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Assessing Illness Acceptance and Quality of Life among the End Stage Renal Disease (ESRD) Patients Undergoing Hemodialysis

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Abstract
Haemodialysis is the best treatment for the long-term survival of end-stage renal disease patients that requires the acceptance of illness, which can maintain patients' Quality of life. Three hundred thirty-seven hemodialysis patients were involved in this study, which reported the acceptance of illness was moderate and was lowest among the males. The Quality of life was good and supported by the emotional well-being, dialysis staff encouragement, social support, and the acceptance of illness. Multidisciplinary intervention should be targeted to address the physical status and disease-specific core aiming to reduce further health complications and improve Quality of life.

Keywords: acceptance to illness; quality of life; hemodialysis, end-stage renal disease patients

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1.0 Introduction

End-stage renal disease (ESRD) is an irreversible decline in renal function, which can be fatal in the absence of dialysis and transplantation. The global prevalence of stage 5 chronic kidney disease or ESRD was 0.1%, which varies between countries (Marthoenis et al., 2021).

The Malaysian Dialysis and Transplant Registry (2019) reported that the incidence and prevalence of treated ESKD have also risen markedly over the last 25 years. About 7,967 new patients received dialysis in 2015, and by the end of 2016, there were 39,711 patients on dialysis. If the present trend continues unchecked, the number of ESKD patients is estimated to reach 106,000 in 2040. This burden will cost the health care system an estimated RM1.5 billion and RM3.2 billion, respectively.

Haemodialysis is a treatment that involves maintaining the normal function of the kidneys for removing the waste matter from the body and maintaining the high water quality and electrolytes balance. National Kidney Foundation (NKF) has stated that hemodialysis has succeeded in increasing the life expectancy of ESRD patients from 5 to over 20 years (Naalweh et al., 2017; Ignatavicius, 2016).

More than 70% of end-stage renal disease (ESRD) patients choose hemodialysis as survival therapy globally. This is the best treatment available for the long-term survival of chronic renal failure patients and can maintain patients' Quality of life at a satisfactory level (WHO, 2016; Meichelboeck, 2017).

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ESRD patients on hemodialysis (HD) spend 3 to 4 hours in each HD session, two to three times per week. Some patients have to travel long distances to the dialysis centre. This routine activity prevents most patients from obtaining a regular job and induces suffering from physical and psychological problems. Although this is the best treatment available, there are still advantages and disadvantages of using hemodialysis. It restricts the patient's mobility and activity, which may affect the patient's Quality of life (Mansor et al., 2015; Marthoenis et al., 2021).

Many factors contribute to the QoL in HD patients, including the age, education level, health problems awareness, good relationships with healthcare staff and other patients, having good social support, and short duration of dialysis (Gerasimoula et al., 2015). Some studies point out other causes, such as patient's health beliefs, self-efficacy, social support, negative nurse-patient relationship, life satisfaction, and illness acceptance (Valez-valez & Bosch, 2016; Marthoenis et al., 2021).

Acceptance of illness is a psychological adaptation to life with disease and implies it is an outcome while still functioning optimally; commonly associated with Quality of life; patient's psychological well-being, and life satisfaction (Moreira et al., 2015; Spigolon et al., 2016; Mroczek, 2017; Pompey et al., 2019).

Thus, the present study was conducted to determine the acceptance of illness, the Quality of life (QOL), and the correlation among ESRD patients undergoing hemodialysis.

2.0 Literature Review

Haemodialysis affects the patient's Quality of life (QOL). The procedure may affect their social and economic status, resulting in psychological problems. The adverse effects and the symptoms that typically include fatigue, nausea, frequent muscle cramps, pruritus, and ease of exhaustion were also responsible for the decline in the QoL in these patients. These symptoms reduce their tolerance for social and professional activities and their capacity to meet basic needs independently (Zazzeroni et al., 2017). Often, patients feel tired or 'lifeless' following a hemodialysis treatment. It is clear that even hemodialysis, a treatment that can extend the life of ESRD patients, places a significant treatment and symptom burden upon patients.

