

Illness Perception and Health-Related Quality of Life among Haemodialysis Patients

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ABSTRACT

Health-related quality of life (HRQoL) is a common issue in end stage renal disease (ESRD) patients. However not many studies focused on HRQoL and its impact on illness perception in Malaysia. The aim of this study was to determine whether illness perception was related to quality of life among end stage renal disease (ESRD) patients undergoing chronic haemodialysis (HD) treatment. A total of 183 HD patients completed the Revised Illness Perception Questionnaire (IPQ-R) and Short Form -36 (SF-36) to measure the quality of life. Results showed that eight components of illness perception (timeline, cyclical (nature), consequences, treatment control, illness coherence, emotional response and causes) were significantly correlated with the Physical Component Summary (PCS) and Mental Component Summary (MCS). Three predictors for PCS and five predictors for MCS were also found. Thus this study demonstrated that illness perception plays a significant role in HRQoL. In future health authorities and healthcare workers should prioritize research into illness perception for patient interventions to enhance HRQoL in these patients.

Keywords: Illness perception, health-related quality of life, end stage renal disease, chronic haemodialysis

INTRODUCTION

Chronic kidney disease (CKD) is a new global pandemic illness and the number of end-stage renal disease (ESRD) patients is also reaching epidemic proportions. At end 2008 there were approximately 19,000 patients with End Stage Renal Disease (ESRD) in Malaysia. Prevalent dialysis patients increased from 5,542 in 1998 to almost 16,000 at end 2007. Intake of new dialysis patients showed a linear increase over the years - from 1,559 in 1999 to 3874 in 2007 with corresponding treatment rates of 69 and 143

per million of the population (National Renal Registry Malaysian Society of Nephrology, 2008). ESRD affects some 20 million Americans and 20 millions more are at risk of developing chronic kidney disease (CKD) (U.S Renal Data System, 2005). CKD is fast becoming a global pandemic just like other chronic diseases such as hypertension, diabetes, heart disease, cancer, and stroke. CKD affects not only the patients but their families too. Patients with CKD face a lot of challenges resulting from various aspects of their health status and lifestyle but also their altered roles in life (Al-Arabi, 2006).

Received: 3 May 2011

Accepted: 28 July 2011

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ESRD occurs when the kidneys are no longer able to clean and filter waste products and remove excess fluids from the blood circulation. This endangers the patient's life due to the accumulation of fluid and waste products of metabolism. The disease can have an impact on patients' health-related quality of life (HRQoL), potentially affecting their physical and mental health, functional status, independence, general well-being, inter-personal relationships, and social functioning (Lok, 1996; Fallon *et al.*, 1997; Blake *et al.*, 1999; Suet-Ching, 2001; Bakewell *et al.*, 2002). The importance of assessing HRQoL in patients with ESRD has been increasingly recognized over the past two decades. Indeed, HRQoL in hemodialysis (HD) patients has recently been shown to be a significant predictor of mortality and hospitalization (Mapes *et al.*, 2003). In order to optimize dialysis therapy, HRQoL of ESRD patients is also important and needs to be improved. To improve the HRQoL of these patients, it is important to identify factors that affect their illness (Kalantar-Zadeh *et al.*, 2001; Stull *et al.*, 2001; Rumsfeld *et al.*, 1999; DeOreo, 1997; Tibblin *et al.*, 1993).

The terms "illness perception", "illness representation", "illness cognition", and "illness belief" are often used interchangeably in the literature. Illness perception is the organized cognitive representation or belief that patients have about their illness. This perception has been found to be an important determinant of behavior and has been associated with a number of important outcomes such as treatment adherence, functional recovery (Leventhal *et al.*, 1997) and HRQoL (Timmers *et al.*, 2008; Fowler *et al.*, 2006). The idea patients have about their illness have been most effectively researched within the Model of Common-Sense, previously referred to as the Theory of Self-Regulation developed by Leventhal and colleagues (Diefenbach and Leventhal, 1996). Such representations come into play as soon as patients experience their initial symptoms and typically change with disease progression, emergent symptoms and treatment responses. Leventhal *et al.* (1984) proposed that the

representations reflect the patients' cognitive responses to symptoms and illness and that emotional responses are processed in parallel with these illness representations.

