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To Link this Article: <http://dx.doi.org/10.6007/IJARAFMS/v12-i3/15089> DOI:10.6007/IJARAFMS /v12-i3/15089

Received: 18 July 2022, **Revised:** 22 August 2022, **Accepted:** 07 September 2022

Published Online: 25 September 2022

In-Text Citation: (Bulot, 2022)

To Cite this Article: Bulot, N. (2022). Conceptual Paper: Developing Financial Toxicity Measurement Model for Patients with Chronic Kidney Disease in Malaysia. *International Journal of Academic Research in Accounting Finance and Management Sciences*, 12(3), 573–580.

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Vol. 12, No. 3, 2022, Pg. 573 - 580

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Conceptual Paper: Developing Financial Toxicity Measurement Model for Patients with Chronic Kidney Disease in Malaysia

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Abstract

Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both. The treatment for this disease is a costly procedure that requires specific resources. This is especially true for Malaysia, where many patients with chronic disease belong to the elderly group, who do not have any source of income and therefore cannot afford the treatment costs, hence, increase the risk of financial distress. It is important to note that, monetary costs are not the only driver of financial distress. Other factors such as patients' experiences and feelings about financial conditions arising from the treatment can negatively affect patient's outcomes, quality of life, financial well-being, psycho-social health, and ultimately the patient's ability to deal with the challenges associated with the treatment. The above-mentioned economic and social changes caused by the treatments of disease and disease itself to patients are known as Financial Toxicity. Knowing the data on financial toxicity will enable us to integrate the financial discussions into treatment plans that will allow for selection of cheaper but equally effective interventions and gives patients time to seek resources that can help them better finance care and avoid catastrophic health spending. However, despite the importance of this topic, little is known about the financial toxicity especially on those with chronic kidney disease. Using primary data (interview and questionnaires), this proposed research expected to come out with a model to assess the degree of financial toxicity for chronic kidney disease patients in Malaysia.

Key words: Financial Toxicity, Financial stress, Chronic Kidney Disease Costs, Financial Toxicity Measurement

Introduction

Chronic diseases have become a major cause of global morbidity and mortality even in developing countries (Nugent et.al., 2011). Patients with chronic disease often present with several coexisting comorbidities that require multiple medications (Ahlawat et al., 2017). The increase in medication bills (along with other factors) increases the cost of the treatment. The increase in the cost of treatment is one of the main contributors to poorer quality of life (Ting et. al., 2020) treatment non-adherence (Smith, 2015) and delayed medical care (Casilla, 2018). Alleviating the impact of financial toxicity requires knowledge of financial toxicity

suffers by the patients. However, little is known about the experience of financial stress for patients with critical disease or their families. Considering patients' experience is essential for optimal decision-making (De Souza, 2013). Nevertheless, despite increasing recognition of the impact of costs on patients' care, there is no patient-reported outcome measure that specifically describes the financial distress experienced by chronic kidney disease patients. The aim of paper is therefore to propose a study to develop the content for an instrument that assesses the degree of financial toxicity for chronic kidney disease in Malaysia. This intended research is different from the one carried out previously, as this research will be estimating the cost from patient's point of view instead of from the Ministry of Health (MOH) perspective. Second, unlike previous literature, this research will be focusing on developing a financial toxicity model specifically for chronic kidney disease patients in Malaysia. The main argument is that the patients socio-economic and demographic characteristics will affect the existence and severity of financial toxicity experienced by the patients. As a result of that, the existing measurement used to measure the financial toxicity for cancer patients cannot be used for chronic kidney disease patients, hence the need to develop the specific model for them. The main questions to be answered with the proposed research are (1) the components of financial toxicity experienced by Chronic Kidney Patients in Malaysia, (2) the best combination of instruments to be included in the model to assess the financial toxicity of chronic kidney patients, and (3) the components of financial toxicity that is practically and statistically important to chronic kidney patients.

