



Burden of Chronic Kidney Disease of Uncertain Etiology on Families of Patients and Their Coping Behaviour in Two Farming Communities in Sri Lanka

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Abstract

Present paper analyses disease burden of two decades-old CKDu on patients' family, their coping strategies and the repercussions of those strategies. CKDu literature in Sri Lanka discloses that there is quite a large number of studies which attempted to determine unknown etiology of the disease. Findings of those studies reveal that no concrete conclusions with regard to the etiology of CKD, instead a number of hypothesis were developed with contradictory arguments. Since there is no sufficient knowledge to comprehend the impact of growing health hazard on affected people, an empirical study was carried out with the purpose of exploring disease burden of CKDu on patients and their families. Medawachchiya and Padaviya DS Divisions were selected to assess impact of longstanding disease as it was initially identified in these two locations in the late 1990s. Mixed-method approach was adopted in the study and the findings reveal that majority of patients were diagnosed as CKDu at acute stage and they were at productive age in their life-span. Majority of patients were reported their identity as sick/elderly and their family has to bear a heavy burden of CKDu. Both formal and informal social support systems were insufficient for affected communities. Family as the most significant entity attempts to minimize psychosocial and economic burden of CKDu while bearing low productivity of ill-member due to illness, by allocating its resources, both human and material, to manage the ill-health and the emotional and social cost of illness on family. Patients' family adopts both problem-solving and emotional-focused coping strategies to combat the crisis situation that leads adverse effects on the wellbeing of family members. Findings suggest that patients' family demands positive coping options including more information with regard to illness, educating them to properly manage the illness, access to professional psychosocial counseling and essential support services. In conclusion, the paper highlights number of issues that policy makers, planners and service providers need to take into consideration in order to mitigate adverse effects of emerging health hazard and to improve wellbeing of the family of patients.

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INTRODUCTION

Two decades old Chronic Kidney Disease of uncertain origin (CKDu) has become a critical health hazard in Sri Lanka. Initially, the disease was identified in the North Central Province by healthcare providers based on data that evolving from records of patients who came to tertiary care hospitals for treatment (Athuraliay, 2009). Subsequently, community-based studies were also confirmed that there is an emerging trend of CKDu, initially from the North Central Province, and later from the surrounding areas such as Uva, North Western and Eastern Provinces (Athuraliya et al., 2011; Jayatilake et al., 2013; Jayasekara, 2013). The disease is now widespread among farming communities in those areas, resulting enormous problems for those who are affected and their families.

Sri Lanka lacks a comprehensive formal social protection system in general, and particularly a protection system targeting vast majority of people who depends on farming, fishing and other informal livelihood activities. The situation becomes further critical in a context where there is a growing trend of public-private mixed delivery system for provision of goods and services. However, in responding towards the emerging health hazard, number of interventions was implemented by the government of Sri Lanka to strengthen curative services in affected areas and started screening programmes for

early detection. The government also initiates a monthly subsidy for needy patients while introducing some preventive measures to minimize harmful effects of emerging disaster (Ministry of Health, Nutrition & Indigenous Medicine, 2016; 2017). Non-governmental organizations, community based organizations and other stakeholders were also initiated various types of interventions to support patients, their families and affected communities (WHO, 2016). Though there are a number of interventions to support the CKDu patients, most of the challenges faced by affected families are remaining unresolved due to loss of productivity as a result of the illness, time allocation for care giving, cost of care for those affected, and preventive actions while bearing emotional suffering with uncertainty. Present paper based on an empirical study focused on analyzing burden of CKDu on patients' family, strategies that they adopt to cope up with the illness burden, and consequences of those coping strategies in return on the family.

LITERATURE REVIEW

The uncertain origin of chronic Kidney Disease was identified as a health problem since the late 1990s and by now there are many attempts including epidemiological, environmental and human studies to determine the etiology of the disease (Jayasekara et al., 2013; Dharma-Wardana et al., 2014; Wanigasuriya, 2014; Nanayakkara et al., 2014;



