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 (Gonamapiryawa)

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?

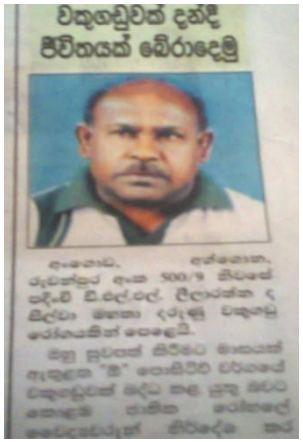
How do we explain a reported higher prevalence among males if that is indeed the case?

- 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



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 in 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 metel 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