Research Report:

SOCIOECONOMIC IMPACT CREATED BY CKDU AND RELATED SERVICE PROVISION DEFICIENCIES ON PATIENTS AND THEIR FAMILY MEMBERS IN WILGAMUWA DSD, SRI LANKA

Assisting Communities in Creating Environmental and Nutritional Development (ACCEND) Project

In collaboration with

Government of Sri Lanka

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Implemented by

ADRA

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Author: Dr. Pasan Jayasinghe, AKP Researches and Academic Writers
Editor: Dr. Khayali S. John
The editor thanks the following work colleagues for their feedback and input –
Matthew Whitty, Visaka Wickramarachchi, Florentia Amarasinghe, Tilak Karunaratne,
Shafeer Mohamed and Rasika Fernando

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ABBREVIATIONS

ACCEND	Assisting Communities in Creating Environmental and Nutritional Development
ADRA	Adventist Development and Relief Agency
CKDu	Chronic Kidney Disease of Unknown Origin
COVID-19	Coronavirus Disease 2019
DS	Divisional Secretariat
GFR	Glomerular Filtration Rate
GND	Grama Niladhari Division
LKR	Sri Lankan Rupee
MOH	Medical Officer of Health
DH	District Hospital
BH	Base Hospital
NHK	National Hospital Kandy
SD	Standard Deviation
CI	Confidence Interval

THE ACCEND PROJECT

ACCEND (Assisting Communities in Creating Environmental and Nutritional Development) is a 57-month project jointly run by ADRA UK, ADRA Sri Lanka, and Oxfam Italy since 2017. Funded by the European Union and implemented in the three districts of Matale, Nuwara Eliya, and Monaragala, the project is to benefit about 300,000 persons from 32 estates and 23 rural communities.

The project's goal is to contribute towards the improvement of the health, hygiene, nutrition, and sanitation of communities in Uva and Central provinces. Project activities are carried out in cooperation with the Divisional Secretariat and the Medical Officer of Health (MOH) offices. The project's operational areas in the Matale and Monaragala districts consist of 10 and 13 Grama Niladhari Divisions (GNDs). The operational areas of NE district includes 32 estate divisions that belong to 10 tea esateate managed by Horna, Maskeliya and Bogarwanthalawa plantation companies.

Main Outcome

To strengthen communities and public institutions towards an integrated, mutually accountable service delivery system in water, sanitation, health, and nutrition.
Gender and Disaster Risk Reduction (DRR) are cross-cutting themes that run through all project activities.

Key Role

To facilitate and assist communities and strengthen government services within the project locations.
This is enabled through the formation and mobilisation of community entities, raising awareness, conducting trainings, constructing and repairing physical structures, piloting innovative ventures, launching studies based on project priorities and being involved in planning and policy development with the government.

INTRODUCTION

CKDu (Chronic Kidney Disease of Unknown Origin) is recognized as a significant health care challenge faced by the health care sector in Sri Lanka. In 2004, the total number of reported CKDu patients was 7763, and in 2010, it increased up to 21219. In 2017, the reported number of CKDu patients was 47891. Due to the rapid progress of disease incidence, personal and social burden coupled with the disease is further worsened. Wilgamuwa is the divisional secretariat situated on the Eastern border of the Matale district. The Wasgamuwa natural sanctuary forms its Northern boundary. The Knuckles Mountain range located in the borderline of the Kandy district forms the Southern limits. The Mahaweli river completely surrounds the Eastern part of Wilgamuwa. Wilgamuwa divisional secretariat consists of 39 Grama Niladhari Divisions. According to the 2019 population estimates, 31794 citizens reside in the Wilgamuwa area. This population is scattered throughout the site, and the calculated population density is 115.2/km2.

