



## LOCAL UNDERSTANDINGS OF CHRONIC KIDNEY DISEASE OF UNKNOWN ETIOLOGY(CKDu): A QUALITATIVE STUDY IN THE MATALE DISTRICT OF SRI LANKA

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### INTRODUCTION

Chronic Kidney Disease of unknown etiology (henceforth, CKDu) is one of the most devastating health problems in Sri Lanka. Despite government and non-governmental organisations' interventions to reduce the problem, the reported number of patients with CKDu has increased over the last several years (Report of the International Expert Consultation on Chronic Kidney Disease of unknown etiology (CKDu) in Sri Lanka, 2016). According to the World Health Organization (2012), a minimum of 15% of people in the 15-70 years age range are affected by CKDu in the North Central and Uva provinces. According to the Government Medical Officer's Association (GMOA, 2013) of Sri Lanka, a total of 400,000 persons are affected countrywide. The total number of annual deaths due to CKDu in 2015 was 1400 while the death rate in the North Central Province alone was 19 per month in the same year, which was also the highest recorded rate of deaths due to CKDu for the country (Ranasinghe, H. & Ranasinghe M. 2015).

Many types of research have been conducted to find the causes of CKDu, primarily from a perspective of biochemistry; moreover, the great majority of these studies focus on finding the causes of the condition. In contrast, the psychosocial aspects of living with CKDu have not received the same research attention. Previously, few studies had been done on the psychosocial aspects of CKDu in the North Central province (Liyanage, 2019). But this study is the first that has addressed the understanding of CKDu in the farming community in the Central Province. Due to the impossibility of diagnosing CKDu until it reaches a chronic level, the condition poses a significant threat to the patient's overall wellbeing. On the one hand, it causes a decline in patients' ability to work. Given that most of the local patients are the breadwinners of their families, failure to engage in their livelihood (i.e., agriculture) causes obvious social, economic and psychological hardships for both the patient and his/her family. The consequent stress then causes conflicts in their relationships. Some CKDu patients are suffering from long-term depression while in some cases, the psychological distress has even led to suicide (Hettiarachi, & Abeysena, 2018). The economic burden, lack of social support and negative attitudes towards CKDu are some of the immediate reasons identified as leading to suicide. An estimated 8,000 Sri Lankans are undergoing dialysis treatment for the later stages of CKDu while the estimated national health budget for CKDu is 4% (Redmon, et al; 2014). Medication and dialysis cost an extensive amount of money; moreover, patients from rural areas have to travel for hours to receive dialysis. Thus, despite the financial support extended by the government, medical expenses are an added cost on the already taxed economy of these families (Elledge, et al., 2014). The current study contextualised CKDu in this larger, psycho-social context, and addressed the question 'what are local understandings of CKDu?'. The aim of the study is to identify and explain the psychosocial factors that effect and shape their understandings of CKDu.

### Objectives

- To identify how do local communities understand CKDu
  - To identify psycho-social (e.g., individual and family stress, cultural demands, economic hardships etc.) factors that affect experiences of CKDu
  - To provide guidelines to the government for effective psychosocial interventions for CKDu patients and their families.



## **METHODOLOGY**

The research design is driven by the research question ‘how do local communities conceptualise and live with CKDu?’ Given the focus on lived experiences of an individual with a chronic condition, this study used a qualitative methodology to collect data. Hence, it used case studies, facilitated by genograms, life narrative interviews, participant observations and focus group discussions.

### **Sample**

Participants were selected from two local communities in the Wilgamuwa Divisional Secretariat in the Matale district, namely Perakanaththa and Naminigama. The sample was selected using a purposive sampling design. From each village, 25 families and a purposive sample of 50 families were selected for the current study. In addition to family case studies, five FGDs (FGDs (with service providers and community representatives) and ten key informant interviews (with service providers) were also conducted.

### **Data Collection and Analysis**

Data collection used several tools: a semi-structured and open-ended thematic guide for the interviews, a genogram guide and family trees. An audio recorder and notebooks were used to record life narrative interviews. A digital camera was used to take photographs related to important psychosocial factors and aspects of the CKDu patients, if and when the patients express their consensus to do so.

Data was analysed using thematic analysis. All the data was first studied to identify psychosocial themes that are commonly referred to by the sample members. These themes were then analysed further to identify emerging patterns and, finally, led to the development of a psychosocial conceptualisation of the local experiences of CKDu patients.

