# Rehabilitation of in-centre haemodialysis patients

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We studied the rehabilitation status of 34 in-centre haemodialysis patients at the Prince of Wales Hospital using a set of questionnaires. Seventy-seven per cent of patients were able to conduct normal physical activities at least part of the time. General wellbeing and treatment-related stress and distress were found to be important factors affecting patients' functional capacity. No significant relationship between the Karnofsky activity index and the haemoglobin, serum albumin, or pre-dialysis plasma creatinine levels was found. Fifty-two per cent of patients were employed, 27% were unemployed, and 21% listed their occupation as housewives. Fifty-six per cent of unemployed patients were young (under 36 years of age). Fifty-three per cent of patients said their employment status had decreased since their illness began. Sixty-two per cent of patients admitted having to play a reduced family role. In order to have optimal rehabilitation for haemodialysis patients, nephrologists, dialysis nurses, social workers, mental health professionals, and patient self-help groups need to cooperate.

HKMJ 1995;1:97-102

Key words: Rehabilitation; Haemodialysis units, hospital; Disability evaluation

### Introduction

Chronic illnesses, such as end-stage renal disease (ESRD), are never completely cured. Health care professionals dealing with chronic illnesses help clients in their rehabilitation, assisting them to move toward optimum function in self-care tasks and in social roles. Rehabilitation has been defined as "a dynamic process of planned adaptive change in lifestyle in response to unplanned change imposed on the individual by disease or traumatic incident. The focus is not on cure, but on living with as much freedom and autonomy as possible at every stage and in whichever direction the disability progresses."1

The goals of a renal team include restoration of the highest achievable state of physical health, and the preservation, restoration, and development of the highest level of social adaptation of ESRD patients. A patient's social adaptation is related to his or her vocational function, participation in leisure and social

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activities, and current family and intimate relationships.<sup>2-5</sup> To increase our understanding of rehabilitation in in-centre haemodialysis patients, information about specific areas of life was needed. A study was developed to establish the degree of rehabilitation of in-centre haemodialysis patients in four areas—physical functioning, working, social, and family life. We also wanted to determine the importance of the impact of medical and social factors on these four areas and to explore the relationship between some background variables and these four specific areas. Such information is useful when assessing patient rehabilitation programmes.

## Materials and methods

A survey study was used to assess the degree of rehabilitation of in-centre haemodialysis patients. The study population consisted of haemodialysis patients who had been receiving haemodialysis for a minimum of three months. The study was conducted at the Renal Unit, Prince of Wales Hospital (PWH), and at the time of data collection, 34 patients satisfied the selection criteria.

Each patient was interviewed for approximately 20 minutes during his or her haemodialysis session. A set of questionnaires was designed to collect information on each patient's employment status, social life, family life, and type of activities that were affected by their health status. Both open and closed questions were included. The Karnofsky scale was used to assess each patient's functional capacity. Sociodemographic data was also obtained. Medical data sheets for all study participants were completed using data from their medical files.

Fisher's exact test was applied to determine if there was a significant relationship between certain variables (blood chemistry parameters and functional capacity, employment status and frequency of dialysis) in the study. Statistical significance was deemed as p < 0.05.

## Results

# Sociodemographic data

Thirty-four patients were recruited (23 males, 11 females). The mean age was 39 years (range, 23 to 59 years). The majority of patients (n = 24, 70.6%) were married, two (5.9%) were divorced, and eight (23.5%) were single. Patient educational levels ranged from primary school to post-tertiary education. Of the 34 patients, 20 (58.8%) had primary school level education, 11 (32.4%) had secondary school level education, and three (8.8%) had tertiary education. There were 18 employed patients whose monthly incomes ranged from HK\$2000 to \$11000. The median monthly income for employed patients was HK\$6250. Patient family incomes ranged from HK\$3000 to \$40000 per month and the median monthly family income was \$10000.

#### Treatment data

The mean length of haemodialysis treatment was 43 months (range, six to 120 months). Patients spent an

average of 11 hours weekly on haemodialysis (range, eight to 15 hours weekly). A majority of patients (61.8%) had haemodialysis twice weekly while the remainder had haemodialysis three times weekly.