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Jayasinghe, 2014; Jayatilake et al., 2013; Jayasumana et al., 2013; Nanayakkara et al., 2012; Senevirathna et al., 2012; Wanigasuriya et al., 2011; Chandrajith et al., 2011; Wanigasuriya et al., 2007). The above studies reveal that there is rather contradictory explanations with regard to unknown/ uncertain etiology of CKD. Wanigasuriya et al., (2011) found that Smoking as a behavioral risk factor on CKDu. However, another study shows that smoking is not a risk factor, but tobacco chewing is significantly associated with CKDu (Nanayakkara et al. 2014). Number of studies show that the history of snake-bite was associated with CKDu (Nanayakkara et al. 2014; Wanigasuriya 2007). Quite a large number of analytical studies reveal that the source of drinking water as a potential risk factor and, among them, a number of studies highlighted that drinking well water as a risk factor (Wanigasuriya et al., 2007; Wanigasuriya et al., 2011; Chandrakumara et al., 2013; Jayasumana et al., 2015; Siriwardhana et al., 2018). Farmer occupation and use of agrochemicals was identified as one of the main risk factors (Jayasumana et al., 2015). Some other studies have identified heat stress & dehydration, genetic susceptibility and water quality with particular emphasis on fluoride and toxin level in water as potential risk factors for uncertain etiology (Chandrajith et al., 2011; Nanayakkara et al., 2014;). In a thorough literature review on causative factors related to CKDu,

Rajapakse et al, (2016) confirms that there is no concrete conclusions with regard to uncertain etiology of CKDu though, a number of hypothesis were developed with contradictory arguments as the outcome of diverse studies (Rajapakse et al., 2016). Initially, it was considered as Chronic Kidney Disease of 'unknown etiology' (Jayasekara et al., 2013). Later on, based on findings of some studies, the etiology has been defined as multi factorial and re-named as Chronic Kidney Disease of 'uncertain etiology' (Jayatilake et al., 2013).

The contradictory arguments with regard to uncertain origin of CKDu has led further confusion among the affected communities. However, quite a few studies from social science perspective have been attempted to explore whether contextual factors such as experience of structural violence associated with resettlement programmes implemented by the government, and political economy of chemically-intensive agriculture are associated or not with CKDu (de Silva et al., 2017; Bandarage, 2013). Besides the etiology of CKDu, available literature reveals that the evidence is inadequate to elaborate adverse consequences generated by-the two decades-old health hazard on patients, their families and the affected communities. Even in the limited studies, the whole family that sharing the painful experience of CKDu was hardly considered and the patient was the major target. Present paper based on an ethnographic study and



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analyses the ways in which how patients' family cope up with adverse effects of CKDu as a collective group, the challenges they face due to adopting problem solving coping mechanisms while being in a vulnerable situation to have cumulative impacts to push into poverty.

METHODOLOGY

Selection of study area

Medawachchiya and Padaviya-Divisional Secretariat Divisions (DSDs) in Anuradhapura district in the North Central Province were selected for empirical investigation by considering the high prevalence of CKDu in those two locations. These two settings have been labeled as 'CKDu high-spots' since the late 1990s (Jayasekara et al., 2013). According to the data available-at the Renal Disease Prevention and Research Unit in the North Central Province, 13,957 CKDu patients were reported from Anuradhapura district by 2016, of which 3,176 patients and 1,423 CKDu patients were from Medawachchiya and Padaviya respectively. These two DS (Divisional Secretariat) divisions were selected to carry out an empirical investigation by considering the following reasons. The two locations are bearing the highest number of CKDu patients in the NCP (Provincial Renal Disease Prevention and Research Unit, 2016). Nevertheless, there are some structural distinctions between the communities in the two locations, the greater majority of the

population in Padaviya are migrants under the government resettlement programme initiated by the government since the late 1950s. Comparatively, the Medawachchiya DS Division is constituted with traditional villages where the social integration is little higher than that of Padaviya. Our empirical study was carried out with a wide ranging scope to explore socio-economic and psychological impacts of CKDu on affected individuals, households and communities with the focus of identifying appropriate strategies for mitigation. However, the present paper focuses only on impact of CKDu on patients' family and their coping behavior.

Sample selection

The empirical study was carried out by adopting mixed-method approach that included both qualitative and quantitative methods and techniques for data collection and analysis. Study sample included 200 CKDu patients and their households, 100 from each location. The sample was selected by using purposive sampling method and snowballing technique was adopted to capture the required number of patients from the two locations. The gender aspect was taken into consideration while selecting the study sample. Accordingly, 65 male and 35 female CKDu patients from Medawachchiya DS division and 66 male and 34 female CKDu patients from Padaviya DS Division were included into the study sample. Thus,



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the study included four focus groups, a male group and a female group from each division and 16 key informants representing community leaders, office bearers of community based organizations and the service providers in both the above two locations.