Studies have highlighted the importance of patients' acceptance of their illness as a factor in the physical and mental health-related QoL in HD patients. This involves self-understanding of the need to tolerate the nature of the illness (Jankowska-Polanska et al., 201; Pompey et al., 2019). A few ESRD patients on hemodialysis who accepted their illness showed better Quality of life than same-group patients who had not yet accepted their illness. Thus, the Quality of life assessment is an essential measure in patients undergoing hemodialysis to monitor their progress and the effectiveness of treatment (Joshi et al., 2017; Ravindran et al., 2020).

Another essential factor that influenced the QoL among hemodialysis patients was the social and family relationships. Good social relationships were important and the source of positive feelings; feelings of hopelessness and helplessness, all of which causes lower mood, depression, feelings of resignation, and a sense of life meaningless and improve the self-esteem and the QoL (Dąbrowska-Bender et al., 2018). Thus, the QoL of patients should be a focus during HD treatment, and assisting patients in accepting their illness was proposed as a way to achieve this goal.

3.0 Methodology

A descriptive cross-sectional study design was used to assess the illness acceptance and the Quality of life among the End-Stage Renal Disease (ESRD) patients undergoing hemodialysis in Selangor. The data was collected among 337 respondents from nine Hemodialysis Centres, representing nine districts in one of the states in Malaysia, from April to June 2021. The respondents were selected conveniently and met the selection criteria such as being diagnosed with ESRD due to Diabetes Mellitus and Hypertension; undergoing hemodialysis for renal disease for more than three months; hemodialysis sessions three times per week; hemodialysis via an external jugular catheter (IJC) or a matured native Arterio-Venous Fistula (AFV).

This study used self-administered questionnaires adapted from the previous research and three sections. First, the sociodemographic characteristics of respondents such as age, gender, ethnicity, educational level, marital status, sexual activity, financial background, employment status, dialysis access, the period of diagnosed Chronic kidney disease (CKD), period of diagnosed end-stage renal disease (ESRD), the hemodialysis treatment period.

Acceptance of Illness Scale (AIS) consists of eight questions describing the negative consequences of poor health, limitations imposed by the disease, lack of independence, dependence on others, and lowered self-esteem. This scale was widely used in to measure the lack of negative responses and emotions associated with the condition of the respondents (Kocjan & Janusz, 2015; Kowalewska et al., 2020). Five points of the Likert-type scale are set from one to 5 points. The complete agreement reflects a poor adjustment to the disease and psychological solid discomfort, whereas complete disagreement indicates the full acceptance of the illness. Total AIS scores ranged from eight to 40. The higher the score, the higher acceptance of the condition and the lesser the negative emotions associated with the disease. Scores below 20 are classified as low illness acceptance, 20 – 30 are moderate illness acceptance, and scores above 30 indicate high illness acceptance. The Cronbach's alpha for this scale was 0.82.

The Quality of life among the hemodialysis patients in this study was measured using Short-Form Health Survey 36-items (SF-36), a generic core of Kidney Disease Quality of Life Short Form (KDQOL-SFTM). This instrument consists of 36 items; of which only 35 items, representing eight scales and two summary measures adapted from previous studies (Md. Yusop et.al., 2013). The two summary measures are the physical component summary (PCS) and the mental component summary (MCS).

The physical component summary comprises scales of pain (2 items), physical functioning (10 items), general health perception (5 items), and role limitations caused by physical health problems (4 items). While the four scales of MCS were role limitations caused by emotional health problems (3 items), social functioning (two items), emotional well-being (5 items), and energy/ fatigue (4 items). The scoring for SF-36 was based on the KDQOL-SF™, which yields a score for each scale; two summary measures and total SF-36. The disease-targeted items focus on particular health-related concerns of the individuals with kidney disease and dialysis. Each scale scored 0-100, with a higher score indicating better QOL. The scores of the two summary measures and the total SF-36 are based on the average of the respective scale components. The Cronbach's alpha coefficient for the 35 items was 0.92.

