



Kidney disease impact on family survival of a sick person in Sri Lanka

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Abstract

Aim: In the mid-1990s, kidney disease was first reported from the Padaviya area; today, it is widespread throughout the dry zone. Most of those who fall income to this disease are farmers from economically disadvantaged communities. Consequently, the question of "how does kidney disease affect the family economy?" was chosen as the focus of the study. This study aimed to quantify the financial burden of kidney disease on rural Sri Lankan families.

Methodology: This study employed a qualitative research approach. For this study, we employed a mix of primary and secondary sources. Primary data was collected from thirty families, and secondary data was gathered from scholarly articles, books, and reports. The research was conducted in the Mahadiwulwawa Grama Niladari division of the Madawachchiya neighborhood of the Anuradhapura district of Sri Lanka. The data were analyzed using a thematic approach.

Findings: According to the results, kidney disease dramatically impacts a family's standard of living and negatively affects every aspect of family income.

Implications/Novel Contribution: The primary manifestation of kidney disease is its medicalization. In addition, it has far-reaching effects on individuals and communities. It is one of the country's most pressing social problems, and it has had a profound impact on Sri Lankan culture. This study adds to the existing body of literature by elucidating the repercussions of kidney disease on family income.

Keywords: Family, income, kidney, disease, agriculture.

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INTRODUCTION

Kidney disease has repercussions that extend beyond the family who is afflicted. The hidden costs of illness to families have been well documented. As a result, illness threatens the family's ability to stay alive. According to studies cited in the article (Jun et al., 2012), Kidney disease also significantly impacts the household.

This study's historical context also demonstrates how kidney disease has evolved into an acute societal disease and how it has been linked to the likelihood of a family's continued existence. The family has been defined as a social entity with the essential functions of shelter, economic cooperation, and procreation (Murdock (1949)). Consequently, the importance of economic cooperation, reproduction, and the distribution of family roles cannot be overstated. When discussing the effects of kidney disease, it is essential to note how it affects the family's financial well-being (Athuraliya et al., 2011).

Since the 1990s, people in the North Central Province and the Uva Province of Sri Lanka have reported kidney disease symptoms. In addition, its spread through those provinces was lightning fast. After that, researchers in Sri Lanka discovered kidney disease had spread to the entire country, including the northern, eastern, and central regions. Dehiaththakandiya, Kabithigollawa, Giradurukotte, Padaviya, Madawachchiya, and Nikawawa have all seen an increase in the number of people suffering from kidney disease.

This data demonstrates the alarming rise of kidney disease in Sri Lanka. In addition, those who rely on farming for a living are most at risk of developing chronic kidney disease (Chandrajith et al., 2011; Groopman, Rasouly, & Gharavi, 2018).

Kidney disease is a significant public health concern in Sri Lanka, and its ripple effects throughout the family make it an important social issue. Kidney disease was initially more common among men over the age

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of 60, but the disease has since spread to women and children. According to the medical literature, exposure to contaminated water has been linked to the development of kidney disease. Jayatilake found that exposure to chemicals used in agriculture plays a significant role in developing these diseases (Jayatilake, Mendis, Maheepala, & Mehta, 2013). Wanigasooriya and Jayasumana warn that drinking water from shallow wells is risky because of the presence of agrochemicals in the water (Jayasumana, Gajanayake, & Siribaddana, 2014; Wanigasuriya, Peiris-John, Wickremasinghe, & Hittarage, 2007).

Numerous grassroots studies have been carried out to understand kidney disease in Sri Lanka better. In particular from the standpoints of biology and sociology. Initiated at a time when kidney disease was a significant health disease, the initiative's initial focus was on its medical causes. Significant effort has been put into studying both the individual and societal effects of kidney disease. However, when a loved one is ill, the family must assume complete financial and emotional control of the family. As a result, it is critical to assess the challenges faced by the loved ones of those in the hospital. The purpose of the research into the effects of kidney disease on the likelihood of a patient's loved ones making it through their illness in Sri Lanka was to answer this question. It assisted in filling the informational void that had plagued sociological research at the outset.