There were 26 (76.5%) patients receiving erythropoietin. These patients had 1500 to 4000 units administered subcutaneously weekly. The average values for haemoglobin, serum albumin, and pre-dialysis plasma creatinine were calculated. Patient haemoglobin levels ranged from 5.1 g/dL to 13.8 g/dL (mean, 8.4 g/ dL). Twenty-two patients (64.7%) had haemoglobin levels above 8 g/dL, while 12 (35.3%) had haemoglobin levels below 8 g/dL. Serum albumin levels ranged from 21.3 g/L to 41.0 g/L (mean, 34.4 g/L). Twenty-two (64.7%) patients had serum albumin levels below 36 g/L and 12 (35.3%) had serum albumin levels above this value. Pre-dialysis plasma creatinine levels ranged from 825 µmol/L to 1609 µmol/L (mean, 1239 µmol/L). Seven patients (20.6%) had pre-dialysis plasma creatinine levels below 1000 µmol/L, while the balance had levels above this value.

## Physical functioning

The functional capacity of the haemodialysis patients was assessed using the Karnofsky scale (Table 1). Factors affecting functional capacity were explored. Most patients (79.4%) considered their subjective feeling of general wellbeing as an important factor affecting their functional capacity. Nearly half (47.1%) of the patients considered treatment-related stress and distress as a very important factor affecting their physical functional capacity. For the patients receiving erythropoietin therapy (n = 26), 14 (53.8%) considered it to be important in improving their physical functional capacity.

Table 1. Karnofsky scale summary for haemodialysis patients at the Prince of Wales Hospital

Group		No	of patients (%)
1	No complaints  Almost normal physical activity	1	(2.9)
2	Active  Able to carry out normal physical activities part of the time		(76.5)
3	Self care Only able to carry out physical activities involving self care		(20.6)
4	Often debilitated  Require some assistance for bodily needs/may require special care		(0)
5	Moribund Require institutionalisation or hospitalisation		(0)
Total	<u>-</u>		(100)

The relationship between functional capacity and certain blood chemistry parameters was investigated. For comparative purposes, patients were divided into two groups with haemoglobin levels either greater or less than 8 g/dL, serum albumin levels greater or less than 36 g/L, and pre-dialysis plasma creatinine levels greater or less than 1000 µmol/L, respectively. In our study group, there were no significant relationships between patients' functional capacity and haemoglobin level, serum albumin level, or pre-dialysis plasma creatinine level (Fisher's exact test, data not shown).

#### Vocational rehabilitation

Fifty-two per cent of patients were currently employed—either full-time (n = 9) or part-time (n = 9). Seven patients (21%) were housewives and nine (27%) did not work. Eighteen patients (52.9%) had reduced employment (from full-time to part-time work, or from full-time/part-time work to unemployed), compared with their status prior to dialysis. Five employed patients (27.8%) had changed the nature of their employment.

Better-educated patients were more likely to be employed. Fifty per cent of patients with primary school education were employed, 54.5% of those with secondary school education were employed, while 66.7% of patients with tertiary education were employed.

Thirty-two patients were of working age (i.e. 16 to 55 years). Patients of working age were divided into two age groups (16 to 35 years, 36 to 55 years). For the employed patients, 38.9% of them were younger than 36 years of age and 61.1% were aged 36 to 55 years. For the unemployed patients, 55.6% of them were younger than 36 years, and 22.2% were aged 36 to 55 years. Twenty-two per cent were older than 55 years and had retired.

The relationship between the in-centre haemodialysis patients' employment status and the frequency of haemodialysis was investigated. For the unemployed patients, 66.7% (n=6) had haemodialysis twice weekly, while 33.3% (n=3) underwent haemodialysis thrice weekly. For the employed patients, these figures were 50% (n=9) for each frequency. There was no significant difference in employment status between the two patient groups. For full-time employed patients, 66.7% (n=6) had haemodialysis twice weekly and 33.3% (n=3) had haemodialysis thrice weekly. For the part-time employed patients, these figures were reversed. There was no significant difference in employment status between the two groups.