The ethical study approval was gained from the institutional organization (REC/12/2020-UG/MR/271) and respective dialysis managers. The researchers explained the purpose and study procedures to respondents and informed them that their involvement in the research was voluntary. The survey took 10 to 15 minutes to complete. No identifying values could link the data; therefore, anonymity was ensured, and all confidential information was kept. Pilot study conducted and the Cronbach alpha result for both instruments used in this current study was 0.82.

The data were analyzed using SPSS version 26.0. The significance level was set at $p<0.05$ for the inferential statistic. Descriptive statistics were used to analyze the demographic characteristics, AIS, and the QoL. Chi-square and correlation coefficients were calculated to investigate the association and the relationships between the demographic characteristic of the respondents, the acceptance of illness, and the Quality of life.

4.0 Results

4.1 Demographics Characteristics of the respondents

Three hundred thirty-seven respondents with a mean age of 54.65 years old participated in this study. The majority of them were at the age of more than 35 years old (39.8%). An almost equal number of male (50.1%) and female (49.9%) patients took part in this study. Most of them were Chinese (39.2%), single (63.5%), unemployed (62.6%), sexually not active (69.1%), and had a good level of education as more than half of them had secondary to tertiary levels of education (68.8%). Only 18.4% were still working in the government sector. Most of them were on arteriovenous fistula (86.6%) and had been on hemodialysis treatment ranging from 1-to 12 months (97.6%). The mean period diagnosed as Chronic Kidney Disease was 4.99 years, while the mean period diagnosed as ESRD was 4.83.

Table 4.1. The characteristics of the respondents (*n*: 337)

Variables	Frequency (n)	Percentage (%)
Age (years old)		
Mean : 54.65; SD:14.03		
Min: 21		
Max : 89		
Less than 24	4	1.2
24-34	24	7.1
35-49	87	25.8
50-64	134	39.8
More than 65	88	26.1
Gender		
Male	169	50.1
Female	168	49.9
Ethnic		
Malay	126	37.4
Chinese	132	39.2
Indian	79	23.4
Others		
Marital Status		
Single	214	63.5
Married	61	18.1
Divorced / Widowed	62	18.4

Work Status		
Employed	126	37.4
Unemployed	211	62.6
Educational Level		
Primary	105	31.2
Secondary	179	53.1
Tertiary	53	15.7
Sexual Activity		
Active	104	30.9
Non-Active	233	69.1
Financial Background		
Government Employee	62	18.4
Government Pensioner	98	29.1
Self-paying	31	9.2
Others	146	43.3
Dialysis Access		
Arteriovenous Fistula	292	86.6
Internal Jugular Vein (IJC, Femoral)	45	13.4
Period of diagnosed CKD		
Mean : 4.99; SD: 2.82 Min : 1 Max : 15		
1-5 years	215	63.8
6-10 years	112	33.2
11-15 years	10	3.0
Period of diagnosed ESRD		
Mean: 4.83 ; SD: 3.01 Min : 1 Max : 16		
1-5 years	235	69.7
6-10 years	91	27.0
>10 years	11	3.3
Hemodialysis treatment (months)		
1-12 months	329	97.6
13-24 months	8	2.4

4.2 The Acceptance of Illness

Table 4.2 portrays the Acceptance of Illness among End-Stage Renal Disease (ESRD) patients undergoing hemodialysis at Dialysis Centres. The mean score for Acceptance of Illness was 25.23 ±5.94, indicating a moderate level of illness acceptance. Most of the respondents exhibited moderate illness acceptance (69.1%), while only 13.1% had high, and 17.8% reported a low illness acceptance.

