Original Article

Psychosocial predictors of non-compliance in haemodialysis and peritoneal dialysis patients

Nancy G. Kutner1, Rebecca Zhang2, William M. McClellan3 and Steven A. Cole4

1Department of Rehabilitation Medicine, School of Medicine, 2Department of Biostatistics, Rollins School of Public Health, 3Department of Epidemiology, Rollins School of Public Health and Department of Medicine, Renal Division, School of Medicine, Emory University, Atlanta, GA and 4Albert Einstein College of Medicine, North Shore-Long Island Jewish Health System, New Hyde Park, NY, USA

Abstract

Background. Non-compliance with prescribed therapy significantly impacts dialysis patient care and outcomes. The underlying psychosocial issues leading to non-compliance are not well understood, especially in peritoneal dialysis (PD) patients.

Methods. A multicentre cohort of 119 haemodialysis (HD) patients and 51 PD patients was studied. In-person interviews were conducted with patients and clinical and laboratory data were obtained from medical records. Missed and shortened dialysis treatments/sessions and excessive serum phosphate values provided indicators of non-compliance. Patients’ perceived health status, perceived self-health care, depression, perceived control over future health, social support, and disease-specific perceived quality of life were measured, along with current smoking status. Associations of predictor variables with non-compliance indicators were examined in univariate and multivariable analyses.

Results. Approximately one-third of both HD and PD patients were non-compliant on at least one indicator. Logistic regression models identified a significant association between smoking and each non-compliance indicator. Patient age (younger) also predicted missed treatments. Perceived (negative) effects of kidney disease on daily life, and (decreased) perceived control over future health, social support, and disease-specific perceived quality of life were measured, along with current smoking status. Associations of predictor variables with non-compliance indicators were examined in univariate and multivariable analyses.

Conclusion. Smoking, one maker of priority placed on health status, and intrusiveness/control issues should be addressed in intervention efforts to improve compliance in patients treated by HD and PD.

Keywords: health-related quality of life; haemodialysis; non-compliance; patient self-assessment; peritoneal dialysis; psychosocial variables

Introduction

Non-compliance with prescribed therapy significantly impacts patient care and outcomes in both haemodialysis (HD) and peritoneal dialysis (PD). An increased risk of complications and death associated with dialysis non-compliance is well documented for HD patients [1–3] and PD patients [4–6]. The association of emotional, psychological, and social factors with dialysis non-compliance is complex [7,8]. The investigation of psychosocial issues that may lead to non-compliance continues to be an important area of inquiry [8], especially with respect to PD patients for whom limited attention has been given to the role of psychosocial variables in non-compliance behaviours.

Dialysis non-compliance research has focused primarily on the HD population. Non-compliance rates of 50% or higher have been reported for varying aspects of the HD treatment regimen [1,7,9–10]. Measurement of non-compliance is more challenging in patients using PD, but a recent study documented non-compliance in 30% of a sample of PD patients during the first 6 months of treatment [6]. While there is some evidence that dialysis non-compliance may be more widespread in the US than in other countries [3,11], improved understanding of the multifactorial nature of non-compliance is universally relevant for improving outcomes among patients undergoing PD as well as HD therapy.

A variety of psychosocial responses may be reflected in patient non-compliance [12–14]. In studies of HD patients, depression, perception of illness, and perceived mental health are variables that have been
suggested as important mechanisms contributing to patient non-compliance [2,15–16]. In a recent analysis of a large sample of HD patients, smoking was a strong predictor of non-compliance with treatment regimen, and the authors suggested that smoking might be an important proxy for a patient’s general ‘priority on health’ [1].

The objective of this study was to investigate the potential association of psychosocial variables with indicators of non-compliance in a multicentre patient cohort that included patients on both HD and PD.

Subjects and methods

Patients and procedures

End-stage renal disease (ESRD) patients aged ≥20 years recently started on chronic HD or PD were recruited from 26 dialysis facilities serving the 23-county area surrounding Atlanta, Georgia, for a study focusing on predictors of new patients’ health-related quality of life and survival. All patients who started dialysis treatment at the 26 facilities from July 1996 to August 1997 were eligible except patients who had documented cognitive impairment or could not be interviewed in English or Spanish. Of 304 eligible patients, a total of 226 gave informed consent and participated in baseline data collection. Non-participation at baseline was due primarily to patients’ death or hospitalization during the first 2 months of treatment. Additional details about recruitment and characteristics of the cohort at baseline are available in Kutner et al. [17].