Problem Statement

The primary manifestation of kidney disease is its medicalization. In addition, it has far-reaching effects on individuals and communities. It is one of the country's most pressing social problems, and it has had a profound impact on Sri Lankan culture. Particularly in the suburbs and cities away from the countryside. Numerous researchers have examined the consequences of kidney disease. A patient's loved ones significantly impact their recovery from family, which is taken into account when treating kidney disease. Therefore, essential facts on the impact of kidney disease in Sri Lanka can be uncovered by investigating the research question, "how does kidney disease affect the family economy?"

Objectives

This study aimed to identify the impact of kidney disease on the family economy in rural Sri Lanka. Except for the main objective, there were a couple of sub-objectives for this research, and those are;

- To identify the expenses of the affected families
- To identify the changes which are taking place in the family after the infection of the disease
- To explore other family members' contributions to the family economy

METHODOLOGY

This study employed a qualitative research approach. For this study, we employed a mix of primary and secondary sources. Primary data was collected from thirty families, and secondary data was gathered from scholarly articles, books, and reports. One technique used for gathering information was interviewing. The research was conducted in the Mahadiwulwawa grama niladari division of the Madawachchiya neighborhood of the Anuradhapura district of Sri Lanka. The data were analyzed using a thematic approach.

FINDINGS AND DISCUSSION

Impact of Kidney Disease on the Family Economy

Chronic diseases are more expensive to treat and require long-term care. Those afflicted with such diseases and their loved ones are the ones who must shoulder the weight of it (Pinikahana, Holloway, & Millen, 2002). This demonstrates that chronic illnesses like kidney disease have a sizable effect on family income. It has been documented that kidney disease has a negative impact on a family's financial well-being (Jayasumana et al., 2013; Jayasekara et al., 2015; Herath et al., 2014). All other family activities must adapt when the primary income is a kidney patient. It has repercussions for the country's economy, and the quality of education children receive.

Some of the most common visitors to public hospitals are poor rural farmers. Getting here is going to cost them a ton of money. But the high price of healthcare and medicines has contributed to a general economic slump. In this way, the school-aged children of these families are profoundly affected by the disease's spread. Due to financial difficulties, these families have to pull their children out of school. This results in a society where people are less likely to have completed high school.

Additionally, low levels of education are associated with a gradual increase in the unemployment rate. Medawachchiya's unemployment rate is 4.2%, while Padaviya's is 7.3% in the dry zone. As cited by (Jayathilaka & Wijesinghe, 2020), a country's economy can take a severe hit if its workforce is poorly educated.

In the decades following the 1970s, the world's economies advanced due to the combined effects of globalization and industrialization. This resulted in transforming conventional farming into industrial endeavor (Pathiraja, 2016). Applying chemical inputs like fertilizers, agrochemicals, and pesticides to boost crop yields has gained widespread recognition as an effective method for expanding agricultural markets. As mentioned in Chapter 2, most Sri Lankans relied on agriculture for their livelihood, and as a result, the Green Revolution was quickly adopted by the income. Thus, farmers had the highest disease of kidney failure. Therefore, the rural population as a whole felt the effects of the disease the most.

The result is the oppression of the rest of the family. As a result, there is a marked change in the academic standing of children enrolled in school after the onset of kidney disease compared to their academic standing before the onset of the disease. One family must work to support the rest of the members because the primary income is ill. The family as a whole, including the spouse and any children, should try to avoid this scenario as much as possible, as it will profoundly impact their financial situation. The amount of income received each month also fluctuates. They have regular medical bills to pay because of their health condition. Consequently, other members of the patient's family should also pitch in financially on the patient's behalf. Many factors have been studied concerning kidney disease and its impact on the family's financial situation.