Although understanding how patients' perception of their illness will impact on how they cope with and adapt to their disease, only few and limited studies have been carried out to date. There is evidence to show that response to an event is flavored by the individual's knowledge, capabilities, life experiences, and socio-cultural background (Holaday, 1989). Some patients may perceive illness in wholly negative terms and define it as a freedom adversary. When illness is perceived with the sense of doom or viewed solely in terms of decline and loss, a negative experience is likely to follow. A negative perception of illness seeds unhappiness and depression. Perception improves when illness is viewed as something that occurs within a context. Viewing illness as a normal part of life allows patients to live more fully in the present, such a view seeds positive return.

Quality of life in patients with chronic illness has been studied extensively and results have shown that the level of disability as experienced by the patients cannot be explained by mere biomedical variables. Therefore, research on HRQoL has focused on other factors that influence the perceived impact of the illness. The patients' own perceptions of an illness were found to play an important role on their HRQoL. Timmers and colleagues (2008) had reported that the illness perceptions of ESRD patients on both HD and peritoneal dialysis (PD) therapies markedly impacted on their HRQoL. Their study involved 91 HD and 42 PD patients assessed with the Revised-Illness perception Questionnaire (IPQ-R) and SF-36. Their results showed that PD patients experienced more personal control and had a better understanding of their illness compared to HD patients. Their illness perception scores ranged from 17% to 51% of the variance in HRQoL. Perception of more symptoms, more consequences and reduced personal control were associated with a lower well-being.

Fowler and Baas (2006) studied illness representations in 42 patients with CKD on maintenance haemodialysis. Illness perception was examined based on the Common-sense Model of Illness as described by Leventhal *et al.* (1997). Their study used the IPQ-R, the Index of Well-being (IWB) and brief demographic forms. Their results showed that there was a strong association between the emotional component of illness perception and QoL. The second subscale used was Consequences which is a strong component of the cognitive process involved in illness perception. That is, as consequences increased, the HRQoL decreased. There was an inverse relationship between consequences and HRQoL. Other scales which included identity, timeline, personal control and illnesses coherence were not associated with HRQoL.

Covic and colleagues (2004) studied illness representations and HRQoL scores in 82 HD patients. In this cross-sectional study, they examined the impact of illness representation on HRQoL of HD patients and the influence of HD duration. They used the Health-related quality of life questionnaire to assess HRQoL and the Revised Illness Perception Questionnaire for assessing illness representations. They found a relatively low HRQoL among HD patients, with a significant proportion scoring less than 43 for the physical component summary (65.9%) and less than 51 for the mental component summary (58.5%). HD patients consider their illness as having a chronic course, which they understood and controlled quite well. A higher personal control was associated with a lower emotional response and a better understanding of their disease. However, the perceived negative consequences of the disease upon patients' personal lives and their emotional response were considerable.

Given the importance of HRQoL measures in predicting patient outcomes and the modifiable nature of illness representations held by ESRD patients on chronic maintenance HD, we aimed to investigate the relationship between their illness perception and HRQoL and to determine whether illness perception predicts HRQoL in these patients.

METHODS

This was a prospective cross-sectional study. Participants were assessed using the Short Form - 36 (SF-36) and Revised Illness Perception Questionnaire (IPQ-R). Patients receiving HD for less than three months were excluded. It was approved by the Hospital Universiti Kebangsaan Malaysia (HUKM) Ethics and Research Committee and informed consent was also obtained from the patients. HRQoL was the dependent variable and illness perception was the independent variable.

The participants in this study included 183 patients with ESRD who were undergoing HD treatment at outpatient facilities affiliated with HUKM. These involved satellite HD centres at Bandar Tasik Selatan, HUKM and Universiti Kebangsaan Malaysia (UKM) Bangi in Selangor. Dialysis patients at MAA- Medicare Kidney Charity Fund Dialysis Centre at Jalan Ipoh, Kajang, and Cheras were also recruited.