Ethics clearance for the study was obtained prior to commencement of the study from Ethics Review Committee for Social Sciences and Humanities, University of Colombo.

Data collection and analysis

Semi-structured questionnaire, in-depth interviews, focus group interviews, key informant interviews, and observations were used as primary data collection techniques to grasp comprehensive insight into the analysis of the illness burden of CKDu at individual, household and community levels and their coping behavior. The semi-structured questionnaire was administered through face-to-face interview with patients, the caregivers and/or other family members. However, there were some instances where the data was collected only from the caregivers/family members as the patient was in a critical condition and was unable to contribute his/her experience. Supplementary to data generated from semi-structured questionnaire, 30 patients and their families from study sample were followed-up through in-depth interviews to comprehend thoroughly the insight of family issues related to CKDu that included four

households where the CKDu patient passed away recently and the data was gathered from family members to scrutinize the entire process from diagnosis up to departure. A group of research assistants were recruited to collect data from semi-structured questionnaire under supervision of the principal investigator. They were given a prior training to collect data from face-to-face interactions with patients/caretakers adherence to ethics concerns.

Focus group interviews were conducted in the two settings to comprehend views and interpretations of concern communities with regard to etiology of CKDu, the impact of disease on their livelihood activities and everyday life, gender issues emerging due to illness and the preventive measures that they use as precautions. Key Informant Interviews were conducted with 16 individuals that included few senior citizens, community leaders, office bearers of community based organizations and service providers in the above locations. Interviews with focus groups and key informants were conducted by the principal investigator where the research assistants helped in note taking.

The data collected from semi-structures questionnaire was analyzed by using computer-SPSS package. The data generated from follow-up study through in-depth interviews, focus group and key informant interviews were analyzed in organizing then



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under identified themes. Quantitative data presents as percentages while the qualitative data organizes under identified themes and present to quotes and summary statements in this paper.

RESULTS

Profiles of patients

In both DS divisions, most of the CKDu-patients were diagnosed while they were seeking treatments from the healthcare institutions for various symptoms. Profiles of patients reveal that 71% of patients in Medawachchiya and 91% of patients in Padaviya were diagnosed as CKDu when they were seeking treatment for symptoms such as back pain, stomachache, muscle pain, swollen body, urine infections, fever etc. It also reveals that majority of them were at acute stage (stage 3 or 4) of disease progression when they were identified as CKDu patients. Comparatively, the numbers are high in Padaviya Division. In both locations a number of screening programmes were conducted for early detection and referred them to clinics for necessary action (Ministry of Health, Nutrition

and Indigenous Medicine, 2017). As a result, 29% of patients in Medawachchiya and 9% of CKDu patients from Padaviya in our sample were identified through those screening programmes. Though the health hazard has become a critical issue in both of the above localities, people were rather reluctant to go for screening assuming the difficulties that would face if diagnosed as CKDu patients. All the patients in both locations are Sinhala Buddhist. Considering marital status by gender of the 35 females in Medawachchiya, 17 were married, 17 were widowed and one individual was never married; while in Padaviya, out of the 34 female patients, 20 were married and 14 were widowed. Likewise among the 65 males in Medawachchiya, 61 are married, 2 are widowed and 2 were never married whilst among 66 males in Padaviya, 63 are married, 2 are widowed and one was never married. Dependency is likely to be a greater issue in the case of females, given the large number of widows despite their not being a significant difference in age between male and female patients in the sample.

Table 1: Age distribution of patients by DS Division

| Age category (Years) | Medawachchiya | % | Padaviya | % | Total | % |
|----------------------|---------------|------|----------|------|-------|------|
| <40 | 9 | 9.0 | 7 | 7.0 | 16 | 8.0 |
| 41-50 | 16 | 16.0 | 23 | 23.0 | 39 | 19.5 |



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|-------|-----|------|-----|------|-----|------|
| 51-60 | 40 | 40.0 | 33 | 33.0 | 73 | 36.5 |
| >60 | 35 | 35.0 | 37 | 37.0 | 72 | 36.0 |
| Total | 100 | 100 | 100 | 100 | 200 | 100 |

The age structure of CKDu patients reveals that majority of patients in both locations are in productive age (i.e. <60 years) and their illness have a tremendous implications on the labor force and the loss of the main income to the family. The number of elderly people among CKDu patients is also

quite high in both locations that included nearly 1/3 (36%) of the total number of patients. The illness burden of those patients directly goes on the family due to lack of proper social security systems for old age people who living in farming communities.

