Patient education: can it maximize the success of therapy?

Thomas Golper

Vanderbilt University Medical Center, Nashville, Tennessee, USA

Abstract
The majority of patients with chronic renal insufficiency (CRI) have only limited knowledge of their condition. Various studies of the benefits of patient education programmes have shown that educated patients have a reduced incidence of emergency dialysis compared with control patients. Additionally, more educated patients are able to start dialysis as an outpatient rather than in hospital. An education programme also allowed a greater number of blue-collar workers to remain employed after starting dialysis. The US National Pre-End-Stage Renal Disease (pre-ESRD) Education Initiative, which is currently in progress, aims to educate a large number of pre-ESRD patients on kidney function, renal failure, dialysis, and transplant options. Preliminary results suggest that the initiative influences the choice of dialysis and that, regardless of race, age, and co-morbidities, the incidence of peritoneal dialysis could be increased in ESRD patients in the US. Education on other components of therapy may also influence patient outcomes. In the management of renal anaemia, improved education, and advances in the delivery systems available for administration of erythropoietin may be important factors in improving patient compliance and maximizing the success of treatment. Thus, education of patients early in the course of CRI offers many potential benefits for patients and healthcare professionals, including improved treatment outcomes, reduced anxiety, greater prospect for continued employment, improved timing for the start of dialysis, and a greater opportunity for intervention to delay disease progression.

Keywords: erythropoietin; haemodialysis; patient education; peritoneal dialysis; pre-end-stage renal disease; renal replacement therapy

Introduction
It is apparent that the majority of patients with renal disease have only limited knowledge of their condition, and the challenge for physicians is to correct patient misunderstandings through education. Although such an approach could maximize the success of therapy, it is time consuming and the resources necessary for effective patient education are often absent. Additionally, patient compliance is a complex issue. For example, compliance with one aspect of treatment does not necessarily predict compliance with another [1], as patients may perceive that certain elements of their treatment are more important than others.

The results of two recent surveys suggest that the provision of patient information can influence patient compliance rates. In the first survey, a questionnaire based on the National Kidney Foundation (NKF) guidelines on treatment of chronic renal insufficiency (CRI) [2] was sent to members of the American Association of Kidney Patients (AAKP) [3]. Analysis of 1700 replies showed that provision of patient information was associated with a greater willingness to comply and achieve successful therapy. Patients were prepared to change their behaviour to feel better and live longer.

A second survey based on the NKF guidelines, this time sent to members of the NKF Patient Organization, showed the need for dialysis patients to receive information on the guidelines themselves [2]. Patients also needed to understand the direct impact the guidelines have on disease outcomes and they felt strongly about participating in healthcare decisions that impact on their treatment and outcome.

The following review addresses the question of whether patient education can, in reality, improve treatment outcome (i.e. reduce the morbidity and mortality associated with renal disease), and influence costs, patient anxiety or apprehension, thereby improving patient quality of life.

Factors that influence choice of dialysis modality

The issue of the relative merits of haemodialysis and peritoneal dialysis is controversial and it is unlikely...
that a randomized trial will be performed to compare both techniques [4]. In practice, the choice of renal replacement therapy in end-stage renal disease (ESRD) patients is made after consideration of quality of life issues, clinical outcomes, relative costs, patient preference, and the availability of resources locally.

In the US, only 12% of patients with ESRD requiring dialysis receive peritoneal dialysis [5]. Other countries, such as Canada, England and Hong Kong have much higher rates of peritoneal dialysis (37%, 51%, and 68%, respectively) [6]. Reasons for the low rate of peritoneal dialysis use observed in the US have been examined in several patient and nephrologist surveys, as discussed in the following sections.

**USRDS Dialysis Morbidity and Mortality Study (wave 2)—patient survey**

Part of the US Renal Data System (USRDS) Dialysis Morbidity and Mortality Study (wave 2) assessed patient and nephrologist choice of renal replacement therapy [7]. Shortly after beginning either peritoneal dialysis or haemodialysis, patients (n = 2400) were surveyed to discover who took the lead in deciding on the mode of dialysis.

