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RESEARCH REPORT



# SOCIO ECONOMIC IMPACT OF CHRONIC KIDNEY DISEASE OF UNKNOWN ETIOLOGY

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# **Socio Economic Impact of Chronic Kidney Disease of Unknown Etiology**



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## FOREWORD

The study on Socio-economic Impact of the Chronic Kidney Disease of Unknown Etiology (CKDu) is a timely national requirement and obligation fulfilled by HARTI. CKDu is a widespread and serious health issue especially in the most rural agricultural districts in Sri Lanka. Incidence of CKDu was first reported in the North Central province of the country. It is the main health hazard in the most affected districts such as Auradhapura, Polonnaruwa in the North Central province, Kurunegala in the North Western province, Monaragala and Badulla in Uva province, and Trincomalee in the Eastern province.

The request for conducting a research on the socio-economic impact of the disease was made by the Ministry of Agriculture due to the absence of such knowledge and most of the studies conducted on CKDu being focused very much on ascertaining the causative factors of the disease rather than contemplating on its socio-economic aspect. As such this study would correctly fill that particular gap while clearing the conflicting ideas which had emerged and are prevailing for long in society over the socio-economic impacts of CKDu.

According to the study, the disease is mainly found among those engaging in laborious livelihoods such as agriculture and in the age category of forty and above. The fact that those affected are largely in the middle age and above has lessened the socio-economic impact which otherwise would have been much severe. However, the study found out that those still in the working age being affected by CKDu would have negative implications on the country's agriculture in a context which the young and new labor participation is declining.

According to the study, drinking water in the CKDu affected areas is suspected to be the main cause of the disease by almost all medical practitioners and other experts interested in the issue. As such it suggests provision of suitable drinking water to the affected areas as a main requirement. Also it strongly emphasizes the need of a screening system to identify the incidence of CKDu at the initial stage and a proper registration system of the patients as well. The report further suggests appropriate action and proper interventions of elements is necessary.

Considering the valuable findings and the suggestions it puts forward, I reckon this study to be a very important work done by the HARTI and appreciate very much the researchers involved in the study.

**Haputhanthri Dharmasena**  
Director

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This study on Socio-economic Impact of Chronic Kidney Disease of Unknown Etiology (CKDu) was conducted under the directions of the Ministry of Agriculture by considering the severity of the disease and its resultant impact to the society. As a result, former Secretary of the Agriculture Ministry, Mr. W.A. Sakalasoorya deserves much of the credit for conceiving the idea of the study and providing the subsequent financial support. The encouragement, managerial and administrative support provided by Mr. E.M Abhayarathna, former Director of HARTI and Mr. J.K.M.D. Chandrasiri, Additional Director, were mainly instrumental for the study's success, hence they deserve the highest gratitude of the study team. Provincial Directors of Health in the North Central, Eastern and Uva provinces are commended for the assistance extended in the study. Divisional Secretaries and the Additional Directors of Planning of the respective administrative districts and divisional secretariat areas where the study was carried out also deserve the praise of the research team as their support eased the burden of carrying out the survey in the ground. Casual investigator of HARTI Mr. Amal Dissanayake provided an enormous support in the collection of primary data and secondary information required. He is praised for a job well done. Mr. H.L.L Salinda, Administrative Assistant of HARTI is also thanked for the assistance provided in typesetting the report. Further, *Grama Niladharis* of the respective villages where the survey was conducted are highly appreciated for their relentless support.

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## EXECUTIVE SUMMARY

This study on the Socio- economic Impact of Chronic Kidney Disease of Unknown Etiology was conducted on the request of the Ministry of Agriculture considering the seriousness of the disease and the speculation over its threats to the affected families and thereby to society at large. While the main objective of the study was to look into the socio economic impact of CKDu on the affected households, it had several specific objectives as well. They were; to look into the impact of disease on the livelihoods of the affected families, to estimate the loss of family income of an affected family due to the disease, to estimate the average monthly cost an affected family has to bear for treatments, to look into the impact of disease on the family bonds, to estimate the impact on consumption of food of the affected families, to find out the impact of the disease on the education of the children of the affected families and to estimate the impact of the disease on the agricultural production of the affected families.

The study area consisted of Anuradhapura, Polonnaruwa, Trincomalee and Moneragala districts. These districts were selected on the basis of the level of incidence or the severity of the disease in the particular districts and geographical spread of the disease. The sample was 200 affected households comprising 50 households from each district. In the first phase of the sample selection, the most affected Divisional Secretariat (DS) division / divisions of the respective districts were selected. Next, the two most affected villages of each DS division were selected based on the information obtained from each DS office. Finally the affected families were proportionately selected from the lists provided by the Grama Niladharis (GNs) of the particular villages. Accordingly the study was carried out in five DS divisions of the four districts; Medrigiriya from the Polonnaruwa district, Madawachchiya from the Anuradhapura district, Padavi Sripura from the Trincomalee district and Buttala and Thanamalwila from the Moneragala district. From the Moneragala district, two DS divisions were selected, considering the nature of the spread of the disease. The total number of villages from which finally the sample was derived was 12.

The study found that most of the affected are male which is 77% of the total sample. Majority of the affected are mature in age and 67% of them are in their 50s. Those affected below thirty were 1.4%, those below 40 were 4.5%. And 82% of those affected were the head of the family. There were 6 households of which both parents had been affected. Of the 200 sample studied households, 17 patients had already died. All those who died had lived less than 10 years after being diagnosed of CKDu. No strong relationship could be traced between alcohol consumption and contracting CKDu at a relatively younger age. Majority of the respondents (67%) had not suffered from any non-communicable disease before contracting CKDu. Further 72% claimed they

subsequently became diabetic after being diagnosed of CKDu while 61% claimed to have suffered from blood pressure.

The source of drinking water for 76% of the affected households is the well, while for 20% it was tube wells. Almost 80% had used aluminum cooking utensils either exclusively or with utensils of other materials. Further, 51% of the total sample households had experienced a loss in income due to CKDu. Also 43% of the total sample households had not spent on medicine in the month prior to the survey. The average cost a household spent on medicine in the particular month was as follows; Anuradhapura district-Rs.330, Polonnaruwa district-Rs.1251. Trincomalee district-Rs.1013, and Monaragala district-Rs.2178. Nearly 40% of the households reported that the disease affected their main occupation, agriculture. The disease had not had much impact on the consumption level of households. However 16% of the total affected households reported that the disease affected the education of their children.

In the study a few short and long term measures that should be taken to prevent and minimize the incidence of CKDu and its socio- economic impacts were identified. In short term it is apparently advisable to take action such as proper screening of the people in affected areas for early detection of CKDu, educating the people in the affected areas on the nature of the disease, adoption of preventive measures and receiving of proper treatment, preventing the exploiting of the affected people by fraudsters, provision of a subsidy or installing a mechanism to support the affected households in buying quality water filters, maintenance of a proper and networked recording of CKDu patients and the re-encouraging of rain water harvesting for the drinking purpose.

In long term, it requires to take action to eradicate the CKDu. The foremost requirement in this endeavor is ascertaining the real cause or the causes of the disease. This seems only possible through multi disciplinary research. Hence encouraging and facilitating the undertaking of multi disciplinary research by experts is vital.

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## LIST OF ABBREVIATIONS

ACE	-	Angiotensin-Converting Enzyme
ARBS	-	Angiotensin II receptor blockers
AKI	-	Acute Kidney Injury
CKDu	-	Chronic Kidney Disease of unknown etiology
CRF	-	Chronic Renal Failures
GFR	-	Glomerular Filtration Rate
DM	-	Diabetes Mellitus
DMO	-	District Medical Officer
DS	-	Divisional Secretary
GN	-	Grama Niladhari
HTN	-	Hypertension
NSAIDs	-	Non-Steroidal Anti Inflammatory Drugs
MOH	-	Medical Officer of Health
PHI	-	Public Health Inspector
WHO	-	World Health Organization

# CHAPTER ONE

## Study on the Socio-economic Impact of CKDu

### 1.1 Introduction

Today, in Sri Lanka the Chronic Kidney Disease of Unknown Etiology (CKDu) has become a major health issue which has captured the attention of society at all levels. The particular kidney disease has severely affected the provinces such as North Central, Uva, Eastern provinces and the North Western. Though the verifiable and accurate data is hardly available on the exact number of CKDu incidents it is suspected that in the North Central and Uva provinces minimum 15% of the population in the age group of 15-70 years have been affected by the disease. All of these areas are mainly agricultural and contribute largely to the country's rice production.

However, with the increasing number of patients affected by the kidney related diseases mainly in agricultural areas, attention of media and interest groups is focused on the issue. This gave rise to multiple views as to what causes the catastrophe. They were coming from a broad segment of the society ranging from scientists of various disciplines to ordinary citizens to religious dignitaries. Among different opinions to the cause of the disease, much suspected was the impact of use of agro chemicals. A study by WHO ([www.whosrilanka.org](http://www.whosrilanka.org)) on Chronic Kidney Disease conducted in combination with the Ministry of Health in 2009 reported higher prevalence of the disease among males over 40 years. A majority of them had been engaged in farming as their livelihood because the study sample consisted of patients from the hospitals in highly affected agricultural areas of the North Central Province. This implied that the exposure to agrochemicals causes or increases the risk of developing CKDu. According to another study (<http://dl.nsf.ac.lk/handle/1/9558>), majority of the men and women suffering from this disease have the symptoms of arsenic poisoning due to use of illegal pesticides.

However, irrespective of the causes it is also assumed to have posed severe socio-economic threats to the households affected by the disease in particular and to the whole society at large. Nevertheless, it seems this aspect of the epidemic disease has not received adequate attention by the interest groups and they mainly focused on finding the causative factors of the disease. While acknowledging the importance of ascertaining the causative factors of the disease, it is vital to examine its impact on socio-economic aspect as well. Thus this study attempts to explore the socio-economic impact of the CKDu on the affected families and the society at large.

## **1.2 Research Problem**

The research problem of the study is the socio- economic consequences the mysterious kidney disease has brought about among the affected families in particular and to the country in general.

## **1.3 Importance of the Study**

This study is immensely important due to several reasons. In the first place, CKDu has undoubtedly become a major health issue that the country facing today when considering the areas and the number of households affected. Secondly, it has largely affected the agricultural areas where much of the country's poverty prevails. With the number of affected families on the raise, it is of utmost importance to look into the real socio-economic issues the disease may bring to the affected families and thereby to the broader society. The particular knowledge would be helpful to determine the magnitude of the socio-economic impact of the disease and the actions that should be taken to minimize and prevent them.