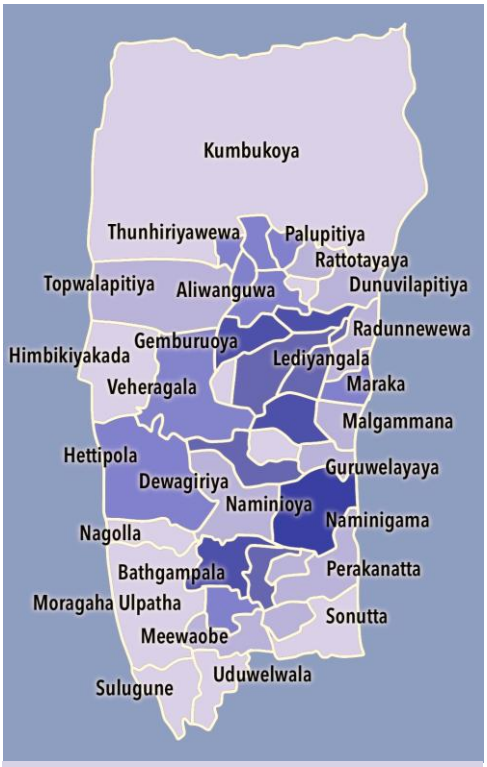


Figure 1: Map of Wilgamuwa DSD, Matale

In Sri Lanka, during the decade of 1990, an unidentified kidney disease was reported. Patients were mainly discovered from the Northern part of the Anuradhapura district and either side of the valley of the lower section of the Mahaweli river. These areas were primarily colonized after establishment of independence in Sri Lanka. Generally, Central province within which Wilgamuwa is located is not prioritized as a province with a higher prevalence of CKDu. But Central province can be recognized as a region where all the climatic and socio-cultural environments are experienced. Although CKDu appears as a health challenge, a multisectoral involvement is mandatary while providing health care services. Basic health care services are provided by the regional hospital Hettipola. Patients are referred to hospitals situated in Mahiyanganaya, Polonnaruwa, Teldeniya and Matale areas for secondary health care services and specialized medical advice. Patients receive dialysis services mainly from the National Hospital Kandy. Patients who require dialysis procedures are also referred to BH Mahiyanganaya and PGH Badulla.

THE STUDY

Objectives

- To describe the socio-demographic characteristics of patients diagnosed with CKDu in the Matale District.
- To describe the patterns of economic hardships faced by the families with a diagnosed CKDu patient.
- To describe the patterns of socio-cultural challenges faced by the diagnosed CKDu Patients in the Matale District.
- To determine the associated factors relevant to economic hardships among diagnosed CKDu Patients in the Matale district.
- To determine the associated factors relevant to socio-cultural challenges among diagnosed CKDu Patients in the Matale District.
- To describe the deficiencies in service provision to patients diagnosed with CKDu in the Matale District.

Methods

A descriptive cross-sectional study was conducted from 1st of March to 31st of August 2021 in Wilgamuwa divisional secretariat area located in the Matale district, Central province. Out of 1161 registered patients diagnosed with CKDu for more than one year duration and patients permanently residing in the Wilgamuwa divisional secretariat area, 262 patients were interviewed for the study.

Following structured data collection tools were used as the study instruments:

1. Interviewer administered questionnaire
2. Self-administered questionnaire
3. Data extraction sheet
4. Guideline for key informant interviews

Collected data were analyzed by using appropriate statistical parameters. Both descriptive and comparative calculations were done. Data analysis was facilitated by SPSS version 25.0. The project proposal was ethically cleared by the Ethics Review Committee of the Post-graduate Medical Centre, Kandy.