Table 4.2 Acceptance of Illness

Items	Frequency	Percentage
Mean: 25.23± 5.94 Min: 8 Max: 40		

Level of Illness Acceptance		
Low	60	17.8
Moderate	233	69.1
High	44	13.1

4.3 The Quality of Life

Table 4.3.1 represented the overall scores of the Quality of Life among the hemodialysis patients using The Kidney Disease Quality of Life- SF 1.3 (KDQOL SF 1.3) presented in Table 4.4.1. The mean total score for the Quality of life was 51.78 ±12.33, while the mean for Physical Component Summary (PCS) and Mental Component Summary (MCS) was 51.04 ± 14.39 52.53 ± 13.23, respectively. As for the PCS, the pain had the highest score (54.58 ± 17.65), while role limitations-physical had the lowest score (47.48 ± 34.63). While for the MCS, the highest score was emotional well-being (56.44 ± 13.18), and the lowest was energy/fatigue (46.39 ± 14.13). It shows that kidney disease has a greater effect on physical health than on mental health.

The disease-targeted items focus on particular health-related concerns of the individuals with kidney disease and on dialysis. The Kidney Disease Composite Summary (KDCS) result was 55.83±9.13, with the highest score being the dialysis staff encouragement (74.55±20.20) and the social support (65.67±24.85). While the lowest score was renal disease overload where the perceptions of frustration and interference of kidney disease in one's life (44.73±22.48), the professional role or work status (47.63±35.49), and the sexual function (47.63±26.06) as portrayed in the Table 4.3.2.

Table 4.3.1 Quality of Life among the hemodialysis patients

No	36-Health Survey Item	Mean	Median	SD
Physical Component Summary (PCS)		**51.04**	**50.00**	**14.39**
	Pain	54.58	55.00	17.65
	Physical functioning	51.28	45.00	22.95
	General health	50.80	50.00	15.41
	Role limitations—physical	47.48	50.00	34.63
Mental Component Summary (MCS)		**52.53**	**50.92**	**13.23**
	Social function	52.86	50.00	15.93
	Emotional well-being	56.44	52.00	13.18
	Energy/fatigue	46.39	50.00	14.13
	Role limitations—emotional	54.40	66.67	35.84
Total score of SF-36		**51.78**	**50.60**	**12.33**

Table 4.3.2: The Disease-Targeted Core

No	Disease-Targeted Core	Mean	Median	SD
Kidney Disease Composite Summary		**55.83**	**55.25**	**9.13**
	Symptoms/Problems (12)	59.03	58.33	17.40
	Renal disease effects (8)	53.00	50.00	20.47
	Renal disease overload (4)	44.73	43.75	22.48
	Professional role (2)	47.63	50.00	35.49
	Cognitive function (3)	63.78	66.67	19.15
	Social interaction quality (3)	59.41	53.33	16.51
	Sexual function (2)	47.63	50.00	26.06
	Sleep (4)	54.47	55.00	10.66
	Social support (2)	65.67	66.66	24.85
	Dialysis staff encouragement (2)	74.55	75.00	20.20
	Patient satisfaction (1)	59.03	58.33	17.40

4.4 The relationship between the sociodemographic characteristic with the acceptance of illness and the Quality of life among hemodialysis patients

This study found that there was an association between the level of illness acceptance and demographic characteristics of the respondents, where male patients had the lowest level of illness acceptance (x2: 6.73; p: 0.03) Table 4.4.1.

The Quality of life among these hemodialysis patients was significantly related to the respondents' age; the older the patient, the less QoL experienced the patients (r: -0.12; p: 0.03).

There was also a weak and positive correlation between the level of illness acceptance and the Quality of life among the ESRD patients undergoing hemodialysis (r: 0.26; p: 0.01), which means the more the patients accept this illness, the better the Quality of life.

Table 4.4.1: The Association between the Demographic Characteristics and the Level of Illness Acceptance

Variable	Low	Moderate	High	x^2	P-value
Male	**39**	111	19	6.73	0.03
Female	21	122	25		

Table 4.4.2: The Relationship between Demographic Characteristics and Quality Of Life

Correlation	
Correlation Coefficient	**-0.12**
Sig. (2-tailed)	0.03
N	337

Table 4.4.3: The Relationship between Level of Illness Acceptance and Quality Of Life

Correlation	
Correlation Coefficient	**0.26**
Sig. (2-tailed)	0.01
N	337

5.0 Discussion

This current study revealed that the ESRD patients undergoing hemodialysis that participated in this study had a moderate level of illness acceptance. This supports the findings of previous studies, which reported that most patients with chronic diseases such as renal disease had moderate levels of illness acceptance (Kowalewska et al., 2020; Pompey et al., 2018; Jankowska-Polańska et al., 2017; Chabowski et al., 2017).