## **1.4 Objectives**

### **Main Objectives**

The main objective of this study was to ascertain the socio-economic impact of the Chronic Kidney Disease.

### **Specific objectives are**

- To look into the impact of the disease on the livelihood of the affected families.
- To estimate the loss of family income of the affected families
- To estimate the average monthly cost an affected family has to bear on treatments
- To look into the impact of the disease on family bonds
- To estimate the impact on consumption level of the affected families
- To find out the impact of the disease on the education of the children of the affected families
- To look into the impact of the disease on the domestic agriculture of the country

## **1.5 Research Methodology**

### **Data Collection**

The study was conducted using both primary and secondary data.

Secondary data was obtained from relevant study reports such as journal articles on the subject, newspaper articles by experts, WHO reports and several websites. In addition to that, certain documents from the government hospitals and MoH offices were also used as required.

### Primary Data Collection

Primary data collection was carried out with a structured questionnaire designed to obtain data from a sample of the affected families. In addition, primary data collecting methods such as key informant interviews and focus groups interviews were also used to obtain the required data.

For the questionnaire survey the affected household sample was 200. These 200 affected households comprised 50 households from each of the four sampling districts; Polonnaruwa, Anuradhapura, Trincomalee and Moneragala. These districts were selected considering the incidence and the geographical spread of the disease. Multi staged random sampling technique was used in the selection of the sample. In the process, firstly the highly affected DS (Divisional Secretariat) area of each district was selected. In case of the Moneragala district, two DS areas were selected considering the nature of the spread of the disease. Next, two villages with the highest number of affected households were selected from each DS area. Finally the number of households from each village to the sample was decided proportionately based on the list of the affected households provided by the GNs of the respective villages.

The following table shows the area of the 200 households sample selected

**Table 1.1: Sample Areas**

District	Divisional Secretariat Areas	Villages
Anuradhapura	Madawachchiya	Helambagaswewa Mahadiulwewa
Polonnaruwa	Medirigiriya	Ambagaswewa Thlakolawewa
Trincomalee	Padavi Sripura	Jayanthiwewa Sri Thissapura
Moneragala	Buttala	Rahathangama Kumaragama
	Tanamalwila	Hambegamuwa

## **1.6 Data Analysis**

Data analysis was carried out using the SPSS Statistical tool while the data presented mainly employed the descriptive statistical techniques.

## **1.7 Organization of the Report**

This report on CKDu consists of five chapters. The first chapter is an introduction to the study. It includes objectives of the study, as to how and why the study was conducted, the area where the study conducted, how the data was analyzed and presented. The second chapter which is the literature review of the study provides a description on the chronic kidney disease and its causative factors based on the literature built on it. Further, it includes important and relevant facts of some of the study conducted on the causative factors on CKDu in the country and some of their findings. It also includes facts on similar experiences from other countries as well. The third chapter mainly discusses the socio-economic condition of the studied sample. That consists of information such as livelihoods and household income of the affected families, consumption habits and level of education. The fourth chapter which is the core of the report includes the findings of the sample survey which was carried out to find information required to address the set objectives of the study. The final chapter summarizes the findings and presents the conclusion of the researchers on the socio-economic impact of CKDu. It also contains the suggestions of the researchers to mitigate the possible socio-economic impact of the CKDu.

## CHAPTER TWO

### Literature Review on Chronic Kidney Disease of Unknown Etiology (CKDu)

#### 2.1 Introduction

This chapter consists of a literature review of the chronic kidney disease prevailing in most of the agricultural districts in the country. In the chapter, special attention is paid to the discussion of the topics such as the nature of the disease, reasons and arguments put forward by different interested groups as perceived causes of the disease. In addition, it also discusses the similar experiences from other affected countries.

#### 2.2 Chronic Kidney Disease

According to the 2003 National Kidney Foundation guidelines of United States of America, Chronic Kidney disease (CKD) is defined as either kidney damage or decreased Glomerular Filtration Rate (GFR) for at least three months (*Am J Kidney Dis*, 2002). The markers of kidney damage stem from the same source as proteinuria, urinary tract abnormalities on imaging, and abnormal, urinary sediment or urinary chemistries.

According to *kidney.org*, Chronic Kidney Disease includes conditions that damage the kidneys and decrease their ability to keep the body healthy. Further, if kidney disease gets worse, wastes can build to high levels in patient's blood and make him or her feel sick. The patient may develop complications such as high blood pressure, anemia (low blood count), weak bones, poor nutritional health and nerve damage. Also, kidney disease increases the risk of the heart and blood vessel diseases. These problems may occur gradually over a long period. Chronic Kidney Disease is considered to be caused by diabetes, high blood pressure and other disorders. Early detection and treatment can often keep Chronic Kidney Disease from being aggravated. When the disease progresses, it may eventually lead to kidney failure, requiring dialysis or kidney transplants to maintain life.

According to World Health Organization's (WHO) Global Burden of Disease Project, diseases of the kidney and urinary tract cause approximately 850,000 deaths every year of which Chronic Kidney Disease (CKD) is the 12th leading cause of death and 17th leading cause of disability in the world (Schieppati, 2005).

#### 2.3 Important Facts on CKD

It is very important to be informed of the main characteristics or facts about the Chronic Kidney Disease. It helps both the non medical policymakers and the general public to have a better understanding of the nature and the gravity of the disease. The particular

knowledge built upon the disease, both directly and indirectly, supports the process and the mechanism of preventing or controlling the disease.

## **2.4 General Principles**

According to De Fer, (2001), the general principles of Chronic Kidney Disease can be identified as follows.

- Risk factors for CKD include age, Low income/education, family history of CKD,DM,HTN, auto-immune diseases, systemic infections, urinary tract infections/obstruction/nephrolithiasis, cancer, prior AKI, reduction in kidney mass, and exposure to certain drugs and toxins
- Identifying and treating CKD early is critical, as disease progression is associated with increased mortality, hospitalization, and cardiovascular events.
- Most patients with CKD have a progressive fairly constant decline in GFR over time. However, some patients may experience stabilization or remission.
- The rate of decline for an individual patient can be somewhat difficult to predict but is known to be dependent on the type of kidney disease. Other factors associated with a faster rate of decline include lower baseline kidney function, gender (male) and older age.
- Acute decline in GFR is not unusual in the course of CKD and may be caused by factors such as volume depletion, radio contrast, NSAIDs, some antibiotics (e.g. amino glycosides, amphotericin B), ACE inhibitors and ARBs, cyclosporine and tacrolimus, and urinary tract obstruction.
- There is a strong association between CKD and cardiovascular disease. Modifiable risk factors ( e.g. HTN, dyslipidemia, DM, and tobacco use) should be treated aggressively.

## **2.5 The Symptoms of CKD**

Most people may not have severe symptoms until the kidney disease reaches the advanced stage (*kidney.org*). However, following symptoms have been established and accepted as the most reported symptoms of the chronic kidney disease.

Feeling more tired and having less energy

Having trouble in concentrating

Having a poor appetite

Having trouble in sleeping

Having muscle cramps at night

Having swollen feet and ankles

Having puffiness around your eyes, especially in the morning

Having dry, itchy skin

Having to urinate more often, especially at night

According to medical revelations anyone can get chronic kidney disease at any age. However, some people are at risk more than others to develop the disease. One may have an increased risk for the kidney disease if he or she:

Has diabetes  
Has high blood pressure  
Has a family history of kidney failure  
Is older

It has also been identified that those belonging to a population group that has a high rate of diabetes or high blood pressure, such as African Americans, Hispanic Americans, Asians, Pacific Islanders, and American Indians are said to be more vulnerable to CKD.

## **2.6 Chronic Kidney Disease of Unknown Etiology in Sri Lanka**

The reason or the etiology of the chronic kidney disease which was first reported in the North Central province and now has spread to several of the main agricultural districts in Sri Lanka is still a mystery. This has led to a commotion in the whole society, different interested groups citing various reasons to which are not fully agreed. This is the very reason for it to be known as the Chronic Kidney Disease of Unknown Etiology.

This is also known as *Raja Rata Kidney Disease* due to the initial geographical orientation of the disease. Majority of the cases were at first reported from the North Central Province. It has also been debated whether the disease is a new entity. In 2008, the World Health Organization along with the Ministry of Healthcare and Nutrition has launched a National Research Program on CKDu. The Scientific Committee of the particular program defines the disease as of unknown origin in the absence of a past history of diabetes mellitus, chronic or severe hypertension, snake bite, glomerulonephritis or urological diseases (Wanigasuriya, 2012).

## **2.7 Arguments over CKDu in Sri Lanka**

During the last decade, certain interested parties and groups have undertaken several studies to identify the prevalence and etiology of the CKDu in the North Central Province of Sri Lanka.

Following are some of the arguments put forward in these particular studies.

1. Excessive quantities of naturally found fluoride in the groundwater can harm the kidneys.
2. Excessive use of fertilizer, insecticides, and weedicides has an impact.
3. The use of aluminum utensils made out of low quality cheap Aluminum to store water and prepare food. The fluoride content found in the groundwater reacts with this aluminum, creating toxic compounds that would harm the kidneys.
4. Entry of toxic elements such as Cadmium and Arsenic via food chain
5. Excessive consumption of poor quality illegal liquor

A descriptive cross-sectional study carried out by Peiris-John *et al* (2006) to determine whether there was a relation between chronic renal failures (CRF) and low-level organophosphate pesticide exposure. This study has been conducted at renal clinics of the Anuradhapura Teaching Hospital (exposed patients) and National Hospital of Sri Lanka (non- exposed patients), Moratuwa fishing village (non-exposed controls), Uda Walawe irrigation scheme (exposed controls). In the study, red cell acetyl cholinesterase levels (AChE) have been measured as a marker of organophosphate exposure. Red cell AChE levels among farmers exposed to pesticides were significantly lower than in unexposed controls ( $p < 0.05$ ). Among the patients with CRF, red cell AChE have been lower in the exposed group as compared to the unexposed group ( $p < 0.05$ ).