Economic Experiences of Family Members

The farmer in the dry area relies heavily on his income production to provide for his family. Among male farmers, the prevalence of chronic kidney disease has been reported to be exceptionally high in recent years (Gunathilaka, 2015; Malwatta & Subasinghe, 2021). The disease has impacted many family breadwinners, leading to many social issues in the local area (Malwatta & Subasinghe, 2021). The resulting poverty is a clear and present danger due to this state of affairs. Because of the high cost of treating the disease, this would be a severe issue for farmers struggling to make ends meet (Malwatta & Subasinghe, 2021).

Therefore, it is evident from the responses that the functioning of the family will change drastically when the primary income earner becomes ill. Their main source of income comes from farming, so they have to be prepared to put some money aside for medical expenses in case any of them become ill. There are a lot of issues at home, and if there's a teenage boy, he has to help with the finances. A sudden and catastrophic income would occur if the primary family was involved in farming and suddenly fell ill with kidney disease. Jayatunga's remarks are further evidence of this.

"I used to work in the fields and do all the housework before I got kidney disease. The same income I had at the time went toward funding the education of my eldest son and two daughters. After finishing finals, the eldest son started working. The son also contributed to family costs while setting aside funds for his future. Nonetheless, because I could not continue farming due to illness, my family took over the business. My eldest child has had a lot of trouble because of me. He's got to work, tend to the farm, and care for me. No income is coming in to cover my medical bills and other household expenses like before " (Interview, 11.08.2018).

Piyasena claims the family has monetary issues.

"As a form of treatment, we are taking on debt and mortgaging our homes and farms. If we all get sick like this, the next generation won't be able to do anything about it. In our case, she did not work at all. Previously, I worked as a farmer. It was essential to our survival. Injections are also required. If the hospital does not carry the required medication, we must purchase it from a third party. If not, at least add me to the list! So, back home, folks do what they gotta do to make it possible and buy stuff because they can't let me die " (Interview, 09.06.2018).

Piyasena claims that he went bankrupt after mortgaging his home and land to pay for medical bills related to his kidney disease. Even members of the same family are having trouble making ends meet. While it's true that hospitals provide free family, it's been reported that patients and their loved ones often have trouble obtaining the medications they need because supply can't keep up with demand. Piyasena claims that if a hospital does not have a vaccine urgently needed, the family must raise a large sum of money and spend it all at once to purchase it. Therefore, the family places a higher value on the patient's life than on their own. They will forego their happiness

and sacrifice everything to ensure the sick relative's survival.

If the patient is the only family member, hospital bills can put them in the poorhouse [Pinikahana et al. \(2002\)](#). Since Silva's salary is the only source of income for his family, they will never see any of him again. Since the price of kidney disease has also increased, it can financially burden the family. Piyasena's family is in a tough spot due to the debt, and things will only worsen now that they have to pay interest on top of the principal. If the loan is not repaid, the debtor will lose everything they have worked for. Ultimately, the family will suffer the loss of their home and land.

Many rural communities have resorted to extreme measures like mortgages and asset sales to pay for medical care, as noted by [de Silva, Albert, and Jayasekara \(2017\)](#). That is also evident from the response given above. Kusumalatha's words carry it even further.

"The medicine itself was cheap, but getting there was very expensive. My husband is a farmer, and I am currently unemployed. To put it bluntly, we are broke. He needs to step up his game now. He was indeed able to provide for his family financially when I got sick, but that didn't stop the people back home from feeling helpless in their own homes. He pawns everything, even gold toys. The children are of marriageable age now. We are hopeless at this point " (Interview, 2018.06.10).

Kusumalatha claims that the family has spent a lot of money on transportation related to the disease's treatment and that while the family's basic needs are met with the money earned from farming, the expenses incurred due to the disease have increased more. For this reason, even the gold toys kept for the kids have to be mortgaged. It is traditional in Sri Lanka to give wedding gifts to the bride and groom, and she has two daughters getting married soon. However, she is so financially strapped that she has to mortgage the jewelry she had custom-made for them. The husband has to work overtime to make ends meet during the holiday season, but they need more money to reduce their savings for food and the kids' education. The burden of saving his wife's life now falls on his shoulders.

