

# Assessing the financial burden of hemodialysis treatment in Malaysia

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## Abstract

**Background:** Patients with chronic kidney disease (CKD) spend substantial money on hemodialysis (HD) treatment. The growing intersection between socioeconomic status and financial burden represents an emerging challenge to the CKD community.

**Objective:** This study assessed the financial burden of HD treatment on patients at a Malaysian tertiary teaching hospital.

**Methods:** A cross-sectional study was carried out in the HD unit at a Malaysian tertiary teaching hospital from January to February 2021. Patients undergoing HD were purposively selected. A self-administered questionnaire was used to collect data on socio-demographic, finances, the patient's health history, treatment costs, and healthcare utilization. In addition, Pearson Chi-Square tests were used to analyze the data.

**Results:** A total of 100 patients receiving HD treatment were included in the study. The mean age was 62.06 years ( $SD = 27.50$ ), with 52% reporting moderate financial burdens. The financial burden was associated with employment status, salary, and income class among HD patients ( $p < 0.05$ ).

**Conclusion:** Evidence showed a large proportion of Malaysian patients receiving HD treatment came from the B40 income bracket. The findings indicate that financial burdens can impact HD patients and are related to employment status, salary, and income class. Therefore, the ability to identify HD patients' financial needs is critical in nursing practice.

## Keywords

hemodialysis; chronic kidney disease; renal dialysis; health care cost; financial burden; nursing; Malaysia

Chronic kidney disease (CKD) is a leading cause of morbidity and mortality worldwide. According to the 2015 Global Burden of Disease report, 1.2 million people died due to kidney disease (Kassebaum et al., 2016). A population-based study of CKD in Malaysia in 2011 found that the prevalence of CKD was 9.07 percent, rising to 15.48 percent in 2018, accounting for approximately 3.85 percent stage 1 CKD, 4.82 percent stage 2 CKD, and 6.48 percent stage 3 CKD, with 0.33 percent stage 4–5 CKD (Saminathan et al., 2020). In Malaysia, an increasing trend of end-stage renal disease indicated a need for dialysis treatment, with an incidence rate of 216 per million in population in 2016 (Wong & Goh, 2018).

For decades, the number of CKD patients requiring dialysis has increased, with 50 million patients worldwide requiring HD treatment. The global dialysis population is

rising, particularly in low- and middle-income countries. However, a significant number of people worldwide lack access to dialysis and kidney replacement therapy, and millions die each year from kidney failure, often without supportive care (Himmelfarb et al., 2020). At the start of treatment, most HD patients were given a thrice-weekly schedule. An incremental approach to dialysis initiation (starting at 1-2/week and increasing as needed) may offer potential benefits such as preservation of residual renal function, fistula preservation, and cost savings (Jahan & Wolley, 2019). However, the demand for HD treatment consumes a disproportionate share of the national healthcare budget (Bavanandan et al., 2016). It consumes a disproportionate share of Malaysia's limited healthcare resources (Surendra et al., 2018).

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Although the cost of dialysis is relatively low in many Asian countries when compared to income, these figures become unaffordable (Prasad & Jha, 2015). HD treatment is an expensive procedure requiring specialized resources and significantly burdens patients, families, and healthcare systems (Al-Shdaifat & Manaf, 2013). In Malaysia, a hybrid private-public model for financing dialysis therapy from non-governmental organizations (NGOs) shows that the cost of HD tripled between 2004 and 2015. According to the 24th Malaysian Dialysis and Transplant Registry (MDTR), 37183 patients received dialysis in 2015. The figure increased by two and a half times from 15087 in 2006. In 2006, there were 3710 newly diagnosed HD patients; however, by 2014, the prevalence had more than doubled to 7597 (Wong & Goh, 2018). In Malaysia, the government has remained the primary source of dialysis funding (63 percent). These funds were used to provide subsidies to non-profit HD centers and payment for dialysis treatment in private facilities for public pensioners, civil servants, and their dependents. Out-of-pocket costs or self-funding accounted for 17.3 percent, with charity accounting for 14.7 percent (Wong & Goh, 2018).