As for patients with chronic diseases, illness acceptance involves psychological adaptation and is impacted by factors that include results of treatment (e.g., therapy modalities), the time needed to complete treatment, and stress caused by the treatment itself. Patients tend to accept the new reality of their lives when they cannot change the situation. They began to accept the treatment and move on by following the health workers' recommendations acceptance (Kowalewska et al., 2020; Agustina et al., 2019; Pompey et al., 2018)

Other factors that influenced the illness acceptance were the psychological adaptation, acceptability of illness, proper social support, health examination, monitoring, and self-management. The patients' roles were significant and the need for acceptance and behavior modification in administering regular HD. Acceptance reflects a positive attitude and appreciation through individual values that are conceived as an effective means of achieving change, which acts as a mechanism for behavior change (Chiang et al., 2015; Esmaili et al., 2016; Agustina et al., 2019).

Although this study reflects that most of the participants were accepting the process of illness, healthcare providers, especially the nurses working in HD centres, should continue to support the patients in achieving the highest illness acceptance situations and alleviating undesirable emotions.

This study reported that the Quality of life among ESRD patients undergoing hemodialysis at nine dialysis centres in Selangor was quite good (51.78 ±12.33). This was supported by another study conducted among 100 patients who were on hemodialysis treatment at Miri Red Crescent Dialysis Centre in Sarawak. Their result was reported higher than this current study. The mean total score of the KDQOL-SF was 69.1± 16.5, while the mean for KDCS, MCS, and PCS were 66.3± 11.20, 52.6 ± 8.8, and 39.4 ± 9.3 respectively. This might be due to the coverage of the study. The current study was conducted more comprehensively, covering nine HD Centres in nine districts in the state of Selangor. Apart from that, the HDC selection covers various organizations, namely from the private sector, NGOs, including certain agencies. Furthermore, most of the respondents in their study at the age of more than 60 years old, in which they were more experienced and able to tolerated with the illness had impact on their QoL (Anak Ngalai & Ali, 2019). These results might reflect the hemodialysis services that support the QoL of the client.

However, this current result was higher than a few studies conducted in Tunisia, Lahore and Pakistan (Zouari et al., 2016; Anees et al., 2016; Laraib et al., 2018). This might be due to the study setting in which the respondents were among the HD patient who received treatment at the hospital-based HD Unit. The respondents were patients receiving treatment at hospital-based HD centres, who were still unstable and needed close monitoring before they could be allowed to seek HD treatment at community-based HD Centres.

In addition, this study revealed that the mean for Physical Component Summary (PCS) was found to be lower than Mental Component Summary (MCS); 51.04 ± 14.39 and 52.53 ± 13.23, respectively. This was similar to previous studies, where the score of the physical health domain is lower than the mental health domain (Laraib et al., 2018; Anak Ngalai & Ali, 2019). This is due to the intensive treatment during the dialysis and the restrictions on diet and fluid intake. Dialysis patients have a considerably higher risk of cardiovascular events than non-dialysis patients and are often associated with severe limitations in activities of daily living (Gadaen et al., 2021). At the same time, older patients are more likely to experience physical ailments that can decrease their ability to take care of themselves, resulting in lower PCS scores (Rao et al., 2022).

As for the PCS, the pain had the highest score of the QoL (54.58 ± 17.65), and the physical limitations had the lowest score in the physical component group (47.48 ± 34.63). This finding is commonly reported in previous studies, locally and internationally (Laraib et al., 2018, Dejvorakul et al., 2019, Anak Ngalai & Ali, 2019). Pain does exist in HD patients, especially in new patients. However, the frequency and duration of dialysis, including the adaption of the chronic illness, cause them to tolerate pain and perform daily activities despite it. Patients with chronic pain who have higher self-efficacy levels are more likely to perform health-related behaviors to alleviate the pain, leading to lower psychological stress and higher QOL (Vergeld & Utesch, 2020; Yang et al., 2019).

