ORIGINAL ARTICLE

Influence of continuity of care on self-management ability and quality of life in outpatient maintenance hemodialysis patients

Bihong Lai ¹	Li Shen ¹ Shuiying Ye ¹ Xia Shen ¹ Dongchi Zhou	1 ²
Xiaocui Guo ¹	Huaxian Zhou ¹ Yangbin Pan ² Jindong Tong ³ 💿	

¹Department of Nursing, Shanghai Pudong Hospital, Fudan University Pudong Medical Center, Shanghai, China

²Department of Nephrology, Shanghai Pudong Hospital, Fudan University Pudong Medical Center, Shanghai, China

³Department of Vascular Surgery, Shanghai Pudong Hospital, Fudan University Pudong Medical Center, Shanghai, China

Correspondence

Jindong Tong, Department of Vascular Surgery, Shanghai Pudong Hospital, Fudan University Pudong Medical Center, 2800 Gongwei Road, Pudong, Shanghai 201399, China.

Email: jindong1220@163.com

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Abstract

Introduction: The objective of this study was to evaluate the effect of continuity of care on self-management ability and quality of life (QOL) in patients undergoing maintenance hemodialysis (MHD).

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Methods: One hundred patients were randomly assigned to the observation group and the control group. In the observation group, patients received a 12-month continuity of care. In the control group, patients were given with routine nursing. Evaluate the patients' self-management ability and QOL between two groups 1 week before discharge and 6 and 12 months outpatient MHD.

Results: Observation group had higher Hemodialysis Self-Management Instrument (HD-SMI) scores and Kidney Disease Quality of Life-Short Form (KDQOL-SFTM) scores than control group at 6 and 12 months outpatient MHD. But patients in observation group had a much lower systolic blood pressure than those in control group at 12 months outpatient MHD.

Conclusions: Our study suggested that continuity of care in the form of online education, telephone visit, and outpatient visit could improve self-management ability and QOL of patients undergoing MHD.

K E Y W O R D S

continuity of care, end-stage renal disease, maintenance hemodialysis, quality of life, selfmanagement

1 | INTRODUCTION

End-stage renal disease (ESRD) is a major public health problem in China [1, 2], with an annual mortality rate of 6.4% reported in 2013 [3]. Currently, maintenance

hemodialysis (MHD) is the major treatment choice for ESRD [2, 4]. But poor compliance to long-term MHD contributes to increased morbidity and mortality in patients with ERSD [5]. In addition, previous studies have shown that many MHD patients cannot self-manage their own conditions successfully [6, 7]. Thus, the suitable nursing strategy is needed to improve the

Shen Li and Lai Bihong contributed equally to this study.

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self-management and quality of life (QOL) of patients undergoing long-term MHD.

Continuity of care is a broad term for continuous care interventions. It promotes the safe and timely transfer of patients between levels of care and across settings, such as from hospital to home or other care settings in the community [8, 9], playing an important role in improving the QOL of patients after discharge, lowering the rehospitalization rates, and even reducing health-care costs [9]. Continuity of care has been adopted by several health systems as a discharge intervention for patients with chronic diseases such as chronic obstructive pulmonary disease (COPD), stroke, and heart failure (HF) [10-12]. For kidney disease, continuity of care also acquired satisfactory results. Li et al. conducted a study enrolled 100 kidney transplant recipients [9]. They proved that continuity of care could increase the patient's QOL through improving the patient's disease knowledge and self-care ability [9]. Hong et al. studied 89 patients with acute kidney injury who were needed prolonged renal replacement therapy, and they found that continuity of care program could facilitate recovery of these patients [13]. Furthermore, continuity of care is also regarded as a new treatment strategy to increase patient confidence to home dialysis and to improve patient outcomes [14]. However, so far, few studies have clearly clarified if continuity of care could improve the self-management and QOL of patients on long-term MHD.

With the aim to improve the self-management ability and QOL of MHD patients, we established a MHD continuity of care group, and conducted this study. We hope that our results can provide a valuable insight toward the continuous care of ERSD patients on longterm MHD.

2 | METHODS

2.1 | Patients

Using the convenience sampling method, a total of 100 patients undergoing MHD at the department of blood purification center of our hospital from December 2018 to February 2020 were enrolled in this study. The inclusion criteria were as follows: (1) aged 18 years or older; (2) underwent regular MHD ($2 \sim 3$ times per week) for at least 6 months; (3) without intellectual and cognitive impairments; (4) without serious diseases in other organs; (5) voluntarily participated in this study and signed informed consent. The exclusion criteria were as follows: (1) without family care; (2) with poor transportation or communication conditions.