In 1997–1998, 1-year follow-up interviews were completed with 170 patients in the cohort who were still alive and on dialysis: 119 HD patients, 30 continuous ambulatory peritoneal dialysis (CAPD) patients, and 21 automated peritoneal dialysis (APD) patients. Data from these interviews are analysed in this paper. Patients in the original cohort who could not be re-interviewed at 1 year were 30 patients who were deceased; seven patients who had developed aphasia or cognitive impairment or had an extended hospitalization; three patients who had moved and could not be located; and six patients who refused a second interview. In addition, 10 patients had received transplants and were no longer on dialysis. In-person interviews were conducted by an experienced interviewer, and a medical abstractor recorded dialysis attendance and laboratory data from the patient’s medical record.

Non-compliance assessment

Three indicators of non-compliance were studied: missed dialysis treatments or sessions, shortened dialysis treatments or sessions, and serum phosphate (PO4) > 7.5 mg/dl. Skipping and shortening dialysis treatments or sessions were measured using criteria defined in the Wave 2 follow-up survey of the United States Renal Data System (USRDS) Dialysis Morbidity and Mortality Study (DMMS) [18]. The number of treatments missed and the number of HD treatments shortened by 10 min or more during the past 4 weeks were determined for HD patients. The number of treatments missed and the number of treatments shortened during the past 2 weeks were reported by APD patients. The number of exchanges missed during the last 7 days were reported by CAPD patients.

For all patients, PO4 values were abstracted from medical records for the month in which the patient was interviewed and for the 2 preceding months, and a mean value was calculated for this 3-month interval. Following Leggat et al. [1], patients were considered non-compliant if mean PO4 exceeded 7.5 mg/dl.

Clinical and dialysis measures

Haematocrit and serum albumin values from medical records for 3 months close to the patient’s interview (as defined above) were averaged to obtain a mean value. Patients’ primary ESRD diagnosis and cardiovascular comorbidity were identified from the Health Care Financing Administration (HCFA) ESRD Medical Evidence Report (2728 Form) completed at treatment start, supplemented by an independent physician chart review which provided increased sensitivity for identifying comorbidity [19,20]. Cardiovascular comorbidity was defined as presence of congestive heart failure, ischaemic heart disease, myocardial infarction, cardiac arrest, cardiac dysrhythmia, cerebrovascular disease, and/or peripheral vascular disease. For HD patients, the mean urea reduction ratio (URR) was calculated using the same 3-month interval as indicated above. For PD patients (cycler and CAPD), weekly total Kt/V was obtained from the available adequacy report dated closest to the date of the patient’s interview.

Perceived health status and psychosocial measures

Perceived health status was measured by the physical component summary score (PCS) and mental component summary score (MCS) derived from the Medical Outcomes Study (MOS) Short-Form 36 (SF-36) instrument [21]. The PCS and MCS summarize the physical health component and mental health component of health status measured by eight multi-item scales of the SF-36. The summary scores are normalized to a general population mean of 50 and a standard deviation of 10 [22].

Smoking status was defined by patient self-report. Smoking status reported by patients has been shown to yield increased sensitivity for this variable compared with information entered on the patient’s Medical Evidence Report [19,20]. In this study, patients’ smoking status was defined by the patient report at the 1-year interview.

Patients’ perceived global self-health care and perceived control over their future health were measured by National Health Interview Survey items which ask ‘How good a job do you feel you are doing in taking care of your health—excellent, very good, good, fair or poor?’ and ‘How much control do you think you have over your future health—a great deal, some, very little, none at all?’ [23]. These are stand-alone measures validated in the general population [24] and in the first author’s previous studies of dialysis patients [25,26]. For data analyses in this study, perceived self-health care responses were categorized as fair/poor vs good/very good/excellent. Perceived control over future health responses were categorized as very little/none vs some/a great deal.

Depression was assessed with two screening questions from an early version of the Primary Care Evaluation of Mental Disorders (PRIME-MD) Brief Patient Health Questionnaire (PHQ): (i) Over the last 2 weeks, how often
have you been bothered by little interest or pleasure in doing things? (ii) Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless? [27] Patients who answered ‘nearly every day’ to either of these two questions were scored as depressed. This measure of depression was significantly correlated in our study with patients’ scores on the mental health subscale of the MOS SF-36 [21]. An algorithm for coding major depressive syndrome using the 1999 version of the PHQ combines responses to the two screening questions and seven additional questions [27].

