achieve following objectives.

a. To identify the impact of CKDu to the patients and their families.
b. To investigate the strength and weaknesses of the welfare strategies implemented by government and non-government institutions to enhance family welfare of such victims.
c. To introduce suitable strategies and methodologies to improve their living through socio-economic and psychological enhancement.

Research methodology

As per the statistics of the Ministry of Health, there has been 4369 CKDu patients identified in Polonnaruwa district by the end of December 2015 and among them many incidents of the sickness were reported from Madirigiriya and Elahera Divisional Secretariat areas. (MOH Office Anuradhapura, 2015) The Elahera DS area where there were relatively a higher number of 402 patients reported, was selected as the study area. For this study a representative sample of 10 percent was randomly selected as the sample is comprising of 40 CKDu patients including 40 families.

This study incorporated mixed research design in a way that both quantitative and qualitative information were easily being collected. In view of gathering information from respondents and their families, the survey design was administered with a structural questionnaire. For the purpose of collecting more reliable and qualitative information, in-depth interviews and focus group discussions were conducted with relevant personnel. In the analysis of causal relationship between certain quantitative variables, it incorporated qualitative information to ensure the reliability of findings.

Socio-economic conditions of the CKDu patients in the sample

This study examined the age structure, gender difference, and educational level of the CKDu affected people in the sample and itwas revealed that the majority of them (37.5%) represents the age category of 49-61 years. Many of such patients were found to be engaged in either agriculture or mining as labourers. Contrastingly, the elderly within 62-74 age category in the sample were limited to 30 percent and the young category within 08-20 years were only 05 percent. It shows that CKDu has prevalent among people in various age categories, while it has was more intensified among working age in rural communities. Therefore, its impact to the rural economy seems to be more challenging over the years. With regard to gender of patients in the sample, it was evident that almost 70 percent were males. Combining the age and gender categories, it is evident that working men in agriculture and mining were highly exposed to this epidemic condition. As one male agricultural worker of 52 years in the sample points out,

> "The main reason for us to expose this disease is our frequent stay in paddy fields. Since we repeatedly apply agro chemicals as fertilizer and pesticides in agriculture, more men are subjected to the disease than women. Nowadays, it is difficult to
>
> cultivate paddy without these agro chemicals which invaraibly caused us exposed to the disease." (Source: In-depth interview of 52 year old famer)

Low education among victims also seems to be contributing to existing ignorance on possible precautions in the use of agro chemicals. Among the victims of the sample 45 percent had never gone to school. Another 25 percent had received education only up to grade one and those who received education up to primary level accounted to 20 percent. Only 10 percent of the patients in the sample received education up to grade 09. Therefore it seems that low level of education has been a significant factor instrumental to high prevalence of this disease.

Possible reasons for the sickness

As per the information received from the study, it is clear that human activities in the area seems to be contributed to widen the exposure to the disease. The following reasons were given by the CKDu patients in the sample affirm the situation.

Table No. 01- Reasons for the CKDu Illness

Reasons for the Illness	Number	Percentage
Contamination of underground water by use of chemicals	12	30
Increased use of agro chemicals	08	20
Higher concentration of chemicals in soil	14	35
Consumption of fresh water fish	06	15
Total	40	100

Source: Filed Survey 2017

The higher concentration of agro chemical in soil has been one of the major reasons contributed to growing the illness. The higher dependency on agro chemicals in agricultural work has caused to contaminate the ground water quality and drinking such water has largely contributed to this situation. Also, the consumption of fish grown in ponds at the areas that were being affected by such chemicals has led to amplify the growth of this illness. Furthermore, frequent work in paddy fields and mines contaminated with

contaminated soil could have been another reason resulting in the higher concentration of this illness among men. As one CKDu affected famer pointed out,

> *"We mostly use agro chemical "Round Up" because it not only eliminate of weeds, but also it reduced the hardness of soil to grow paddy very well. When we drink such water we invariably become victims of the illness. Since we don't have any other source of drinking water, this has been the main reason to affect kidney disease among many people in the vicinity." (Source: In-depth Interview with a farmer 52 years old)*

With regard to the problems confronted by CKDu patients, following issues were revealed from the sample.

Table No. 02- Problems Confronted by the Victims of CKDu

Problems	Number	Percentage
Labelling	18	45.0
Livelihood breakdown	11	27.5
Dependency on children	06	15.0
Psychological loneliness	05	12.5
Total	40	100.0

Source: Filed Survey 2017

The above table shows that CKDu affected people were found to be confronting various socio-economic problems in their communities due to this illness. Majority of them were of the view that they have been socially marginalized by the rest of the community labelling as ill fated. They have been avoided from maintaining social relations such as matrimonial and friendship. One such individual in the sample pointed out,

> *"Villagers used to name us as "Vakugadu Karayo- Kidney affected people." They think probably we will die by tomorrow and useless to have relations with us. Even some people refuse to give us wage labour too. This situation more depressive than the illness itself." (Source: Focus group discussion held in 26-04-2017 with a group of victims)*

As revealed from the discussion with a group of CKDu patients, many farmers who previously engaged in paddy cultivation with a good income have either leased or sold their land. This is because they are physically not fit enough to carry out such work. This unfavourable situation has caused them mostly to depend on their children's income.

It is evident that this livelihood of many farmers, labourers and mine workers has been lost creating a dependency syndrome.

As some respondents in the sample pointed out, they were not able to either find a source of income, or spend for their familys' basic needs such as food and education of their children. Various other family issues has developed unexpectedly through such livelihood issues.