Table 2: Patient's relationship to head of the household by DS Division

| Relationship to Household Head | Medawachchiya | % | Padaviya | % | Total | % |
|--------------------------------|---------------|-------|----------|-------|-------|-------|
| Household Head | 67 | 67.0 | 71 | 71.0 | 138 | 69.0 |
| Spouse | 15 | 15.0 | 16 | 16.0 | 31 | 15.5 |
| Son/daughter | 2 | 2.0 | 1 | 1.0 | 3 | 1.5 |
| Parents | 9 | 9.0 | 9 | 9.0 | 18 | 9.0 |
| Other relatives | 7 | 7.0 | 3 | 3.0 | 10 | 5.0 |
| Total | 100 | 100.0 | 100 | 100.0 | 200 | 100.0 |

The vast majority of patients in both locations are the heads of their households (69%) while 15-16% of patients are spouse of the head of the household which has direct impact on their roles and responsibilities with regard to the family. In Medawachchiya 51% and Padaviya 53% of households encompass nuclear

families. Thus, the data reveals that there is a considerable number of extended families in both locations which has both positive and negative consequences with regard to resource allocation, sharing responsibilities and care giving/receiving within the family.


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Table 3: Activity status of patients by DS Division

| Activity | Medawachchiya | % | Padaviya | % | Total | % |
|---------------|---------------|-------|----------|-------|-------|------|
| Domestic work | 10 | 10.0 | 8 | 8.0 | 18 | 9 |
| Employed | 43 | 43.0 | 27 | 27.0 | 70 | 35 |
| Unemployed | 1 | 1.0 | 0 | 0.0 | 1 | 0.5 |
| Retired | 1 | 1.0 | 1 | 1.0 | 2 | 1 |
| Sick/Elderly | 45 | 45.0 | 64 | 64.0 | 109 | 54.5 |
| Total | 100 | 100.0 | 100 | 100.0 | 200 | 100 |

It is significant to note that 64% patients in Padaviya and 45% of patients in Medawachchiya are in the category of sick/elderly status, which reveals that the dependency rate is quite high in both locations resulting an adverse consequences on the family. In both divisions, the majority of those who are employed, involved in agriculture (51% in Medawachchiya and 65% in Padaviya). This is more ostensible in Padaviya as it is an irrigated settlement area where cultivation is the main economic

activity for many people. In Medawachchiya, 31% have joined in Civil Security Department and others are involved in skilled labour/ casual labour. In Padaviya, 12% are in forces and the others involved in clerical/technical/ transport sector employments. Moreover, 52% and 20% of patients in Medawachchiya and Padaviya respectively are Samurdhi Beneficiaries, the subsidy giving for low income families by the government.

Table 4: Monthly income of patient's family by DS Division

| Monthly Income (Rs.) | Medawachchiya | % | Padaviya | % | Total | % |
|----------------------|---------------|------|----------|------|-------|------|
| 5001-15000 | 29 | 29.0 | 49 | 49.0 | 49 | 24.5 |
| 15001-25000 | 23 | 23.0 | 23 | 23.0 | 43 | 21.5 |
| 25001-50000 | 41 | 41.0 | 26 | 26.0 | 60 | 30.0 |



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|--------|-----|-------|-----|-------|-----|-------|
| >50000 | 7 | 7.0 | 2 | 2.0 | 9 | 4.5 |
| Total | 100 | 100.0 | 100 | 100.0 | 200 | 100.0 |

In Padaviya, 49% of patients' monthly income is Rs.5,000 to 15,000 while 41% of patients at Medawachchiya earn Rs.25,001 to 50,000 as monthly income mainly because a considerable number of patients have joined the Civil Security Department having access to permanent income for the family. Nearly 70% of patients in both divisions have permanent houses and the balance have either semi-permanent or temporary houses.

Profiles of patients clearly reveals that the majority of patients were diagnosed as CKDu at acute stage; majority are in the productive age category and monthly income of most of the families are at a marginal level. Therefore, the family has to bear heavy burden of CKDu as both formal and informal social support systems are limited for both affected communities. As mentioned earlier, these two settings have labeled as "CKDu hot spots" since the late 1990s which also have negative social consequences for the members of patients' family.