Literature Review

Introduction to Financial Toxicity

Since all healthcare systems around the world differ, their organizations and funding mechanism largely determine the degree of financial burden experiences by its citizen when major health shock occur. In low-income countries, where the treatment for chronic disease is not affordable and the access to healthcare is low, patients with chronic disease may only present to a doctor when the disease has spread and death is imminent (Jan et al., 2015). In high-income countries, patients with chronic disease often believe they are sufficiently protected from high costs of treatment through their public health system or health insurance policies. Additional patient out-of-pocket expenses are common even in countries where there is universal health care or when individuals purchase private health insurance (Delgado et. al., 2015). High out-of-pocket healthcare costs have led to the recent conceptualization of financial toxicity'. The financial toxicity – a new term originating in oncology by Zafar et. al., (2013) is broadly used to describe the financial burden (Gordon et. al., 2017), financial hardship (Delgado et. al., 2015), financial distress (Workman et. al., 2017) faced by patients with chronic disease.

Measuring Financial Toxicity

There have been numerous studies over the last 10 years specifically among individuals and families on the topic of the financial burden, especially cancer. The measures of financial toxicity varied widely among the studies and therefore were categorized into three types of measures (Gordon et. al., 2017): (1) Monetary – currency values of out-of-pocket expenses and percentage of out-of-pocket spending to income ratios. 2) Objective - question sets on tangible solutions to ease financial burden such as to increase debt levels, borrow money from family or friends, sell assets, withdraw money from retirement or savings funds, file for bankruptcy. 3) Subjective - question sets on perceptions of cancer-related financial burden

and which cover the psychological impacts. However, even within these three categories, there was heterogeneity relating to the scope of data collected. For example, monetary measures included either direct medical expenses or direct and indirect expenses such as travel, accommodation, or parking. Monetary measures are problematic when relying on participant recall, while comparability across studies is difficult when cost components differ and cover different time periods. In addition to that, financial hardship may have existed prior to the disease or due to other concurrent health conditions. The disease might have not caused but exacerbated existing financial problems. Considering the measurement variation and issues reported above, evidence for the extent of financial toxicity is imprecise. Despite the importance of understanding this topic, very few extensive studies have been conducted, especially in Malaysia. Latest studies on this topic have been conducted in countries such as Tunisia (Mejri et. al., 2021), US (Ver Hoeve, et. al., 2021) and Australia (Durber et. al., 2021). In addition to that, the discussion on the existence and severity of financial toxicity has always been associated with various types of cancer disease such as breast (Willians et, al., 2021 & Politi et. al., 2021), Colorectal (Edward et. al., 2021), Bladder cancer (Ehlers et. al., 2021) and gynaecologic cancer (Esselen et. al., 2021). It is important to note that cancer is not the only chronic disease that is costly. The economic distress can also cause by the treatment of other chronic disease such as chronic kidney disease. This study will contribute to the existing literature by examining and studying the existence and severity of financial toxicity experienced by patients other than the one suffered by cancer patients.

Financial Toxicity and Its Impact

There is a great interest currently on the issue of financial toxicity (FT) with research papers, commentaries, and press articles on the topic substantially growing. The term FT is used to describe the financial distress or hardship as an outcome of a disease treatment. The increasing burden of chronic kidney disease is a matter of great concern as it leads to high level of mortality. The unaffordability of the treatment (high cost of medication) is one of the main obstacles in the successful treatment of CKD (Ahlawat et. al., 2017). Chronic kidney disease has huge economic impact on healthcare system (Agrawal et. al., 2005). It is known to affect not only the patients but also caretaker (Anapuma et. al., 2015). In addition, its effects on patient's health and quality of life, it also negatively affects their lifestyle, relationships, family, emotions, and employment (Ahlawat et. al., 2017). The development of financial toxicity model for chronic kidney disease could help the relevant parties to assess the degree financial toxicity suffers by the patients. This information is important to provide the necessary and effective prescribing and financial counseling while ensuring that patients have the financial supports, they need to obtain medication.

Materials and Method

Patients

Following the previous studies, patients who were receiving ongoing treatment in the Nephrology Clinic Hospital will be included, regardless of prior disease. Eligibility criteria included patients receiving treatment for at least 2 months at the time of the interview and aged 18 or older will be approached for participation. Because the goal of this study is to develop a model to measure financial toxicity, this research will choose patients who had been receiving treatment for at least 2 months as a sample, as they are most likely to have received health care bills and to have experienced financial issues.