HD treatment is an expensive procedure that burdens patients and necessitates social care. Therefore, HD imposes a significant burden on patients and the healthcare system (Al-Shdaifat & Manaf, 2013; Li et al., 2021). The rise in the incidence and prevalence of HD and CKD, as well as the loss of financial support, household income, HD medication, and treatment costs, all play a significant role in influencing the financial burden (Al-Shdaifat & Manaf, 2013; Ismail et al., 2019; Li et al., 2021). Malaysians are classified into three income groups based on their median monthly household income: B40, M40, and T20. B40 represents the bottom 40% of Malaysian household income, M40 represents the middle 40%, and T20 represents the top 20%. B40 are lower-income groups, with monthly household incomes less than MYR4850. M40 is a middle-income group, with monthly household income ranging from MYR4851 to MYR10970. The upper class, T20, is defined as a household with a monthly income that exceeds MYR10971 (Department of Statistics Malaysia (DOSM), 2019). As a result, the operational definition of financial burden in this study is those HD participants who earn a monthly household income of less than MYR4850, implying that they are financially incapable of paying for HD treatment. In light of this burden, nurses play an essential role in determining a patient's financial capacity for medical treatment costs, including social referral coordination (Karam et al., 2021). Therefore, this study could help the nursing profession assess patients' socioeconomic status, especially those in the lower-income bracket, for the social and financial referral. While evidence suggests that the prevalence of CKD is rapidly increasing in Malaysia, little is known about how much HD treatment costs due to the financial burden. As a result, the purpose of this study is to assess the financial burden of HD treatment on patients at a Malaysian tertiary teaching hospital.

## Methods

### Study Design

A cross-sectional study was conducted at a Malaysian tertiary teaching hospital. The study setting was selected based on the hospital committed to achieving functions as a teaching and referral hospital in the northeast of peninsular Malaysia.

### Participants

A purposive sampling technique was adopted in this study. The study population comprised patients in the HD unit with the following inclusion criteria: 1) Diagnosed CKD patients aged 18 years and above undergoing HD and 2) consented voluntarily in the study. Participants who had dialysis time <1 year or dialysis is not regular, who cannot cooperate in the survey, with dementia, mental problems, disturbance of consciousness, abnormal communications, or severe complications, were excluded from the study. The sample size was calculated based on Thapa et al. (2021) using the following parameters: the standard normal distribution value was 1.96,  $\alpha$  (two-tailed) of 0.05,  $\beta$  of 0.20, and the expected correlation coefficient ( $r$ ) of 0.3, the minimum required sample size was 85. There may have been cases where patients were unwilling to continue participating in the study. As a result, a 20% non-response rate was used, and the sample size was 102.

### Measures

Data collection utilized a self-administered questionnaire adapted from Al-Shdaifat and Manaf (2013) with permission. The questionnaire consisted of four parts, A, B, C, and D. Part A consists of socio-demographic data such as age, gender, employment status, treatment status, and monthly household income. Part B consists of items on financial data such as monthly household income, financial use before and after treatment, the main source of income before and after treatment, and any prescriptive on traditional. Part C consists of items about the patient's health history and related costs such as a session of HD a week, type of transportation, cost of transportation go and return of HD, medications and other medical supplies, and any alteration in working hours during HD treatment. Finally, part D consists of items that aim to trace the number of visits to the clinic, private or public hospital, and the amount spent.

Scoring for the socioeconomic was performed on employment status, treatment status, and impact. For employment status, no score for unemployment and one score for employed. For funded treatment status, fully funded was 0, semi-funded was two scores, and self-funded was three. For impact, one score was allocated for negative impact while no score for no negative impact. Participants with 1-2 (76-100%) scores for negative impacts were labeled as a less financial burden. Participants who scored 3-5 (51-75%) scores were labeled as a moderate financial burden. Those participants who scored 6-8 (76-100%) were labeled as having a significant

financial burden. In determining questionnaires' appropriateness and ethical soundness, a pilot study was performed to pretest the questionnaire with 5% of the sample size among HD patients who did not form part of the study participants. The internal consistency coefficient (Cronbach's  $\alpha$ ) was 0.74, considered a good reliability value.

### Data Collection

Data collection was performed at the HD Unit from early January 2021 to the end of February 2021. A structured self-administered questionnaire in Bahasa Malaysia language (local language), forward-backward translated and validated, was employed to suit the study participants' language. Two independent researchers and one from the Language Unit reviewed and pre-tested the final Bahasa Malaysia questionnaire for appearance and content. A pilot test was performed on 5% HD patients, not included in the actual study. The selected HD patients' lists were disseminated to the researchers for verification and recruitment by the HD nurse on duty. In addition, the researchers verified participants' status for recruitment eligibility for any disabilities that prohibit them from participating in this study. If the selected participant refused to participate in the study, the participant was excluded, and a new participant was selected purposively by the researchers.

### Data Analysis

The collected data were entered into the Statistical Package for Social Sciences (SPSS) version 24 program. Descriptive statistics were used (means, standard deviations, frequencies, and percentages). Pearson Chi-square was used to test the association between socio-demographic data (employment status and monthly household income) and financial burden in HD patients. The results of the pilot test and incomplete questionnaires were excluded from the final analysis. A  $p$ -value of 0.05 was considered significantly associated with the outcome variable in all variables.