"I had to take more and more time off work to see a doctor as my kidney disease progressed, so I decided to leave my job. I wanted to keep teaching badly because I had spent so much time and energy becoming one. It was different in the past, but not any longer. This is challenging for me to work with. This gets extremely challenging at times. Because of this, I was told I couldn't resign from my position. To say that these things are a hardship for the family would be an understatement. Given the current price, they are effectively trapped on all fronts " (Interview, 2018.06.30).

Although Wasantha's salary and household needs have been met so far, it can be said that her home income has been affected since she had to quit her teaching job due to illness. Wasantha's comment further demonstrates how difficult it is for locals to earn enough money to pay for upcoming medical care. Residents are having financial difficulties due to Wasantha's illness, even though she quit her job because she was aware that she was unfit for regular treatment of the disease.

"Because I was ill, my daughter returned home from studying abroad. She came to take care of me and is now working for less than she was. It would have been much easier for her to save for a wedding present and start a family if she had been there. After I became ill not too long ago, my husband also had trouble getting to and staying at work. That's why he didn't get wealthy" (Interview, 2018.06.11).

Sumanawathi claims that the illness has prevented family members from working, reducing the household's income. Despite her daughter's higher salary from her job abroad, she returned to Sri Lanka to care for her ailing mother. Even though her daughter now has a job, she makes less than she did while living abroad, so the family's income has decreased. In addition, she will not be able to fulfill her future marital plans, such as building a house, if she stays in the country. Their financial situation has worsened because Sumanawathi's husband cannot keep his job due to his illness. As a result, kidney disease affects family members' propensity to give financially.

The expense of treating kidney disease can significantly affect national and international economies ([Axelrod et al., 2018](#)). Because of this, families will inevitably feel the effects of the financial burden that kidney disease imposes on the family as a whole. Some chronic patients also struggle with the difficulty of controlling their disease and anticipating future disease fluctuations ([Pinikahana et al., 2002](#)). Therefore, it is impossible to predict the future course of the disease, and it is also impossible to provide an exact cost estimate, as chronic diseases like

kidney disease require lifelong treatment. Because of this, it is evident that kidney disease increases the risk and responsibility of family members and has a negative impact on the family's ability to make ends meet.

Changes in Monthly Income Status

As we examine the sample families' sources of income, we find that most of those earnings come from the following three industries: There were a total of 06 public sector employees and seven private sector employees. They all lived off the land and farmed for a living. As a result, we can safely assume that all 30 of the sampled families were farmers. Rural communities typically relied on agriculture for their income, and this was no exception. However, it demonstrates that there have been several shifts in revenue streams due to exposure to kidney disease. As a result, it was evident that the family's monthly income had undergone several changes alongside the changes in the family economy.

Additionally, the number of government workers who resigned from their positions to pursue medical care was observable in the sample. The percentage of total family income provided by the breadwinner has fallen. People in the private sector were also seen quitting their jobs and going to the doctor because of kidney disease. Overall, income has decreased. Family issues have arisen directly from insufficient funds for basic living expenses. When the primary means of support for a family is cut off, the standard of living for all family members suffers. Even though they had begun working after the primary breadwinner in the family became ill, it proved difficult for them to continue supporting the family at the same standard. That's because medical care is costly.

In addition, the sample households all displayed small retail businesses and the income or absence of farming as a source of income. In addition to providing for the family's basic needs, they also helped to supplement the income. The illness has also significantly impacted the monthly income of both public and private sector workers' families.

Table 1: Family income level before illness

Income Level	Number of Families
20000 <	0
20000 -30000	09
30000 - 40000	10
40000 – 50000	07
50000>	04

Source: Field Data, 2018

According to their pre-illness income levels, four of these families make more than Rs. 50,000 annually. There, it was common for multiple family members to work, which increased the household's potential income. The family, which included members working in both the public and private sectors, had brought in this much income even before the illness struck.

