Chronic Kidney Disease with Unknown Etiology: The discourse, lay perception, behaviour and coping mechanisms

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The Background

Chronic Kidney Disease of Unknown etiology (CKDu) is one of the leading health issues prevailing in contemporary Sri Lanka. It has been rapidly increasing in some of the agricultural zones in Sri Lanka since the 1980s and by now it has become a disaster (Wanigasuriya 2007). The problematic nature of the phenomenon is that the etiology of the disease is unknown and the impacts are major: poor health, low productivity from livelihoods and several other negative impacts for people living in the respective geographical locations of the county. It's really a challenge for the experts to find out the cause of the disease for its management and prevention. There have been several efforts by various experts to identify the etiology but no concrete conclusions have been researched to date. The present study was undertaken in this context with the focus on understanding sociological factors affecting human behavior related to the prevalence of chronic kidney disease in the North Central Province. This paper attempts to explore the discourse, lay perceptions, behavior and household coping mechanisms with regard to CKDu.

The Methodology and the Setting

An empirical study was undertaken in the Padaviya and Madawathchiya DS divisions in the Anuradhapura District in the North Central Province where there is a comparatively high prevalence of CKDu. The Padaviya and Madawathchiya DS divisions were selected as compared with other DS divisions within the district because they had a high concentration of CKD patients. According to the statistics available at the Disaster Management Centre, 1122 CKD patients have been reported from Padaviya and the second largest number of CKD patients, (931 patients) has been reported from the Madavachchiya DS division (Disaster Management Center 2008). A purposive sample of 170 patients from the above two DS divisions was selected for the investigation. Another 60 individuals who were not diagnosed as CKD patients by the screening test were selected as a control group to make a comparison of behavioural patterns of the villagers. Different types of health care providers and other service providers were also incorporated

into the investigation in order to understand the provider perspective. Both qualitative and quantitative methods such as key informant interviews, focus group discussions, household surveys, and observations were used to collect the necessary information.

Results/Outcome:

Unlike experts, the lay people also have their own explanatory models with regard to health and ill-health (Kleinman 1980). The findings of this study suggest that the local discourse has become a critique of the available explanations given by various experts who come from outside the village as they happen to be contradictory to one another. At the same time the lay people who are living in the locality since their birth also have their own explanations and interpretations regarding the etiology, the origin and the prevalence of CKD in their localities. People's knowledge base is created through contradictory explanations of CKD given by various experts in different socio-political contexts. However, lay persons similar to the professionals are confused as some of their experiences go against all rational explanations on the cause/s of CKD. There are diverse opinions among the villagers on the origin and the cause of the disease. While some argue that CKD is a new phenomenon, others believe that it was prevalent even in the past but not diagnosed as CKD. Those who believe that it is a new phenomenon interpret it as a result of the life-style changes due to mismanagement of the natural environment within the social environment. Empirical data indicate that people attribute the poor quality of drinking water as the main cause. This has led some villagers to walk several miles to obtain daily supplies of water from sources they believe are not contaminated. The treatment seeking behavior of patients is complicated as they use multiple therapeutic options while moving from one option to the other. Some of the patients bypass the nearest facility just to avoid the stigma attached to the disease. Households adopt various types of coping mechanisms to deal with the disaster. However, these mechanisms are not effective as which has a negative impact on the patient and his/her family. Further, the findings of this study highlight a number of drawbacks of the health care delivery system which are needed to be address by the policy makers and the political leadership for mitigation and prevention of the disaster.

Conclusions with Recommendations

The paper concludes by highlighting the inadequacy of the social protection network available to vulnerable sections of the society. The findings of the study further highlight

the drawbacks of the health care delivery system and other supportive services of the country in the face of such a disaster. With regard to social capital, the family is crucial as the main care provider for CKD patients and such families need to be assisted by the state and by civil society organizations. There is no indication that the issue of CKD being address at a community level, and at present it is based on individual coping strengths. The villagers have a keen interest to know the cause/s of the disease and are willing to take any necessary steps for prevention. The study has come out with following recommendations: strengthening multidisciplinary team work to discover the etiology; adopt strategies to reduce the gap between the user and the provider perspectives; strengthening family and community supportive systems and social interventions at individual, group, community and institutional levels to manage the disaster effectively.

References

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