THE RESULTS

Socio-demographic associations of the patients

Sample Size

262

Out of 1161 registered patients

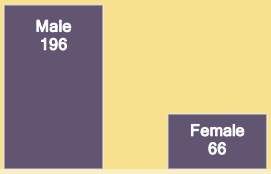
Age

Range: **29 to 90 years**

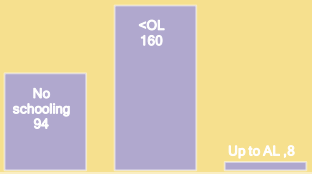
Majority (38%) were between

60 – 69 years

Sex



Education

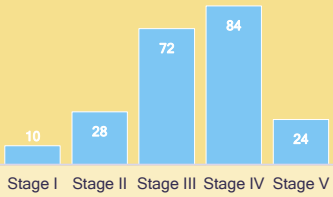


Income

65% were **Farmers**

90% earning an average monthly income **<10,000 LKR**

Disease stage



- A higher risk of developing the disease was noted with increased age - above **50 years**.
- Majority of the patients were diagnosed before the age of **55 years** (N=135:51.1%).
- None of the study participants were graduates, and none completed Advanced Level. **36%** of study participants had not received school education.
- Majority of the disease population affected were farmers.
- Monthly income of majority of the study participants was less than LKR 10,000, among which **3 in 5** patients **earned less than LKR 5000 per month**.

Treatment Centers

Majority of the study participants were visiting the closest clinic for their general treatment needs. **DH Wilgamuwa provides clinic services for 58% of the patients**. 16.1% (N=42) of the patients attend clinics at institutions away from the district.

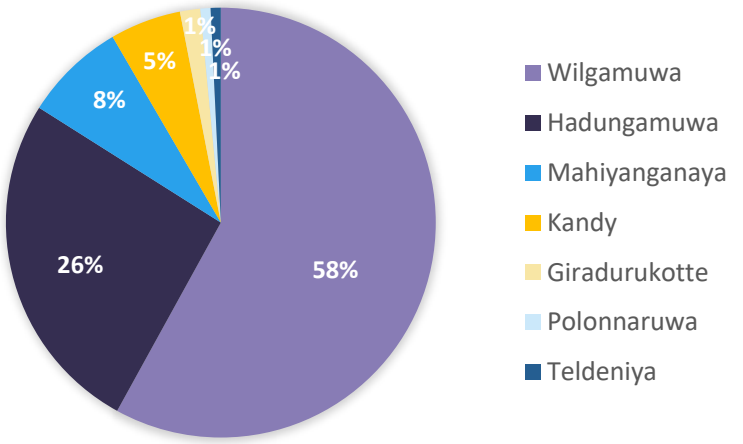


Figure 2: Treatment centers utilized by patients (N=262)

European Union ADRA OXFAM

Perception of Clinic services by the CKDu patients

- **73.8%** of the patients had encountered problems while obtaining essential travelling facilities to attend the clinics.
- **65.4%** of the patients receive transport facilities through healthcare services units.
- Extremely minimal attention is provided to the psychological status of the patients and their family members by healthcare staff.
- Patients' clinic visit is restricted to provision of direct treatment facilities for the medical conditions only.
- A significantly longer time is required to prepare for clinic visits and transport activities.