Also, because most families have multiple breadwinners, seven out of the ten have annual incomes of between Rs.40,000 and Rs.50,000.

The highest income lies between Rs.30,000 and Rs.40,000, and it is striking that not a single family is located below the low end of the range, at Rs.20,000. Although agriculture played a central role in the economy, the Green Revolution helped ensure that it did not generate the lowest income.

Table 2: Family income level after illness

Income Level	Number of Families
20000 <	15
20000 -30000	09
30000 - 40000	04
40000 – 50000	02
50000>	0

Source: Field Data, 2018

After a diagnosis of kidney disease, there is a noticeable shift in family income. There may have been no previous cases of the disease in low-income families, but that has changed. Fifteen previously middle-income households have dropped to the lower-middle class category. Two families have incomes between Rs. 40,000 and Rs. 50,000, but they also include people with stable incomes. Consequently, a significant shift in financial resources typically occurs after an income crisis.

"My family and I were doing well before I quit my job. The three of them managed to maintain high academic standards. Everyone was content, so we all ended up building houses and putting aside Rs. 50,000. But ever since I developed kidney issues, it has been impossible for me to land a government job. The first son to take up farming was the oldest. While working another job, the second son also pitched in to help the family farm. I can only afford to take care of the bare minimum in family upkeep, and I have no way of putting money aside or adding to my savings the way I once did. A big chunk of my income goes toward medical expenses. Despite my best efforts, I can't provide for my two sons. However, the family still does not have a reliable source of income since I quit my job" (Interview, 14.07.2018).

Piyadasa claims that his monthly income has drastically dropped since he quit his government job, and his family's primary source of income has dried up. From what he has said, it is clear that the family's monthly income had remained the same as before he became ill, even though both of his sons earn income each month from their jobs. That's why the monthly income is so low now.

"After I became ill, nobody could tend to the paddy fields as I had previously. People toiled away in the paddy fields without a reliable income. Three kids are in the family, but only two work because one is still in school. Otherwise, my family and I would starve, so my wife helps on the farm ". The interview took place on July 15th, 2018 (Teaser).

According to his financial disclosure, Piyadasa's family's income has steadily decreased since he was diagnosed with kidney disease, causing his monthly income to plummet. This was because the primary source of income had dried up.

The monthly income is clearly below a minimum level because of this. Income was the backbone of the local economy and provided a family for most families that didn't work in the public sector.

As the risk of developing kidney disease has increased, so has the number of people putting their energy into farming. When a family's primary means of support begins to dwindle, it can dramatically impact the family's standard of living and the amount of money they bring in each month. Due mainly to a decrease in monthly income, these families have been struck by the recent job losses in the public sector. Meanwhile, private sector workers lost their monthly income as they missed work to seek treatment.

People who had jobs before they got sick quit once they could not participate in their previous roles due to their illness. As a result, the average monthly income has dropped due to people quitting their jobs or not showing up to them. The low-income level is a significant contributor to the rise in family poverty. As a result, the pre-illness higher income levels decreased after the illness.

Contribution of Other Family Members to Strengthening the Economy

Changes in the family's economic process can be traced back to the onset of kidney disease, allowing for earlier intervention. If the primary breadwinner in the family falls ill, the rest of the family needs to pitch in to help with the finances. As a result, the family's children helped the economy recover after their father got sick, and the wife helped the economy recover after her husband got sick, too. The husband's interest in contributing to the economy spikes after his wife falls ill. Evidence from studies (Jun et al., 2012; Jayasumana et al., 2013; Gunathilaka, 2015; Malwatta & Subasinghe, 2021) demonstrates that the disease often strikes the breadwinner of a family. Because of this, the rest of the family will be impacted and need to pitch in.