Among the patients who received haemodialysis, physicians had taken the lead in the decision-making process in 53% of cases (Figure 1). Patients took the lead in 17% of haemodialysis cases, and a joint decision was made in 30% of cases. Of patients undergoing peritoneal dialysis, the decision was physician-led in 17% of cases, patient-led in 36% of cases, and a joint decision in 48% of cases (Figure 1). Thus, of all the patients undergoing peritoneal dialysis, 84% had contributed substantially to the decision, whereas of all patients undergoing haemodialysis, only 47% contributed to the decision. These results suggest an overall preference by patients for peritoneal dialysis.

**CHOICE study—survey of nephrologists**

As part of the Choices for Healthy Outcomes in Caring for ESRD (CHOICE) study, a survey was carried out to investigate the factors that influence nephrologists in their initial choice of renal replacement therapy [6]. The nephrologists (n = 271) were randomly assigned hypothetical patient scenarios and asked to recommend a dialysis modality based on patient demographics, and clinical and social factors.

The results, adjusted for demographics, showed that peritoneal dialysis was most likely to be selected for men, and for patients with a history of good compliance, those with existing residual renal function, aged 51–65 years, weight < 90 kg, without a history of diabetes and those living with families. Peritoneal dialysis was also likely to be recommended for patients with congestive heart failure, fitting in with current opinion that it is a more gentle technique than haemodialysis [6]. There was no evidence that race was an issue in the selection of dialysis modality, in contrast to previous studies that have suggested that Afro-Americans are frequently not offered peritoneal dialysis [8,9]. Ninety-eight per cent of the nephrologists who completed the questionnaire ranked patient opinion as either extremely or very important in the selection of dialysis modality.

**National Kidney Foundation Council on Dialysis—survey of nephrologists**

To better understand the attitudes of American nephrologists towards dialysis modality choice, a questionnaire was sent to 507 members of the NKF Council on Dialysis [5]. In contrast to the CHOICE survey (which included both academic and clinical nephrologists), the majority (93%) of the respondents were heavily involved with clinical dialysis work, thus ensuring that the sample represented clinicians with current knowledge of developments in dialysis mode.

The survey showed that choice of dialysis mode was strongly influenced by patient preference, quality of life, morbidity, and mortality issues. Contrary to the CHOICE survey, the decision was not influenced by age, gender or the presence of diabetes. In addition, facility and physician reimbursement were not considered to be very important factors in the decision-making process.

In a hypothetical situation, clinicians stated that if maximizing survival, wellness, and quality of life were the most important factors in deciding mode of dialysis, 67% of patients should be prescribed haemodialysis and 33% should be prescribed peritoneal dialysis. Conversely, if cost effectiveness was the most important factor, 60% of patients should be prescribed haemodialysis and 40% should be prescribed peritoneal dialysis. This suggests that American nephrologists would, in principle, support greater peritoneal dialysis use and that they do not consider patient outcomes would be adversely affected by this trend.

The results of this survey are strikingly similar to those obtained from a survey of a sample of Canadian Society of Nephrology clinicians [4]. The Canadian nephrologists listed (in order of importance) patient preference, quality of life, morbidity, mortality, and rehabilitation as influential factors in the decision-making process, whilst physician and facility

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**Fig. 1.** Patient involvement in selecting mode of renal replacement therapy (adapted from USRDS [7]). ■ Haemodialysis; □ Peritoneal dialysis (reproduced with permission from Am J Kidney Dis).
reimbursement were not considered important. Like the CHOICE study, large body size was found to favour haemodialysis, but patient age and gender did not influence the choice of modality.

In each of the nephrologist surveys, patient preference and quality of life were cited as the most influential factors in the choice of dialysis modality. In practice, however, other factors are also likely to play a role. Late referral to the nephrologist has a large impact on patient choice and modality selection. Patients referred late are almost always started on haemodialysis and only occasionally is the modality changed at a later date [5]. Conversely, early referral and education about renal replacement therapy are more likely to result in patients choosing home- and community-based dialysis, such as peritoneal dialysis [5], and this is likely to reduce overall costs of renal replacement therapy.