Factors affecting a patient's working life were explored. The three most important factors listed were physical wellbeing (63.6%), financial status (57.6%), and family support (63.6%). Patients also said that a regular haemodialysis schedule and discrimination by employers made it difficult for them to find employment. All of the employed patients could be categorised as "no complaints" or "active" according to the Karnofsky scale, whereas over half (55.6%) of the unemployed patients were categorised as "self-care" according to the Karnofsky scale.

## Social life

Information on social life was gathered by survey questionnaires, and factors affecting patient's social activities were identified. Table 2 illustrates the patients' present social lives. Table 3 lists perceived factors affecting social activities. For the employed patients, a limited monthly income often meant a restricted social life, with 37.5% of patients who had a monthly income of less than HK\$6000 and 10% of patients with monthly incomes above this amount having social lives categorised as "isolated" or "limited".

## Family life

An assessment of family life is shown in Table 4. Factors considered to be "very important" in affecting family life are listed in Table 3. As regards employment status and family life, 11.1% of employed patients and 33.3% of unemployed patients categorised their family life as "problem" or "family breakdown". Those patients who said they could still play the expected family role, were mostly employed full-time (66.7%).

Monthly income and retention of a key family role were linked. Fifty per cent of patients who had monthly incomes of more than HK\$6000 could play the expected family role and concomitantly, 50% had reduced influence. For patients with monthly incomes below this amount, 75% had less influence in the family, and 25% had problems in the family or family breakdown. For the patients who were housewives, most (71%) had to play a less important role in the family.

## Influences on daily activities

Daily activities affected by the patients' present health status were identified. Fig 1 shows various activities and the reported effect on them of ill-health by male and female renal patients.

## Discussion

This study assessed 34 patients who received incentre haemodialysis at the PWH and revealed the

Table 2. Summary of the present social life of haemodialysis patients at the Prince of Wales Hospital

Group		No. of patients (%)
1	Almost normal social life No problems joining all social functions	1 (2.9)
2	Active  Can join some social functions part of the time	15 (44.1)
3	Basic Only involved in necessary social activities	10 (29.4)
4	Limited  Only involved in activities under special arrangement	4 (11.8)
5	Isolated Cannot attend any social activities	4 (11.8)
Total		34 (100)

Table 3. Factors which haemodialysis patients perceived as having an important effect on their social and family lives (n=34)

	Social life	Family life	
Factors	No. of patients (%)	No. of patients (%)	
Physical wellbeing	21 (61.8)	22 (64.7)	
Employment status	14 (41.2)	19 (55.9)	
Financial status	19 (55.9)	21 (61.8)	
Peer support	11 (32.4)	7 (20.6)	
Social acceptance	12 (35.3)	9 (26.5)	
Professional support/encouragement	12 (35.3)	17 (50)	
Family support	17 (50)	_	
Relationship with spouse*	_	17 (65.4)	
Relationship with family members other than spouse	-	15 (44.1)	
* Applicable to 26 patients only			

rehabilitation status of these patients. Most patients (79.4%) said that their capacity for physical activity was greatly affected by their general physical wellbeing. Generalised lack of energy, weakness, and tiring easily were reported by most haemodialysis patients. Treatment-related stress and distress were found to be contributing factors affecting haemodialysis patients' functional capacity. Adequate dialysis and reduced treatment-related stress and distress are some possible means of improving haemodialysis patients' functional capacity. Close monitoring of each patient's general condition, observation for signs of inadequate dialysis, and prevention of complications due to long

term dialysis are important steps for improving patients' functional capacity.

Nearly 80% of the haemodialysis patients said that their working life was affected by their health status. It was found that most of the employed patients possessed special skills. Many patients had changed the nature of their job because their previous employment was either physically demanding or required long working hours. Patients also said that the haemodialysis schedule and discrimination by employers made it difficult for them to find a new job. A high percentage of employed patients was found (52%), compared with

Table 4. Summary of the family life status of haemodialysis patients at the Prince of Wales Hospital