2.2 | Interventions

The patients included were randomly divided into control group and observation group according to time sequence of admission (n = 50 for each group). For patients in the control group, routine nursing was given 1 week before discharge and 6 and 12 months outpatient MHD. Nursing methods included psychological nursing, health education, disease observation, diet and exercise guiding during the hemodialysis period, and reasonable use of anti-hypertensive drugs.

Patients in the observation group were given continuity of care, the duration of the continuity of care was 1 year, specifics as follows:

- 1. The establishment of a continuity of care team: our continuity of care team had seven members including two attending physicians, four specialist nurses, and one dietician.
- 2. The creation of patient's Individual File: 1 week before discharge, the members of study team assessed and recorded the patient's mental state, pathogenetic condition, self-management ability, diet condition, and activities. Then, the patient's Individual File was created after obtaining consent from the patients. The manual of outpatient MHD care plan, which included knowledge of MHD, complications and medication record requirement, diet guidance, hemodialysis access monitoring requirement, weight management, and exercise record requirement, was distributed to the patients and their family members in outpatient MHD.
- 3. Online education: the study team organized online education for all the patients in the observation group every Tuesday and Thursday night. The patients and their family members could inquiry any question about MHD. Then, the study team answered patients' questions one by one. Furthermore, the study team also given systemic health education for patients during the online education including the guidance of dietary, medication use, and exercise.
- 4. Telephone visits: we conducted the telephone visit every 1 month. The content of the telephone visits included patient's general condition, diet intake condition, blood pressure and body weight monitoring, and the use of medication. During the telephone visit, the study team supervised the patients to carry out selfmanagement of MHD, giving maximum physical and psychological help for the patients and their family members.
- 5. Outpatient visits: the outpatient visit was conducted at 6 and 12 months outpatient MHD. When patient visited the outpatient department, member of study team instructed the patients to complete the

questionnaires of QOL, analyzed the behaviors of self-management, and measured the patients' blood pressure. Meanwhile, hematology and chemistry tests were performed.

2.3 | Survey tools and methods

2.3.1 | Hemodialysis Self-Management Instrument (HD-SMI)

HD-SMI was used to evaluate the self-management ability of patients in both groups 1 week before discharge and 6 and 12 months outpatient MHD. HD-SMI was originated from Taiwan and adjusted by the team of Peking Union Medical College Hospital. The questionnaire had 20 items involving in four dimensions: partnership, problem solving, self-management execution, and emotion processing. The scores for "Never," "Sometimes," "Often," and "Always" are 1, 2, 3, and 4 points, respectively, and the total score was 80 points [15]. A higher score indicated better self-management ability.

2.3.2 | Chinese version of the Kidney Disease Quality of Life-Short Form (KDQOL-SF[™])

KDQOL-SFTM was used to evaluate the QOL of patients in both groups 1 week before discharge and 6 and 12 months outpatient MHD. The KDQOL-SF™ comprised a general SF-36 assessment, which included analyses of physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH), and a dialysis-related QOL (KDTA) field, which included a symptoms/discomfort list (SPL), effects of kidney disease (EKD), burden of kidney disease (BKD), work status (WS), cognitive function (CF), quality of social interaction (OSI), sexual function (SeF), sleep, social support (SoS), dialysis staff encouragement (DSE), and patient satisfaction (PS) [16]. A 100-point system was used to score each field, in which the higher scores indicated a better QOL of patients.

2.3.3 | Safety assessments

One week before discharge and 6 and 12 months outpatient MHD, the patients in the two groups underwent safety assessments. Safety assessments included clinical laboratory tests and vital sign measurements. The clinical laboratory tests included hematology and chemistry tests. The values of hemoglobin(Hb), serum creatinine (Scr), intact parathyroid hormone (iPTH), serum phosphorus (P), and serum calcium (Ca) were recorded and compared. Vital sign measurements included sitting blood pressure, heart and respiration rate, and body temperature.

2.4 | Sample size

The sample size of this study was estimated by PASS 15.0 software. According to the results from similar studies, the effect rates of the control group and the observation group were calculated with a 0.75 effect size. The α was 0.05 and the power was 0.9. Seventy-six patients were calculated to include in this study. Considering an attrition rate of 20%, the sample size was ultimately expanded to 100 patients (n = 50 for each group).