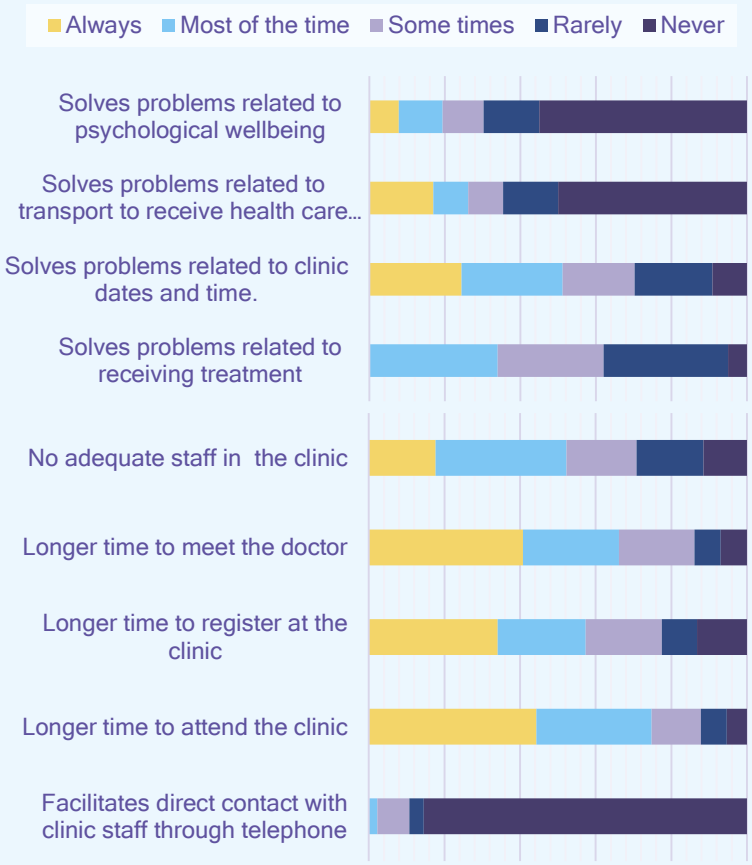


Figure 3: Perception of clinic services by CKDu patients (N=262)

- Even after approaching the clinic premises, a longer time is required for registration and consultation procedures.
- **70%** of the patients had not missed a single clinic day during last year.
- **5%** had not attended a single clinic.
- Patients tend to attend the clinic early to obtain an early place in the queue for registration. Even after registration, patients are expected to wait for a longer period to meet the medical officer. Although it is possible to guess that, this situation could be a result of lack of adequate number of staff members, patients had a dispersed knowledge regarding the adequacy of staff members at the clinic set up.

Nature of clinic services received by the patients

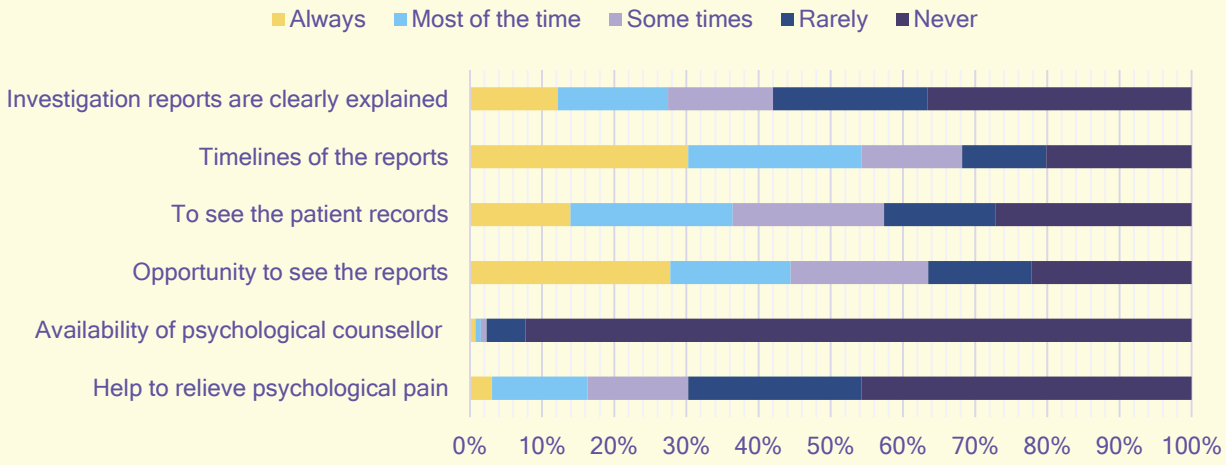


Figure 4: Nature of clinic services received by CKDu patients (N=262)

- Less attention is observed at clinics regarding evaluation of the psychological states of the patients and improving their mental wellbeing. Additional support is merely provided.
- Although it was possible to obtain lab reports without delay, most of the patients did not show an adequate interest in collecting the reports at the earliest time or getting a proper in-detail understanding regarding their disease status.
- Patients had the opportunity to review the clinic records and lab reports relevant to their disease condition. However, they had minimum chances to clarify and understand the details recorded in those documents.
- Study findings revealed that no face-to-face conversations were held to clarify the questions patients had regarding the changes in the severity of their disease condition and the possible usage of laboratory investigations to avoid complications.

