Sociological Aspects of CKD (UE) in Sri Lanka

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Outline

1. CKD as a Development-induced Disease
2. Social Epidemiology of the Disease
3. Stigmatization of CKD (UE)
4. Coping Strategies
5. CKD Activism
6. Possible Remedies
CKD as a development induced disease

- Mostly reported in newly developed areas or dry zone populations undergoing rapid change
  - New settlement areas like Padaviya, Madirigiriya and Giradurukotte
  - “border villages” affected by war-induced population movements
- Related to adoption of green revolution technology in rural agriculture from 1960s
  - heavy use of chemical fertilizer
  - Overuse of chemical pesticides and weedicides
- Parallel changes in ecosystems, society, livelihoods and lifestyle
- Many of the reported agents of the disease such as arsenic, cadmium and lead may be seen as products of environmental change
- Irrigation systems
  - small tank cascades systems
  - areas with high density of agro-wells
  - tail end of large scale irrigation systems like Mahaweli system
CKD as Development-induced
Socio-economic changes

- Increased social and economic polarization
- Emergence of a layer of farm/off-farm workers who are mobile
- Increased indebtedness of small farmers
- Opportunities and risks associated with military employment
- Changes in family structures and relations
CKD ss a potential cause of poverty and underdevelopment

• Increased impoverishment of affected families
• Often the patient is the main breadwinner of the household
• Impacts
  – Loss of livelihood
  – Loss of productivity
  – Cost of treatment
• Some families move from affected new settlement areas such as Padviya to areas outside the epidemic zone
• As a new challenge for the health sector
Social Epidemiology

• All single cause explanations problematic
• Even if we say arsenic, cadmium, fluoride or algae, agrochemicals or a combination of them are causative agents we need to explain the specifics in the social epidemiology of the disease.
• Differential exposure to these risk factors according to socio-economic status must be explored.
• Factors like drinking water, food consumption, environmental changes and direct exposure to agrochemicals are common to all residents in an area and, therefore, cannot explain observed differences in disease prevalence
• Folk beliefs: natural spring water gives them protection (Gonamapirya)
Gender profile of CKD patients

- Early hospital data indicated a greater prevalence among males (70% vs 30%). CKDue patients more likely to be male as compared to females (OR 1.9).
- Community studies by Liyanage and Jayathilaka also point to a similar gender profile.
- WHO study, which examined a randomly drawn large population sample, found a higher prevalence among females (16.8%) compared to males (13.3%).
- A sample bias or a change in the epidemiology of the disease?
How do we explain a reported higher prevalence among males if that is indeed the case?

- Males and females live in the same physical environment so that they share the same sources of drinking water and same food.
- Greater male involvement in risk behaviors such as application of agrochemicals without using protective gear
- Gender-based differences in lifestyle in matters such as alcohol use, smoking and consumption
Coping Strategies

• Moral panic about the disease
• Cost of medicines
• Impact on livelihoods and living standards (sale and mortgage of assets)
• Availability and accessibility of services including dialysis, renal transplantation
• Fund raising from sympathizers
• Appeals for kidney donations
  – Most donations from within the family or by voluntary donors such as Buddhist monks
  – Newspaper appeals (“Save life of so and so”)
  – Ethical issues
  – Legal regulation
Appeals for Kidney Donations

Kidney patient needs donor

Wijitha Jayanti (39) of Parakakhottuma, Kalawila, Beruwala is suffering from chronic kidney disease and is warded at the Colombo National Hospital. Consultant Nephrologist Dr. R.D. Lanerolle has recommended a kidney transplant to save her life. She appeals to donors of the A or O group. For details, please contact: 071 8875627 or 077 2689207.

SOS Kidney transplant

Fifty-seven year old W.D.N.S. De Abis of Co. Old Kotte Road, Ratibhanapitiya, Boralagunawwa is at end stage renal failure. Consultant Nephrologist of the National Institute of Nephrology, Colombo, Dr. S.M. Seneweer has recommended immediate kidney transplantation.
Stigmatization of CKD

• View that members of some families are genetically vulnerable as more than one member of the same family had contracted the disease
• Labelling process.
  – pipihaluwa in Madawachchiya and Pitapanduwa in Padaviya (Dr. Chandani Liyanage’s research)
  – “wakugadu Karayo”, “Waku gadu set eka”, Waku gadu gansiya” (Prof. Ramani Jayathilaka’s research).
• Near certainty of death
• Identified as a family catastrophe (Prof. K. Karunathilake’s research) and a karmic disease (karuma ledak/vindavanava)
• It was difficult for young men and women in such families to secure marriage partners
• Denial of the disease
CKD Activism

• Currently driven mostly by committed doctors and health workers

• Need for empowering, organizing and networking CKD patients and their families

• Need for social services and assistance for affected families

• Pressure for remedial action at various levels
Other social issues requiring further research

• Clearer understanding of gender and age differential in CKD morbidity
• Ethnic and genetic differences in morbidity, exposure and vulnerability
• Occupational differences in morbidity; different population categories in farming populations, owner-farmers vs wage labourers
• Which specific forms of development drive the epidemic?
• GIS type analysis of regional differences in CKD prevalence
• The role of religion in coping with the disease
Conclusion

• Need to move away from a single cause explanations to multi-causal explanations
• Apart from being an important cause of morbidity and mortality in selected farming areas, CKD can be a major obstacle to the ongoing strategy of development
• Need to identify and disseminate methods of prevention
Recommendations

• Rethink about development strategies incl. fertilizer subsidy
• Changes in farming systems and promotion of organic farming
• Improved regulatory framework for distribution and application of agrochemicals
  – Safeguards in agrochemical application
• Improved procedure for checking heavy metal content in agrochemicals
• Improved drinking water supply
• Educate the public about hazards of overuse of agrochemicals
Recommendations, Cont.

• Collaborative Research
  – Any genetic differences in vulnerability and exposure?

• Special Social Science Unit in the Ministry of Health

• Role for civil society organizations to network, educate and assist the patients and their families