Influence of a Pre-Dialysis Education Programme (PDEP) on the mode of renal replacement therapy

Tony Goovaerts, Michel Jadoul and Eric Goffin

Department of Nephrology, Cliniques Universitaires St Luc, Université catholique de Louvain, 1200 Brussels, Belgium

Abstract

Background. The distribution of renal replacement therapy (RRT) modalities among patients varies from country to country, and is often influenced by non-medical factors. In our department, patients progressing towards end-stage renal disease (ESRD) go through a structured Pre-Dialysis Education Programme (PDEP). The goals of the programme, based on both individualized information session(s) given by an experienced nurse to the patient and family and the use of in-house audio-visual tapes, are to inform on all modalities of RRT, in order to decrease anxiety and promote self-care RRT modalities.

Methods. To evaluate the influence of our PDEP on the choice of RRT modalities, we retrospectively reviewed the modalities chosen by all consecutive patients starting a first RRT in our institution between December 1994 and March 2000.

Results. Two hundred and forty-two patients started a first RRT during the study period. Fifty-seven patients, median age 66 (24–80) years, were directed towards in-centre haemodialysis (HD) for medical or psycho-social reasons (seven of whom were not involved in the PDEP); the remaining 185 patients, median age 53 (7–81) years, with no major medical complications, went through our PDEP. Eight of them (4%) received a pre-emptive renal transplantation. The therapeutic options of the other 177 patients were as follows: 75 (40%) patients, median age 65 (20–81) years opted for in-centre HD, while 102 patients opted for a self-care modality; 55 (31%) patients, median age 56 (7–77) years, chose peritoneal dialysis, 30 (16%) patients, median age 49 (21–68) years, chose to perform self-care HD in our satellite unit, and 17 (9%) patients, median age 46 (19–70) years, opted for home HD. Interestingly, in the whole cohort of patients, the cause of ESRD was associated with the RRT modality: the proportion of patients with chronic glomerulonephritis or chronic interstitial nephritis on self-care therapy was significantly higher than that of patients with nephrosclerosis, diabetic nephropathy or unknown cause of ESRD.

Conclusion. In our centre offering all treatment RRT modalities, a high percentage of patients exposed to a structured PDEP start with a self-care RRT modality. This leaves in-centre HD for patients needing medical and nursing care, or for patients refusing to participate in their treatment. Additional large studies, preferably with a randomized design, should delineate the cost-benefit of such a PDEP on the final choice of a RRT modality.

Keywords: autodialysis; end-stage renal disease; haemodialysis; patient education; peritoneal dialysis; self-care dialysis

Introduction

The incidence of end-stage renal disease (ESRD) is steadily increasing worldwide, with annual dialysis growth rates ~6–8% per annum [1]. In Belgium, this increase averages ~4.5% yearly [2]. The distribution of renal replacement therapy (RRT) modalities among chronic kidney disease (CKD) patients varies from country to country, and is often influenced by non-medical factors such as reimbursement policies, physician biases, resource availability, social mores and cultural habits, access to hospital dialysis beds or lack of experience of nephrologists and nurses with some treatment modalities [3].

It is now well recognized that a Pre-Dialysis Education Programme (PDEP) should be an integral part of care for patients with ESRD [4,5]. Through such a programme, a broad scope of information can be provided at an early stage to the patient and his family; a PDEP should cover the disease process, the different treatment modalities, the diet and drug prescriptions,
etc. The objectives of such a PDEP are to decrease the mystique surrounding dialysis, provide patients with objective information about ESRD treatment alternatives, help them make a proper treatment choice and promote self-care. While many reports on the influence of early or late referral, counselling and informed choice on modality selection refer to peritoneal dialysis (PD) as the only self-care therapeutic modality [6–10], much less is known of the determinants of the choice between the various haemodialysis (HD) modalities. In our department, we also offer ESRD patients both home and self-care HD in a satellite unit, as RRT alternatives. Indeed, we have tried over the years to reserve in-centre HD either for patients needing close medical supervision and/or nursing care or for patients not wishing to participate actively in their treatment. We here present the distribution of the RRT modalities chosen by our patients given a PDEP over a 64 month period.