Method of transport among the patients for clinic visits

50.3% of the patients use public transport measures to visit the clinics. Only **16.7%** of the patients use their own vehicles to visit the clinics. **9.9%** of the patients could afford to hire a private vehicle to visit the clinics.

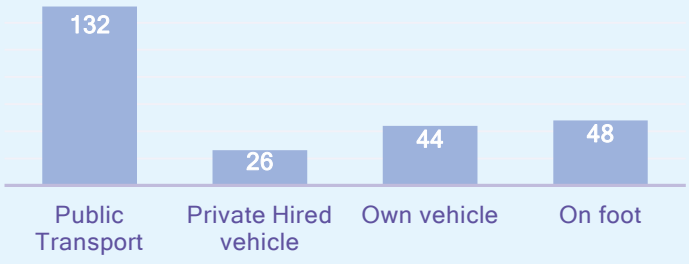


Figure 5: Method of transport utlised by CKDu patients (N=262)

Perceived knowledge on disease condition of the patients

An adequate perceived knowledge regarding the signs and symptoms of the disease condition and its control measures was observed among **52.3%** of patients. But patients do not have a distinct understanding of the disease condition, its consequences, treatment methods, side effects of the drugs, and available alternative treatment procedures.

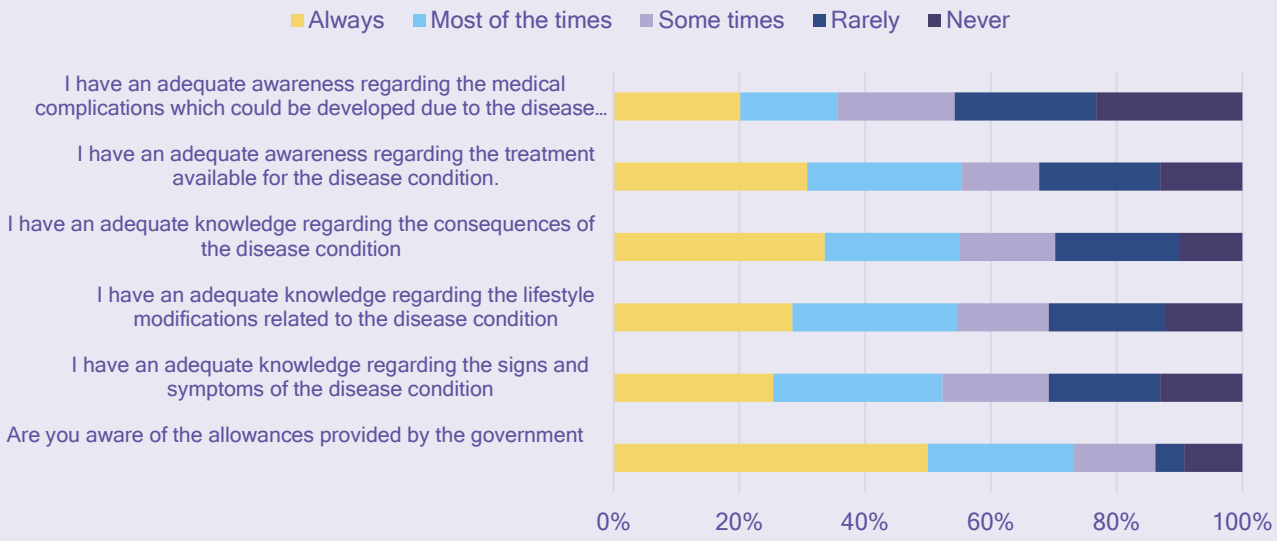


Figure 6: Perceived knowledge on disease condition of CKDu patients (N=262)