Short Form - 36 (SF-36): Quality of life was assessed using the Short Form-36 (SF-36). The SF-36 evaluates various aspects of functioning and well-being so as to provide an overall impression of HRQoL and was developed as the best compromise between response burdens. It is a generic self-completed questionnaire with eight dimensions. These eight dimensions include physical functioning, physical role limitation, emotional role limitation, social functioning, pain, mental health, social functioning, and general health perception. These contribute to the evaluation of two major aspects of patients' functioning - physical (physical component summary, PCS) and mental (mental component summary, MCS) (Ware *et al.*, 1993). It takes about 15 minutes to answer the question. Scoring is by summing the responses for each of the items in the dimensions and converting them by a scoring algorithm to a scale from 0 (poor health) to 100 (good health). A higher score indicates better functioning, less pain or greater well-being.

Revised Illness Perception Questionnaire (IPQ-R): Illness perception was assessed with the well-validated Revised Illness Perception

Questionnaire developed by Moss-Morris *et al.* (2002). The IPQ-R assesses nine components of illness representation in three sections. The first section asks about the subscale Identity – in which participants are asked yes/no questions about 18 different symptoms and whether they believe these symptoms to be related to being on HD. The second section consists of 38 questions which address seven subscales - time-line, cyclical (nature), consequences, personal control, treatment control, coherence and emotional response. The patients rate the items on a five-point scale, ranging from ‘strongly disagree’ to ‘strongly agree’. The Time-line dimension is assessed by six items. A higher score on this dimension indicates the patient’s perception of the chronic course of the disease. Cyclical is assessed by four items whereby patients view their illness as episodes that come and go over time. The Consequence dimension is assessed by six items and a higher score indicates that the patient considers the disease as having serious consequences upon his/her life. Personal control dimension assessment comprises five items and a higher score indicates the perception of better personal control of the disease.

Treatment control is assessed by five items, and a higher score indicates that the patient considers HD to be efficient in controlling ESRD. Coherence is a measure of how well the patient understands his illness. It is evaluated by five items - a higher score indicates the patient’s increased understanding of ESRD. The last dimension assesses Emotional response and has six items. A higher score in this dimension indicates more intense emotional reaction to the disease. The final section focuses on the subscale Causes. This scale consists of 18 possible causes for being on dialysis (e.g., lifestyle, hereditary factors, chance, behaviour, uncertainty). This scale also uses the five point Likert scale.

A cross-sectional design to investigate illness perception and HRQoL at a certain moment in time was used. Data were analysed with SPSS for Windows (version 18.0). Correlation analysis used the Pearson correlation coefficient. A stepwise multiple regression

procedure was conducted to predict illness perception on patients’ HRQoL (PCS and MCS).

RESULTS AND DISCUSSION

The patients’ demographic profiles are as shown in Table 1. Of the 183 patients 54.1% were male and 44.9% were female. There were 40.4% Malays, 44.8% Chinese, 12% Indians, and 2.7% others. With regards to their religious affiliation, there were 44.3% Muslims, 31.1% Buddhists, 12% Hindus, 4.9% Christians, and 7.7% others. Majority (80.3%) of the participants were married.

TABLE 1
Demographic profile of study patients

Variable	Frequency	Percentage (%)
Gender		
Male	99	54.1
Female	84	44.9
Ethnicity		
Malay	74	40.4
Chinese	82	44.8
Indian	22	12
Others	5	2.7
Religion		
Islam	81	44.3
Buddhism	57	31.1
Hinduism	22	12.0
Christianity	9	4.9
Others	14	7.7
Marital status		
Married	147	80.3
Single	15	8.2
Divorced	5	12.7
Widowed	16	8.7
Total (n)	183	100%

The reliability of both the instruments - SF 36 and IPQ-R - was first assessed in the study. The Cronbach alpha reliability coefficients were calculated for each of the subscales of the IPQ-R and the SF-36. The alpha levels are presented in Table 2. All illness perception subscales demonstrated adequate reliability

(alpha levels > 0.70) with the exception of the treatment control subscale of the IPQ-R, which had a reliability of only 0.51. The SF-36 demonstrated excellent internal consistency in this sample of patients with ESRD with Cronbach alpha values 0.65 to 0.89.