While for the MCS, the highest score was emotional well-being (56.44 ± 13.18). This finding portrayed the excellent result of the illness acceptance, the encouragement from dialysis staff in the centre, and strong social support from the family, which strengthened the respondents' emotional well-being and caused the better QoL. However, the lowest score of the MCS was energy/fatigue (46.39 ± 14.13). The effect of kidney disease on daily life; the repetitive and exhausting routine evokes a reduction in the QoL (Dejvorakul et al., 2019; Anak Ngalai & Ali, 2019; Ravindran et al., 2020).

Other factors influencing the QoL among these patients were the renal disease overload (44.73±22.48) and the professional role or work status (47.63±35.49), which reported the lowest score under the disease-targeted items that focus on particular the health-related concerns of the individuals with kidney disease and on dialysis. The perceptions of frustration and interference of kidney disease in the respondents' life; the difficulties in continuity work due to the physical limitation and the effect of the disease, and the haemodialytic treatment burden affect the respondents' QoL (Libardi da Silva et al., 2017; Dejvorakul et al., 2019; Anak Ngalai & Ali, 2019)

This study found an association between the level of illness acceptance and demographic characteristics of the respondents, where male patients had the lowest level of illness acceptance (x2: 6.73; p: 0.03). Previous studies reported no statistically significant differences in acceptance of illness with gender (Staniszewska et al., 2017; Kowalska et al., 2019).

However, some findings showed that the acceptance of illness was lower in males (Jankowska-Pola'nska et al., 2016), and some were found lower in females (Libardi da Silva et al., 2017).

The Quality of life among these hemodialysis patients was significantly related to the respondents' age; the older the patient, the less QoL experienced the patients (r: -0.12; p: 0.03). Previous studies revealed that the younger age groups had a significantly better quality of life (Lemos et al., 2015; Anak Ngalai & Ali, 2019). This decline in scores for older age was attributed to the fact that there is deterioration in the physical status of the patient, i.e., energy, work capacity, and Quality of sleep, including the several comorbidities, and with increasing age, there is a decrease in scores of the psychological domain. (Ravindran et al., 2020; Ramatillah et al., 2019)

There was also a weak and positive correlation between the level of illness acceptance and the Quality of life among the ESRD patients undergoing hemodialysis (r: 0.26; p: 0.01), which means the more the patients accept this illness, the better the Quality of life. Hwang et al., 2016, supported that illness acceptance was positively correlated with Quality of life and suggested the importance of adaptation to address symptoms following diagnosis of a chronic illness.

6.0 Conclusion

In this study, the respondents' acceptance of illness was moderate and was lowest among the males. The Quality of life was quite good and supported by the mental component such as the emotional well-being, dialysis staff encouragement, social support, and the acceptance of illness. However, attention should be focused on the physical component, especially the physical limitation that dramatically affects the decline of QoL. The acceptance of disease significantly impacts the perception of Quality of life in hemodialysis patients; the greater acceptance, the higher the Quality of life rating. There were apparent effects of illness acceptance on the QoL of HD patients. The limitation of this study was the method of sampling technique used. However, this study contributed the understanding of the illness acceptance and the QoL among HD patients that will help the health team to develop better interventions and plans of care for the future. Multidisciplinary intervention should also be consider to address the physical status and disease-specific core to reduce further health complications and improve QoL.

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Paper Contribution to Related Field of Study

Karina Abdul Wahid Pereira and Nurulhafizza Abdul Latif carried out the research and wrote the article. Fatimah Sham supervised the research progress, designed the research, conceptualized the central research idea, and provided the theoretical framework. Fatimah Sham and Ayat Al-Sawad anchored the review, edited the final manuscript, and approved.

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