Patients’ views regarding choice of dialysis modality

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Abstract

Background. Increasing patient numbers have resulted in pressure on dialysis centres and a need to reorganize dialysis treatment. This study explored patients’ experiences with different dialysis modalities and investigated issues related to the patient’s choice of modality, especially ‘out-of-centre’ dialysis (i.e. modalities other than CHD).

Methods. Six focus group interviews were conducted with 24 dialysis patients, 3 pre-dialysis patients and 18 relatives. Each focus group comprised patients on one type of dialysis, i.e. CHD, self-care CHD, HHD, CAPD/APD, aAPD or pre-dialysis patients. Based on a semi-structured interview guide, the group discussions centred on advantages and disadvantages of dialysis modalities, problems experienced and their (possible) solutions and patient involvement in choice of modality.

Results. The focus groups participants considered that each dialysis modality has its advantages and disadvantages. Flexibility, independence and feelings of security were key factors in determining choice of modality, with maintenance of a normal life being a major goal. Patients and their relatives want to participate in choice of modality, but a genuine offer of out-of-centre dialysis including professional support and appropriate and timely education is needed to encourage a greater use of modalities other than CHD.

Conclusions. No single dialysis modality emerged as offering the best solution for patients with end-stage renal disease. In the absence of absolute clinical contraindications, the treatment of choice should be the modality that best accommodates the patients preferences for their daily activities and lifestyle. A move towards more patients on out-of-centre dialysis requires a greater focus on pre-dialysis patients and closer consideration of patients’ preferences and current lifestyle.

Keywords: dialysis; modality; patient views; quality of life; choice

Introduction

The number of Danish patients on chronic dialysis has more than doubled over the last 10 years [1], with the elderly being the largest and the fastest growing patient group. This puts pressure on the 14 Danish dialysis centres, prompting a possible reorganization of dialysis treatment towards a greater use of ‘out-of-centre’ dialysis.

About 70% of Danish dialysis patients are on hospital in-centre haemodialysis (CHD) and 30% are on other modalities, encompassed here by ‘out-of-centre dialysis’: haemodialysis at a centre with reduced staff involvement (self-care CHD or limited care dialysis), home haemodialysis (HHD) and peritoneal dialysis (PD)—whether continuous ambulatory PD (CAPD), automated PD (APD) or nurse-assisted APD (aAPD) [2–4]. A Danish health technology assessment suggests that the proportion of CHD patients could be reduced to 55% through organizational changes [4], while English nephrologists propose 27% of patients on CHD [5].

The present study was part of a larger health technology assessment commissioned by the Danish Board of Health to investigate the feasibility of increasing the number of patients on out-of-centre dialysis [4]. The aim of the present study was to explore patient’s views i.e. experiences with different dialysis modalities and key issues related to patient’s choice of modality. It should be noted that dialysis treatment in Denmark is publicly funded. Patient expenditure in relation to choice of modality has thus not been taken into account here.

Subjects and methods

Six focus group interviews with dialysis patients and relatives were held in 2006. A semi-structured interview guide was developed based on findings from a systematic literature review of patient preferences and patient outcome related to dialysis treatment. Primary subjects for discussion were advantages and disadvantages of dialysis modalities, problems experienced and their (possible) solutions and patient involvement in choice of modality.
Each focus group comprised patients on one dialysis modality, i.e. CHD, self-care CHD, HHD, CAPD/APD, aAPD or pre-dialysis patients. This qualitative approach was chosen so as to generate more in-depth discussion of the selected topics and to increase the likelihood that different opinions and experiences would be examined.

Patient participants were recruited through dialysis centres throughout Denmark and comprised dialysis patients above 18 years of age. Each focus group was aimed to include men and women of different ages, civil status and with a varied duration of dialysis. Pre-dialysis patients who had recently participated in a pre-dialysis educational programme were also included.

Each participant was informed orally and in writing about the study and gave formal acceptance of own participation and of ‘a significant other’ of their choice. Interviews were held in a hospital meeting room. Anne Lee acted as the moderator for each focus group interview while a student recorded observations regarding participants’ interactions. The interviews were tape recorded. The study was registered with the Danish Data Protection Agency.

The interview material was fully transcribed and analysed by Anne Lee through the coding of statements and identification of themes within and between the six focus groups. The initial codes were assigned through listening to the tape recordings and discussions between the moderator and students. Adjustments of codes were made as necessary to take account of the material emerging from all six groups. The data were analysed using the software program NVivo [6].