Results in Table 2 showed that patients described their illness as chronic and perceived the symptoms of their disease as changing over time. Patients also perceived that the disease had a high impact on their life style. However, they still believed that the treatment they received could control their illness. Patients also strongly believed in personal control towards the disease and understood their illness well. In terms of emotional response, a high emotional instability was evident. Patients also described that although many causes had led to the ESRD, they experienced few symptoms. The patients in this study had a high HRQoL

in all eight components namely, physical functioning, physical role limitation, emotional role limitation, social functioning, pain, mental health, and general health perception.

The relationship between the dimensions of Illness perception and HRQoL are presented in Table 3. Except for personal control with PCS, all other components of illness perception which included identity, timeline, cyclical, consequences, illness coherence, emotional response, and causes were highly correlated with PCS and MCS. However, the correlations with identity, time line, cyclical, consequences, emotional response and causes were in a negative direction. Thus patients perceived their illness to be of a chronic and cyclical nature (comes and goes over time) with associated low PCS and MCS. Patients who perceived their disease as having serious consequences also had associated low PCS and MCS. On the other hand, patients

TABLE 2
Mean scores, standard deviation and reliability analysis

Scale	Score range	Mean	SD	Alpha value
Illness perception(IPQ-R)				
Time line (acute-chronic)	6-30	23.94	4.91	0.82
Cyclical	4-20	13.60	3.36	0.72
Consequences	6-30	21.60	4.63	0.70
Personal control	6-30	18.70	4.25	0.70
Treatment control	2-25	16.91	3.23	0.51
Illness coherence	5-25	16.03	4.49	0.77
Emotional response	2-30	18.13	5.30	0.72
Causes	19-95	49.51	10.79	0.79
Identity	0-18	8.84	3.96	0.80
Quality of Life (SF 36)				
Physical functioning	0-100	72.57	18.15	0.89
Role physical	0-100	68.44	19.78	0.84
General health	0-100	74.07	22.34	0.68
Vitality	0-100	58.56	15.54	0.82
Bodily pain	0-100	60.22	19.77	0.75
Social functioning	0-100	77.32	21.53	0.65
Role emotional	0-100	74.95	21.74	0.84
Mental health	0-100	71.04	19.44	0.87

with a lower emotional response to the disease attained a better PCS and MCS. Patients who perceived more symptoms and causes related to their illness also had a lower PCS and MCS.

However, there was a positive association between personal control with MCS and illness coherence components with PCS and MCS. Patients who scored higher on personal control had a better MCS. Positive correlation for illness coherence means that the more the patient understood his/her disease, the better his/her PCS and MCS.

TABLE 3
Pearson's correlations between illness perception and health related quality of life - physical component score (PCS) and mental component score (MCS)

Variable illness perceptions	PCS	MCS
Identity	-0.40**	-0.35**
Time-line	-0.17*	-0.18*
Cyclical	-0.25**	-0.21**
Consequences	-0.48**	-0.40**
Personal control	0.13	0.15*
Treatment control	0.17*	0.23*
Illness coherence	0.31**	0.35**
Emotional response	-0.36**	-0.44**
Causes	-0.29**	-0.22**

**p<0.01 *p<0.05

A stepwise multiple regression procedure was conducted to examine the relationship between Illness perception with PCS and MCS. Results are shown in Table 4. Of the nine predictors, only three (Model 3) contributed to the variance in PCS with 33.3%. The highest contribution came from the Consequences variable (22.6%).

TABLE 4
Predictors of PCS using multiple regression analysis

Model	R	R Square	Adjusted R square
1	0.475 ^a	0.226	0.221
2	0.552 ^b	0.304	0.296
3	0.577 ^c	0.333	0.322

- a. Predictors:(Constant), IPQ consequences
- b. Predictors:(Constant), IPQ consequences, Identity
- c. Predictors:(Constant), IPQ consequences, Identity, IPQ coherence
- d. Dependent Variable: PCS

The results in Table 5 show that five predictors (Model 5) had contributed 31.8% to the variance in MCS. The highest contribution came from the emotional variable (18.9%).