2.5 | Statistical analysis

SPSS 22.0 software (International Business Machines) was used to analyze the data. Continuous variables were shown as the means \pm SDs, comparing by independent two-sample *t*-tests or the analysis of variance (ANOVA) with repeated measures. Categorical data were presented by frequency and percentage, comparing by the χ^2 test or the Fisher's exact test. A *p* value of <0.05 (two sided) was considered statistically significant.

3 | RESULTS

3.1 | Participant characteristics

All 100 patients recruited completed this study. Among them, 63 (63.00%) were male and 37 (37.00%) were female. The mean age of these patients was (60.06 \pm 11.48) years. For educational status, 31 patients (31.00%) had an education background of middle school or lower, 47 (47.00%) graduated from high school, and 22 (22.00%) graduated from junior college or above. For dialysis duration, 24 patients (24.00%) had a duration less than 1 year, 49 (49.00%) had a duration of 1–5 years, and 27 (27.00%) patients had a duration re than 5 years. The medical payment modes included individual payment (10.00%), medical insurance (58.00%), and agricultural endowment insurance (32.00%). The comparison of general data between observation group and control group is shown in Table 1.

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TABLE 1 General data of participants

Characteristic	Total ($n = 100$)	Observation group $(n = 50)$	Control group $(n = 50)$	p Values
Age, years, mean (SD)	60.06 (11.48)	60.14 (11.38)	59.98 (11.70)	0.945
Gender, <i>n</i> (%)	00.00 (11.10)	00.11(11.50)	55.56 (11.76)	0.534
Male	63 (63.00)	30 (60.00)	33 (66.00)	0.554
Female	37 (37.00)	20 (40.00)	17 (34.00)	
BMI, kg/m^2 , mean (SD)	21.14 (1.14)	20.88 (1.95)	21.40 (2.01)	0.193
Education level, n (%)	21.14 (1.14)	20.00 (1.95)	21.40 (2.01)	0.605
Middle school or lower	31 (31.00)	17 (34.00)	14 (28.00)	0.005
High school	47 (47.00)	21 (42.00)	26 (52.00)	
Junior college or above	22 (22.00)	12 (24.00)	10 (20.00)	
Annual income, n (%)	22 (22.00)	12 (24.00)	10 (20.00)	0.209
>150 000 RMB Yuan	20 (20 00)	17 (24.00)	12 (24.00)	0.209
	29 (29.00)	17 (34.00)	12 (24.00)	
100 000–150 000 RMB Yuan	55 (55.00)	28 (56.00)	27 (54.00)	
<100 000 RMB Yuan	16 (16.00)	5 (10.00)	11 (22.00)	0.44 -
Medical payment mode				0.465
Individual payment	10 (10.00)	4 (8.00)	6 (12.00)	
Medical insurance	58 (58.00)	33 (66.00)	27 (54.00)	
Agricultural endowment insurance	32 (32.00)	13 (26.00)	17 (34.00)	
Dialysis duration, <i>n</i> (%)				0.368
<1 year	24 (24.00)	10 (20.00)	14 (28.00)	
1–5 years	49 (49.00)	28 (56.00)	21 (42.00)	
>5 years	27 (27.00)	12 (24.00)	15 (30.00)	

3.2 | Self-management ability in outpatient MHD patients

Our results showed that the HD-SMI scores among 50 patients in observation group gradually increased 6 and 12 months outpatient MHD (p < 0.01). However, the HD-SMI scores among 50 patients in control group did not increase significantly (p > 0.01). The HD-SMI scores in the two groups measured at 1 week before discharge were not significantly different (p = 0.146). But at 6 months or 12 months outpatient MHD, observation group had higher HD-SMI scores than control group (p < 0.001, Figure 1). These results indicated that continuity of care could improve self-management ability of patients.

3.3 | Comparison of QOL at different time points

The QOL of patients in this study was measured by KDQOL-SFTM. The KDTA-SF scores measured at 1 week before discharge were 54.42 ± 12.21 in

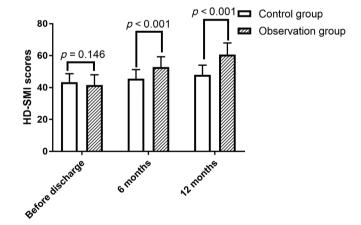


FIGURE 1 HD-SMI scores among patients in observation group and control group 1 week before discharge and 6 and 12 months after discharge

observation group and 52.06 ± 10.21 in control group, respectively. The KDTA-SF scores between the two groups were not significantly different at this time point (p = 0.297). Compared with the day of outpatient MHD, the KDTA-SF scores in observation group