Material and methods

We retrospectively reviewed the modalities chosen by all patients starting their first RRT between December 1994 and March 2000 (64 months) in our hospital. Patients transferred from other centres after starting RRT and those restarting dialysis after failure of a renal graft were excluded from this analysis.

The options of RRT available in our centre are renal transplantation, either with a living-related or a cadaver donor (enrolment on the Eurotransplant waiting list for cadaver graft is possible as soon as creatinine clearance falls below 15 ml/min), PD [either continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD)], in-centre HD, self-care HD in a satellite unit and home HD, with or without a partner, or, since 1998, nurse assisted.

The satellite unit (with six dialysis machines) is open from early morning till midnight, allowing patients with a full-time job to undergo dialysis before or after working hours. With a design similar to a home setting, the centre is easily accessible, situated near an underground station. A nurse is always present to assist the patients, if needed.

The PDEP principles

The nephrologist in charge of the patient explains the general principles of HD and PD at the out-patient clinic and evaluates the co-morbidity factors present in each patient. This information is provided as soon as the creatinine clearance is ~20–25 ml/min (CKD stage 4, according to the recent K/DOQI guidelines) [1]. In the case of absolute contraindications for PD, such as the presence of an enterostomy, enormous polycystic kidneys, inappropriate abdomen or morbid obesity [11], the patients may still choose among the various HD modalities. It should be noted that hepatitis B virus carriers are not admitted to the self-care HD satellite unit.

Patients claimed not suitable by their nephrologist for any self-care therapy (based on clinical impression) are briefly informed about the different RRT modalities and referred to in-centre HD. All other patients go through the PDEP, run by the nurses in charge of the self-care treatment modalities [a team of eight nurses (three males, five females), with a mean age of 41 (range 24–49) years, working as dialysis nurses for an average of 16 (range 1.5–25) years at study onset].

The patient and family are informed on an individual basis. They are also invited to watch three in-house videos: one on HD and its modalities, one on CAPD and one on APD. The time spent to watch the three videos is 60 min in total. After the video session, the patients receive a brochure, summarizing the key points of what has been shown. Patients are also offered the possibility to speak to patients with experience of a given modality, and to visit the in-centre HD unit and the self-care satellite HD unit.

A contact with the social worker and/or the dietitian is also arranged. Finally, the patient has a further discussion with the nephrologist at the next outpatient clinic, where, in most cases, the final decision is taken.

Statistical analysis

The comparison of the age of patients on in-centre HD and on self-care RRT modalities was made using unpaired Student’s t-test. The impact of the cause of ESRD on self-care RRT modalities vs in-centre HD was analysed by Fisher’s exact test. The proportion of RRT modalities chosen by the patients in the different age groups was analysed by the Mann-Whitney U-test, and by analysis of variance (ANOVA) and post hoc Scheffe tests, respectively. The proportion of patients choosing a self-care treatment in the ‘late referral’ patients group was compared with that of patients choosing in-centre HD by χ² test. A P-value <0.05 was considered as statistically significant.

Results

During the 64 month observation period, 242 patients started a first RRT in our hospital. Among these 242 patients, 185 (76%) were exposed to the PDEP; they were younger (52.8±17.6) than patients not exposed to the PDEP (66.6±13.6; P<0.001). The decision of non-exposure to the PDEP in the remaining 57 (24%) patients was mainly based on medical impression (50 patients). In seven patients, no clear reason for non-exposure to the PDEP could be identified in the medical charts. All these seven patients suffered from severe co-morbid conditions: liver transplantation (n=2), advanced neoplasia (n=2), unstable diabetes (n=2), severe ischaemic heart disease (n=1); they were thus excluded from the analysis (Figure 1).

Distribution of the patients’ cohort

Fifty patients ([25 males, 25 females], median age: 67 (range 24–90) years) were thus directed by their respective nephrologists to in-centre HD, for either psycho-social or medical reasons (Table 1). Among them, 25 (50%) were late referral patients, i.e. they had to start dialysis <3 months after a first contact with a nephrologist.
Influence of the cause of ESRD and age on the RRT modalities (whole population)

The impact of the cause of ESRD on the RRT modality choice (in-centre HD vs self-care RRT modalities) is presented in Table 2: the proportion of patients with chronic glomerulonephritis or chronic interstitial nephritis who opted for a self-care RRT modality was significantly higher than that of patients with nephrosclerosis, diabetic nephropathy and unknown cause of ESRD ($P<0.05$, for each; Fisher’s exact test).