Programs implemented to enhance the family welfare of CKDu patients

There were a number of welfare programs implemented by the government organizations to improve the family welfare of the affected families in the area. Many such programs were specially aimed at improving the socio-economic environment of the patients. However, there were no evidence to trace the interference of NGOs in assisting them.

As one CKDu patient in the area pointed out,

"There were no mentionable program implemented by NGO sector in the area. One medical clinic held in the area by one philanthropist had meagre impact to the patients as there was no continuity in that program. However, at present the government grants Rs. 3,000 per patient as a subsidy and it seems to be significant to those who did not have any income. Also the Housing Development Authority provides a housing grants to affected families ranging from Rs. 2, 50,000- 500,000 free of charge. Since, this grant is available on progressive stages of construction, the grantees are compelled to complete the construction continuously without wasting the fund. However, there are some problems in the implementation of this program due to the interference of some politicians of the area and consequent malpractices." (Source: In depth Interview with a farmer of 65 years old)

It is evident that, there are some formal mechanisms adopted by the government for the family welfare of the CKDu patients. However, psycho-social programs targeting to uplift those victims who confronted social isolation and frustrations seem to be marginal. Also, political interference to the government subsidy programs have resulted to depriving these assistance to some needy families.

Views of respondents for suitable programs to minimize CKDu

Other than the existing programs for enhancing the welfare of CKDu affected families, respondents were proposing following other measures to overcome this problem.

Table No. 03- Proposed Measures to Minimize the Impact of CKDu

Proposed Activities	Number	Percentage
Organizing clinical service locally	18	45.0
Carrying out village level psycho-social programs	11	27.5
Introducing new livelihood activities	06	15.0
Continuously taking part in Clinics	05	12.5
Total	40	100.0

Source: Filed Survey 2017

As per the views of respondents, activities such as establishing clinics at village level for facilitating necessary treatments for patients, psycho-social programs aiming at to solve socio-economic and psychological problems confronted by such families, introducing appropriate livelihood earning activities for needy families seem to be more important. As revealed from a group discussion with patients it revealed following requirements.

"Presently, there is an increasing prevalence of CKDu in the area. This has affected both adults and children differently. Therefore it is better to expand the clinical services for patients at village level. This need to be held at least twice a month in collaboration with Medical Office of Health (MOH) and Divisional Secretariat office DSO). Sensitizing people about the illness and its possible precautions might definitely help to reduce the prevalence, since such programs are rarely visible locally. There seems to be poor attention to sensitize students at school level too." (Focus Group Discussion with victims, 25-03-2017)

Some respondents were of the view that psycho-social programs to assist the patients and their families seems to be a growing necessity of the area. Since there are no such programs, it has negatively affected the mental stamina of the affected people and families.

Changing the existing poor attitudes of peer villagers towards patients, encouraging patients and their families to find alternative livelihoods, assisting victim families to solve their multitude of issues are some needs that requires implementation at village level through such programs.

As one mine worker in the sample pointed out,

> *"Many people have become depressed with the illness. Some are even reluctant to engage in treatments due to labelling and isolating them as kidney patients. They believe that it will not be possible to engage their daily work while receiving m medical treatments. With the frustration that they will die soon, some victims neglect the illness and continue their wage labour or agricultural work." (Source: In depth interview with a mine worker of 54 years old)*

It was visible that some patients seem to neglect the recommended medical treatments such as dialysis since it may hamper their day to day earnings. Therefore, it seems the necessity of implementing psycho-social programs to improve the mental health of victims and their families.

Among the other proposed activities, introducing new and suitable livelihood strategies in the area also seems to be a practical need. Many depend on paddy cultivation as livelihood and it has presently turned into market oriented strategy rather than traditional subsistence agriculture. This situation has compelled many farmers to use agro chemicals to increase the yield of farming. As one women in the sample pointed out,

> *"It is difficult to cultivate paddy twice a year due to shortage of water in the area. Therefore, in cultivating improved draught prone paddy, farmers had to depend on agro chemicals. It increases the yield but we used to consume same rice grown with such chemicals. The best possible solution to this issue is to introduce carbonic agriculture which uses naturally available material as the manure." (*Source: In-depth interview with a female farmer of 46 years old)

This shows that there are some possible measures that need to be implementing to enhance the victims of CKDu and their families. Furthermore, as suggested by people in the sample and in group discussions, it is worthwhile to sensitize victims as well as general public in the area to follow the precautions and get necessary treatments timely to mitigate the negative impact of the illness.

CONCLUSION

Based on the above findings the study concludes followings.

a) The grant of Rs.3,000 per victim needs to be revised to receive funds on the real necessity based on the aggravation of the illness. Patients in the last stage that requires undergoing treatments such as dialysis have higher expenses to cover in comparison to the earlier stages of the disease.

b) There is a need of tracing out of unidentified CKDu patients as many of such patients used to reach medical clinics at the last stages of the illness.

c) It would be profitable to introduce an income generation programs with financial assistance instead of CKDu allowance. Animal husbandry including raring cows would be profitable as there are grasslands in the area and patients also easily can look after them with the support of family labour.

d) In case of enhancing family welfare of such families, it is better to introduce employment generation programs such as garment industry to absorb the unemployed labour of such families. Also, providing specific assistance to school children to continue their education, introducing insurance scheme to ensure the living condition of these families, granting State land among landless families, providing NGO support to alleviate living standards are some other possible measures that can suggest to improve the family welfare of CKDu affected families.

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