**Multidisciplinary education of pre-ESRD patients**

Levin et al. [10] performed a prospective, controlled study to establish whether the introduction of a progressive renal insufficiency education programme was of benefit to patients. The education programme involved discussions on renal function, blood pressure control, bone disease, and dietary advice. The frequency of clinic visits was predetermined based on the severity of renal disease. Time at each visit was divided equally between a nurse educator, physician, social worker, and nutritionist. A control group of patients did not attend the education programme and were managed according to conventional practice.

Over the course of the study, the time spent on each patient differed considerably between groups. The estimated time spent in the programme was between 15 and 33 h per patient per year of renal insufficiency for the educated group, depending on the degree of renal impairment. The estimated time spent on each patient in the standard care control group was between 7 and 15 h per patient per year of renal insufficiency.

The study highlighted several benefits in favour of the educated group. There was a significant reduction in the incidence of urgent dialysis in the educated group compared with the control group (13% vs 35%, respectively). Given that the mortality rate in an emergency situation is as high as 25% [10], these results could have a significant impact on patient survival. More patients in the educated group (76%) than in the control group (43%) were able to begin dialysis as an outpatient rather than in hospital. Likewise, the mean number of days spent in hospital during the first month was lower in the educated group (6.5 days) than the standard care group (13.5 days). If these encouraging results can be confirmed in clinical practice, patient education is likely to result in considerable cost savings, even when taking into account the additional time spent with each patient during the education programme [10].

The authors concluded that a multidisciplinary approach to education of pre-ESRD patients could have a positive impact on quantitative outcomes. Success, however, will depend on early referral to a nephrology centre, adequate resources for dedicated pre-dialysis programme staff and available resources for patients with ESRD.

**Effect of education on continuing employment**

The numbers of patients remaining in employment after starting dialysis are low and patients who receive in-centre haemodialysis and blue-collar workers have particularly low rates of continued employment [11]. This prompted Ragon et al. [11] to evaluate whether the initiation of an education programme could increase the rate of continued employment. Employment status for 45 patients who received a pre-dialysis orientation programme followed by in-centre dialysis was compared with that for a control group of 57 patients treated at centres that did not offer pre-dialysis intervention.

In white-collar workers, the likelihood of staying employed after starting dialysis was similar regardless of whether the patient had been in an education programme or not (47% of the educated group and 48% of the control group remained employed). However, in blue-collar workers, representing the majority of Americans, more patients who underwent the education programme remained employed after starting dialysis: 47% of the educated group remained employed vs 24% of the control group.

**The National Pre-ESRD Education Initiative**

The largest pre-ESRD education programme to date is the National Pre-ESRD Education Initiative, involving 932 referring nephrologists and 28 educators throughout the US. The initiative is currently ongoing and 15,000 patients were enrolled between 1997 and February 2001. The programme includes education on kidney function, kidney failure, renal replacement therapy, transplantation, and all other treatment options [12,13].

**Scheme for the standardized programme**

Following physician referral, patients initially attend a standardized education session. Subsequent sessions become more customized to the patient and any family members who also attend. Patients choose their dialysis modality upon completion of the education session and questionnaires are completed by the patients shortly after starting dialysis.

**Interim results**

Questionnaires have been completed by 2580 patients to date. Their demographics (age, race/ethnicity, gender, presence of diabetes, and primary causes of ESRD)
were found to be similar to the USRDS-defined dialysis population, which implies that the results are applicable to the US as a whole.

At the end of the education programme, haemodialysis was chosen by 55% of patients and peritoneal dialysis by 45% of patients (Figure 2). Of the patients who chose peritoneal dialysis, 75% actually started dialysis with this modality. In contrast, almost all patients (98%) who chose haemodialysis ended up on haemodialysis. The main reason for the discordance between patient choice and final dialysis modality was the patient or the patient’s family changing their minds; other reasons included a change in health status or a physician-driven change.

The results of this survey suggest that choice of dialysis modality is influenced by the extent of education received by the patient. The rate of peritoneal dialysis within the Education Initiative was two to three times higher than the incidence rate for the US generally (Figure 2). Thus, regardless of age, race, and co-morbidities, the incidence of peritoneal dialysis could be increased in American ESRD patients.