Patients' everyday life with CKDu

CKDu articulates in both Medawachchiya and Padaviya as "a struggle between life and death of a person". It was observed during the fieldwork; the people in the locality just use the term 'wakugadu' (kidney) in order to refer the whole tragedy of

CKDu but not simply the kidney. In such situation, CKDu is associated with a great distress and fear, anxiety, anger, sleeping disorders and lack of appetite which are seen as common features among all CKDu patients. While explaining emotional distress associated with CKDu, the Monk in-charge of the village temple pointed out that

"Most of the patients in this village live 'in between a dual world' (delovak-atara), though they are physically live in the present-world, mentally they are moving fast from the present world to next world after death".

(Monk at one of the temples in Medawachchiya).

Effect of CKDu on everyday life of patients can be evaluated with reference to their participation in four domains such as the personal activities of the individual, livelihood activities, domestic task including duties and responsibilities of patient's social role/s within the family and social activities in their community. Except only few patients, the greater majority of them are in a position to manage their personal domain independently while few others were depending on their family members.

Loss of productivity due to illness, costs of care for those affected, and the preventive measures have taken a toll



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on the life of these communities, some of whom were anyway surviving in a subsistence economy. In Medawachchiya and Padaviya 86% and 91% of patients respectively mentioned that their livelihood was affected due to illness. The data reveals that 21% of patients do continue with their livelihood activities as before, in spite of their sickness as the family income has to be sustained for survival. As one of the patients pointed out

“Doctors at the clinic gives us many instructions to manage our illness. Asked us not to use chemical fertilizers/pesticides in agriculture, not to use alcohol, betel etc. However, the harvest would not be successful without applying fertilizers/pesticides. I am also not in a position to stop cultivation as it is the only source of income for my family. Even now I came back from the paddy field just after spraying pesticide for the cultivation. I never share the truth with doctors at the clinic that I am continuing with farming by using pesticides. If so, I am sure they will throw out my clinic file away. I know my life is very uncertain. So, I don't feel even of buying a Shirt or Sarong thinking that it may be useless”

(65 years old male CKDu patient at Medawachchiya).

As revealed from patients' narratives, they have to bear the discomfort as continuing with their livelihood that essential for family survival. However, this is possible only at the early stages of the sickness as at subsequent stages the patient will be confined to the

house. There are 29% of patients who continue with their livelihood activities with the help of family members. This is possible only when family members are available to assist with the livelihood activity. According to the narratives, a number of alternative measures are adopted, such as renting out the land for cultivation, use of hired labour, use of machinery and few patients have removed from cultivation and resorted to new livelihoods such as running a small shop/ boutique close to their home. As elucidates from narratives, most of the patients are struggling to continue livelihood activities and the domestic tasks with little adjustments, even after the diagnosis and they physically become inactive or incapable of movement. Besides medical explanations, the patients have their own criteria in evaluating health condition, such as the physical fitness and the ability to work. Except few individuals, patients who mentioned their health or activity status as 'sick /elderly' have hardly engaged in livelihood activities but rather active in their personal domain and to a great extent in domestic tasks.

The lifestyle of patients who diagnosed as CKDu at a critical condition had been changed within a short period of time after the diagnosis. It is of vital importance to note that there are some exceptional cases where patient's everyday life has become more active after diagnosis where patients have expedited certain tasks in order to fulfill the social



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responsibilities with regard to the family before the illness become worst. The narratives further suggest that most of the patients voluntarily become silent within the family by disengaging themselves from important activities while accepting sick role when started experiencing physical discomfort as a result of the progression of the illness. Most of the patients have reduced their involvement in community activities such as attending meetings and communal activities which are organized by various community based organizations in the village. It's a common feature that most of the patients have considerably increased the amount of time in their everyday life set aside to engage in religious and ritual activities due to illness, that can be seen as the main strategy adopted by them for restoring and enhancing the mental wellbeing.

Family as a unit of collective suffering due to CKDu

Family as a major social institution, plays a decisive role in dealing with psycho-social and economic burden of CKDu. According to experience by patients in both locations, their family has given its foremost priority to manage ill-health of the CKDu patient while scarifying most of the needs of other family members, and they are collectively bearing the emotional distress of illness as a collective unit of suffering. As shown in profiles of patients, the majority of patients in both DS divisions, Medawachchiya and Padaviya, are the heads of their

household and the breadwinner of the family. Comparatively, the family members have to suffer more when the patient functions as the head of the family. Thus, the spouse too, faces a lot of difficulties in order to deal with duties and responsibilities at the family. The children of the family were also affected badly when the head and breadwinner of the family became ill.