In another case controlled study carried out by Wanigasuriya *et al* (2012), 183 CRF patients of unknown etiology attending the renal clinic at Teaching Hospital Anuradhapura were compared with a control group from the general medical clinic of the same hospital. The evaluated risk factors of CRF of unknown etiology in the particular study have been as follows. Being a farmer ( $p < 0.001$ ), using pesticides ( $< 0.001$ ), drinking well water at home ( $p < 0.001$ ) and in the field ( $p = 0.036$ ), having a family member with renal dysfunction ( $p = 0.001$ ), having taken ayurvedic treatment in the past ( $p < 0.001$ ) and a past history of snakebite ( $p < 0.001$ ). The study found significant predictors of CRF of unknown aetiology to have a family member with a renal dysfunction (4.2–5.9,  $n = 2600$ ) compared to 2.3% in Hambantota (95% CI 1.8–2.9,  $n = 2844$ ) and 9.5% in Yatinuwara (95% CI 7.5–12.0,  $n = 709$ ). Conventional risk factors of CKDu such as diabetes and hypertension had not been found in the majority of patients from Medawachchiya. The percentage of patients with CKDu had been higher in (109/130, 84%) Medawachchiya compared to Yatinuwara (2/68 2.9%) and Hambantota (6/66, 9.1%). A high proportion of CKDu patients in Medawachchiya had found to be young farmers, they have had mild proteinuria without active sediment, had bilateral small echogenic kidneys and renal biopsies showed tubulointerstitial disease according to the study. On the basis of that particular clinical profile, the authors had proposed a possible toxic etiology that makes farmers in a specific geographical area being more vulnerable to the disease.

Chandrajith *et al* (2011) illustrates possible fluoride mediated mechanism for renal damage in people living in CKDu endemic areas in Sri Lanka. The study has been on the geo-chemical properties of water. In the study, well water samples have been randomly collected from both CKDu endemic regions as well as from non-endemic regions. CKDu endemic regions had included Giradurukotte, Nikawewa, Medawachchiya and Padaviya while Huruluwewa and Wellawaya were included as non-endemic regions. Huruluwewa, village in the North Central Province had been identified in the study as a village which has a very low prevalence of CKDu. In the study, Electrical Conductivity (EC), alkalinity and fluoride levels of the water were measured. The mean content of fluoride in endemic CKDu areas of Girandurukotte, Nikawewa, Medawachchiya and Padawiya had been reported to be 0.66, 1.21, 1.03 and 0.62 (in mg/L) respectively. In non endemic areas of Huruluwewa and Wellawaya the mean fluoride content had been reported as 1.42 and 1.05 respectively. According to the study, Fluoride content of well water in all

these areas had exceeded the WHO recommended level of 0.6 mg/L. Apart from that, the Ph value of the water in the areas had been greater than 7 which is said to be having the possibility of facilitating the mobilization of fluoride from minerals. There had been a large variation in the Na/Ca ratio between endemic and non-endemic areas. It had been noted that Ca-bicarbonate type water is predominant in endemic CKDu regions whereas Na-K-non dominant anion type water is common in the non-endemic regions. The study had concluded that the cytotoxicity properties of fluoride appear to be due to the effect of Ca and Na of the ingested water on the fluoride metabolism. This study illustrates a possible fluoride mediated mechanism for renal damage in people living in endemic areas.

However, the most alarming hypothesis on the CKDu in Sri Lanka came from the Jayasumana, (2010). According to the particular study the cause behind the unknown chronic kidney disease in Sri Lanka is arsenic poisoning. Jayasumana *et al* (2011) reported the presence of arsenic in drinking water, rice grown in the affected area, hair and urine of patients of Chronic Kidney Disease of unidentified etiology (CKDu) as well as in body parts of diseased CKDu patients from Sri Lanka's largest rice cultivating areas in the North-Central Province. This led to the hypothesis that presence of arsenic compounds in drinking water and food may be a potential cause of CKDu and the pesticides containing arsenicals may be the potential source of it.

Further, according to Jayasumana *et al* (2011), during an assessment of CKDu patients, hyper-pigmentation and keratosis of their palms and soles were detected. This was identified as a symptom characteristic to chronic arsenic poisoning. The particular assessment had revealed that out of 156 patients examined, 125 had got hyper-pigmentation and keratosis; 44.8% and 39.2% of the CKD patients have got hyper pigmentation of palms, and soles respectively while 23.2 and 17.6 of them have got keratosis respectively on their palms and soles.

In addition to that the recently published WHO report (*SciDev.Net*) over the issue of CKDu in Sri Lanka also mentions the impact of agrochemicals as the causative factor behind the disease. The particular study was carried out by a team of Sri Lankan and WHO scientists. They have attributed the high prevalence of chronic kidney disease of uncertain etiology (CKDu) on the island to the indiscriminate use of agrochemicals including fertilizer and pesticides.

In its final report released on 28<sup>th</sup> February 2013, the WHO research team identified districts in the North Central and East of the island and the rice-growing areas as "most vulnerable" (*SciDev.Net*). According to the report, while uncertainty prevailed over the exact cause of CKDu, the number of affected people in the country had grown to 450,000.

According to WHO representative in Sri Lanka, Firdosi Rastam it is a new form of chronic\_kidney disease which has spread in the above areas and the cause of it is unknown and different from other causes of CKDu such as diabetes mellitus,

hypertension, kidney damage or any other known disease. Further the WHO researchers found one or more pesticide residues above reference levels in 31.6 percent of people living with CKDu (*SciDev.Net*).

The particular WHO study states that Cadmium, lead and arsenic values in phosphate fertilizer from the endemic areas are higher than the levels reported in agricultural soils in many other countries. It is also reported to have detected pesticide residues in urine, hair and nail samples taken from people in the worst-affected North Central Province.

However apparently there is no common consensus over the affecting factor or factors of this chronic kidney disease prevailing in some major agricultural areas in the country. Prof. R. O. Thattil, University of Peradeniya, an eminent statistician in Sri Lanka expressed his displeasure over the conclusions of the final report of WHO referred here, and those of most other studies carried out in this issue. According to him, the insufficiency in the method of analysis has been a common weakness in these studies including the WHO report.

*“The WHO report deals with the establishment of a hospital based CKD registry, establishment of a literature repository for CKD and population prevalence, analytical and environmental studies.*

*The establishment of a hospital based CKD registry is a very important step in studying diseases of uncertain aetiology. However, the analysis performed on the data is unsatisfactory, since it is based on categorical variables which were dichotomized, analyzed individually and interpreted based on odds ratios (which is a simplistic form of analysis). Obviously this type of analysis is not sufficient to attribute CKDu to any particular cause. In the population prevalence, analytical and environmental studies conducted by the WHO, no attempt has been made to consider multiple factors and their interactions in the planning of the study as well as in the analysis. The references quoted are divergent on the role of Cadmium in the causation of CKDu in Sri Lanka. The results also imply that fertilizer application could be the source of Cadmium, Lead and Arsenic. A very guarded statement! However, these elements have not been detected in sufficient quantities in the water sources. Overall the statements made in the discussion are very superficial with no attempt being made at recognizing that CKDu can be caused by a multiplicity of factors. It is also worth noting that factors need not be independently associated while interactions between factors are more likely. Interactions can also mask main effects and therefore Univariate analysis will be non – conclusive.” (www.island.lk, August 1, 2013, 12:00 pm)*

His conclusion over other studies of the subject is as follows:

*“The conclusions reached in other studies are diverse and questionable. No attempts have been made to treat the cause of CKDu as a multivariate problem. No multivariate analytical procedures have been used. Therefore, no valid conclusions are possible. Whatever model used for the study should include interaction effects, while proper*

*sampling techniques should be used to obtain data*" (www.island.lk, August 1, 2013, 12:00 pm)

In addition to that, Professor Oliver Illeperuma, Head of the Chemistry Department, Peradeniya University also commented that the real cause or the knowledge over the cause of the disease has still not been found. As he states it "*There are multiple causes identified through different research attempts, but we do not have sound knowledge on this growing health crisis,*" (*SciDev.Net*).

## **2.8 Similar Experiences from Other Countries**

According to WHO, Chronic Kidney Disease has become a global health issue. It reveals that the disease of the kidney and urinary tract causes approximately 850,000 deaths every year of which Chronic Kidney Disease (CKD) is the 12th leading cause of death and 17th leading cause of disability in the world. CKD is associated with increased cardiovascular mortality and a loss of disability-adjusted life years. The global increase in CKD is being driven by the global increase in diabetes mellitus, hypertension, obesity, and aging.

According to WHO (<http://renalcareindia.org/Statistics.aspx>) recent research have suggested that one in 10 of the population may have CKD, but it is less common in young adults, being present in one in 50 people. In those aged over 75 years, CKD is present in 1 out of 2 people. However, many of the elderly people with CKD may not have 'diseased' kidneys, but have normal ageing of their kidneys.

Chronic kidney disease (CKD) has become an important public health problem in China (Zhang et al, (2012). The overall prevalence of CKD is 10.8%, and that the number of patients with CKD in China is about 119.5 million. It is reported that high prevalence and low awareness of CKD are present in the adult population of Guangzhou city in Southern China (Chen *et al*, 2009). Prevalence and risk factors associated with chronic kidney disease in the adult population from Southern China have not reported adequately. (Chen *et al*, 2009).

According to Liu *et al*, (2013) previous studies reported mainly the traditional risk factors for CKD: age, hypertension, diabetes, metabolic syndrome etc. However, little attention has been paid to the nontraditional risk factors associated with CKD. Accumulating evidence has demonstrated that inflammation is one of the important pathogenic factors in renal injury, and inflammation markers (high-sensitivity C-reactive protein (hsCRP), tumor necrosis factor- $\alpha$  (TNF- $\alpha$ ), and interleukin-6 (IL-6)) were positively associated with the prevalent CKD (Kidney International (2011).

However, as some sources reveal, India and certain Central American countries reported to have a chronic kidney disease of the almost same identity as the CKDu in Sri Lanka.

According to Sundaytimes.lk reports “A mysterious form of chronic kidney disease – CKD – is afflicting thousands of people in rural, agricultural communities in Sri Lanka, India and Central America. The struggle to identify its causes is baffling researchers across multiple continents and posing a lethal puzzle worthy of Sherlock Holmes. The three epidemics have crucial threads in common. The victims are relatively young and mostly farm workers, and few suffer from diabetes and high blood pressure, the usual risk factors for renal disease. They experience a rare form of kidney damage, known as tubulo-interstitial disease, consistent with severe dehydration and toxic poisoning”.