Likewise, the proportion of patients with diabetic nephropathy on self-care therapy was significantly lower than that of patients with autosomal dominant polycystic kidney disease (ADPKD; $P<0.01$). Also, among patients with chronic glomerulonephritis and ADPKD, the mean age of those who opted for self-care dialysis was significantly lower than that of those who were treated by in-centre HD (Table 2).

PDEP and RRT modality

One hundred and eighty-five patients [(114 males, 71 females), median age 53 (range 7–81) years] entered our PDEP (Table 3). Eight of them (4%) received a pre-emptive renal transplantation. Seventy-five (40%) patients [(46 males, 29 females), median age 65 (range 20–81) years] opted for in-centre HD. Among them, 33 patients [(21 males, 12 females), median age 70 (range 27–79) years], living in the neighbourhood of our hospital, started HD in our own in-centre facility, while the other 42 patients [(27 males, 15 females), median age 56 (range 20–81) years] were transferred to centres closer to their home. The remaining 102 (55%) patients opted for a self-care modality: 55 (31%) patients [(33 males, 22 females), median age 56 (range 7–77) years] for PD, 30 (16%) patients [(18 males, 12 females), median age 49 (range 21–68) years] for self-care HD in our satellite unit, and 17 (9%) patients [(11 males, six females), median age 46 (range 19–70) years] for home HD.

Self-care patients were younger than in-centre HD patients. Patients’ ages in all self-care therapy modalities (home HD, HD in the satellite unit, PD and pre-emptive transplant) were lower than those of in-centre HD patients ($P<0.001$ for each, respectively.

Table 1. Reasons for ineligibility for the PDEP ($n=50$ patients)

<table>
<thead>
<tr>
<th>Psycho-social reasons</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &gt;85 years</td>
<td>10</td>
</tr>
<tr>
<td>Language barrier</td>
<td>6</td>
</tr>
<tr>
<td>PDEP refused by the patient</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medical reasons</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe ischaemic heart disease</td>
<td>11</td>
</tr>
<tr>
<td>Severe psychiatric disorder</td>
<td>4</td>
</tr>
<tr>
<td>Advanced myeloma</td>
<td>3</td>
</tr>
<tr>
<td>Severe alcoholism</td>
<td>3</td>
</tr>
<tr>
<td>Cachexia</td>
<td>3</td>
</tr>
<tr>
<td>Cholesterol emboli</td>
<td>1</td>
</tr>
<tr>
<td>Systemic vasculitis</td>
<td>1</td>
</tr>
<tr>
<td>Goodpasture syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Advanced neoplasia</td>
<td>1</td>
</tr>
<tr>
<td>Advanced HIV disease</td>
<td>1</td>
</tr>
</tbody>
</table>

Influence of the cause of ESRD and age on the RRT modalities (whole population)

The impact of the cause of ESRD on the RRT modality choice (in-centre HD vs self-care RRT modalities) is presented in Table 2: the proportion of patients with chronic glomerulonephritis or chronic interstitial nephritis who opted for a self-care RRT modality was significantly higher than that of patients with nephrosclerosis, diabetic nephropathy and unknown cause of ESRD ($P<0.05$, for each; Fisher’s exact test). Likewise, the proportion of patients with diabetic nephropathy on self-care therapy was significantly lower than that of patients with autosomal dominant polycystic kidney disease (ADPKD; $P<0.01$). Also, among patients with chronic glomerulonephritis and ADPKD, the mean age of those who opted for self-care dialysis was significantly lower than that of those who were treated by in-centre HD (Table 2).
ANOVA and Scheffe tests) (Table 3). The proportion of RRT modalities chosen in the different age groups is illustrated in Figure 2: the younger the age group, the higher the probability of choosing a self-care modality ($P<0.01$ Mann–Whitney U-test). In the patients younger than 40, > 60% opted for self-care, vs 40% of the patients in their 60s. Above the age of 70, the few patients on self-care therapy (10%) chose PD.