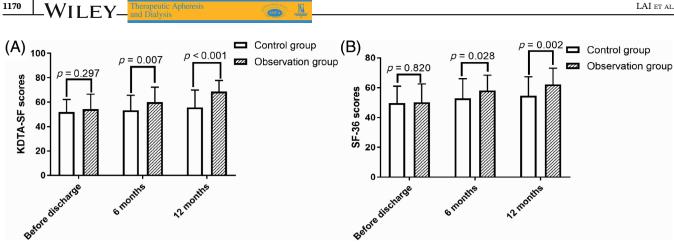


FIGURE 2 Comparison of quality of life in two groups at different time points. (A) KDTA-SF scores among patients in two groups. (B) SF-36 scores among patients in two groups

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Scale	Observation group ($n = 50$)	Control group ($n = 50$)	<i>p</i> Values
ESRD-targeted areas			
Symptoms/discomfort list	77.24 ± 20.01	70.51 ± 15.62	0.064
Effects of kidney disease	65.04 ± 15.24	62.10 ± 17.68	0.375
Burden of kidney disease	62.24 ± 21.23	30.20 ± 18.80	< 0.001
Work status	32.02 ± 12.21	28.56 ± 10.15	0.127
Cognitive function	70.10 ± 18.46	65.45 ± 20.10	0.231
Quality of social interaction	82.30 ± 17.24	68.20 ± 16.68	< 0.001
Sexual function	33.40 ± 13.24	28.78 ± 11.46	0.065
Sleep	57.68 <u>+</u> 14.45	53.26 ± 15.28	0.141
Social support	70.28 ± 23.25	52.78 ± 28.02	0.001
Dialysis staff encouragement	92.51 ± 18.61	78.06 ± 16.50	< 0.001
Patient satisfaction	66.04 ± 21.45	52.67 ± 14.89	< 0.001
36-item health survey (SF-36)			
Physical functioning	44.50 ± 22.34	41.02 ± 21.02	0.424
Role physical	40.56 ± 21.02	37.67 ± 18.05	0.463
Bodily pain	68.34 ± 25.65	60.24 ± 28.40	0.138
General health	49.20 ± 15.24	43.16 ± 19.06	0.083
Vitality	63.56 ± 15.10	55.48 ± 20.50	0.027
Social functioning	82.45 ± 31.04	69.20 ± 26.45	0.024
Role emotional	62.20 ± 13.65	45.68 ± 16.86	< 0.001
Mental health	74.89 ± 20.12	54.85 ± 18.60	< 0.001

TABLE 2 The comparisons of subscales of KDQOL-SF™ between two groups at 12 months after discharge

Abbreviations: ESRD, end-stage renal disease; KDQOL-SFTM, Kidney Disease Quality of Life-Short Form.

gradually improved 6 months and 12 months outpatient MHD (p < 0.05). However, KDTA-SF scores in control group did not change significantly at 6 and 12 months outpatient MHD (Figure 2A). The SF-36 scores in the two groups had a similar trend. In addition, the KDTA-SF and SF-36 scores in observation group were significant higher than those in control

group at 6 months and 12 months outpatient MHD (Figure 2A,B). The comparisons of subscales of KDQOL-SFTM between the two groups at the 12 months outpatient MHD are shown in Table 2. For ESRD-targeted areas, observation group had much higher scores of BKD, QSI, SoS, DSE, and PS than control group (p < 0.05). For 36-item health survey,

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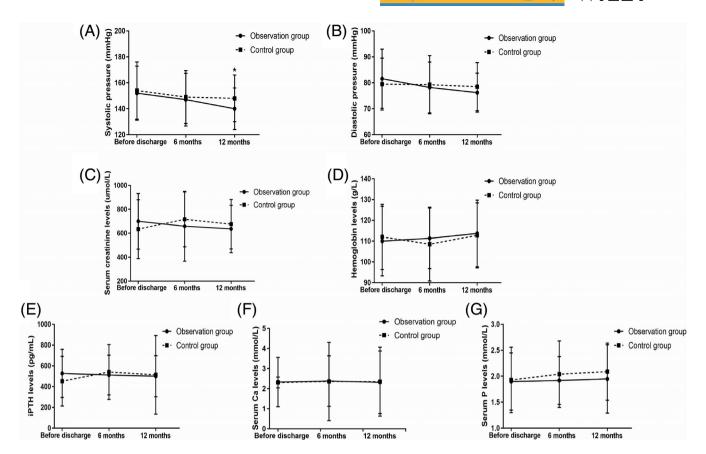


FIGURE 3 The results of safety assessments in two groups. (A) Systolic blood pressure measured at different time points. (B) Diastolic blood pressure measured at different time points. (C) Serum creatinine levels measured at different time points. (D) Hemoglobin levels measured at different time points. (E) Intact parathyroid hormone (iPTH) levels measured at different time points. (F) Serum calcium (Ca) levels measured at different time points. (G) Serum phosphorus (P) levels measured at different time points. *p < 0.05 versus control group

observation group had much higher scores of VT, SF, RE, and MH (p < 0.05).