In India the approximate total burden of CKD is said to be 800 per million populations (pmp). It has been reported that diabetes mellitus as the cause of CKD was found in 31.2-41% of patients in India (Acharya *et al*, 2011). However, according to a recent study (biomedcentral.com, 2010) in India diabetic nephropathy was the commonest cause (31%), followed by CKD of undetermined etiology (16%), chronic glomerulonephritis (14%) and hypertensive nephrosclerosis (13%). About 48% cases were presented in Stage V; they were younger than those in Stages III-IV. Diabetic nephropathy patients were older, more likely to present in earlier stages of CKD and had a higher frequency in males whereas those with CKD of unexplained etiology were younger, had more female patients and more frequently presented in Stage V. Patients in lower income groups had more advanced CKD at presentation. Patients approaching public sector hospitals were poorer, younger, and more frequently had CKD of unknown etiology.

As revealed in the (icij.org), with little noticed by the rest of the world, chronic kidney disease is cutting a swath through one of the world’s poorest populations, along a stretch of Central America’s Pacific Coast that spans six countries and nearly 700 miles. Its victims are manual laborers, mostly sugarcane workers.

According to the International Consortium of Investigative Journalists’ analysis referred above, in the region of Central America each year from 2005 to 2009, kidney failure of unknown etiology has killed more than 2,800 men. In El Salvador and Nicaragua alone, over the last two decades, the number of men died from kidney disease has risen to fivefold. According to the above consortium, now more men are dying from the ailment than from HIV/AIDS, diabetes and leukemia combined.

## **2.9 Studies on Socio-economic Impact of CKDu in Sri Lanka**

Irrespective of the informal discussions and media reports of non analytical and ad hoc in nature over the socio-economic impact of the disease, there is a lack of in depth studies conducted on the particular aspect of the disease. The reason for this could be, despite numerous efforts by the interested groups to find the causative factors of the disease, its mysterious nature. That is clearly evident from the studies already published on CKDu from various stakeholders. Even the National Research Programme on CKDu, jointly formed by the Ministry of Health and WHO had recognized a series of studies exclusively aimed at investigating the cause or causes of the disease.

## CHAPTER THREE

### Socio-economic Situation of the Study Sample

#### 3.1 Introduction

This chapter deals with the socio-economic characteristics of the sample selected for the study. The important areas such as the composition of affected families, their level of education, livelihoods, involvement in agriculture and the monthly income are the focal points discussed in the chapter. The chapter expects to provide an over view of the population affected by the disease.

#### 3.2 Size of Families

The average family size of the sample is four members in all four districts studied. In Anuradhapura and Polonnaruwa districts the average number of family members is 3.8 and 4.4 respectively while in Trincomalee and Moneragala the respective numbers are 4.2 in each district.

The Table 3.1 shows the number of households and family composition.

**Table 3.1: Number of Members in the Households**

No. of Family Members	No. of Households				Total(200)	(% n=200)
	Anu'pura	Polonnaruwa	Trincomalee	Moneragala		
1-2	10	04	08	05	27	13.5
3-5	35	33	35	35	138	69.0
6-7	05	13	07	10	35	16.5

Source: Survey Data

According to the above table it is obvious that the majority of the households of all three districts have 3 to 5 members. This as a percentage of the total sample households is 69.

The highest number of members in a family does not exceed 7 in any district while the number of households with seven members are a very few.

#### 3.3 Gender Distribution of the Sample Households

From the table no.3.2 it is apparent that in the sample households in Polonaruwa and Moneragala districts the number of males is slightly higher than the number of females, whereas in Anuradhapura and Trincomalee districts it is the other way. Nevertheless,

according to the surveyed sample in the Anuradhapura district a noticeable difference can be seen in the number of males and females in the composition of households.

**Table 3.2: Gender Distribution of the Sample Households**

District	No. Male	%	No. Female	%	Total
A'pura	89	46	103	54	192
Polonnaruwa	111	51	108	49	219
Trincomalee	102	49	107	51	209
Moneragala	109	52	102	48	211

Source: Survey Data

### 3.4 Age Structure of the Sample Household Members

From the Table 3.3, it is apparent that in the all four districts the age structure of the sample household members is largely similar. In keeping with the demographic change taking place in the country, the study sample also shows a significant increase in the older population. This is evident when comparing the category of age over sixty of the sample with all top three age categories in the table. Further it is observed that top two categories together do not equal or excel the number in the last age group which is of the oldest. This depicts the general demographic trend in the country.

**Table No.3.3: Age Structure of the Household Members**

Age Category	District							
	A'pura	%	Polonna ruwa	%	Trinco malee	%	Monera gala	%
<1	04	2	06	3	02	1	03	1
1-5	12	6	14	7	17	8	10	5
5-14	22	11	20	9	24	12	20	10
14-60	129	67	153	70	151	73	156	75
>60	25	13.0	27	12	12	6	19	9
<b>Total</b>	<b>192</b>	<b>100</b>	<b>220</b>	<b>100</b>	<b>206</b>	<b>100</b>	<b>208</b>	<b>100</b>

Source: Survey Data

### 3.5 Level of Education of Household Members

Table 3.4 shows the level of education of the households members of the CKDu affected families. Accordingly, the highest majority in the all four districts had received education up to grade 10 or less. The particular group takes an overwhelming percentage of nearly 75% of the total sample. The percentage of those passed O/L and A/L together makes up around 25% of the total which is 774. However, seemingly not many graduates have come from the CKDu affected families.

**Table No. 3.4: Level of Education of the Household Members**

Level of Education (Grade)	Districts					Total	(%)
	A'pura	Polonnaruwa	Trincomalee	Moneragala			
<5	51	69	46	65	231	30	
5-10	61	87	111	86	345	45	
Passed O/L	46	33	37	31	147	19	
Passed A/L	19	10	06	08	43	05	
Graduate	01	01	02	04	08	01	
<b>Total</b>	<b>178</b>	<b>200</b>	<b>202</b>	<b>194</b>	<b>774</b>	<b>100</b>	

Source: Survey Data

### 3.6 Employed Household Members

A considerable number of household members of CKDu affected families are engaged in various non agricultural employments. They range from public sector employment to certain lower strata jobs such as wage laborers. The majority serving in the public sector jobs are related to the defense sector. The following table shows a household wise calculation of the members employed in non agricultural sector.

**Table 3.5: Number of Members Employed in Non Agricultural Livelihoods**

No. of Employed Family members	District and the No. of Hoseholds				Total	(% n=200)
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
One	21	28	12	21	85	41
Two	06	08	11	05	30	15
Three	01	02	04	04	11	05
>3	00	00	01	00	01	1
None	20	12	22	20	76	38
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100</b>

Source: Survey Data

However, as it is evident from the table, still a large segment of the sample households had no members engaging in non agricultural livelihoods. The percentage of such houses is as many as 37% of the total.

### 3.7 Involvement in Agriculture

Most of the sample households affected with the CKDu were engaged in agriculture as their main livelihood. This is clear in the Table 3.6 which shows the particular

percentage as 87% of the total household sample. In Polonnaruwa, only one household is not involved in agriculture. In other districts almost an equal number of households are not involved. Nevertheless apparently all together, a fairly insignificant number of households are not involved in agriculture in all the four districts. Out of them, while some households are not involved in agriculture due to non availability of agricultural land, few have abandoned it due to the absence of a person to take care of the cultivation.

**Table 3.6: Household Involvement in Agriculture**

District	No. of Households (n=200)			
	Involved	%	Not Involved	%
A'pura	43	21.5	08	04.0
Polonnaruwa	49	24.5	01	0.5
Trincomalee	41	20.5	09	04.5
Moneragala	41	20.5	08	04.0
<b>Total</b>	<b>174</b>	<b>87.0</b>	<b>26</b>	<b>13.0</b>

Source: Survey Data

### 3.8 Monthly Income

The monthly income of the most of the sample households comprises both agricultural and non agricultural livelihoods. In the table no.3.7 and the table no.3.8 the monthly income from non agricultural livelihoods and that of agriculture is depicted respectively. The table no.3.9 shows the total monthly income of the affected households which comprise both types of livelihoods.

**Table 3.7: Income from Non Agricultural Livelihoods**

Income	District and the No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
4000-10000	03	04	03	02	12	01
10000-20000	05	14	05	15	39	19
20000-30000	15	10	10	05	40	20
30000-40000	01	02	05	02	10	05
40000-50000	03	06	01	04	14	07
>50000	01	02	04	02	09	04
No Income	22	12	22	20	76	38
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100</b>

Source: Survey Data

**Table 3.8: Income from Agriculture**

Income	District and the No. of Hoseholds				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Monaragala		
1500-10000	16	24	10	12	62	31.0
10000-20000	12	11	11	13	47	23.5
20000-30000	05	09	11	05	40	20.0
30000-40000	05	02	07	05	19	9.5
40000-50000	00	02	01	02	05	2.5
>50000	05	01	01	04	11	5.5
No Income	07	01	09	09	26	13.5
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100</b>

Source: Survey Data

The above table shows that more than 50% of the total sample of CKDu affected households earn a monthly income of less than Rs.20,000 from agriculture. When comparing with other districts around 50% of the farmers in the Polonnaruwa district fall in the lowest monthly income group. On the whole, it is also evident from the table the largest majority i.e. around 75% households together in all four districts receive a monthly income less than Rs.30,000. Only a small percentage of households like 8% from the total sample receives a higher monthly income which is more than Rs.40,000. The average monthly income of the whole affected households of the four sampling districts is Rs.30,490. The standard deviation counted for the monthly income is  $\pm$ Rs.21,722. This shows that there is a considerable income disparity even among rural households in the country.

**Table 3.9: Total Monthly Income of the Sample Households**

Income	District and the No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
1500 -10000	05	06	04	02	17	8.5
10000 -20000	08	12	06	15	41	20.5
20000 -30000	11	12	16	08	47	23.5
30000 -40000	10	06	09	08	33	16.5
40000 -50000	04	07	05	08	24	12.0
50000 -75000	05	05	06	02	18	09.0
>75000	03	02	02	05	12	06.0
No Income	04	00	02	02	08	04.0
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100</b>

Source: Survey Data

The above table shows the households' total income, the monthly income of 52.5% of the total sample is less than Rs.30, 000. Further, from the table it is apparent that while there are 8.5% of sample households in which the total monthly income is less than Rs.10, 000 a month, 14% of households of the sample have a total income of more than Rs.50, 000.

## CHAPTER FOUR

### Findings of the Study

#### 4.1 Introduction

This chapter which is the core of the study consists of the findings of the survey. The particular findings spread on a broader range such as habits of CKDu affected patients; the cost of medicine; the impact of the disease on the households' consumption, income as well as the education of the children.