### Timing of dialysis initiation/the problem of late referral patients

The exact timing of dialysis initiation was not known for patients who chose to be treated by HD in a centre close to their home (42 out of 185 patients who had entered the PDEP); RRT modalities were, however, not changed by the medical team in these dialysis units. For the 135 patients who started a dialysis modality in our hospital, the average length of time elapsed between the referral to the PDEP and the first dialysis was 25.5 (range 0–186) weeks. Twenty-seven of the 33 patients who chose to be dialysed in our in-centre facility were informed at a mean of 28 (range 0–110) weeks before treatment onset; the remaining six patients received the information after their first HD session. RRT was started a mean of 22 (range 0–186), 28 (range 8–101) and 29 (range 3–115) weeks after referral to the PDEP in PD, home HD and HD (satellite unit) patients, respectively.

A total of 58 patients were ‘late referrals’: 25 of them were directly referred to in-centre HD, as mentioned above. The remaining 33 patients entered the PDEP <3 months before dialysis onset or even after their first treatment: 20 (61%) chose a self-care treatment modality while 13 of them opted for in-centre HD, a proportion similar to that in the rest of the PDEP cohort ($P<0.01$ Mann–Whitney U-test).

### Outcome data

The outcome at 2 years of the 102 patients who have chosen a self-care RRT modality is presented in Table 4. The majority of them had received a renal transplant (43.2%) or were still on the same RRT modality (38.2%). Nine (8.8%) of the 102 patients only had to
be transferred to another technique modality: five from PD to HD (three to in-centre HD; two to home HD) because of severe infectious peritonitis, one from PD to in-centre HD because of a stroke, one from home HD to HD in the satellite unit by personal choice, one from home HD to HD in the satellite unit because the presence of a nurse during the HD sessions was advised, and one from home HD to in-centre HD because of non-compliance.

**Discussion**

Fifty-five percent of the patients who went through our PDEP opted for a self-care dialysis modality. The younger they were, the higher the probability of choosing self-care dialysis. However, up to 40% of the patients in their 60s did not choose in-centre HD. Why did we observe such a success with self-care dialysis therapies? First, the majority of these patients were referred to the PDEP at an early stage, i.e. when creatinine clearance is still >20 ml/min (or when they are at CKD stage 4, according to the recent K/DOQI guidelines) [1]. Initiating the information regarding dialysis while the patient still feels well has, according to many authors, several advantages, such as an increased potential to delay the initiation of ESRD treatment, an increased selection of self-care modalities, an optimal retention on the selected modality, an increased quality of life and rehabilitation, and a decreased hospitalisation time at initiation of treatment [4]. Recent K/DOQI guidelines further emphasize the need for preparation for RRT as soon as patients reach stage 4 CKD classification [1].

Secondly, the majority of the RRT options are available in our centre. Many authors reporting on dialysis modality selection just mention PD (CAPD and APD) as a self-care modality [12,13]. A recent American survey performed an average of 7 weeks after dialysis initiation indicates that patients receiving PD rated their care higher than those receiving HD, but no possibility of self-care HD was provided [14]. In contrast, our facility also offers self-care HD. Seventeen patients (9%) chose home HD. To promote the latter RRT option, we now further encourage patients to adapt the treatment schedule to their lifestyle: patients can dialyse three times weekly, every other day, daily, with or without a partner, or with the assistance of a nurse. In addition, patients may also be dialysed in a low-care HD satellite unit, a modality chosen by 16% of the informed patients. The self-care satellite unit is a good alternative for patients living in the vicinity of the centre, not having a lot of space at home or not willing to take full responsibility for their treatment.

Thirdly, since all ESRD treatment modalities are offered, the information provided is neutral. The small number of patients with a ‘self-care’ RRT who had to be transferred to another technique (Table 4) confirms this hypothesis. The patients know from the beginning that they are allowed to choose the modality they prefer. If there are absolute contra-indications for PD but if patients are physically and mentally well, they still can choose one of the HD modalities.