CKDu has a tremendous impact on the economy of patients' family that has to bear the loss of physical assets and potential loss of human capital due to illness on one hand, and on the hand it incurs out-of-pocket expenses for the patients and their families in accessing healthcare which includes transport, expenses during hospital stay, expenses during out-patient visits, special diets for patients, expenditure for medical care using complementary systems such as indigenous medicine, religious, ritual and other healing systems, and preventive measures such as obtaining or purchasing water from different sources etc. In addition to the above expenses, they also have to bear indirect costs such as lowering of productivity due to ill-health, absence from work due to illness/care giving and all above resulted in pushing them into poverty.

The everyday lives of family members of CKDu patients have been affected in various ways. In one hand, the patient's family members have to replace the workload that was previously done by the patient



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concerned due to his/her illness. One the other hand, the family members have to accept an additional workload related to care giving for the CKDu patient. In some families, the members had to find new income generating activities in order to cope up with additional expenses incurred due to illness. By contrast, there are some families where the members had to stop/reduce their livelihood activities in order to provide necessary care for the CKDu patient. During our qualitative interviews it was revealed that some households had sold their land due to being unable to farm it now as the main labor source become ill. In Padaviya it has resulted in many household selling livestock. Many households have also resorted to pawning jewelry in order to overcome financial difficulties. More significant however is the potential loss of human capital arising from CKDu. In Medawachchiya 20% of households reported that the illness is affecting children's education while 18% do so in Padaviya. As evident from this study most of the family members have adjusted to the situation by adopting different strategies where in most families the members have limited engaging themselves in leisure activities, sacrificed future endeavors to cope up with the illness. The family members are further affected by illness as it gets critical time to time and, this in turn results in emotional harm while neglecting most of the other activities. As mentioned by one of the family members;

"We also mentally go mad when our son's illness becomes serious and hardly do any work at that time. Even mid-night we should be ready to take him to hospital. Both his father and myself spending most of our time to attend his needs"

(Mother of unmarried male CKDu patient at Medawachchiya).

The evidence clearly shows that the family has given its foremost priority to managing the ill-health of CKDu patients while allocating most of both its material and human resources for this purpose. Thus, managing of ill-health related to CKDu has been receiving more attention within the family while neglecting, delaying or sacrificing most of the needs of other members of the family. The case histories of patients who passed away due to CKDu provide a comprehensive representation in this regard which further verifies the fact that family needs to be considered as a collective unit of suffering. As the mother of CKDu patient who passed away few years back pointed out,

"We had to spend all most all the assets that we had for the illness of our younger son. His kidney transplantation was successful. However he passed away after one year of the transplantation. All of a sudden he got a fever. The doctor mentioned that it was due to a germ entered into his body. After few days he passed away. We lost not only the child but we sold 4 paddy-fields that we had to save the life of our son. By now we have no source of income. Therefore my husband cultivates in a rented land and I am doing



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different handicrafts and earning some money for our survival. Elder son is married but he helps us financially when there is a need. I have no hope for the future but doing little things only for the survival. Once a month I go to meditation center that helps a lot to prepare my mind and even to understand the meaning of life"

(60 years old mother who lost her son due to CKDu after kidney transplantation at Medawachchiya)

There are number of evidence which are quite similar to the above narrative which explore many dimensions of family suffering due to CKDu. The family has already spent its most of the asserts to manage ill-health of CKDu patient but later on they face lot of difficulties due to shortage of resources to manage their everyday life. CKDu has had a major impact on consumption patterns of the household by fulfilling only minimum level of survival needs and spending the rest for ill health management with regard to CKDu rather neglecting other health issues of the family members. It was observed that all the CKDu patients' families in both locations use filtered water from the Reverse Osmosis system for which they have to pay though the prices are reduced for patients' family.

The empirical evidence further reveal that CKDu has negative impact on marriage that can be seen in two ways. In some cases, parents had arranged early marriages for their children due to illness of mother/father and in some

cases marriages of children have been delayed due to sickness of the mother/father. There are some exceptional cases as well, for example where a young boy who decided to never marry as he has to look after his widowed mother since the father died due to CKDu. The empirical evidence suggests that finding suitable marriage partners for the children of CKDu patients have become problematic due to stigma associated with the illness. As mentioned earlier, some geographical locations in the area have been labeled as high risk areas for CKDu which also have negative impact on people who live in those areas including marriage. There is a trend of hiding the illness mainly due to avoiding negative consequences of stigma associated with CKDu. As one of the patients who diagnosed as CKDu recently pointed out that he will never disclose it for others as the three daughters may face difficulties to find their marriage partners due to his illness.