### Ethical Considerations

The study was approved by the institution's human research ethics committees (USM/JEPeM/20120645). All participants were given patient information sheets and signed informed consent forms to give their permission to be a part of the study. The study was carried out following the Helsinki Declaration and institutional requirements. Coded numbers were used during data collection to ensure anonymity and confidentiality.

### Results

The study enlisted a total of 100 HD patients (98% response rate). The participants' mean age was 62.06

years ( $SD = 27.50$ ), with females outnumbering males by 55% to 45%. More than three-quarters (77%) belonged to the aged group of 40-55 years. Most of the participants (78%) were married. A little less than half of the HD participants (46%) had completed secondary school. Most HD participants (55%) were unemployed during HD treatment, while 45% were employed. For treatment status, it was observed that the government fully funded most participants (62%). The remainder, 13% and 25% were semi-funded and self-funded, respectively. On monthly household income, 7% of participants had more than MYR5000, and 27% ranged from MYR3000-5000. The remainder, 35% had MYR2000-3000; 12% had MYR1000-2000, while 19% had MYR below MYR1000 (**Table 1**).

**Table 1** Socio-demographic characteristics of the participants ( $N = 100$ )

Variables	Mean (SD)	n	%
<b>Age (year)</b>	62.06 (27.50)		
18-28		9	9.0
29-39		14	14.0
40-55		77	77.0
<b>Gender</b>			
Male		45	45.0
Female		55	55.0
<b>Employment status</b>			
Employed		55	55.0
Unemployed		45	45.0
<b>Treatment status</b>			
Fully funded		62	62.0
Semi funded		13	13.0
Self-paid		25	25.0
<b>Monthly household income (MYR)</b>			
< MYR 1000		19	19.0
MYR 1000-2000		12	12.0
MYR 2000-3000		35	35.0
MYR 3000-5000		27	27.0
MYR >5000		7	7.0

MYR – The Malaysian Ringgit, the currency of Malaysia

On the level of financial burden, it was observed that most HD participants (52%) faced a moderate burden, of which the remainder 24% and 24% had a high and low burden, respectively. There was no significant association between the level of the financial burden and the variables (gender, age, and treatment status). However, a significant association was found between the level of the financial burden and socio-demographic variables, monthly household income ( $p = 0.006$ ), employment status ( $p = 0.001$ ), and income categories ( $p = 0.023$ ) of HD participants with more than three-quarters (93%) falling into the B40 category. Therefore, the distribution of five categories of monthly household income was listed B40, M40, and T20 to categorize the participants' income tiers (**Table 2**).

**Table 2** Association of socio-demographic variables and financial burden among HD participants ( $N = 100$ )

Variables	Level of financial burden, $n$ (%)			$p$ -value*
	Low	Moderate	High	
<b>Employment status</b>				0.001*
Employed	45 (45.0)	22 (22.0)	0 (0.0)	
Unemployed	55 (55.0)	30 (30.0)	24 (24.0)	
<b>Monthly household income</b>				0.006*
< MYR1000	1 (1.0)	13 (13.0)	7 (7.0)	
MYR1000-2000	3 (3.0)	13 (13.0)	11 (11.0)	
MYR 2000-3000	10 (10.0)	11 (11.0)	4 (4.0)	
MYR3000-5000	8 (8.0)	11 (11.0)	2 (2.0)	
>MYR5000	1 (1.0)	5 (5.0)	0 (0.0)	
<b>Income tiers categories</b>				0.023*
B40	23 (23.0)	47 (47.0)	23 (23.0)	
M40	1 (1.0)	5 (5.0)	0 (0.0)	
T20	1 (1.0)	0 (0.0)	0 (0.0)	

\*Pearson Chi-square test,  $p \leq 0.05$ , was considered to be statistically significant

## Discussion

CKD is a significant and growing driver of the global non-communicable disease burden. Approximately 40,000 individuals are on dialysis in Malaysia, and an estimated more than 7000 new patients are diagnosed with CKD every year (Murugesan, 2019). According to this study, the average age of HD participants was 62.06 years ( $SD = 27.50$ ), and 55 percent were female. In contrast to the Malaysian Dialysis and Transplant Registry 2015 (Malaysian Society of Nephrology, 2015), our study found that patients diagnosed with CKD under 65 had an increased need for HD treatment. Worldwide, the incidence of the elderly has increased in recent decades, resulting in a rapidly growing number of older patients beginning HD treatment (Shah et al., 2018). As a result, our healthcare systems will face significant challenges, as this population will require more healthcare for comorbid conditions. Our study observed that females comprise the higher proportion of the HD population. Similar results were also found in Shah et al. (2018) on 1247 HD patients in Portugal and Poland, where a higher percentage of women had HD treatment. Although CKD disproportionately affects both genders and ages, disparities in HD utilization among males and females; and age groups after accounting for pre-dialysis health are not well studied. According to Maddux (2018) on gender differences in CKD, people have come a long way in understanding how CKD affects men and women differently. She also emphasized the importance of better understanding why women are more likely than men to be diagnosed with CKD but have poorer treatment outcomes, indicating the need to investigate this issue. As a result, efforts and research are required to investigate the systematic underlying mechanisms of gender and age group disparities in HD practices.