## **RESULTS AND DISCUSSION**

The data clearly indicates several factors about local understandings of CKDu; the key theme that emerges is about the way people conceptualise CKDu also as ‘just another’ sickness, and lets go of the related fears about death, as death and suffering is a part of life. These understandings are clearly linked to the socio-cultural values and beliefs that are rooted in Buddhist philosophy. Another key theme is the way people worry about pain. While death is acceptable, a painful death is not. This fear of pain can be so intense that they would even avoid treatment at the risk of a quicker death as some treatments are considered to be too painful. Their understandings of the cause of CKDu are linked to their everyday behaviors, such as drinking water from a well near the paddy field or not wearing protective gear. While medical models identify the etiology in chemicals, the patients see the causes as being related to the behaviours that are quite normal and regular for them. Moreover, there are many people who have drunk the same water but shows no signs of the sickness; thus, they question the medical explanation.

The same disparity can be observed in the way the patients understand treatment and medical recommendations. Many of those within the sample who should go for dialysis have refused to follow the medical recommendations properly, such as stopping farming activities and going for dialysis. As their everyday lives and demands, and the need of an income, are much more pressing, and staying at home without work is not possible. More than an inability itself, attitudes also matter; thus, they feel it is okay to miss one or two doses of medicine because going to the farm or visiting a distant relation for a special function is much more important to them. In a few cases (15 cases), some have decided to take only medicine and not go for dialysis, against medical advice, due to side effects of dialysis treatments. A clear observation is how the effect of CKDu is not limited to the patient him/herself. In many cases (30 out of 50), more than one family member/close relative, such as siblings or a parent, has been diagnosed with CKDu. The economic hardships caused by CKDu was a shared concern. Given the condition, it not only makes it impossible to continue with their



main livelihoods, but also the cost of treatments has been an added stress on their lives.

Community support is almost absent in the research field. While one may interpret this as an absence of close relationships or selfishness, the data demonstrates that people do not want to rely on another because they feel it will be a trouble to others who are also struggling in various ways. The sickness impacts everyone and the whole community is struggling. Thus, trying to solve things on their own and not depend on others is a reflection about people's understandings about each other, and a way in which people help each other.

In terms of their treatment expectations, one of the key themes that emerged is about wanting to be treated better. While everyone expressed gratitude towards the medical professionals who treat them, they also expressed their frustration with the fact that the medical professionals are not available to answer their many questions and clarify their doubts. A key request was about increasing the number of professionals available and facilitating a quick process of getting the medicine from the pharmacy. Both these suggestions are not necessarily about what they receive as treatment, but about how they receive it; in other words, what the patients describe is their frustration with the process of treatment.

All the professionals who participated for in the key informant interviews emphasised that no reason has been identified for CKDu yet. Especially medical officer of Hettipola hospital mentioned that while the cause is identified, there is no significant change in the medicines used for CKDu patients. So, according to him, the important thing is finding the cause and trying to eliminate the cause from society. The Assistant Director (Planning) at the Divisional Secretariat office emphasised that people use pesticides regardless of officers' advise and listen to shop owners (of fertiliser and chemical products), and that they use chemicals without having a significant reason to do so. Apart from this, the use of chemicals without wearing masks and security equipment in farming activities, not drinking water properly, inappropriate food habits and other habits, such as chewing betel and alcohol consumption, can be identified as other causes associated with CKDu.

According to Director (Planning), some people wish to get the disease as it allows patients to receive allowances from the state. Further, sometimes patients feel hopeless and do not have a positive perception towards research happening in this area as they have not received any benefits from such research. These findings of the study were supported by the Focus Group Discussions conducted in the research.

## **CONCLUSION**

As the discussion shows, the data clearly indicates disparities between patient population and service providers in relation to the conceptual understandings of the disease, and its etiology and interventions. Such disparities have a direct impact on patients' psychosocial wellbeing, as is evident in the way their economic, social and psychological wellbeing has been negatively affected. The negative impact on patient wellbeing can be observed at the individual, family and community levels. Thus, interventions for the condition need to address all these conditions. Beyond specific suggestions such as opening a special clinic for CKDu patients in relevant government hospitals and increasing the number of medical professionals with expertise in CKDu, an underlying theme that runs through the data is about attitudes; in other words, the study highlights the importance of the quality of care offered rather than quantity.

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