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## Original Articles

# The Illness Representation and Treatment Adherence of Patients with End Stage Renal Disease Receiving Hemodialysis in Malaysia

Ali Aminuddin\* Charuwan Kritpracha\*\* Ploenpit Thaniwattananon\*\*\*

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### Abstract

**Objectives:** *This study aimed to explore the Illness Representation and Treatment Adherence of patients with end stage renal disease (ESRD) receiving hemodialysis (HD).*

**Method:** *Ninety patients with ESRD receiving HD were recruited from one public hospital in Kelantan, Malaysia. Questionnaires consisted of three parts: 1) Demographic Data Questionnaire (DDQ), 2) the modified Brief Illness Perception Questionnaire (B-IPQ), and 3) the Treatment Adherence Questionnaire (TAQ). The questionnaires were validated by three experts. The questionnaires were translated from English to Malay language using the back translation technique. The test-retest reliability was tested for the stability of the modified B-IPQ with the result of correlation coefficient of 0.90. The TAQ was tested for internal consistency yielded value of Cronbach's alpha coefficient of 0.83. The data were analyzed using descriptive statistics and Spearman's rho correlation statistic.*

**Results:** *The results revealed that the patients with ESRD receiving HD had the illness representation total mean score of 37.02 (SD = 4.17). The analysis also showed that the patients had a median score of 48 (IQR = 6) for the treatment adherence. The results also showed that illness representation has a negative correlation with treatment adherence, which was statistically significant as shown by Spearman's rho correlation statistic ( $r_s = -0.33, p < 0.01$ ).*

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\* Lecturer, Department of Medical-Surgical Nursing, Faculty of Nursing, International Islamic University Malaysia, Malaysia. Corresponding author: arely0105@gmail.com

\*\* Lecturer, Ph.D., Department of Medical Nursing, Faculty of Nursing, Prince of Songkla University, Songkhla, Thailand.

\*\*\* Assistant Professor, Ph.D., Department of Medical Nursing, Faculty of Nursing, Prince of Songkla University, Songkhla, Thailand.

**Conclusion:** *This study identified the negative correlation between illness representation and treatment adherence of patients with ESRD receiving HD, implying that patients with more negative illness representation were more likely to have difficulty in following their treatment adherence. Therefore, it is recommended that an experimental study should be developed and tested the illness representation promoting program to enhance treatment adherence for patients with ESRD receiving HD.*

**Keywords:** end stage renal disease; hemodialysis; illness representation; treatment adherence

## Background

In the past two decades, the number of patients diagnosed with end-stage renal disease (ESRD) has increased greatly in Malaysia. There were an estimated 28,590 people living with ESRD in Malaysia at the end of 2012, which shows an increase from a mere 1,396 patients in 1993.<sup>1</sup> ESRD is the final stage of kidney failure, where congenital or inherited diseases have progressively destroyed the normal structure and function of the kidney.<sup>2</sup> At the end stage of renal insufficiency, kidney function has declined to less than 10% of normal function and renal replacement therapy (RRT) has become a necessity.<sup>2</sup> RRT including hemodialysis (HD) can be used to replace some of the functions of the non-working kidneys. HD involves the circulation of the body's blood through a machine that cleans the blood of waste products, which takes 3-5 hours and is performed three times per week.<sup>3-4</sup> In 2012, the most common form of RRT in Malaysia was HD (92%).<sup>1</sup>

Illness representation is a person's thoughts or beliefs or ideas about illness.<sup>5</sup> A few studies have shown that illness representation contributes to a patient's treatment adherence.<sup>6-7</sup> ESRD patients did not have appropriate representation of their illness and felt that adherence to their treatment was both a physical and emotional burden.<sup>6</sup> Most ESRD patients believed that receiving HD weakened their body and health.<sup>6</sup> Moreover, most of them viewed their lives as being controlled by the treatment.<sup>6</sup>

Treatment adherence can prevent the progressive worsening of ESRD and recurrent hospitalization. Treatment adherence includes adherence to HD, adherence to medication, and adherence to fluid and dietary restrictions.<sup>8</sup> Patients with ESRD are at higher risk in developing complications such as hypertension and cardiovascular disease if they do not adhere to prescribed fluid restrictions and other treatment regimens over time.<sup>9</sup> For patients with ESRD receiving HD, serious consequences can occur if they fail to adhere to medications, fluid and dietary restrictions.<sup>10-11</sup> In Malaysia, previous study identified adherence to fluid restriction was prevalent among patients undergoing HD in a single center.<sup>9</sup> High proportion of HD patients in Malaysia had difficulty in