Additional psychosocial variables were measured by disease-specific scales from the Kidney Disease Quality of Life Short Form instrument (KDQOL-SF®) [28]. The scales used in this study assess effects of kidney disease (extent that patient is bothered in his/her daily life by issues such as fluid restriction and dietary restriction, feeling dependent on doctors and other medical staff, and stress or worries caused by kidney disease), burden of kidney disease (extent to which kidney disease interferes too much with patient’s life, takes too much of patient’s time, makes patient feel frustrated dealing with it, makes patient feel like burden on his/her family), degree of patient satisfaction with care received for kidney dialysis, perceived dialysis staff encouragement (extent to which staff encourage patient to be independent and support patient in coping with kidney disease), and perceived social support (satisfaction with togetherness and support from family and friends). Each of these KDQOL® scales is scored 0–100, with higher scores indicating more positive psychosocial outlook.

Statistical analysis

HD and PD patients were compared on sociodemographic and clinical characteristics using \( \chi^2 \)-tests for categorical variables and \( t \)-tests for continuous variables.

Associations of potential predictor variables with non-compliance measures were investigated in univariate analyses using \( \chi^2 \) and \( t \)-tests and were investigated in multivariable analyses using stepwise logistic regression with backwards elimination. CAPD patients were not included in logistic regression modelling of dialysis treatment shortening due to no available measure of shortened dwell times for these patients.

All analyses were conducted using SAS 6.12 for Windows 98 (SAS Institute, 1990). \( P < 0.05 \) (two-tailed) was considered to indicate statistical significance.

Results

Patient characteristics

As shown in Table 1, patients treated by PD were significantly younger (\( P = 0.001 \)), less likely to be black (\( P = 0.001 \)), and more likely to have at least some college education than patients treated by HD (\( P = 0.001 \)). The difference in average income of HD and PD patients approached statistical significance (\( P = 0.059 \)), with PD patients more likely than HD patients to report an income \( \geq 20000 \). Serum albumin level was higher among HD patients than among PD patients (\( P = 0.02 \)). The average URR of HD patients was \( 68.3 \pm 6.8 \), and the average weekly total \( K_t V \) of PD patients was \( 2.5 \pm 0.8 \). Patients on HD and PD were similar with respect to gender, likelihood of living alone, average haematocrit, presence of diabetic ESRD, and presence of cardiovascular comorbidity. The mean length of time that patients had been on dialysis was approximately 14 months (HD patients 433.0 ± 22.0 days, PD patients 433.0 ± 29.7 days); the range was 377–525 days.

Prevalence of non-compliance in patients on HD and PD

Almost one-third of both HD and PD patients were non-compliant on at least one of the indicators that were examined. Among HD patients, 19% had skipped at least one HD session and 31% had shortened at least one HD session in the past 4 weeks, and 19% had a PO4 > 7.5 mg/dl. Among PD patients (APD and CAPD), 30% had recently skipped at least one treatment and 10% had a PO4 > 7.5 mg/dl. Two APD patients (10%) had shortened at least one treatment during the past 2 weeks.

Predictors of non-compliance

Univariate associations of patient sociodemographic, treatment, and health status characteristics with non-compliance indicators are shown in Table 2. Treatment modality was not significantly associated with any of the indicators. Patients who had skipped treatments were younger (\( P = 0.0007 \)), more likely to be black (\( P = 0.02 \), and less likely to report a household

<table>
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<tr>
<th>Table 1. Characteristics of patient cohort by dialysis modality</th>
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<tr>
<td>Characteristics</td>
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</tr>
<tr>
<td>Sociodemographic</td>
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<tr>
<td>Age (year), mean ± SD</td>
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<tr>
<td>% Black*</td>
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<tr>
<td>% Male</td>
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<tr>
<td>% At least some college</td>
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<td>% Income ( \geq $20000 )</td>
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<tr>
<td>Clinical and treatment</td>
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<tr>
<td>Haematocrit, mean ± SD</td>
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<td>Serum albumin (g/dl), mean ± SD</td>
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<tr>
<td>% Primary diagnosis of diabetes</td>
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<tr>
<td>% Cardiovascular comorbidity</td>
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<td>Days on treatment at interview, mean ± SD</td>
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<tr>
<td>Adequacy</td>
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<td>Mean URR ± SD</td>
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<td>Mean weekly total ( K_t V ) ± SD</td>
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*Non-black, Non-Hispanic white (\( n = 67 \)), Hispanic (\( n = 3 \), and other (\( n = 6 \)).
income > $20,000 (P = 0.03) than patients who had not skipped treatments. Patients who had skipped treatments, shortened treatments, or had high PO4 assigned ratings to their physical health that were similar to the ratings assigned to physical health by compliant patients, but a trend was observed for patients categorized as non-compliant to rate their mental health lower than did patients categorized as compliant.