Source of disease-related information:

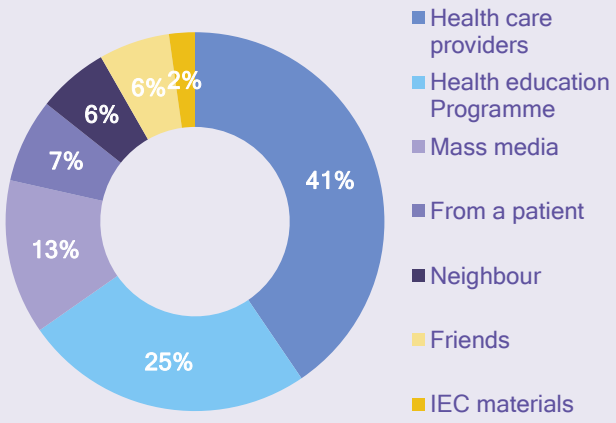


Figure 7: Sources of disease related information (N=262)

All the participants demonstrated a better knowledge and understanding regarding the incentives they receive compared with their knowledge regarding the disease condition. Patients predominantly depend on the health care workers for details regarding their disease condition. Knowledge gained from media and IEC materials is significantly low in comparison.

Nature of affordability of medicine by the participants

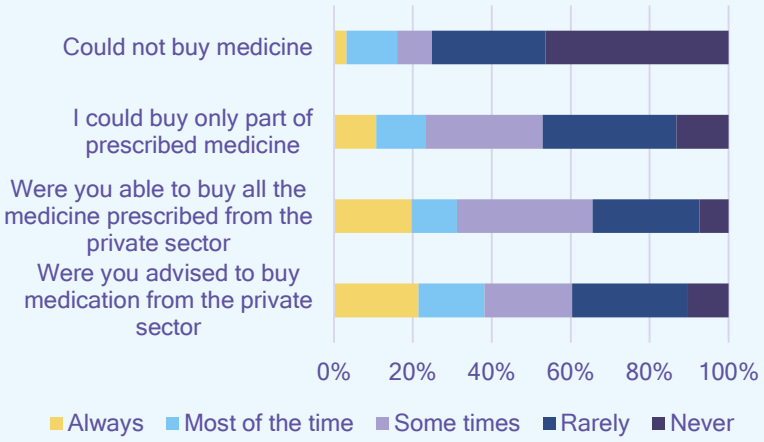


Figure 7: Nature of the affordability of medicine by patients (N=262)

- **60.3%** of the patients were advised to buy medicine from private pharmacies at least once during last year.
- **46.3%** of the patients had bought those medicine from pharmacies, but only **19.6%** of the patients could afford to buy all the prescribed medicine for the total period of time.

Impact of COVID-19 pandemic on routine CKDu patient management

- The study participants faced difficulties in receiving clinic services due to the current COVID-19 pandemic.
- Medicines, however, were compensated by over 50% of the participants through postal services.

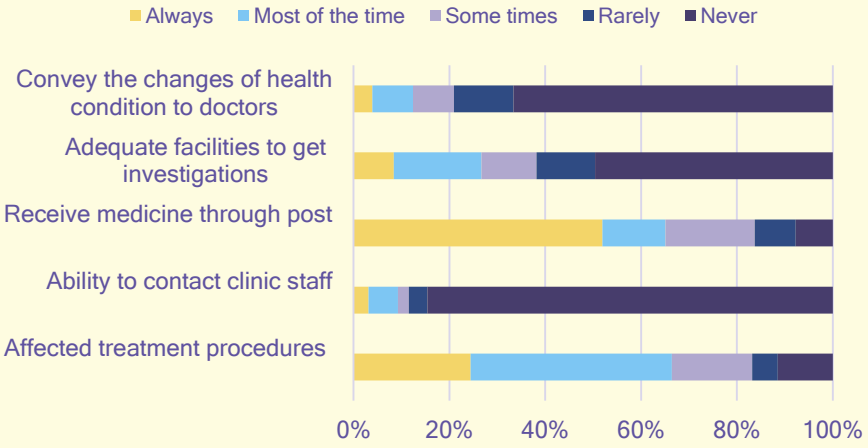


Figure 8: Impact of COVID-19 Pandemic on routine CKDu patient management (N=262)