#### 4.2 Number of Affected Patients in the Households

As already mentioned, the sample of the study was 200 affected households from four of the severely CKDu affected districts. A few households of the sample had more than one patient. Also in certain households a few members had already died due to CKDu. Table No.4.1 shows the number of CKDu patients in the sample households.

**Table 4.1: Number of Affected Patients in the Households**

No. of patients	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
One	44	50	46	50	200	95.2
Two	06	0	04	00	10	4.8
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>210</b>	<b>100.0</b>

Source: Survey data

The table shows that a great majority of the sample households have only one CKDu patient. Only in two districts; Anuradhapura and Trincomalee a few households had more than one CKDu patient. When combined those make only 10 households together in both districts.

The Table 4.2 has depicted the number of male and female CKDu patients of the sample households. Accordingly the males have been the significant majority of the CKDu patents of all four districts. They comprise more than 77% of the total CKDu patents of the entire sample. This suggests that males are more vulnerable to CKDu than females.

**Table 4.2: Patients of CKDu by Gender**

No. of patients	Districts & No. of Households				Total	% n=210
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Male	41	38	40	43	162	77
Female	15	12	14	7	48	23
<b>Total</b>	<b>56</b>	<b>50</b>	<b>54</b>	<b>50</b>	<b>210</b>	<b>100</b>

Source: Survey data

Further, in 98% of the sample households either the father or the mother has contracted the disease. Only in four households (2%) in the sample someone other than the parents had been affected by the disease. In six households of the sample, 3 each from Anuradhapura and Trincomalee districts both parents suffered from CKDu.

#### 4.3 Deaths Occurred due to CKDu in the Sample Households

Table 4.3 shows the number of CKDu related deaths occurred in the sample households. According to the table, deaths have occurred in 17 of the total 200 households due to CKDu. This as a percentage is 8.5%. The total number of deaths which occurred in the entire sample households is 22. In most of the households which had experienced CKDu deaths only one person has died. One household from the Moneragala district had lost 3 members from CKDu. The mean ages of those died of the disease are 52 and 51 years, respectively in Anuradhapura and Polonnaruwa districts while it is 52 and 47 years in Trincomalee and Moneragala districts. The youngest died of CKDu had been 30 years.

**Table No.4.3: Number of Family Members Died from CKDu**

No. of Deaths	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
One	05	03	04	01	13	6.5
Two	00	00	02	01	03	1.5
Three	00	00	00	01	01	0.5
None	45	47	44	47	183	91.0
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100.0</b>

Source: Survey data

However, it was also found in the study, in certain families kidney related deaths had occurred in previous generations as well. In such families more descendents seemed to have been the victims of disease. This is evident from the members of some closely related families of certain villages being contracted with the disease and many CKDu deaths as well have been reported from such families. As a result it can be assumed that certain genetic traits also support the chronic kidney disease of unknown etiology.

#### 4.4 Age of the Patients Affected with CKDu

Table 4.4 shows the age of the CKDu affected patients. It is observed that the majority of the CKDu affected patients falls into middle or older age categories. This is evident from the fact that in each studied district the mean age of CKDu patients is over fifty. While Anuradhapura and Polonnaruwa districts the mean age of CKDu patients was 59 years and 56 years respectively and in Trincomalee and Monaragala districts that was 51 and 58 respectively.

**Table 4.4: Age of the CKDu Affected Patients**

Age Category	District & the Number of Households				Total	% n=207
	A'pura	Polonnaruwa	Trincomalee	Monaragala		
20-30	00	00	02	01	03	1
31-40	02	03	02	02	09	4
41-50	05	13	23	06	47	23
51-60	23	18	16	23	80	39
61-70	14	08	07	11	40	19
>70	10	08	03	07	28	14
<b>Total</b>	<b>54</b>	<b>50</b>	<b>53</b>	<b>50</b>	<b>207</b>	<b>100</b>

Source: Survey data

According to the above table it is evident that more than 70% of the CKDu patients are over 50 years of age. It is also evident that except in the Trincomalee district, in all other three districts the majority of the patients are in the 51 to 60 years of age group. The percentage of those under 40 years contracting the disease is less. On the whole, it appears that the risk of getting CKDu, starts after forty years. According to the table only 6% of the sample has contracted CKDu before reaching the age forty. This shows that youngsters are less vulnerable to CKDu.

**Table 4.5: Level of Education of the CKDu Patients**

Level of Education	Districts & the Number of Respondents				Total	% n=209
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
< 5 (Grade)	36	35	28	39	138	66
5-11(Grade)	15	15	26	09	65	31
O/L Passed	02	00	00	01	03	2
A/L Passed	02	00	00	01	03	2
<b>Total</b>	<b>55</b>	<b>50</b>	<b>54</b>	<b>50</b>	<b>209</b>	<b>100</b>

Source: Survey data

Table 4.5 shows the levels of education of the CKDu patients in the sample. According to that the highest majority of the CKDu patients have received comparatively a lower level of education. It is evident from the fact that as many as 97.2% of the sample respondents are educated below than the Ordinary Level (O/L). The number of those who have passed O/L and A/L are insignificant. This proves that most of the CKDu patients are a less educated segment of the society.

#### 4.5 Duration Spent with the Disease

The sample patients had spent different durations since they had contracted the disease. While certain respondents have got it fairly recently some have lived with the disease for a fairly long time. The Table No.4.6 shows the number of years the sample respondents have lived with the disease.

**Table 4.6: Duration Spent with the Disease**

Duration (Years)	Districts & the Number of Respondents				Total	% n=209
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
<1	05	04	03	06	18	8.6
1-5	20	21	21	27	89	42.7
5-10	27	18	27	16	88	42.1
>10	04	07	02	01	14	6.7
<b>Total</b>	<b>56</b>	<b>50</b>	<b>53</b>	<b>50</b>	<b>209</b>	<b>100.0</b>

Source: Survey data

Accordingly the above table it is apparent that many of the CKDu patients have lived from 1 to 10 years with the disease. Almost a similar number of respondents have suffered from the disease for 1 to 5 years and from 5 to 10 years. However, it is significant that a very few number of patients are in the group of those lived 10 or more years after contracting the disease. This implies that the majority of CKDu patients survive less than 10 years after contracting the disease. Table 4.7 shows the duration that a person survived after being diagnosed of CKDu.

**Table 4.7: Period Lived after being Diagnosed of CKDu**

Period Lived after being Diagnosed (Years)	Districts & No. of Patients Died				Total	% n=22
	A'pura	Polonnaruwa	Trincomale	Moneragala		
<1	04	02	03	01	10	45.5
1-3	00	00	03	03	06	27.3
3-5	01	00	00	02	03	13.6
5- 8	00	01	00	00	01	4.5
>9	00	00	02	00	02	9.1
<b>Total</b>	<b>05</b>	<b>03</b>	<b>08</b>	<b>06</b>	<b>22</b>	<b>100.0</b>

Source: Survey data

According to the above table, out of those died from CKDu around 50% have died within the first year of diagnosis. Very few have survived a little longer. It was revealed in the study, that the duration that a person survived after being diagnosed of CKDu depends on how early the disease is identified and on how well the treatments are received and quality of life is maintained.

#### 4.6 Livelihoods of the CKDu Patients

It could ascertain from the study that the patients of CKDu had been engaged in different types of livelihoods. However, the majority, both males and females had been farmers. Most of the patients whose livelihood was not farming still had been engaged in more laborious and hardwork for a living. Apart from that, a very few whose main source of income had been a public or private sector job had contracted the disease. However, these patients also had been involved in farming a lot as their secondary source of income. As a result it appears that all most all CKDu patients had been engaged in hardwork such as farming or other laborious manual work. Table 4.8 shows the livelihoods of the respondents in the sample.

**Table 4.8: Main Livelihoods of the CKDu Patients**

Livelihood	Districts & No. of Patients				Total	%
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Farming	48	41	43	43	175	83.8
Public Sector	02	03	02	03	10	4.9
Private Sector	01	00	00	02	03	1.4
Business	01	01	01	00	03	1.4
Laborers	00	05	05	02	12	5.7
None	03	01	02	00	06	2.8
<b>Total</b>	<b>55</b>	<b>50</b>	<b>53</b>	<b>50</b>	<b>209</b>	<b>100.0</b>

Source: Survey data

The above table shows that the main means of living of most of the patients of the sample is farming. Almost 85% have been farmers. Not many are engaged in other activities as their livelihoods. However, in designing the above table, rarely reported livelihoods were incorporated in the categories which they were closely related. For example, few cattle farmers from Pollonnaruwa and Trincomalee districts had been categorized under farming. Similarly carpenters and masons who are very few in number were put in the laborer category.

#### 4.7 Other Diseases the Respondents had Contracted before CKDu

The Table 4.9 shows the other diseases which the CKDu patients had suffered before they contracted CKDu. While the larger majority reported that they have not had any disease before getting CKDu, 14% of the respondents from the entire sample had reported that they had high blood pressure before. Around eight percent of the total respondents had been diabetic. However, most of the respondents claimed they got diabetes and high blood pressure after contracting CKDu.

**Table 4.9: Other Diseases the Respondents Contracted before CKDu**

Diseases	Districts & the Number of Respondents				Total	%
	A'pura	Polonnaruwa	Trincomale	Moneragala		
Diabetes	05	03	06	04	18	8.1
High Blood Pressure	12	11	02	12	42	18.8
Wheeze	01	02	04	03	10	04.5
Piles	00	03	00	00	03	01.3
None	39	37	38	36	150	67.3
<b>Total</b>	<b>57</b>	<b>56</b>	<b>55</b>	<b>55</b>	<b>223</b>	<b>100.0</b>

Source: Survey data

#### 4.8 Consumption Related Habits of the CKDu Patients

In this study, attention was paid to certain food habits of the affected people. Some of these habits were medically proven and deemed to influence kidney dysfunctions or failures. Those habits include consumption of alcohol and smoking. In addition, it was also suspected that consumption of certain edible plants and roots of watergrown plants and fish from tanks in the disease prevalent areas may cause CKDu. This is due to the possible presence of the residues of heavy metals in them. Another view is that the use of aluminum cooking utensils may trigger CKDu when the water contains fluoride. As a result, in the present study, attention was paid to the information on the above aspects as well.

#### 4.8.1 Consumption of Alcohol

The Table 4.10 shows that the number of patients addicted to or often consumed alcohol had been only 38% of the sample. The highest majority which is over 60% percent is either sobers or rarely consumed alcohol. Accordingly, alcohol consumption apparently does not have a direct relation to CKDu in the sample respondents.