Results

The six focus groups involved 27 patients and 18 relatives (Table 1). Three patients were in a pre-dialysis stage and the other 24 had been on dialysis for 6 ± 6.8 years. The mean age was 54 ± 16.2 years; most patients lived with a spouse and 70% were either retired or on disability pension. Only a few had attended a pre-dialysis educational programme. Detailed information on renal diagnosis and comorbidity was not available for all patients.

Several main topics emerged from the interviews: (i) flexibility and independence in relation to treatment, (ii) feelings of insecurity, (iii) physical space and noise, (iv) maintenance of a normal life, (v) pre-dialysis information and (vi) involvement in choice of modality. Overall advantages and disadvantages of each modality are summarized in Table 2.

Flexibility and independence

CHD patients felt that dialysis-free days and a home life free of illness were advantageous, but some felt exhausted after days involving transport to the dialysis centre, dialysis treatment for several hours and then transport home again. In comparison, the aAPD patients and their relatives appreciated that the dialysis could be conducted at home. The ability to plan and maintain a dialysis routine gave a sense of confidence although it was frustrating if the routine could not be altered to take account of special occasions or holidays.

Some of the HHD patients dialyzed while family members were at home, while others chose to dialyze when they were alone in the house. Both patients and relatives appreciated the flexibility that HHD gave them in planning dialysis times, especially in relation to work. Three of the four HHD spouses felt that it was harder to have a relative on CHD than on HHD.

Sense of security

HHD relatives who were not at home during dialysis reported that they had felt nervous at the start, but had gradually become accustomed to the routine. One expressed a need to stay in telephone contact with the spouse who was dialysing alone at home. Relatives of patients on CHD and PD also expressed the need to know about the dialysis technique in order to feel more confident about it: ‘I told them [at the hospital] that I wanted to see how he was connected up to the machine, so I could understand it better’ (wife of a CHD patient). A sense of security was also gained by knowing that a health professional was involved in the dialysis (either in the hospital or as aAPD at home).

The focus group participants felt it important for children of dialysis patients to have knowledge about the dialysis treatment, especially as children might worry that the parent could die. ‘We arranged for my daughter and her classmates to come to the hospital to see the dialysis . . . they had had some terrible ideas of what it was, but when they had seen it, they just thought, oh, OK’ (woman now on HHD but previously on CHD).

The patients on HHD, PD and aAPD stressed the importance of 24-h telephone access for advice and instructions, especially in the event of technical problems. HHD patients also considered it essential that a technician could visit them when needed.

Physical space and noise

Patients and their relatives thought that the (HHD and APD) machines, bags and other equipment took up a lot of space and was unsightly. The machine noise and the various alarm signals were also irritating. Some of the HHD patients who dialyzed at night had chosen to set themselves up in a separate bedroom. This was not an option for all patients, and some felt it important that they were together with their spouse during treatment: ‘It took six months for my wife and I to adjust to the noise, but now things are beginning to go well’ (man on HHD).

Maintenance of a normal life

The patients felt it important to distinguish between the person and the illness. They had to accept they were chronically ill, but at the same time the illness (represented by dialysis) should be separated from the rest of life. Coping with dialysis could take place through normalizing one’s life.

The CHD and self-care CHD patients distinguished between days on dialysis and days without dialysis. When they
Table 1. Characteristics of focus group participants

