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Symptoms and Health-Related Quality of Life in Patients with Heamodialysis and Continuous Ambulatory Peritoneal Dialysis

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Abstract: The purpose of this study was to identify the symptoms experienced by patients, to evaluate the differences in Health-Related Quality of Life (HRQoL) by the type of dialysis treatment and to examine the relationship between symptoms and HRQOL. The study involved 274 End-Stage Renal Disease (ESRD) patients, comprising 183 treated by Haemodialysis (HD) and 91 by Continuous Ambulatory Peritoneal Dialysis (CAPD). Short Form 36 (SF-36) was used to measure HRQoL, Physical Health Component Summary (PCS) and Mental Component Summary (MCS). Meanwhile, symptoms were tested by using the list of disease symptoms according to the Revised Illness Perception Questionnaire (IPQ-R). Results showed that many patients reported symptoms of fatigue, weakness, muscle cramps, body itchiness and sleeping difficulty. CAPD patients were found to have higher PCS and MCS scores than the HD patients. The results also showed the relationship between the symptoms experienced with PCS and MCS. In conclusion, both type of dialysis treatment and symptoms impacted the HRQoL of ESRD patients with CAPD patients having a superior HRQoL than HD patients.

Key words: Health related quality of life, end-stage renal disease, haemodialysis, continuous ambulatory peritoneal dialysis, Malaysia

INTRODUCTION

Decline in quality of life of patients with chronic illness can lead to socio-psychological problems such as degradation of their mental and physical health status, roles within family, freedom, prosperity, personal relationships and societal roles (Bakewell *et al*., 2002; Suet-Ching, 2001). Furr (1998) and Valderrabano *et al*. (2001) reported that patients with End-Stage Renal Disease (ESRD) not only suffer from kidney failures but they also experience physiological and psychological changes such as fatigue, eating disorders and limited activities. According to Frank *et al*. (2003), the effects of changes in the economic status of patients due to high medical costs were also presented.

The options available to patients with ESRD are either chronic dialysis or kidney transplant. However, the lack of kidney donors especially in Malaysia has resulted in patients undergoing endless dialysis therapy either Haemodialysis (HD) or Peritoneal Dialysis (PD). For example in 2004 from the National Kidney Organ Sharing System name list to undergo cadaveric kidney transplantation only 17% of the patients received a kidney transplant. In Malaysia, most of new kidney transplant are commercially done in China. This source has also been declining since 2005, 143 transplants in 2000-192 in 2004 and only 109 transplants in 2009. This decline may be due to the result of commercial transplants banning together with the decrease of the number of transplants performed in China (MDTR, 2009).

Hence, the type of dialysis received influenced patients' quality of life. Gokal *et al*. (1999) and Majkowicz *et al*. (2000) have reported the Health Related Quality of Life (HRQoL) of patients undergoing CAPD treatment is better than HD treatment patients. On the other hand, other studies reported no difference in HRQoL of patients who received CAPD and HD (Mittal *et al*., 2001; Wasserfallen *et al*., 2004). Studies by

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Griffin *et al.* (1994) found that patients who received HD treatment experienced more pain, felt very uncomfortable and experienced more serious symptoms than those on CAPD.

Some researchers found that the HRQoL of HD patients was worse compared to CAPD while other workers reported no significant differences based on the type of dialysis. Kalander *et al.* (2007) believed that the reported differences in HRQoL based on treatment type could have been due to social differences in the demographic and clinical characteristics of patients or perhaps the method used to measure the HRQoL itself.

The perception of patients of the symptoms they experienced was also related to the HRQoL. Studies by Kimmel *et al.* (2003) for HD patients found that patients who perceived having a greater number of symptoms as a result of their illness had lower HRQoL and life satisfaction compared with patients who reported fewer symptoms. Among the common symptoms experienced by patients are pain, insomnia, tiredness and shortness of breath. However, not many studies have been focused on symptoms and HRQoL in the context of ESRD. Therefore, this study aimed to identify the symptoms experienced by dialysis patients and their relationship to HRQoL. It also aimed to examine whether there are differences in HRQOL based on the type of dialysis treatment.

MATERIALS AND METHODS

Research design: This was a cross-sectional study. HRQOL was measured using a generic questionnaire, the Short Form-36 (SF-36) health survey. The socio-demographic data were obtained directly from patients. Patients receiving dialysis for <3 months were excluded. The interviews were held at a time when the patients were on dialysis treatment or when patients were a waiting their turn. The SF-36 physical and mental component summaries were used as dependent variables and the symptoms variables were used as independent variables.