The development activities related to family have been impacted by CKDu in many ways. Of the households 43% commented that household construction work is incomplete at present. As it is evident, most of the construction work of family has been delayed due to illness but there are a few exceptional cases where the family has taken immediate action to complete construction of house and other arrangements quite rapidly before the patient's condition becomes critical. However most of the evidence



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suggests that people had sold some of their lands, livestock, vehicles and equipment related to agriculture due to CKDu of one of the members in the family while some people had to delay purchasing land, equipment etc. as they have given their main priority to managing the ill-health related to CKDu.

The empirical evidence suggests that social relationships of the family have been affected by CKDu both negatively and positively. The patient has attracted a lot of attention within the family where emotional bonds among the members have been further strengthened due to illness. The married children who live in distant places come to see the patient very often and even children who didn't have close relationship with family became closer due to mobilizing their resources to deal with the crisis situation. However, the general pattern is that family ties with relatives and neighbors become strengthened at the initial stage of diagnosis of a family member as CKDu and they are weakened in the middle stage and re-strengthening at the end stage. Thus, there were some occasions where family networks become weakened throughout the process and, only few cases, the family continuously mobilizes its resources to manage ill-health of patient. The evidence clearly suggest that the experience of patients and their family members differ from one to the other depending on availability of resources, strengths of family social networks

and specific characteristics of an individual which further suggest that each family needs to be taken into consideration as unique in designing interventions to minimize adverse effect of CKDu on family.

Coping strategies of patients' family and the repercussions

Coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to control, tolerate, reduce, or minimize stressful events. Thus, there are problem-solving strategies as well as emotion-focused coping strategies. The problem-solving efforts focus on with particular actions to alleviate stressful circumstances, while the emotion-focused coping strategies involve efforts to regulate the emotional consequences of stressful or potentially stressful events. The evidence generated from this study reveals that the patients' family adopt both the above coping strategies when and where necessary as a collective unit of suffering.

Though free healthcare facilities available for CKDu patients at the nearest hospitals, the family has to bear additional expenditure on transport, testing, dialysis, transplantation etc. Comparatively, quite a similar pattern of coping behavior can be observed among CKDu patients and the family. Frequently, they begin the process by using family savings while reducing consumption expenditure. In both locations nearly 34% of patients



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mentioned that they get the support from married children who live separately. The next step of most of the patients is to mortgaging jewelry and then moving to selling livestock/household items, borrowing money from relatives and friends. Then there is a trend of borrowing money from the money lenders on credit (11%) and selling lands as the final resort. Following narratives further reveal that the pattern of coping behavior among CKDu patients and their families.

Sharing her experience one of the family members pointed out that

“At the beginning the money that had been saved from cultivation was used for medical expenses. In due course more money was needed. When we ran shortage of money we pawned gold jewelry which we gradually recovered. We then mortgaged our land and we were unable to recover it”

(Family member of CKDu patient at Padaviya).

As another family member pointed out that

“We had to sell our cows and received Rs. 7,000. We also had to pawn jewelry which we could not recover”

(Family member of a CKDu patient at Padaviya)

Adding to this another family member pointed out that

“When he was ill our children gave money for treatments. But when that money was not enough we pawned our jewelry and

got money from the bank. At times my brothers also helped us”

(Family member of a CKDu patient at Medawachchiya)

These are some of the problem solving coping strategies among CKDu patients and their family. However, it is important to note that although such coping strategies are needed for the patients to meet their medical expenses they could also push patients and their families into a vulnerable position and push into poverty. The risk of increasing vulnerability of the whole family is quite evident and it could have a disastrous outcome. Thus, the family adopts number of emotion-focused coping strategies predominantly based on religious/ritual practices in the absences of professional psychosocial support service for CKDu patients and the family.