Univariate associations between psychosocial variables and each measure of non-compliance are shown in Table 3. Current smoking was associated with non-compliance as measured by all three indicators. Patients who had skipped treatments (P = 0.01), patients who had shortened treatments (P = 0.02), and patients who had a PO4 > 7.5 mg/dl (P = 0.002) were more likely to be smokers.

Perceived global self-health care was significantly associated with high PO4 level; patients whose PO4 was > 7.5 mg/dl were more likely to report that they were doing only a fair or poor job of taking care of their health (P = 0.03). In addition, three psychosocial variables were significantly associated with shortening of dialysis treatments: little or no perceived control over future health, depression, and perceived effects of kidney disease on daily life. Patients who had shortened treatments were more likely to feel little or no control over their future health (P = 0.007), to be depressed (P = 0.01), and to be bothered by the restrictions that kidney disease placed on their daily lives (P = 0.006).

Variables found to be significant predictors of non-compliance in the univariate analyses were then investigated in multivariable logistic regression models, adjusting for the effects of patients’ age, gender, race, and treatment modality (Table 4). Dialysis modality (HD/PD) was not a significant effect.
in any of the models, i.e. treatment by HD vs PD was not significantly associated with a particular non-compliant behaviour. Patient age and smoking were statistically significant effects in the model predicting skipping treatment; current smoking ($P = 0.04$) and younger age ($P = 0.008$) were significantly associated with skipping treatments. In the model predicting shortening treatment, statistically significant effects were observed for perceived effects of kidney disease on daily life ($P = 0.02$), perceived control over future health ($P = 0.02$), and smoking ($P = 0.03$). Finally, a statistically significant effect was observed for smoking in the model predicting high PO$_4$ level ($P = 0.002$).

### Discussion

Our study focused on patients treated by dialysis for 1 year, who have had some time to adjust to the treatment regimen and the stress associated with beginning chronic dialysis. It is possible that non-compliant behaviour was among the contributors to patient deaths that occurred in our sample prior to the 1-year follow-up, and patients who died prior to the 1-year follow-up are not included in this paper. Missing and shortening treatment sessions are among the most common manifestations of non-compliance [1], but it is difficult to identify comparable measures of these behaviours for patients on HD therapy and patients on PD therapy. We replicated the measures used in the USRDS DMMS Wave 2 to assess skipping and shortening treatment by HD and PD patients, and these measures are based on different time periods for HD, APD, and CAPD patients.

The majority of dialysis non-compliance research has focused on the HD population. Non-compliance by PD patients is less visible, and we must acknowledge our reliance on PD patients’ self-reported non-compliance. Although it is challenging to assess, non-compliance among PD patients appears to be substantial and is an important topic for study. Using home visits to monitor patients’ supply inventories, Bernardini et al. reported that 30% of the 92 PD patients they studied performed fewer than 90% of their prescribed exchanges [6]. Similarly, we found that 30% of the 51 PD patients in our study had missed at least one recent treatment. The risk of technique failure and transfer to HD is greater for PD patients who are non-compliant [6]. Moreover, these same patients may also continue to be non-compliant after switching to HD treatment.

The prevalence of skipping and shortening treatments among the patients we studied was quite consistent with data reported for a national sample of HD and PD patients in the US who were surveyed after 1 year of dialysis therapy for the DMMS Wave 2 study [18]. Similarly, the prevalence of PO$_4$ levels $>7.5$ mg/dl among the HD patients we studied (19%) was consistent with data reported by Leggat et al. for HD patients included in the CMAS/DMMS Wave 1 studies, among whom 22% were non-compliant on PO$_4$ by this criterion [1]. Although PO$_4$ levels can be considered a marker of dietary and medication compliance, 50–60% of both HD and PD patients with high PO$_4$ in our study also missed and/or shortened their dialysis treatments and were, therefore, at increased risk of inadequate dialysis. HD patients with high PO$_4$ levels had a mean URR (65.0 $\pm$ 7.0) that was significantly lower than patients who did not have a high PO$_4$ level (69.2 $\pm$ 6.6); $P = 0.008$. While high PO$_4$ levels may be due to non-compliance, it should be noted that high PO$_4$ levels might also be due to other causes, including complications associated with chronic renal failure such as severe secondary hyperparathyroidism.