Sample: This study involved 274 ESRD patients which comprised of 183 patients on HD and 91 on CAPD. HD patients were recruited from dialysis centers managed by the University Kebangsaan Malaysia Hospital (HUKM) based at Bandar Tasik Selatan, UKM Bangi Health Center and HUKM itself. HD patients were also recruited from dialysis centers run by the Charity Dialysis Centre MAA-Medicare (MAA-Medicare Kidney Charity Fund) at Jalan Ipoh, Cheras and Kajang. CAPD patients were enrolled from HUKM and the Putra Specialist Hospital, Batu Pahat, Johor.

Instruments

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, emotional role, 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). It takes about 15 min to answer the questionnaire. 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): The Revised Illness Perception Questionnaire (IPQ-R) assesses nine components of illness representation in three sections. However, in this study only the 1st section was chosen which is subscale identity. Participants are asked yes/no questions about 18 different symptoms and whether they believe these symptoms to be related to their disease or treatment. A few items were added based on symptoms usually experienced by ESRD patients.

RESULTS

A total of 274 ESRD were enrolled and gave informed consent to the study. There were 51.5% males and 48.5% females. The majority were Malays (49.3%), married (75.9%), Muslims (52.2%) and aged 51-60 years (37.6%). Most of the patients were unemployed and had no pensions (56.2%), 18.2% were unemployed with pension and the remaining 25.5% were still working. Nearly two-third (66.8%) of the patients were on HD and the remaining (33.2%) were on CAPD. Majority of patients (50.7%) were on dialysis for <36 months (3 years), 36.6% for 36-120 months (3-10 years) and the remaining 12.8% for >120 months (>10 years) (Table 1).

Symptoms experienced by patients: The number of symptoms and the percentage of patients who experienced symptoms are as shown in Table 2. The most frequent symptoms were fatigue (86.1%), followed by weakness (79.9%), muscle cramps (66.1%), pruritus

Table 1: Demographic profile of ESRD patients

Variables	Frequency	Percentage
Gender		
Male	141	51.5
Female	133	48.5
Ethnicity		
Malay	135	49.3
Chinese	110	40.1
Indian	23	8.4
Others	6	2.2
Religion		
Islam	143	52.2
Buddhism	80	29.2
Hinduism	22	8.0
Christianity	11	4.0
Others	18	6.6
Age		
<40 years	50	18.2
40-50 years	53	19.3
51-60 years	103	37.6
>60 years	68	24.8
Marital status		
Married	34	12.4
Single	208	75.9
Divorced/Widowed	32	11.7
Working status		
Employment	70	25.5
Unemployment without pension	154	56.2
Unemployment with pension	50	18.2
Type of dialysis		
HD	183	66.8
CAPD	91	33.2
Lenght of treatment		
<36 months	139	50.7
36-120 months	100	36.5
>120 months	35	12.8

Table 2: Number of symptoms experienced and percentage of patients who experienced them

	Experienced symptoms		Symptoms related to illness	
Symptoms	n	%	n	%
Fatigue	236	86.1	228	83.2
Weakness	219	79.9	212	77.4
Muscle cramps	181	66.1	168	61.3
Pruritus	176	64.2	157	57.3
Sleep difficulties	169	61.7	158	57.7
Stiff joints	160	58.4	135	49.3
Dizziness	152	55.5	127	46.4
Pain	150	54.7	121	44.2
Nausea	147	53.6	131	47.8
Numbness in leg	145	52.9	126	46.0
Weight loss	111	51.5	135	49.3
Wheeziness	137	50.0	123	44.9
Breathlessness	133	48.5	129	47.1
Headaches	128	46.7	101	36.9
Constipation	81	29.6	63	23.0
Upset stomach	78	28.5	59	21.5
Sore eyes	72	26.3	48	17.5
Sore throat	65	23.7	42	15.3

(64.2%), sleep difficulties (61.7), stiff joints (58.4%) and so forth as listed in order of frequently in Table 2. Although, patients had reported these symptoms, they were aware that not all symptoms they had experienced were associated with the ESRD disease that affected them.

Table 3: Comparison of the health related quality of life components between HD and CAPD patients

	HD		CAPD	
Components	Mean	SD	Mean	SD
Physical functioning	72.568	18.151	75.275	17.307
Physical role	68.443	19.778	76.786	21.616
Bodily pain	74.069	22.339	81.818	20.146
General health	58.557	15.538	64.396	15.238
Vitality	60.223	19.770	66.026	15.847
Social functioning	77.322	21.533	83.516	17.344
Emotional role	74.954	21.743	80.952	22.848
Mental health	71.038	19.435	78.022	17.377

Table 4: Differences between physical component summary and mental component summary by type of treatment

Groups	Type of dialysis	N	Mean	Between subject effect (F)
PCS	HD	183	68.41	11.95**
	CAPD	91	74.57	-
MCS	HD	183	70.88	9.30**
	CAPD	91	77.13	-

**p<0.01

Table 5: Association between symptoms with PCS and MCS

Variables	PCS (r)	MCS (r)
Symptoms	-0.40**	-0.35**

**p<0.01

Health related quality of life components in HD and CAPD patients: The eight components of HRQOL and the scores by the HD and CAPD patients were compared as shown in Table 3.