<table>
<thead>
<tr>
<th></th>
<th>All patients</th>
<th>CHD</th>
<th>Self-care CHD</th>
<th>HHD</th>
<th>PD</th>
<th>aAPD</th>
<th>Pre-dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>27</td>
<td>5</td>
<td>5 (1 will shortly change to HHD)</td>
<td>5 (2 on night dialysis, 3 on daily dialysis, 1 assisted by spouse)</td>
<td>5 (3 CAPD, 2 APD)</td>
<td>4 (all assisted by a community nurse)</td>
<td>3 (likely to choose: CHD: 1, HHD: 1, PD: 1)</td>
</tr>
<tr>
<td><strong>Men:women</strong></td>
<td>15:12</td>
<td>5:0</td>
<td>2:3</td>
<td>2:3</td>
<td>3:2</td>
<td>2:2</td>
<td>1:2</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td>25–87 years</td>
<td>30–69 years</td>
<td>25–72 years</td>
<td>45–63 years</td>
<td>42–62 years</td>
<td>75–87 years</td>
<td>38–47 years</td>
</tr>
<tr>
<td><strong>Living circumstances:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>26%</td>
<td>60%</td>
<td>40%</td>
<td>0</td>
<td>0</td>
<td>50%</td>
<td>0</td>
</tr>
<tr>
<td>With spouse</td>
<td>63%</td>
<td>20%</td>
<td>40%</td>
<td>100%</td>
<td>100%</td>
<td>50%</td>
<td>67%</td>
</tr>
<tr>
<td>With parent/child</td>
<td>11%</td>
<td>20%</td>
<td>20%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>33%</td>
</tr>
<tr>
<td>Working full-time</td>
<td>11%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>20%</td>
<td>0</td>
<td>80%</td>
</tr>
<tr>
<td>Working part-time</td>
<td>19%</td>
<td>0</td>
<td>20%</td>
<td>40%</td>
<td>20%</td>
<td>0</td>
<td>20%</td>
</tr>
<tr>
<td>Disability pension</td>
<td>37%</td>
<td>60%</td>
<td>60%</td>
<td>20%</td>
<td>40%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Retired</td>
<td>33%</td>
<td>40%</td>
<td>20%</td>
<td>0</td>
<td>20%</td>
<td>100%</td>
<td>0</td>
</tr>
<tr>
<td>Time on dialysisb</td>
<td>0.5–28 years</td>
<td>0.5–17 years</td>
<td>1.5–10 years</td>
<td>3.5–28 years</td>
<td>1–6 years</td>
<td>2–5 years</td>
<td>100%</td>
</tr>
<tr>
<td>Pre-dialysis educationc</td>
<td>33%</td>
<td>None</td>
<td>80%</td>
<td>None</td>
<td>40%</td>
<td>None</td>
<td>100%</td>
</tr>
<tr>
<td>Previous experience with other modalities</td>
<td>–</td>
<td>Transplant: 1</td>
<td>CHD: 5</td>
<td>CHD: 5</td>
<td>CHD: 3</td>
<td>CHD: 1</td>
<td>2 had parents on dialysis</td>
</tr>
<tr>
<td><strong>‘Significant others’ interviewed</strong></td>
<td>18</td>
<td>1 (spouse)</td>
<td>4 (2 spouses, mother, friend)</td>
<td>4 (2 spouses)</td>
<td>4 (spouses)</td>
<td>3 (1 spouse, 2 daughters)</td>
<td>2 (spouses)</td>
</tr>
</tbody>
</table>

aA prerequisite for Danish patients starting on HHD is that the patient will be able to handle the dialysis alone; this arrangement with the spouse assisting the patient with dialysis was a reminiscence of a former period on HHD.

bTime since starting dialysis, i.e. including periods with a kidney transplant.

cOf the 14 Danish dialysis centres, 8 currently offer pre-dialysis education programmes, of which some are newly established.
left the dialysis centre they did not consider themselves ill until the next dialysis session: ‘I don’t want it at home. I don’t want to be reminded of having an illness. When I come here [dialysis centre], when I enter that door I am ill—at home I am not ill’ (man on CHD).

Several patients had sought to incorporate dialysis as a normal part of their life: ‘I look at it as a job. [On dialysis days] I leave for dialysis when my boyfriend leaves for work’ (woman on self-care CHD). ‘Of course you think about it . . . you have to try to make it a routine, like having dinner, it has to be that way’ (woman on HHD). ‘In daily life I don’t really see it as a disease—I look at it as a job. [On dialysis] I have arranged it all so that I don’t think about it [the bags with dialysis fluid]’ (man on CAPD).

Others sought to hide the dialysis equipment away when it was not needed: ‘In the morning I hurry to tidy it away and close the door to the bedroom’ (woman on APD).

For PD and HHD patients, avoiding the hospital could be a way of normalizing their everyday life: ‘My problem is that when I come here [the hospital], I become a patient and I don’t like being a patient’ (woman on HHD).

For the older, frail participants the assistance from community nurses had made it possible for them to be treated at home; this seemed to be their only way to have a life at all: ‘I couldn’t do it [CHD], I was totally worn out when I came home’ (woman formerly on CHD, now on aAPD).