Ours is the second study to report that patients who skip or shorten treatments and patients with high PO$_4$ levels are more likely to be smokers. The likelihood of current smoking was not significantly different for patients on HD (21.4%) and patients on PD (11.8%) in our study; $P = 0.14$. Leggat et al., the first to consider smoking as a potential predictor of non-compliance, suggested that smoking is a marker of...
a patient’s lower priority on health [1]. In this sense, patients’ smoking status essentially functions as a psychosocial variable.

To further analyse the association we observed between smoking and patients’ non-compliance behaviours, we compared smokers and non-smokers on several variables assessing patients’ social background, outlook on life, and general attitude toward health. We found no statistically significant differences between smokers and non-smokers in reported depression [27], perceived control over future health [23], or sense of personal mastery for positive and negative events [29]. Education and income differences were found, however; patients who were current smokers were significantly less likely to have completed at least some college \((P = 0.01)\) and less likely to report an annual income \(> \$20 000\) \((P = 0.03)\). Smokers were also significantly less likely than non-smokers to describe their global self-health care as good to excellent \((P = 0.009)\), although 71% of patients who were current smokers did describe their global self-health care as good to excellent. It would be useful to further explore these patients’ interpretation of the concept of ‘taking care of your health’.

Logistic regression results showed that patients who shortened treatments were more likely to be bothered by the effects of kidney disease on their daily lives and more likely to report perceived lack of control over their future health. Kimmel et al. found a small but significant correlation between patients’ increased perception of disruptive effects of illness, as measured by the Illness Effects Questionnaire (IEQ), and worsened attendance at HD sessions [2]. The IEQ, a generic instrument that measures a patient’s perception of the extent to which illness interferes with or modifies personal and social behaviour, i.e. is intrusive in the patient’s life, assesses a psychosocial domain similar to the domain assessed by the KDQOL scale that measures effects of kidney disease on daily life [30].

Thus, both missing and shortening HD treatments may reflect patients’ efforts to restore a sense of self-determination in their lives.

Although it was not significantly associated with high PO4 levels in the multivariable logistic regression analysis, the univariate analyses showed that patients with high PO4 levels were more likely to report that they were doing only a fair or poor job of taking care of their health. This patient response may reflect negative feedback given to the patient from healthcare professionals at the dialysis unit about the patient’s PO4 values in laboratory results.

Despite awareness of their non-compliance, patients may believe that their physical health status allows them to ‘get away’ with non-compliance. In a large sample of HD patients, DeOreo found that patients who skipped treatments (‘skippers’) judged themselves more physically healthy (higher PCS scores), but less mentally healthy (lower MCS scores), than patients who did not skip treatments [16]. Our data suggested a similar pattern. Although there was not a significant difference in MCS scores of patients classified as non-compliant and compliant on the three indicators we examined, a trend toward lower MCS scores among non-compliant patients was evident, whereas non-compliant and compliant patients had very similar PCS scores.

There was no evidence in our data that patient dissatisfaction with dialysis care, perceived lack of staff encouragement, or perceived lack of social support from significant others was associated with non-compliance indicators. Even when patients feel that they have adequate support from staff and significant others, however, psychosocial issues in their lives may create a ‘compliance-independence tight rope’ [7]. Individuals with a chronic disease who experience a diminished sense of control often seek alternative ways to re-establish control [31]. Non-compliance behaviours provide one readily available way for ESRD patients to deflect the perceived intrusion of kidney disease and dialysis into their daily lives.

The clinical significance of dialysis non-compliance behaviour is clear. In addition to increased mortality risk, non-compliant patients are at increased risk of hospitalization [6]. Rehabilitation potential is diminished if patients’ behaviour compromises their achieving maximal physical well-being on dialysis therapy. It does not necessarily follow, however, that patients will choose to adhere strictly to a treatment regimen as a way to maximize their perceived functioning and quality of life. Health behaviours reflect issues that are of greatest concern to the individual [14]. Depresion and perceived quality of life are states that characterize individuals at a particular point in time and may be modifiable with appropriately targeted interventions. The role of psychosocial variables, including smoking, as contributors to non-compliance merits continued study amongst both HD and PD patients.

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