**Table 4.10: Alcohol Consumption**

Level of Consumption	Districts & the No. of Patients				Total	% n=209
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Addicted	13	11	11	08	43	21
Often Consumed	10	08	07	10	35	17
Rarely	10	14	14	15	53	25
Not at all	23	17	21	17	78	37
Total	56	50	53	50	209	100

Source: Survey data

Further, the Table 4.11 shows a comparison of the level of alcohol consumption and the age groups of the CKDu patients. The particular comparison was intended to see whether the higher level of alcohol consumption may cause CKDu at a younger age. Accordingly there seems to be a clear positive relationship of the above assumption as 79% and 94% of patients who had been addicted to and often consumed alcohol respectively were victims of CKDu before they reached 60 years of age.

Nevertheless, the fact that 57% of the patients who consumed alcohol rarely and as many as 38% of non alcohol consumers contracting the disease when they were in 50s makes it difficult to draw a relationship that alcohol consumption may increase the risk of CKDu at a younger age.

**Table: 4.11: Alcohol Consumption and the Age of CKDu Victims**

Level of Alcohol Consumption	Age Groups and the No. of Patients						Total	% n=207
	20-30	31-40	41-50	51-60	61-70	>71		
Addicted	0	2	12	20	06	03	43	21
Somewhat Addicted	0	2	15	16	02	00	35	17
Rare	2	3	11	13	18	04	51	25
Not at all	1	2	09	31	14	21	78	38
Total	3	9	47	80	40	28	207	100

Source: Survey data

#### 4.8.2 Smoking

As discussed in the second chapter, smoking is also included among the causative factors of chronic kidney diseases. As a result this particular study looked at whether the habit of smoking has a perceivable positive relationship with the incidence of CKDu in the sample patients. According to the findings, the Table 4.12 shows that almost 50% of the CKDu patients are non-smokers. Another 31% smoked only occasionally. In accordance with the survey findings, tracing a relationship between the smoking and the CKDu is not possible.

**Table 4.12: Level of Smoking by the CKDu Patients**

Level of Smoking	Districts & the No. of Patients				Total	% n=209
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
addicted	13	14	08	11	46	22
Occasionally	12	11	17	26	66	32
Not at all	31	15	28	23	97	46
Total	56	50	53	50	209	100

Source: Survey data

#### 4.8.3 Consumption of Fish from Local Irrigation Tanks

It is a known fact that certain quarters held the firm belief that agro-chemicals cause the incidence of CKDu in Sri Lanka. They also claimed that water sources of CKDu affected areas are highly contaminated with chemical pollutants. This led to the assumption that the consumption of fish from irrigation tanks and such other water bodies of the affected areas as well have contributed to the disease. This is because the fish in the water bodies may retain the residues of heavy metals such as cadmium and arsenic. As a result, this study looked at the consumption of the fish caught from local irrigation tanks in the sample areas.

**Table 4.13: Consumption of Fish from Local Irrigation Tanks**

Frequency of Consumption	Districts & the No. of Patients				Total	% n=207
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Very Often	31	33	37	27	128	62
Occasionally	16	11	11	17	55	27
Rarely	05	02	03	05	15	7
Never	02	04	02	01	09	4
Total	54	50	53	50	207	100

Source: Survey data

The Table 4.13 shows that almost 90% of the sample patients regularly or occasionally consumed fish from local tanks. The particular fact suggests that consumption of fish from irrigation tanks in the study area is a normal practice which is not limited to CKDu patients. Therefore any direct relationship of consumption of the particular fish to CKDu cannot be made. Also the fact that around 12% of the CKDu patients being none or rare consumers of fish further undermines any strong impact of it to the disease.

#### **4.8.4 Drinking Water**

Among various reasons presented as the cause of CKDu, water in the affected area is assumed to be the main factor behind the disease. Many of the wells that had been in use as the source of drinking water in the affected area had been checked and condemned. As a result, majority of the sample households have had to find alternatives to obtain safe drinking water. Some had bought purifiers or the filters to purify the water. The prices of the water purifiers or the filters vary in terms of the quality. It was revealed that during the time of the survey of this study the price of high quality water machines ranged from Rs.32,000 to Rs.40,000 while the low quality ones ranged from Rs.2500 to Rs.8000. It was found that the choice of the filter is based on the purchasing power of the households. Those who have bought the cheaper ones reported to have faced problems in operation shortly after purchasing.

Moreover this context has given rise to a lucrative business of selling purified water in the affected districts. A liter of purified water was reported to be sold at Rs.3 to Rs.3.50 at the time of the survey. Certain households that could not afford water purifiers tended to buy these purified water especially for patients and small children. However, it was also revealed no regular check -up or control is exercised over these businesses to assure the safety and the quality of the product.

Further, it is reported that some households in the sample travel 15km to 20km to collect water from reliable sources. People at Madawachchiya in the Anuradhapura district in groups or individually go to a natural water source located at a village called Gonamadiyawa. They were reported making this trip weekly or fortnightly incurring a cost of more than Rs.1000 for the hired vehicle.

Table 8.14 shows the sources of drinking water the sample CKDu patients had used for a long time.

**Table No: 4.14: Source of Drinking Water**

Source of Drinking Water	Districts & the No. Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Well	35	41	44	32	152	76
Tube well	01	05	01	11	18	09
Well & Tank	03	02	03	00	08	04
Well & Tube well	11	02	02	07	22	11
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100</b>

Source: Survey data

According to the above table it is clear that the wells have served as the main source of drinking water of the large majority of the sample households in the affected areas. Tube wells also have been used by a substantial number of households. However, these sources fulfilled their drinking water requirement only when they were at home. Nevertheless many of the CKDu patients revealed that when they were in the *chenas* or field they used to drink whatever water they found in the around if the quantity they took with them from home was over. Some stated that they have drunk even the water that is collected in the holes created by the elephants' foot print. Further, most of the households had not been in the habit of treating the water before consuming. Only around 15% of the total sample had at least filtered (using a piece of cloth) the water before drinking. Even lesser percentage i.e. around 4% had boiled it. However, the high salinity level in the drinking water has been the common issue in all the areas of the study.

#### 4.8.5 Cooking Utensils

When considering the cooking utensils, many households had used aluminum utensils either exclusively or in combination with clay pots. For preparing tea 90% of the households still use aluminum kettles. However, with the increasing awareness in harmful effects of using aluminum with the water which contains a higher level of fluoride, households seem to avoid aluminum utensils in cooking.

The Table 4.15 shows the types of cooking utensils being used by the affected households for preparing food.

**Table 4.15: Cooking Utensils Used by the Sample Households**

Cooking Utensils	Districts & the No. Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Aluminum	14	16	10	11	51	25.5
Clay	09	13	15	04	41	20.5
Both	27	21	25	35	108	54.0
<b>Total</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>50</b>	<b>200</b>	<b>100.0</b>

Source: Survey data

It was observed as shown in the above table that around 80% of the households used aluminum utensils in cooking while more than 25% households from the sample have used them exclusively.

However, still a larger majority of the sample continues to use the aluminum kettle for preparing tea.

#### **4.9 Impact on the Household Income**

It is evident from the data above that most of the CKDu patients are still in the working and economically productive ages. As a result, the disease has a considerable impact on the households' income. Majority of the affected households which is 51% of the total sample claim that their income has dropped due to the disease. Table No: 4.16 shows that how the disease has affected the households' monthly income.

Accordingly, the monthly income of more than 25% of the sample households has gone down from an amount between Rs.3000 to Rs.15, 000 due to CKDu. Also 11% of the households has experienced an income loss of more Rs.25,000 per month. However, the disease has not reduced the income of almost half of the sample households which is 49%. This can be attributed to several reasons. The main reason is the presence of other family members who are capable of carrying on the livelihood unhindered. Especially in the cases where the patients had grown up children they carry on the livelihoods. Further in many households where there are female patients the impact of the disease to the households' income was found to be less because in those families males are the breadwinners.

**Table 4.16: Reduction of Household Income**

Lost Income(Rs.)	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
3000-5000	01	02	04	01	08	04
5000-10,000	08	08	06	04	26	13
10,000-15,000	02	04	01	09	16	08
15,000-20,000	03	04	06	01	14	07
20,000-25,000	05	00	06	05	16	08
>25,000	05	03	08	06	22	11
No Lost	26	29	19	24	98	49
Total	50	50	50	50	200	100

Source: Survey data

#### 4.10 Cost on Medicine

The study revealed that the majority of the patients receive treatment from government hospital. In the entire study sample it was only 27 patients reported to have received private medical treatment. This is merely 13% of the total sample. However, the tendency of opting for private treatment differs in the districts. A notably high percentage such as 27% of the patients in the Monaragala district was reported to have sought private treatment.

Nevertheless in the Anuradhapura district only one person had opted for private treatment. In case of Polonnaruwa and Trincomalee districts the number of persons who sought private treatment was 5 and 7 respectively. However, it could also be observed that a small percentage of patients had stopped treatment at their own will. Such patients are just 3% of the sample. The reasons for stopping medication as cited by some were feeling better and the inability to follow the medical advice which did not comply with their livelihoods. According to them when they are under treatment, a huge dose of drugs per day is prescribed with dietary restrictions which immensely affect their strength and subsequently they could not pursue their livelihoods. They are also of the view that as the death is certain due to the disease there is no point in restricting foods and living on medicine.

In the Moneragala district, a large number of patients as high as 14 out of 53 seek private treatment. Most of them prefer indigenous medical practitioners. There seems to be several reasons for patients' opting for indigenous medicine. Mainly the patients' reluctance to have western medicine and the success stories about certain indigenous practitioners.

Patients taking indigenous treatment expressed their reluctance to follow western treatment as it requires them to take in huge doses. Further, unlike in western

treatment it was not required to abstain from any food in the indigenous treatment. Patients do not have to pay routine visits to the indigenous practitioners and wait in the queue for hours as opposed to in hospital clinics. Further, patients seeking indigenous treatment visit the practitioners around once in three months and collect all the medicine required for the whole period.