Procedure

Eligible patients will be required to provide informed consent and will be given the questionnaire which they could fill in at home and return it by post or leave it at the clinic to be collected by the team. Postal envelopes (if needed) with stamps already attached will be provided to the patients.

Technique

Mixed methods research will be employed in this research. This method will enable us to collect, analyze and integrate data from quantitative (survey) and qualitative (interviews & focus group) research.

Data Collection and Analysis Steps

The study will be conducted at selected MOH hospitals in Malaysia. Patients diagnosed with chronic kidney disease will be included in the study. The step to be employed in this study is adapted from (Ahlawat, 2017). The data collection procedure to be applied in this research is described below.

Preliminary steps: the main objective of this preliminary step is to get approval, consent, cooperation from the relevant authority for us to conduct this research.

- a) To obtain the approval from the relevant authorities / Ministry of Health to undertake the research, in compliance with the ethical standard provided by the Ministry of Health of Malaysia.
- b) To obtain the cooperation from the National Institute of Kidney to conduct the research.
- c) To obtain the list of patients who were diagnosed with chronic kidney disease.
- d) To obtain the written informed consent from the patients to participate in the research. Patients, who do not give their consent, will be excluded from the study.

Item Generation (Interview & Distribution of questionnaires): this step defines the content of the instrument and ensures that all important variables are considered for inclusion in the instrument. A literature search will be followed by qualitative interviews with chronic kidney patients and expert will be conducted to elicit themes on financial issues related to their disease and treatment. Items will then be reviewed for redundancy, overlapping content, as well as problematic language. Duplicate items will be eliminated, and the remaining items will be classified into theoretical themes based on the qualitative interviews.

Determine the Items Importance: in this step, patients will be approached to assess the importance of the items to their quality of life. The items will be presented with a 4-point scale for the participants to rate the importance. The items will then be ranked according to the importance score from highest to lowest. The objective of this phase is to elicit themes on financial issues related to their disease and treatment.

Item Analysis: pilot testing assessing inter-item and item-total (ITC) correlation will be conducted to identify redundancy (spearman rho > 7) and statistically unrelated content ($p > 0.05$). Each duplicate item will be dropped, and the remaining items will be classified into theoretical themes based on the qualitative interview.

Exploratory factor analysis (Socio-demographic data will be collected): the factor structure will be assessed by a principal factor analysis. The sample size for this analysis to be determined based on the expected numbers of variables and factors observed in a preliminary exploratory factor analysis of the patients who participated in step 3. The number

of final factors underlying the data was identified using the combination of a Cattell scree plot evaluation (number of factors on scree plot just before elbow), Kaiser Criterion (eigenvalues >1.0), and percentage of variance criterion. Any factor loadings that is greater than 0.5 will be considered factor specific and of statistical and practical significance.

The final patient-reported outcome measures (PROMs) will be assessed for internal consistency using the Cronbach alpha coefficient, and coefficients >0.9 were regarded as excellent. Correlations among items (IICs) and between each item and the total score (ITCs) were calculated using Spearman rank correlation coefficients, as in step 3. Associations between the provisional COST measure total score and self-reported socio-demographic variables (age, sex, race, household income, insurance type, education, and marital status) were assessed using Spearman rank correlations, *t-tests*, or analyses of variance, as appropriate. A chi-square test was used when examining the association between education and the COST score dichotomized at the median. Patients who had greater than 50% missing items will be excluded from the factor analysis, and a simple imputation method using means will be applied to the missing data, excluded from the factor analysis, and a simple imputation method using means will be applied to the missing data.

Conclusion

The aim of this paper is to propose a study on the development of financial toxicity measurement model for patients with chronic kidney disease in Malaysia. The development of this model is important for at least three reasons: (1) knowing the degree of financial toxicity and treatment cost estimate will enable us to design an intervention strategy to lessen the financial effect of this treatment; (2) to provide evidence on the prevalence of financial toxicity among chronic kidney disease patients and identify clinical and demographic characteristics associated with financial toxicity. This data can be used to assess the economic benefits of interventions that slow the progression of kidney disease, and (3) the government through Ministry of Health and other stakeholders can implement several strategies to lessen the financial distress that complicates the lives of patients with chronic kidney disease and their families. High-quality, comprehensive chronic kidney disease care should involve attention to the financial toxicity and financial complications arising from the treatment.

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