Group		No.	of patients (%)
1	No problem Almost normal family life	0	(0)
2	Normal role  Able to play the expected family role (breadwinner, housewife)	8	(23.5)
3	Altered role  Family role changed, now plays a reduced role (breadwinner, housewife)	21	(61.8)
4	Problem Requires assistance/counselling to maintain family relationships	4	(11.8)
5	Family breakdown  Poor relationship with family members	1	(2.9)
Total	•	34	(100)

some studies which reported only 19% to 42% of incentre haemodialysis patients remaining employed while on dialysis.<sup>7-10</sup> This may be partly related to the fact that the haemodialysis patients at the PWH were a pre-selected group of patients who were younger, and many of them were employed prior to dialysis. Another reason for a lower employment rate in countries such as the United States may be related to a better unemployment welfare benefits system there. Many

unemployed patients (55.6%) in our unit belonged to the young age group (< 36 years). Factors have been identified that adversely affect the vocational rehabilitation of these young patients. They may have fewer job skills, less seniority, and less working experience prior to the onset of haemodialysis. They cannot perform physically demanding jobs with inflexible working hours. In general, the determinants of patient vocational rehabilitation included sociodemographic and

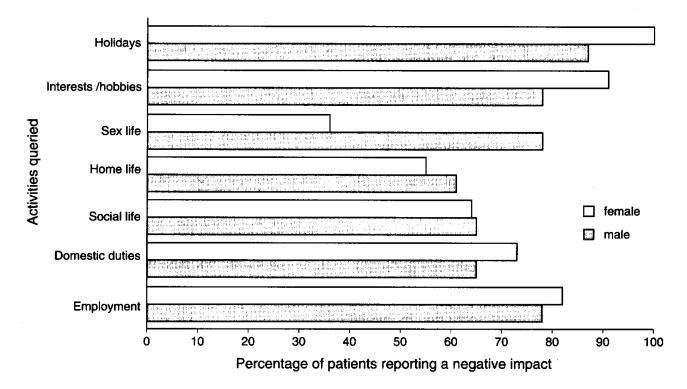


Fig 1. Impact of health status on renal patients' activities

personality factors, previous working experience, job requirements and employer attitudes, the patient's physical functional capacity, family support, and government policies. 11,12 Job retraining for haemodialysis patients may be a way to increase their employability. Offering more flexible dialysis schedules to help meet the needs of working patients may improve patients' chances of employment. The institution of "night shift" dialysis may assist some patients in finding daytime employment.

From our study, it is apparent that patients' social lives, interests/hobbies, and holidays were affected by their health status. Some patients said that others did not like to be involved in activities with them, which made them more isolated. In addition, haemodialysis patients often restricted their participation in many activities because of their health status and medical treatment. The dialysis unit, social worker, and patient self-help groups need to promote programmes which increase patients' opportunities for participation in recreational activities and help patients develop and maintain optimal social roles and relationships. To increase the general public's understanding of renal patients, social programmes that involve both the general public and patients may be useful.

More than 60% of the haemodialysis patients in the centre were forced to play a reduced role in the family, compared with their role before dialysis. Home life, ability to look after the home, and sex life were affected. A majority of patients (65.4%) considered their relationship with their spouse to be a very important factor affecting family life. The disruption of role functioning in the family often leads to very stressful problems in patients' relationships with family members. Staff-family or staff-patient-family meetings may help to increase understanding amongst family members and thus alleviate the stressful relationships. Involvement of family members in the patient education programmes and in the long term planning of treatment may promote understanding and concern within the family.

Rehabilitation is seen as a lifelong process carried out by the patient, family, health care professionals, and society together. For the optimal rehabilitation of haemodialysis patients, cooperation between nephrologists, dialysis nurses, social workers, mental health professionals, and patient self-help groups is

required. Adequate funding and resources from the government are essential. Funds can be used to provide facilities with more flexible dialysis schedules, medications such as erythropoietin, the development of job retraining schemes, and special social programmes for dialysis patients. Frequent and open communication between patients and staff, and between members of the dialysis team is equally important in the understanding and solution of individual patient problems.

# Acknowledgements

We would like to thank all staff of the Renal Unit, Prince of Wales Hospital, for their support of this study. We also extend our sincere appreciation to Mr SM Tsui, medical social worker at the Prince of Wales Hospital, for his valuable advice.

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