It was identified that patients had to face many interruptions while obtaining laboratory reports, communicating with the health care staff regarding the alterations in their disease condition.

Psychological status of patients

- Properly maintaining a healthy mental status among patients appears to be a significant challenge. Due to chronic kidney disease, most of the patients had experienced fear of death and as a result, some of them have progressed to an anxious status.
- Patients had experienced uncontrollable anger most of the time and felt left out from the society as they tend to think that they are not valuable to others. Patients had experienced that; they were repeatedly rejected from the society due to their disease condition. As a result, they had undergone an extremely difficult psychological status, which persuaded them to become pessimistic regarding their future. Observations reveal that patients tend to lose their life expectations and optimism effortlessly.
- It was possible to observe some disappointment and frustration among the patients. Patients did not demonstrate any habit of adjusting their daily routine to achieve their goals or expectations.
- Majority of the patients thought that their needs should be fulfilled by the government or any other institution.
- None of the patients had received a psychological rehabilitation therapy, and none had identified the need for such a facility. They themselves have made them self-refused patients.

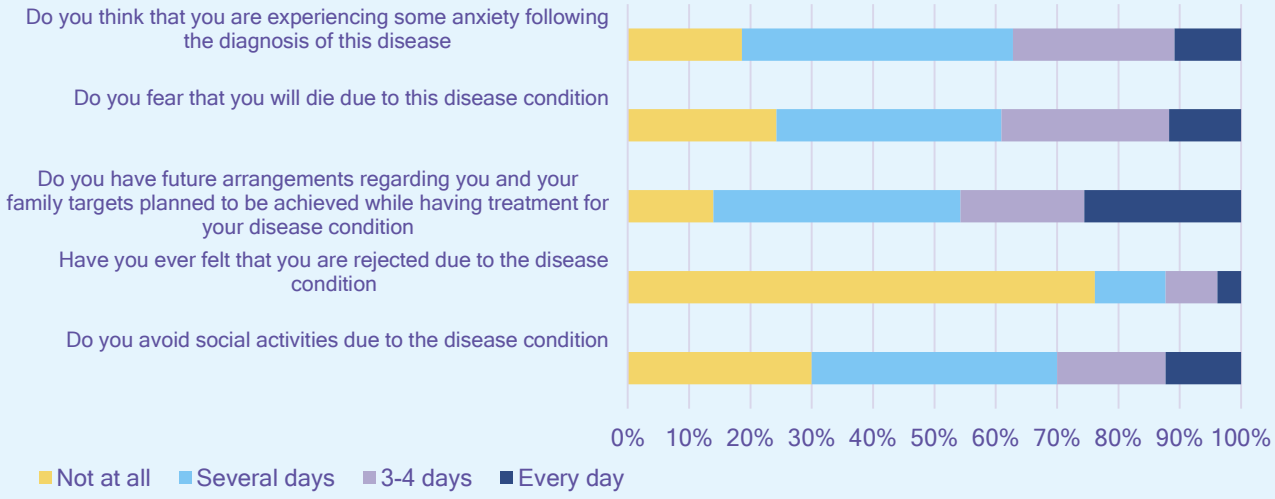


Figure 9: Psychological impact of disease on CKDu patients. (N=262)

It is noted that patients suffered more due to the socio-economic and socio-cultural problems they face during the management of their disease condition, but not due to the life challenges they face due to the disease condition.