TABLE 5
Predictors of MCS using multiple regression analysis

Model	R	R square	Adjusted R square
1	0.435 ^a	0.189	0.185
2	0.485 ^b	0.235	0.227
3	0.517 ^c	0.267	0.255
4	0.543 ^d	0.295	0.279
5	0.564 ^e	0.318	0.299

- a. Predictors: (Constant), IPQ emotional
- b. Predictors: (Constant), IPQ emotional, IPQ consequences
- c. Predictors: (Constant), IPQ emotional, IPQ consequences, Identity
- d. Predictors: (Constant),IPQ emotional, IPQ consequences, Identity, IPQ treatment control
- e. Predictors: (Constant),IPQ emotional, IPQ consequences, Identity, IPQ treatment control, IPQ coherence
- f. Dependent Variable: MCS

The results of this study showed the reliability of the majority of subscales on the IPQ-R to be an adequate and well-developed tool for measuring illness perception in the sampled Malaysian ESRD patients. All subscale items via timeline (acute/chronic), timeline (cyclical, illness coherence, consequences, personal and treatment control, emotional response, illness symptoms, and the quality of life scales (SF-36)) had item-total correlations greater than 0.51. Eight out of nine subscales in the illness perception and six HRQoL subscales showed high internal consistency. However, the treatment control subscale may perform poorly because there is little that one can do to improve or reverse the effects of ESRD other than dialysis with its attendant chronic complications. As the Revised Illness Perception Questionnaire was only recently revised, lower reliabilities on these newly developed subscales are to be expected and further development is needed.

This study is one of the few reported in the literature which systematically investigate the illness perception of patients with ESRD on chronic HD and how their illness perception may impact their HRQoL. Except for the personal control component of the illness perception which did not correlate with the PCS, all the other eight components performed well and were correlated with the PCS and MCS. There were negative correlations between identity, timeline, cyclical, consequences, emotional response, and causes. Personal control and illness coherence had positive significant correlations with the PCS and MCS.

In this chronic HD study cohort, the perception of more symptoms, more consequences, more causes to the illness and higher emotional response was associated with lower PCS and MCS. Patients who perceived their illness to come and go over time (cyclical) also experienced lower PCS and MCS. Perception of more personal control and better understanding of the illness (coherence) were associated with a higher quality of life. Whereas Fowler and Baas (2006) found that consequences

and emotional response were correlated with HRQoL. These differences can be explained by the larger number of the patients in our study - 183 compared with Fowler's 42 subjects.

Three predictors were identified to contribute to the variance in PCS viz consequences, identity and illness coherence and five predictors to MCS namely emotional, consequences, identity, treatment control, and illness coherence. Consequences and emotional response were major predictors of PCS and MCS in our patients on chronic HD treatment. Covic *et al.* (2004) reported similar findings in studies using the Common Sense Model as a theoretical framework. They reported that lower emotional responses were related to and were predictive of better physical and mental health scores. In their study of ESRD patients, Diefenbach and Leventhal (1996) reported that a higher emotional score provoked by the illness was significantly correlated with HRQoL (Fowler and Baas, 2006). In post-myocardial infarction patients, Moss-Morris *et al.* (2002) found that lower scores on the emotional representation subscale were associated with a positive effect. Albeit somewhat different in the various subscale scores, the findings from this and other studies emphasize the importance of how illness perception may determine the HD patients' HRQoL. In other words, what the patient feels and believes regarding him or herself, their disease and the treatment affects all aspects of their physical and mental functioning.

CONCLUSION

The results of this study showed that various aspects of illness perception can predict the HRQoL of ESRD patients on chronic HD. Some of these factors are amenable to modification and intervention. Hence there is an urgent need for healthcare authorities and healthcare workers to prioritize research into illness perception for patient interventions to enhance HRQoL in these ESRD patients on chronic HD.

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