Nephrologists worldwide (Canadian, American and British) believe that self-care therapies are currently underused and proposed an ideal distribution of modalities [15–17]. A recent British nephrologists’ report suggested that an ideal dialysis entity should have 27% of patients dialysed using hospital-based HD, 24% in a satellite unit, 11% using home HD and 38% on some form of PD [17], proportions amazingly close to our respective percentages. This report also mentions that patients’ choice should be the most important factor in modality selection. Our study, like others [7,18], confirms that when the choice is left up to the patients whenever possible, almost half of the patients will choose a self-care-based therapy (24.2% of our total dialysis population were on PD, 13.3% dialysed in our satellite unit and 7.6% were on HD at home) leading to what integrated care should be, as recently discussed by Mendelssohn and Pierratos [19].

Although we try to start the PDEP early, some patients were referred late. This represents 25 out of 50 (50%) patients who were unsurprisingly directed to in-centre HD by their nephrologists because of co-morbid conditions, but also 33 out of 185 (18%) of the patients who received the PDEP. Amongst this latter group, 20 patients (61%) opted for a self-care modality, which is an unexpectedly high percentage. Late referral is indeed usually associated with a high percentage of patients treated by in-centre HD. A recent multicentre European study even showed that only six of 14 centres involved in the study could reach a percentage of patients treated by PD >30%, when patients are referred <1 month before the start of dialysis. In contrast, 11 out of the 14 centres reached that goal for patients referred >1 month before the start of dialysis [10]. A good information programme could thus perhaps decrease the percentage of late referral patients who opt for in-centre HD.

It is of note that our results are probably not applicable to all centres worldwide: the population recruited by our hospital includes a low percentage of patients with a low socio-economic status and, until recently, a low proportion (~10%) of diabetics.

**Table 4. Two year outcome in the 102 patients who had chosen a self-care RRT modality**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Renal transplantation</th>
<th>Still on therapy</th>
<th>Transfer to another technique</th>
<th>Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home HD</td>
<td>9</td>
<td>6</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>(n = 17)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HD in satellite unit</td>
<td>16</td>
<td>14</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>(n = 30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>19</td>
<td>19</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>(n = 30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (102)</td>
<td>44 (43.2%)</td>
<td>39 (38.2%)</td>
<td>9 (8.8%)</td>
<td>10 (9.8%)</td>
</tr>
</tbody>
</table>
In addition, the size of our unit allows us to offer all RRT modalities. Such a policy would probably not be economically possible for smaller centres.

As our study was an observational study, we have to acknowledge some limitations such as the potential differences that may exist between the members of the medical team in selecting or not selecting patients for the PDEP, or the lack of analysis of the milieu in which CKD patients live (socio-economic status, type of work, educational level, marital status, existence or not of a complementary revenue, etc). In this context, it is of interest to note that, when the whole population (and not only the patients who entered the PDEP) is taken into account, the cause of ESRD is associated with the RRT modality chosen by the patients: the proportion of patients with chronic glomerulonephritis or chronic interstitial nephritis on self-care therapy is higher than that of patients with nephrosclerosis, diabetic nephropathy or unknown cause of ESRD. The cost-benefits of an education programme such as our PDEP should thus be analysed prospectively in a larger cohort of patients randomized in two groups, with or without (medical information only) PDEP, respectively. In addition, this would allow a better understanding of the distribution of the various RRTs according to the patients’ co-morbid conditions and a precise definition of when is the appropriate time to offer PDEP to CKD patients. The reasons for the patients’ choices should also be analysed through a questionnaire to determine future guidelines for education programmes.

Conclusion

In an era where an increasing number of patients have to be treated with more and more restricted resources, ESRD patients should be informed on the various RRT modalities, to choose and participate in their medical management.

An adequate, objective and early PDEP could allow a high percentage of patients to start a self-care RRT modality. It is our experience that by leaving the choice to the patients and by offering all treatment modalities, an optimal distribution can be obtained, leaving in-centre dialysis for patients needing medical and nursing care, or for patients not wishing to participate in their treatment.


Conflict of interest statement. None declared.

References


Received for publication: 15.3.04
Accepted in revised form: 20.4.05