DISCUSSION AND CONCLUSIONS

Discussion

Social capital is very crucial in everyday life of people to face stressful events in their life (Dekker, 2001). The present study highlights patients' family as the most significant entity that attempts to minimize most of the psycho-social and economic burden of CKDu while bearing low productivity of the ill-member due to illness, by allocating its resources, both human and material, to manage ill-health of that particular member and the emotional and social cost of illness on family. Thus, the findings of this study



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reveal that patients' family functions as a unit of collective suffering due to CKDu in a context that fully occupied with uncertainty and hardly any professional psycho-social support services for affected communities who face lot of challenges due to this health hazard during past two decades. As King (2005) pointed out, according to conceptualization of Western countries, the self and emotional stress of human subject is held to be singular and unique. However, in the Asian context, the individual is not an autonomous independent agent where it would be impossible to evaluate mental wellbeing of an individual by investigating them from the Western notion of authority (King, 2005). Illness narratives of all CKDu patients support the argument that family suffering as a unit dealing with the emotional dimension with other burdens. Mental wellbeing refers to a capacity of an individual to deal with personal and social responsibility and emotions where the individual can make rational decisions, cope adequately with personal stresses and maintain satisfactory adjustments to society (Krist Ashman, 2003). Thus, mental wellbeing is a state of harmonic balance between the individual and the surrounding that includes both subjective wellbeing and the objective wellbeing (Todur 1996). Subjective wellbeing of patients and the family can be assess with reference to four domains, contentment, unpleasant emotions, global life judgments and domain satisfaction (Bruni and Porta,

2009). The evidence confirm that not only the patient but also the entire family is suffering due to CKDu with unpleasant emotions and also unsatisfied in other domains in their life.

The patients' family adopts both problem-solving and emotion-focused coping strategies to combat crisis situation. Similar behavior was observed by other researcher who worked in stressful events where people use both types of coping strategies (Folkman and Lazarus, 1980; Van der Sanden et al., 2014; Karnieli-Miller et al., 2013; Senger et al., 2016). The patients' family creates different types of coping strategies to carry out their new roles, some of them may be positive while the other strategies may have negative consequences (Medeiros et al., 2013). Thus, the members of family would experience high anxiety status due to ineffective coping strategies (Simons et al., 2010). Though each member of the family may have different personalities, habits, perspectives and interpretations of different events, as a group they are collectively sharing the painful experience of CKDu. However, this aspect is neglected by formal organizations in designing interventions and implementation. The lack of professional social workers who could perform the task of advocates on behalf of the patients and the family is a huge shortcoming in service delivery sector in Sri Lanka. Most of the time the family seek and use social support to face stressful



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events due to ill-health (Hall et.al 2011). However, in this context social support the family would expect from their neighborhood is very limited as most of them are also face similar situation. Patients compelled to hiding their illness due to stigma that further minimize support from their social networks (Laar et al., 2015). The evidence support the argument that family use both problem-solving and emotion-focused coping strategies where most of them have negative consequences while there only a very few positive outcomes such as the family bonds get strengthen preventing the patients isolating due to illness.

Though CKDu is a health hazard at community level, no evidence to see that they are organizing as a community to combat adverse effect of CKDu highlighting more assistance required from outside to strengthen the capacity of family. All the evidence confirm that the patients' family has to bear a heavy weight of the burden of CKDu. However, in most of the interventions, dominant attention was given to patient but not the patients' family. A comprehensive family policy in Sri Lanka yet to be implemented.

Conclusions

Patient's family has given its foremost priority to face immediate needs arising from psychosocial and economic burden of CKDu. The affected families adopt number of coping strategies such as reducing

expenditure on food consumption, education, leisure activities etc. while neglecting physical and mental health issues of family members, selling family assets including paddy lands, livestock which provides a source of livelihoods for the family and less priority given for investment and development activities of the family. Most of those coping strategies have cumulative impacts to push families into poverty losing its stability. Interventions which are imitated by the government and civil society organizations to support CKDu patients have number of limitations as most of those interventions have targeted the individual patient but not the family. The emotional dimension of CKDu seems to be absolutely neglected in the clinical setting that added an additional burden on family. Although, CKDu has become a critical issue since during past two decades, very essential services such as professional psychosocial counseling, family and community social work services are not introduced yet into the relevant context. Thus, the patients' family have very limited access to use positive coping mechanisms such as social support from relatives and neighborhood as the entire community is in vulnerable position and there is no signs to see that the community itself get organized to combat adverse consequences of CKDu. Findings strongly suggest that patients' family should be considered as a unit of collective suffering in designing policies and programmes to mitigate



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disease burden of CKDu. Positive coping options should be improved by providing sufficient information to patients in a culture competent manner, educating them to properly manage ill-health, providing access to professional psychosocial counseling and other needed services while continuing the process of determining uncertain etiology of the disease. Most of the coping strategies used by CKDu patients' family have a negative consequences on wellbeing of family members. Thus, the evidence highlights a trend of emerging new type of poverty due to adverse consequences of CKDu that demands strengthening a formal social security systems for farming communities who are in a vulnerable situation.

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