3.4 | The results of safety assessments

As shown in Figure 3A,B, the systolic blood pressure (SBP) and diastolic blood pressure (DBP) in two groups were not significantly different. But at the 12 months after discharge, the SBP in observation group was much lower than that in control group (p = 0.021). The levels of Hb, Scr, iPTH, Ca, and P in observation group were not significantly different from those in control group at any time point (Figure 3C–G).

4 | DISCUSSION

Findings from our study suggested that continuity of care in the form of online education, telephone visit, and outpatient visit could improve self-management ability and QOL of patients undergoing MHD who were in outpatient MHD from hospital to home.

Self-management has been suggested to be a key intervention to effective care of chronic diseases [17]. For patients with kidney disease undergoing long-term hemodialysis, appropriate self-management interventions are efficacy [17, 18]. Continuity of care is one of the methods to improve patient's self-management ability in outpatient MHD. Miao et al. found that continuity of care could improve the self-management of the patients with cancer pain [19]. For diabetes patients, Shah et al. indicated that continuity of care in the form of inpatient education improved self-management of patients in outpatient MHD, thus improving outpatient adherence rate with medications [20]. In this study, our continuity of care team attempted to improve patient's self-management ability via health education through online education, telephone visit, and outpatient visit. The health education included self-monitoring methods, exercise, reasonable diet, and medication use. Thus, the patients in observation group had more opportunities to learn knowledge of the disease

and of how to follow a healthy lifestyle, and to communicate with medical staffs. As expected, our results showed that HD-SMI scores in observation group gradually increased 6 and 12 months outpatient MHD. Furthermore, observation group had higher HD-SMI scores than control group at 6 and 12 months outpatient MHD. The above results indicated continuity of care could strongly improve patient's self-management ability.

QOL is an important indicator of health care in various chronic diseases [21, 22]. For patients with ERSD, long-term MHD often results in loss of freedom, dependence on family care, disruption of social life, and reduced of financial income [21]. Due to the above reasons, ERSD patients often had poor QOL. Improving QOL of patients is the ultimate goal of continuity of care. In previous studies, continuity of care has been shown to improve QOL of patients with kidney transplant [9] and acute kidney disease [23]. In the present study, we also found that continuity of care could improve QOL of patients undergoing MHD. Both KDTA-SF and SF-36 scores in observation group were significant higher than those in control group at 6 months and 12 months outpatient MHD. A higher KDTA-SF or SF-36 score indicates higher QOL of patients [16]. Thus, patients in observation group who received continuity of care had better QOL in outpatient MHD. The subscale analysis showed that continuity of care improved QOL especially in the fields of BKD, OSI, SoS, DSE, PS, VT, SF, RE, and MH. The continuity of care helps to lower psychological burden of patients, and provide a healthy lifestyle, thereby improving the ability of self-management and finally improving the QOL of patients.

The hematology and chemistry indicators were not significant difference between the two groups at any time point. But patients in observation group had a much lower SBP than those in control group at 12 months outpatient MHD, indicating patients received continuity of care controlled blood pressure well. Medication guide for antihypertensive drug in observation group may contribute to this result. Hypertension is a known poor prognostic indicator for patients on MHD [24, 25]. Optimal blood pressure control can obtain a better survival for MHD patients [24]. Thus, the effect of continuity of care on blood pressure may contribute the prognosis of MHD patients.

Despite these encouraging findings, our study also had several limitations. Firstly, the duration of interventions was short. The effect of long-term continuity of care of outpatient MHD should be investigated. Secondly, all patients in this study were from one hospital in China. This may lead to selection bias. Thus, a multicenter study with more patients is really needed. Finally, we only used two questionnaires to evaluate self-management ability and QOL of patients. More tools in this field should be used in further studies.

In conclusion, our continuity of care team conducted a 12-month follow-up study on patients undergoing MHD and found continuity of care in the form of online education, telephone visit, and outpatient visit could strongly improve self-management ability and QOL of patients.

CONFLICT OF INTEREST

All of the authors had no personal, financial, commercial, or academic conflicts of interest separately.

ORCID

Jindong Tong D https://orcid.org/0000-0001-5996-7134

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