Although our study only included HD patients from a single-center, it demonstrates that the financial burden of HD treatment costs can be substantial and overwhelming when correlated with socioeconomic status. This study adds to the body of knowledge about monthly household income, employment status, income categories, and the

financial burden of HD treatments in Malaysia. We discovered that more than three-quarters (93%) of Malaysian households with HD patients were in the B40 income bracket. For people with low and middle incomes, the rising out-of-pocket costs of HD treatment, as well as living with CKD and its comorbid conditions, can be overwhelming. According to the World Bank's Human Capital Index 2018, Malaysia ranks 55th out of 157 countries, achieving the country's goal of becoming a developed country while remaining classified as a middle-income country (World Bank, 2020). Thus, the scenario for B40 CKD patients appears bleak and disheartening. The public sector funds the majority of HD treatment (67.1 percent), which includes not only the Ministry of Health (MOH) but also multiple organizations owned by either the federal or state governments (Malaysian Society of Nephrology, 2015).

However, only a few people were able to receive dialysis treatment. Therefore, making life-changing decisions about affording HD treatments and managing life can be difficult for the B40 category group. Furthermore, dialysis treatment rates in all Malaysian states have surpassed 100 per million state population. As a result, the financial burden of HD may be stressful for the B40 group, which accounted for 93 percent of the study subjects. In line with previous research (Prasad & Jha, 2015; Surendra et al., 2018), our findings show that the financial burden of HD treatment is significant. Although the cost of dialysis in Malaysia is relatively low with income, these figures quickly become unaffordable. However, our study's findings indicate that participants (62 percent) who reported being fully funded may not have faced a financial burden.

Nonetheless, 13% and 25% were semi-funded and 25% self-funded, respectively, while 45% were unemployed. As a result, this suggests that the HD patients in the B40 category were from a lower socioeconomic background and were more likely to succumb to the disease if they did not receive HD treatment. The national dialysis provision is awaiting approval of a dialysis welfare subsidy from the Malaysian Ministry of Health (MOH) or acceptance into the MOH dialysis program when a vacancy



becomes available. According to Himmelfarb et al. (2020), the global dialysis population is growing, particularly in low- and middle-income countries. As a result, millions of people die each year from kidney failure, often without receiving supportive care. As a result, nurses can play a significant role in assessing the patient's financial capabilities for medical treatment costs in nursing practice, including social referral coordination as needed (Karam et al., 2021).

Similarly, World Kidney Day (2015) reported that millions of people die each year because they do not have access to affordable dialysis. Furthermore, Malaysia's economy has been at its worst since the Asian financial crisis of 1998 (Shukry, 2021). The financial burden can have an impact on patients' access to medical care. A CKD or ESRD patient, for example, may avoid HD treatment. As a result, this study emphasizes the overarching message that significant efforts are required to support transformative changes in accessible HD treatment.

The current study finds no significant association between the level of financial burden and variables (gender, age, and treatment status). As a result, additional research is required to confirm it. In addition, other studies on HD treatment costs and outcomes are also necessary for the government to provide dialysis in Malaysia. In addition, there are several limitations to the study. For starters, only HD patients in one setting were included for practical reasons, which may not represent the entire picture of Malaysia's household financial burden and poverty impacts of HD treatment. Second, due to a lack of local data, it is impossible to compare the findings of this study to those of other contexts.

## Conclusion

Evidence shows a large proportion of Malaysian patients receiving HD treatment came from the B40 income bracket. The findings indicate that financial burdens can impact HD patients and are related to employment status, salary, and income class. As a result, the ability to identify HD patients' financial needs is critical in nursing practice.

## Declaration of Conflicting Interest

The authors have no conflict of interest to disclose.

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## Authors' Contributions

All the authors contributed equally to the conception and design of the study; approved the final version of the article. NFA conducted the study and data analysis. AAMR supervised the research activities. AAMR and SLK contributed to drafting the article and involved the critical revision of the article.

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## Data Availability Statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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