According to Jayatilake et al. (2013) and Herath et al. (2014), the spread of the disease significantly impacts children who are still in school. As a result of their family's financial situation, these children are forced to forego an education. Therefore, these families are where you're most likely to find this variation. When Dad gets sick, the kids drop out of school and start working. It was discovered that even economically disadvantaged minors could forego schooling to help with household chores. The employed children worked long hours, and the males in those families typically helped out on the family farm. Finding out what percentage of boys were interested in working

in more menial or occupational capacities was also possible. Examining kids' levels of schooling and interest in finding work before and after they get sick sheds light on this phenomenon.

Table 3: Condition before kidney disease

No of the Children in the Sample	No of the Children who are Schooling	No of the Children who are Employed
67	29	09

Source: Field data, 2018

The statistics presented in Chapter 2 show that 29 kids attended school before falling ill, and nine were working. The children who were part of these families and received an appropriate education before the illness has changed, as shown in the table below.

Table 4: Condition after kidney disease

No of the Children in the Sample	No of the Children who are Schooling	No of the Children who are Employed
67	11	27

Source: Field data, 2018

As a result, dropping out of school increases a child's contribution to the economic process of the family, even if the child needs to be involved in education. Before becoming ill, only nine people had the appropriate age for employment. Nonetheless, the epidemic's spread can be observed by adding 27 people to the original count. Those who should be in school drop out to help support their families financially. As an additional point, college grads tend to be married. A few years before the disease's onset, some people have finished school at the proper age in both the pre-and post-disease conditions. Thus, children under the age of 18 are the ones who have dropped out of school because of the disease, even though it may appear that they have found employment. Because of this, the disease also impacted the quality of some forms of schooling.

"In our case, my husband's income came from farming. He spent even our kids' college funds. Everything turned upside-down after he became ill. We have three kids, and all of them are school-aged. His illness prevented all but the youngest child from attending classes. After completing the ordinary level, the two eldest sons would move on to advanced. Only one person was able to take the test. Both have found jobs in the city at this point. Yet their pay needs to be improved. We have to pay for my husband's medicine and hospital visits, and somehow we manage to make it work with the income from our two children. We have mortgaged even our rice paddies. The kids can't cover one whole field, and we must keep going (Interview, 20.07.2018).

Vinitha's comment suggests that kids help out financially. It's clear, though, that this can only replace one means of support. As a result, the economic burden of caring for her ailing husband has been spread among other family members. It demonstrates how the next generation of a family is also vital to the economy's success (Herath et al., 2014).

As an employee of the city council, my husband was able to support us. Due to his need to frequently visit dialysis centers, he was forced to resign from his position due to his kidney disease. For our financial stability, the husband has kept working in the fields. When my husband lost his job, however, we found ourselves in a very hopeless position. I also have kidney issues, which I discovered later. It was easy for me to help out around the house because I was the husband. Our kids are all of marriageable age now. Since no one cares for their father and me, all three of my kids have jobs. They can legally get married now. Since we cannot work, they support themselves by practicing medicine. Using his inheritance, the eldest son rents out the paddy fields and reaps a paddy " (Interview, 2018.10.07).

This demonstrates how, when both parents have kidney disease, it falls on the children to provide for the family. The money these kids earn can be used to pay for medical expenses and other necessities for their families. The parents' sicknesses make it abundantly clear that the kids should be invested in improving the family's financial situation.

Despite their lower education levels, children are making an effort to contribute to the family's economic well-being by working outside the home. In addition, these kids need education to work for the government, so they have to settle for low-paying private-sector jobs. Therefore, it is evident that the wife and children will have to contribute to the economic process once the primary income earner in the family becomes ill.

CONCLUSION

The vast majority of farmers who rely on agriculture as their primary source of income are afflicted with kidney disease, and the disease directly impacts the economic status of their families, as shown by research on the topic. The disease thus threatened the primary breadwinners and the rest of the family's well-being. The family's financial plans will need to be adjusted due to the loss of the primary source of income. Here, it's clear that the family's pre-illness economic situation changed significantly after the illness and that other family members focused on financial gains to improve their financial situation. Recognizing that this economic shift also altered traditional family roles and responsibilities was a priority.

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