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

- Majority of the patients had become victims of the disease at a relatively younger and productive age. A male predominance was noted among the patients, and majority of them were breadwinners of their families.
- Health care facilities required for the patients were adequately established, but from the patient's viewpoint, many difficulties were identified with the affordability and accessibility of these health services.
- Many economic hardships were generated due to the disease condition. Patients experienced considerable difficulties when they struggled to cope with the other personal and socio-cultural challenges caused due to CKDu.
- Maintaining optimum psychological wellbeing among patients was difficult, and the existing system did not contain adequate psychological and physical rehabilitation interventions.
- Patients did not possess adequate and accurate knowledge regarding their disease condition. This situation should be addressed directly and in a well-organized manner.
- Measures established within the health care system for prevention, early detection and delaying complications of CKDu as well as primary and secondary prevention strategies with recommended targets demonstrate minimum integration with patients and the general population.
- A proper coordination was not observed with health care and other services established for patients. As a result, most of the resources were not adequately used. Productivity achieved by minimizing the health care burden and upgrading patients' lifestyle was not adequately accomplished.
- A continued supply of the patients' pharmaceutical requirements was not observed, and as a result, treatment default incidences were common.
- Regular monitoring and direct observation regarding obtaining health care services by the patients and integrating patients into the health care system were not observed. As a result, number of patients with treatment defaults is increased, and patients rapidly advance into the end stages of the disease.
- Attention of the health care sector and other sectors was specifically focused on the treatment measures and strategies observed to promote primary and secondary preventive measures were minimum.

Recommendations

- Healthy individuals should be screened regularly to identify kidney diseases at the primary level. It is essential to implement an orderly methodology to achieve this goal. It would be more beneficial to implement an active surveillance strategy to correct defects in the existing passive surveillance system.
- Accessibility of patient care services should be improved. It would be more appropriate to provide transport facilities for attending clinics and obtaining laboratory investigation reports. It is possible to enhance compliance of treatment procedures and laboratory investigations by establishing a mobile sample collecting method for blood and urine samples at the domiciliary level.
- Provision of regular adequate, and satisfactory allowances to the patients could be more effective, and the current economic incentives should be increased. The possibility of providing a floating allowance based on the severity of the disease and the manner of recommended treatment procedures should be considered.
- Both physical and psychological rehabilitation programs should be arranged for patients and their family members. They should be adequately planned for short-term and long-term supportive measures. Patients should be psychologically strengthened to cope with the consequences created on themselves and their families and continue their treatment procedures.
- Methodical and formal health education programs should be conducted on target groups, and it is essential to recruit dedicated and qualified personnel for these programs. They should communicate with the patients for a more extended period of time and should be motivated to be consistently updated with new knowledge. Modern and sophisticated communication strategies should be introduced during these health education programs.
- Pharmaceutical supply within the clinic should be continuous. Stakeholders' attention should be drawn to inquire regarding the problems with pharmaceutical supply chains, and they should be encouraged to take opportunistic solutions for emerging issues regarding medications.
- It is preferable to establish a regional methodology to directly monitor the patients to avoid treatment defaults and minimize the effects created. To achieve this goal, a new designated officer should be appointed, attached to the MOH office of the area. Regular documentary returns regarding the tasks should be generated through this officer.
- Patients' information should be digitalized in detail, and more improvements should be made to the existing system. It should be established to access the patient's disease condition and its complications at any time by any health care worker.
- A focal point should be established to create proper coordination between health care services, other welfare services of patients and the governmental and non-governmental institutions providing services at present. It should be located in a place that is easily accessible for the patients. It should be organized to allow patients to connect with service providers without difficulties.
- Attention should be paid on encouraging patients to manage the disease condition parallel to improving the health system and healthcare facilities.

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- Miss. Janadari Gunasena - Development Officer CKDu - Divisional Secretariate office, Wilgamuwa
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