The Table 4.17 shows the cost incurred by the affected households on medicine in the month prior to the survey

**Table 4.17: Cost on Medicine**

Cost (Rs.)	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
10-100	08	00	01	00	09	4.5
100-250	09	03	02	01	15	7.5
250-500	03	05	12	04	24	12.0
500-1000	03	04	05	10	22	11.0
1000-1500	02	00	02	04	08	4.0
1500-3000	01	01	04	08	14	7.0
3000-5000	00	00	02	11	13	6.5
>5000	00	02	01	06	09	4.5
No cost	24	35	21	06	86	43.0
Total	50	50	50	50	200	100

Source: Survey Data

From the above table it is obvious that the highest majority of the households have spent zero or less than Rs.500 on medicine per month. A little more than 20% of the total households have spent over Rs.1000 on medicine. As mentioned earlier in case of patients visiting government hospitals for treatment, it costs very less as they have to buy only a few drugs from outside in case they are not available. In certain months they had to purchase none from outside as they receive all from the hospital free of charge. The above costs on medicine include even the charges of laboratory tests done outside. As such it is observed much of the burden of treatment for CKDu patients is borne by the government. In contrast, those seek private treatment either in western medicine or indigenous have paid a high price. This is understood when looking at the monthly average cost of medicine a household in each district has incurred. Average costs of medicine for households in the four sample districts are Rs.330, Rs. 1251, Rs.1013, Rs.2178 respectively for Anuradhapura, Polonnaruwa, Trincomalee and Moneragala districts. In those districts where a higher number of patients receiving private treatment the cost has increased.

More than the cost on medicine, it was noticed that households have to make a higher expenditure on traveling to receive treatment.

**Table 4.18: Cost on Traveling for Medicine**

Cost (Rs.)	Districts & No. of Households				Total	% n=199
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
50-100	01	02	01	01	05	3
>100-250	24	27	14	08	73	37
>250-500	22	10	15	13	60	30
>500-1000	00	04	03	06	13	6
>1000-1500	01	00	02	07	10	5
1500<	00	01	07	14	22	11
No Cost	02	06	07	01	16	8
Total	50	50	49	50	199	100

Source: Survey Data

It is evident from the comparison of the Table 4.17 & 4.18 that for most of the households the expenditure on traveling for treatment is higher than their cost for medicine. For a large number of households i.e. as many as 43% of the total sample it costs nothing for medicine as shown in the Table 4.16 while around 70% of the total sample households have spent Rs.100 to Rs.1000 for traveling (Table 4.17). The average travelling cost of the households for obtaining treatment for the patients are Rs.232, Rs.255, Rs.1348 and Rs.1200 in the four respective sample districts such as Anuradhapura, Polonnaruwa, Trincomalee, Moneragala.

Traveling cost shown here includes the expenses made by the patients on refreshment as well on their visits for treatment. It was also found a very few patients who undergo dialyzing have had to spend over Rs.5000 to Rs. 10,000 a month for traveling. One household from Padavi-Sripura in Trincomalee district was found to have spent Rs.12,000 per month as his traveling cost to Anuradhapura hospital from where he received the dialyzing treatment. He had to make a travel to Anuradhapura from Padavi Sripura twice a week for dialyzing.

#### **4.11 Impact of the Disease on Agriculture**

Impact of the disease on agriculture is visible from many facets. Future challenges on agriculture seem to be formidable if the disease continues to spread and those engaged in agriculture become patients in large numbers. In the study, it was found that the highest majority of the affected are farmers who have been engaged in agriculture for long. Most of them were capable of continuing their livelihood for many years, had they not been affected by the disease. In the face of new trends in domestic agriculture

which is marked by the less involvement of youth, this situation poses an invariable threat to the economy.

However, it was revealed in the study, despite the disease some patients are still actively engaged in agriculture. They comprise a considerable portion of the total sample of respondents of the respective districts as follows, 36% in Anuradhapura, 68% in Polonnaruwa, 38% in Trincomalee and 58% in Moneragala. The period they are able to hold on to their livelihood invariably depends on their health condition. Nevertheless, it was revealed that, early detection of the disease, proper medication and adherence to medical advice would be instrumental in leading a normal life for many CKDu patients for a considerable period.

It was found that due to the disease there has not been a substantial reduction in the cultivation of lands owned by the affected households. This is because somebody in the family has very often taken over the job or in the absence of such a person lands had been given on tenancy. This has reduced the household income considerably, because when given on tenancy the quota received for the land ownership falls into one fourth of the total income. Apart from that, it was also revealed that though another member of the family continues the cultivation, the production and productivity become less due to reasons such as lack of experience, poor knowledge and less interest. In addition, certain respondents had cultivated several acres of land on the basis of tenancy before being affected by the disease. But due to the disease now they have given up those cultivations. Most respondents stated that they have had to hire labor to do what they did alone before. This has eroded their income. In Anuradhapura and Polonnaruwa districts 24% and 18% households respectively have hired labor due to being affected by CKDu. In Trincomalee and Moneragala districts the percentage of such households are 22% and 30% respectively.

Of the total extent of their land, the sample households could not cultivate only 20.5 acres of upland and 36.75 acres of low land due to the disease. However if the health condition of the patients who are still engaged in agriculture deteriorates, there is a likelihood of increasing the uncultivated extent of land.

#### **4.12 Impact of the Disease on the Household Consumption**

Findings of the study reveal that CKDu has not affected the household consumption very much. Only few families from the sample districts had reported that the disease affected their food consumption. The percentage of those affected households is only 6% of the total sample. In Polonnaruwa and Trincomalee districts the number of households of which the consumption was affected by the disease was three each, while those in Anuradhapura and Moneragala districts it was 2 and 4 respectively. Several reasons can be identified for the less impact of the disease on household consumption. The most significant of them is that in most affected households there are

members who make income either by farming or being engaged in other employment. Majority of the households have members employed in other livelihoods except agriculture.

As shown in the Table No: 3:5 in Chapter Three, it is clear that more than 60% of the households of the sample have at least one member engaging in a source of income other than agriculture. In a little over one fifth of the households, at least two members are employed. This clearly depicts that the consumption of the bigger half of the households is less vulnerable as the members are employed. Further, since most of the CKDu patients receive treatment from the government hospitals, they have to spend very less on medicine as shown in the Table No: 4.16. This has considerably reduced the burden on household expenditure. Apart from that, cultivation of their own land does not seem to have been disturbed much due to the disease. Because, very often if the condition is not serious the patient himself continues with it or else somebody in the family takes over. Except 13% of the total sample, all others receive an income from agriculture. The percentage of the number of households which receive income from both agriculture and other non agricultural sources is 44% out of the entire sample households.

#### 4.13 Impact of Disease on Assets and Borrowings

It was revealed in the study generally the disease had not forced much for the households to borrow money. Only a very few had borrowed money for the expenses of the disease. Another few had borrowed to buy water filters. Several households had pawned their jewelry rather than borrowing from others to obtain money they required for the above needs. The source of almost all borrowings was either relatives or friends. This has relieved them from any interest on the borrowed money.

Table 4.19 shows that the number of households which had obtained loans due to the disease and the amount obtained.

**Table 4.19: Household Borrowings due to the Disease**

Amount Borrowed (Rs.)	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
5000-10000	00	00	00	01	01	0.5
10000-30000	00	01	02	00	03	1.5
30000-50000	00	00	00	02	02	2.0
>50000	00	01	01	01	03	1.5
Borrowed None	50	48	47	46	191	95.5
Total	50	50	50	50	200	100.0

Source: Survey Data

It is evident from the above table that no household in the sample of the Anuradhapura district had borrowed money due to the disease. Even in other districts the households which had borrowed money due to the CKDu are very few. The percentage of the total sample households borrowed due to the disease is altogether less than 5%.

From the entire sample households numbering 200, just five households, one each from Anuradhapura, Polonnaruwa, Monaragala and two households from Trincomalee districts have mortgaged agricultural land due to the disease. The total extent of this mortgaged land is 5.5 acres from the entire 200 sample households. The number of households pawned their jewelry due to the disease are four, as two each from the Trincomalee district while one each from Polonnaruwa and Moneragala districts.

Accordingly, the households affected by the CKDu on the whole had not experienced a significant erosion of their assets or their amount of debts has not been very high

#### 4.14 Impact on the Children's Education

According to the findings of the study, it could be observed that the disease has affected the education of the children of some affected households. The number of households, education of whose children were affected was 16 all together i.e. 8% of the total sample households. In the Table 4.18 it has been shown how the disease has affected the education of the children of particular households. The table shows in 16 households at least part or the total burden of agriculture had fallen on the children. Also in 12 households, 6% of the sample households, at least one or more children had dropped out of school. In most cases it was the eldest boy of the family who drops out of school to take up agriculture.

**Table 4.20: Impact of CKDu on the Education of the Children in Affected Households**

The Impact	Districts & No. of Households				Total	% n=200
	A'pura	Polonnaruwa	Trincomalee	Moneragala		
Dropped out of school	03	04	02	03	12	06.0
Stopped tuition	01	02	04	05	12	06.0
Had to spend much time in Agriculture	02	04	04	06	16	08.0
Lost interest to study	00	01	02	02	05	2.5

Source: Survey Data

#### **4.15 Impact of the Disease on Family Bonds**

It was found that the disease has not affected the family bonds. On the contrary the affected families often receive the support of their immediate and close relatives. Lands of some affected families were also cultivated by the relatives for them. Further, the majority affected being aged members in the families; the possibility of the disease in damaging the family bonds looks very slim. Majority of the affected are the parents of grownup children who are already employed and settled. They have been very often the caretakers of the parents. This ground situation has reduced the impact of disease on family bonds and the creation of undesirable social issues.

Nevertheless, it was also revealed and noticed in the study that certain households affected by the CKDu try to conceal it fearing social stigma. Some avoid going to the clinics in their own area or stealthily seek private treatment incurring an additional cost in their attempt to hide it from other villagers. It was reported that this situation has arisen as some believe that the disease would be a negative factor when entering matrimonial relationships.

## CHAPTER FIVE

### Conclusion and Suggestions

#### 5.1 Introduction

This chapter mainly contains a summary of the findings of the study and the view of the research team on the socio-economic impact of the Chronic Kidney Disease of Unknown Etiology that has affected the major agricultural areas of the country. Further, the chapter contains a few suggestions made based on the findings. These suggestions and findings of the study are expected to be helpful in preventing and reducing the harmful socio-economic impact of CKDu.