Education programme in Nashville

The promising results of the National Pre-ESRD Education Initiative prompted the initiation of two education programmes at the Vanderbilt Hospital, Nashville, in collaboration with other nephrologists in the greater Nashville area. The first programme targets patients with early renal insufficiency (glomerular filtration rate <30 ml/min) and aims to educate patients in all areas of kidney function and renal failure. The second programme targets patients with pre-ESRD (glomerular filtration rate >50 ml/min) and aims to educate patients on dialysis and transplant options.

An important aspect of the Nashville programme is its multidisciplinary approach. Members of the education team include a nurse who is familiar with all modes of therapy and has an interest in education, a dietician, a social worker, financial aid/insurance adviser, family and friends, other patients, and the physician. As in the National Pre-ESRD Education Initiative, the persistent and increasing referral rates of the physicians is an indication of their satisfaction with the programme.

Educating patients on anaemia management

Recombinant erythropoietin (epoetin) treatment in patients with renal anaemia can reduce the morbidity and mortality of renal disease and is associated with an improvement in quality of life [2]. Anaemia often occurs early in the course of CRI [14,15] and it is important to begin treatment as soon as possible, before the pathophysiological consequences of anaemia have the chance to develop. This is one area where patients and healthcare professionals alike can be educated in both the importance of early recognition of anaemia and the optimum delivery of treatment.

A retrospective analysis of compliance to self-administered epoetin has been carried out in 55 peritoneal dialysis patients followed up for 12 months [1]. Only 45% of the patients were found to be compliant with their anaemia therapy. Generally, compliant patients were older, had more co-morbidities and were more likely to have someone else do their injections. Compliant patients had significantly higher mean haematocrits than non-compliant patients. The probability of compliance was independent of race, gender, and insulin use. Interestingly, compliance to epoetin was not associated with compliance to the dialysis regimen and, thus, compliance with one component of treatment does not necessarily imply compliance with another component.

The poor compliance rate reported by Nicoletta et al. [1] gives cause for concern and begs the question whether compliance could be improved by implementing patient education measures. Improvements in delivery systems for self-administration that make epoetin easier to use, as well as more comfortable and more flexible, may also enhance compliance, and there have been many advances in this area recently.

The Reco-Pen\textsuperscript{16} device for subcutaneous self-administration of epoetin beta is now available in Europe, and has been shown to be effective and well tolerated in the treatment of renal anaemia. In addition, the device has proved to be flexible, convenient and easy to use. In a study of 420 patients with ESRD who had previously been maintained on other epoetin therapies, 82% of patients considered the Reco-Pen\textsuperscript{16} device to be either less painful than their previous treatment or not painful at all [16]. The ability to self-administer and the virtually pain-free method of administration of Reco-Pen\textsuperscript{16} are important factors in patient acceptability and should aid compliance to this important, life-long therapy.

Several other advances for the treatment of anaemia are currently in development; all are intended to be more acceptable to the patient in the hope that this will lead to improved compliance. These include

![Percentage of patients choosing and actually starting haemodialysis (■) and peritoneal dialysis (□) in the National Pre-ESRD Education Initiative Survey. Current US incidence of haemodialysis and peritoneal dialysis is also shown for comparison.](image)
the needle-free injection device for epoetin beta (Reco-Jet®), currently in phase II/III trials, implantable depot devices, as well as oral, inhalation, and transdermal formulations.

Conclusions

Early education offers many potential benefits both for renal patients and healthcare professionals. For the patient, early education allows an informed choice of renal replacement therapy, improves the timing for the initiation of therapy and increases the likelihood of continuing employment. Patient education may also enhance compliance to all aspects of treatment.

For healthcare professionals, early education gives a greater opportunity for intervention to delay disease progression (through management of anaemia, use of ACE inhibitors, and control of hypertension and hyperglycaemia) and to attenuate or even prevent the occurrence of co-morbid conditions. Early education allows the patient to participate in treatment issues, which may aid the doctor–patient relationship and also gives the opportunity to prepare patients for ESRD, particularly with regard to access creation and choice of modality.

Early referral to the nephrologist has a significant impact on the choices available to the patient. Patients referred late usually start on haemodialysis, whereas early referral and improved education result in a higher incidence of peritoneal dialysis. It is becoming increasingly clear that providing early patient education can improve the morbidity and mortality of chronic renal failure, as well as reduce the costs of treatment and the anxiety and apprehension associated with the condition.

References