Table 3 shows that compared to HD patients, CAPD patients had higher mean scores for all eight components of HRQoL. Multivariate Analysis (MANOVA) (Table 4) showed that there were significant differences in the PCS ($F = 11.96$, $p<0.01$) and MCS ($F = 9.30$, $p>0.01$) between the two treatment groups. Both PCS and MCS were higher in CAPD patients.

The relationship between symptoms with PCS and MCS: As shown in Table 5, there were significant negative correlations between the symptoms experienced by patients with the PCS ($r = -0.40$, $p<0.01$) and MCS ($r = -0.35$, $p<0.01$). Thus, the greater the number of symptoms perceived by patients, the lower the PCS and MCS.

DISCUSSION

ESRD patients on chronic maintenance dialysis experience multiple symptoms as result of both the disease and treatment received. Patients perceived that not all their symptoms were due to their kidney failure. The percentage of patients who associated symptoms experienced as being related to their kidney disease was low. Fatigue was the most frequent symptom experienced.

Followed by weakness, muscle cramps, pruritus, sleep difficulties, stiff joint, dizziness, pain, nausea, leg numbness, weight loss, wheeziness, breathlessness, headache, constipation, upset stomach, sore eyes and sore throat. These finding concur with those reported by Murtagh *et al.* (2007) who had performed a systematic review of these symptoms. Fatigue was one of the most disturbing symptoms (Polaschek, 2003).

The PCS and MCS of CAPD patients were much better than those of HD patients. This is consistent that reported by previous studies which had demonstrated that patients undergoing CAPD had better HRQoL compared with the HD counterparts (Gokal *et al.*, 1999; Majkowicz *et al.*, 2000; Norshad *et al.*, 2009; Russo *et al.*, 2010). Several factors contribute to the superior HRQoL of CAPD patients. These include the fact that CAPD can be done at home by the patient or with the help of family members. Thus, allowing patients be more flexibility and mobility (Prokesch *et al.*, 1999). They are not hooked to a machine.

Whereas HD patients are bound by the strict and structured schedules that require them to attend hospitals or dialysis centers for their treatment or blood cleansing 3 times a week, each session for 4 h. This restricts patients' movement and activities. In CAPD the exchange of dialysis solution is performed by 4-5 times a day depending on the patient's lifestyle and needs. However, since it can be done at home at work or while on holiday, it is much more flexible than HD. Even when the dialysis solution is in the peritoneal cavity, patients are free to carry out normal daily activities such as cooking, clerical duties and other light activities. Hence, CAPD patients enjoy higher levels of involvement both in vocational and in community activities (Wolcott *et al.*, 1988).

Thus, dialysis modality impacts the HRQoL of dialysis patients. Unfortunately, not all patients are given the freedom to choose their treatment modality. Many factors need to be considered in determining the treatment modality. Apart from identifying patients' medical and physical factors, psychosocial factors and economic are also paramount such as the patient's own motivation to self-care, lifestyle, educational background, health beliefs, availability of family and community support system, the ability of patients in decision making, the distance the dialysis center, household characteristics (in terms of sanitation, water facilities, electricity, telephone and storage for CAPD related equipment) and the ability of spouses, relatives, parents and friends to provide the necessary assistance (Holloway *et al.*, 1999). All these factors have to be consider to ensure that patients can benefit from their treatment. The finding of this study strengthen the evidence that CAPD patients are more satisfied with their dialysis treatment than HD patients (Juergensen *et al.*, 2006)

There was also a relationship between the symptoms experienced by patients with their PCS and MCS. Kimmel *et al.* (2003) also reported that the number of symptoms perceived by patients with ESRD were related to their quality of life. This study also supports the common-sense model also known as the self-regulation model, proposed by Leventhal *et al.* (1984) and confirmed by previous studies on the perception of patients with chronic diseases. The meta-analysis of Hagger and Orbell (2003) also confirmed the finding that patients perception of their disease and their symptomatology can affect the way they cope and act. The patients' interpretation of their disease in relation to their own bodies has a strong influence on the activities of their daily lives. These beliefs are formed as a result of their exposure to various social and cultural resources such as through reading, learning in school, personal experiences associated with the disease, the observation of the pain experience by family members or friends and through books and movies (Cameron and Moss-Morris, 2004). Irrelevant and inappropriate past experiences together with errors in interpreting issues will result in patients forming wrong perceptions of the disease encountered.

CONCLUSION

This study shows that the HRQoL of CAPD patients is better than that of their HD counterparts and the symptoms experienced by patients also related to HRQoL. Thus the choice of dialysis modality and minimizing the symptoms impact the HRQoL of patients on chronic maintenance dialysis and treating physicians should give wise counsel.

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