#### 5.2 Summary of the Findings

1. A great majority of the sample households have only one CKDu patient. In the sample only in two districts (Anuradhapura and Trincomalee) few households had more than one CKDu patient. When combined those make only 10 households together in both districts.
2. Males are the significant majority of the CKDu patients of all four districts. They comprise more than 77% of the total CKDu patients of the entire sample studied. This suggests that males are more vulnerable to CKDu than females.
3. The majority of the CKDu affected patients are in the middle or older age categories. More than 70% of the CKDu patients are over 50 years of age. The percentage of those under 40 years contracting the disease is less. On the whole, it appears that the risk of developing CKDu, starts after forty.
4. Around 50% of the CKDu patients have died within the first year of diagnosis and more than 90% had died within a period of seven years since diagnosis. Only a few have survived more than five years after being diagnosed. Nevertheless it was revealed in the study, that the duration that a person survived after being diagnosed of CKDu depends on how early the disease is identified and on how well the treatment is received and quality of life is maintained.
5. Almost all CKDu patients had been hardworkers engaged in farming or other laborious manual work
6. Consumption of alcohol and smoking was found not be directly related to CKDu in the sample area as many patients had been not addicted to it or had never consumed them.
7. Many of the wells that had been in use as the source of drinking water for a long time in the affected area had been checked and condemned. This has led majority to look for alternative source of water. Some people travel up to 15km to 20km for safe water.

8. Impact of the disease to the households' income is less due to the majority of CKDu patients having adult children who are able to support the families and carry on the livelihoods
9. Most of the CKDu patients receive medicine from government clinics and as a result, except in serious cases, the cost they have to incur on medicine is not high.
10. There is a tendency of CKDu patients opting for indigenous medicinal practitioners due to several reasons. This increases their cost while having a risk of worsening the health of patients due to the possibility of the presence of quack indigenous practitioners.
11. Several unscrupulous businesses such as selling of purified water without proper certification and quality assurance have emerged misleading and exploiting the CKDu affected families
12. CKDu has adversely affected the education of the children of certain affected families directly and indirectly. Most of the instances the education of the eldest child in the family has been affected.
13. CKDu has not affected the consumption of the families due to majority affected by the disease being adults over forty and having children who make a living.
14. CKDu has not strained the family bonds

### **5.3 Conclusion**

Chronic Kidney Disease of Unknown Etiology as already mentioned has affected many of the agricultural districts of the country. The disease has affected many, generally with a back pain, irritation on the body or swelling of limbs. A host of different arguments and counter arguments have built up over probable causes of the disease based on different perceptions, attitudes and knowledge of the relevant groups or the individuals. The argument which caused much panic in society was the impact of agrochemicals in causing CKDu. According to those heralding the particular view, paddy, freshwater fish and water based edible plants and roots in the affected areas were reported to contain agrochemicals such as cadmium, and arsenic which damage the kidneys. Similarly the use of low grade aluminum cooking utensils and several other unhealthy food habits were also blamed for the disease. However, much accepted reason for the disease by many interested groups including medical authorities lately is the quality of groundwater. In the affected areas where the study was carried out, authorities have condemned the majority of the wells and deep wells of the households which had been used as sources of their drinking water for containing elements which can damage kidneys.

Moreover as shown in the survey findings, it was observed that most of the patients of kidney disease are relatively mature in age and had been engaged in rather tiresome livelihoods including agriculture. Accordingly, it is also apparent that there is a certain relationship between a person's involvement in laborious livelihood in the area for a considerable period and the kidney disease. Other than the hard work required in

livelihoods such as agriculture, the effects of wrong handling of agrochemicals and natural harmful substances in the water in the epidemic areas can be suspected to have acted together in causing the disease which is not prevalent in other areas.

As viewed by certain respondents a disease with similar symptoms of the CKDu has been in the same areas where the study was conducted, in the past as well. Though it had not then been much noticeable it was revealed that the particular disease caused the death of some middle aged and elderly people with similar symptoms of the CKDu. This disease which has become a main cause of death then had been named as "*naraka lede*" means the "bad disease". By the name denotes it is understandable it has been a serious disease and, rarely any one who contracted it survived. As it appears, if this had been the same kidney disease it is more likely to be caused by one or a few area specific factors. According to the common belief, the main probable reason is the groundwater. As many groundwater sources in the entire affected areas have been condemned the particular opinion cannot be dismissed.

However, as evident from the study, the social impact of the kidney disease has softened owing to several reasons. This is mainly because the majority of the patients belong to the upper middle age or above. Most of them are already relieved of their family obligations due to being parents of grownup children. The children in many an instance, are the caretakers of the patients as well as the ones making living. Early marriages in the agricultural areas seem to have helped relieving the many affected at a relatively young age of their family obligations. In the survey it was witnessed that many patients in their forties had children who are married. This as well has made a favorable impact reducing the social consequences of the disease considerably.

Due to the fact that the majority of kidney patients receive treatment from the government hospitals, the expenses of the affected seem low. Once a month they have to purchase one or two medicines from pharmacies in case those are not available in the hospital. It could be observed that those medicines which have to be purchased outside also do not cost much. However, for medical laboratory tests the cost increases because the patients often have to get those checkups done outside. Besides, in case of serious patients, households have to make a substantial expenditure because they require to undergo frequent blood check-ups and purchasing of certain costly medicine from outside. Apart from that, households with patients requiring dialysis have to bear a huge cost on traveling. Some patients have to have dialysis thrice a week. Since the hospitals with dialysis facilities situated far away the cost they have to incur is very high. Few patients were found in the survey spending over Rs.10, 000 per month on traveling for dialysis.

The number of patients seeking private treatment is also on the rise. Many patients also look prefer indigenous medicine. Several factors have triggered this situation. Some are reluctant to have western medicine which they said, has to be taken in a high dose day

and causes irritation. Also they find it difficult to adhere to the confinements and dietary restrictions prescribed under the western medicine. Some dislike routine visits to hospital and the time consuming process for treatment which they think is a waste of time. When receiving indigenous medicine as to the respondents' opinion, though it costs more, they do not have to waste their visiting every month for treatment. According to the respondents, they usually receive medicine for three months in a visit and further indigenous doctors do not impose dietary restrictions as well.

However, it could be noticed that people go for indigenous medicine without proper awareness and understanding of those practicing it and how it would affect them. This may bring disastrous effects to patients, such as worsening the condition of disease besides the financial loss. Therefore patients need proper awareness to make correct decisions.

In the study it was also found that a number of CKDu patients to a certain extent is double counted. This is because certain patients get registered in several clinics. This happens due to changing the clinic for reasons such as convenience or better treatment. Once registered in a clinic he/she is counted as a new patient in a particular clinic. This is caused due to absence of a networked system to record CKDu patients, also falsely inflates the number of such cases.

Moreover, in the study area, there is no mechanism to distinguish between the CKDu and non CKDu kidney patients. All kidney patients in the study areas seem to be indiscriminately counted as the CKDu patients though there may definitely be other kidney patients for whose disease there could be known reasons. However, this situation may inflate the number CKDu cases and alarm the public.

## **5.4 Suggestions**

### **5.4.1 Short Term**

- Periodical screening of people in the affected areas should be made for early detection of CKDu.  
This can be better implemented through mobile screening program conducted periodically in vulnerable villages.
- Educating people on the areas such as nature of the disease, adopting preventive measures and obtaining treatment.  
This can be done through awareness programs, informing through leaflets, booklets, and other appropriate use of media and passing the knowledge via officers close to the ground level like PHIs and Midwives.
- Action should be taken to prevent exploiting of the affected people by fraudsters.

Certain unscrupulous businesses thrive by taking advantage of the misfortune of the affected people. Speculations on "miraculous" indigenous practitioners have mushroomed and in the affected areas they make money at the expense of patients' lives. With the apparent tendency of a larger number of patients preferring indigenous medicine the number that fall victim to them may also go high. As a result, authorities concerned have to take action to prevent that.

As mentioned earlier the business of selling purified water which is carried out by a few affluent people using large water filters moves around in the affected villages. At the time of the survey, a liter of purified water was Rs.3.00 to Rs.4.00 and many in a village used to buy them for children or affected patients specially. Yet the people are not certain of the quality of that water.

In case of water filter, people complained about the high prices and low quality. Hence these businesses require regulations.

- A financial subsidy or other mechanisms should be introduced to support the affected households to buy quality water filters. The government should also certify and ensure the quality of the brands of water filters reaching the market.
- Proper recording of CKDu patients at Divisional Secretariat level or a national level should be established.
- Rain water harvesting should be re-introduced and facilitated as a mean to ensure safe drinking water.

#### **5.4.2 Long Term**

- Priority should be given to provision of safe drinking water for the affected areas
- A research team of multi disciplinary experts should be formed and facilitated to identify the real and the most acceptable causative factor and their magnitude

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**Annex 01:**

**Officers assisted and were contacted for receiving information**

<b>Name of the Officer</b>	<b>Designation</b>	<b>Place of Work</b>
Dr. Mrs.P.K.Gnana Kunalanlan	Provincial Director of Health Service	Trincomalee
Dr. V.S.K.Subasinghe	Provincial Director of Health Service	Anuradhapura
Dr. Chaminda Kumara	MOH	Medirigiriya
Dr. Mohan Premalal	District Medical Officer	Madawachchiya
V.P. Suneth Ginendrasena	Divisional Secretary	Padavi Sripura
Mis.T.U.Keeragala	Assistant Divisional Secretary	Medirigiriya
Dr.Shamitha Dassanayake	Acting Consultant Physician	Base Hospital –Padaviya
Dr.Mrssl.K.Innoka	MOIC	Divisional Hospital Padavi Sripura
Dr. Noyel Udugama	Regional Director of Health Service	Polonnaruwa
Dr.R.M.D. Rathnayake	Medical Superintendent	District General Hospital Monerragala
Dr.J.M.Wimalasuriya	MOH	Buttala
Mr.Chandana Lokuhewage	Divisional Secretary	Sevenagala
Mr.Dayananada Rathnayake	Divisional Secretary	Thanamalwila
G.U.K.Algewaththage	Divisional Secretary	Buttala
Mr.Kavindra Algalla	Asst.Divisional Secretary	Madawachchiya
Mr.Duminda Bandara	Asst. Director Planing	District Secretariat-Badulla
Mr. Gunaselkarage Thilakarathna	Administraive Grama Niladhari	Padavi Sripura
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Mrs.D.M.P. Amarathunga	R.S.P.H.N. Officer	RDH Service-Moneragala
Mr.P.Wanigasekara	Deputy Director Planning	Divisional Secretariat- Buttala
Mr.G.W.G. Priyantha	PHI	PDH Office-Anuradhapura
Miss. P.R.M. Chandrani Rathnayake	Managemant Assistant	Divisional Secretariat- Medirigiriy
Mr.K.Sugathadasa	Grama Niladhari	Thalakolawewa- Medidrigiriya

SOCIO ECONOMIC IMPACT OF CHRONIC KIDNEY  
DISEASE OF UNKNOWN ETIOLOGY

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