**Pre-dialysis education**

Six of the 24 dialysis patients had attended a pre-dialysis educational programme. Patients who had not attended a programme wished they had had the opportunity to do so: ‘If you are going to do it [dialysis] anyway, they might as well prepare you so it does not hit too hard . . . I would have liked to have time to find out what was happening and what to choose. If the information had been better, I might have chosen differently and not have missed almost a year of my life’ (woman on APD, who had started on CHD).

The CHD patients received no formal pre-dialysis educational programme within the previous 6 months. They emphasized that timing of dialysis education was important. They appreciated early information, although acknowledging that the information was rather abstract, and knew that they later on would need more information and counselling from health professionals and preferably also fellow patients in the process of becoming a dialysis patient and choosing modality.

The CHD patients received no formal pre-dialysis education. All were dissatisfied with the information received (two received information after dialysis had been established).

**Involvement in choice of modality**

None of the CHD patients had been given a choice of dialyze modality; most of the others had been involved in choosing their current modality if not the initial modality. A few patients had experienced difficulties in obtaining their choice or felt that their own fear of incompetence had been a barrier in choosing the most appropriate modality: ‘When I restarted in dialysis I wanted it home again, but I had moved in the meantime and at the [new] hospital they...’

<table>
<thead>
<tr>
<th>Focus group participants</th>
<th>Advantages</th>
<th>Disadvantages</th>
<th>Literature findings: advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHD</td>
<td>Security (known professionals carrying out the treatment), freedom from illness at home and on dialysis-free days, socializing (mainly with staff)</td>
<td>Transport time, fixed time in dialysis (no flexibility in extent or time of dialysis), limitations to holidays</td>
<td>Dialysis-free days, having others do the dialysis while the patient sleeps, reads, etc. [25,40]. Good for patients who are uncertain about ability to dialyze without direct supervision or have limited space at home [41]</td>
</tr>
<tr>
<td>Self-care CHD</td>
<td>No waiting time when starting a dialysis session, possible flexibility in extent and time of dialysis</td>
<td>Transport time, limited flexibility in extent and time of dialysis, limitations to holidays</td>
<td>Greater flexibility with respect to choice of day, time and frequency [38]</td>
</tr>
<tr>
<td>HHD</td>
<td>No transport, greater flexibility, better social life, possibility of work, dialysis at night means that days are free</td>
<td>Takes up space, technical problems and noise, limitations to holidays</td>
<td>Flexibility with respect to choice of time and frequency, less time consumption, no transport, possibility for doing other things (watch TV, use PC, read, sleep, etc.) while on dialysis [41,42]</td>
</tr>
<tr>
<td>CAPD</td>
<td>No transport, greater flexibility, better social life, possibility of work, possible to take equipment on holiday</td>
<td>PD bags are heavy and both full bags, used bags and other equipment takes up a lot of space</td>
<td>Flexibility, possibility of night treatment [18,25,33,40], greater self-care and autonomy, privacy, no transport, possibilities for work [18,25,33,42]. Good for patients fearing needles but considerations related to body image [18]</td>
</tr>
<tr>
<td>APD</td>
<td>As for CAPD plus dialysis at night means that days are free</td>
<td>As for CAPD plus technical problems and noise</td>
<td>Improves the lifestyle for the frail and the elderly by avoiding travelling to the HD unit three times weekly. Allows patients to remain on PD in their own environment even though they have become dependent on a caregiver [2,3]</td>
</tr>
<tr>
<td>aAPD</td>
<td>As for APD plus security (known professionals carrying out the treatment)</td>
<td>As for APD plus dependence on community health nurses</td>
<td></td>
</tr>
</tbody>
</table>

Table 2. Patients’ views (focus group interviews) and literature findings regarding the advantages and disadvantages of different dialysis modalities
did not know anything about HHD. It took me one year before I succeeded’ (woman needing dialysis after kidney transplant failure).

The motivation for choosing PD and HHD was primarily the greater flexibility these modalities offered, avoidance of travelling time and, for some patients, a better possibility to continue working. Factors in choosing self-care CHD were greater flexibility and the chance to carry out one’s own dialysis. Two CHD patients had been offered self-care CHD, but had declined, as it had to involve five weekly dialysis sessions (instead of their current three sessions). Most of the focus group patients were generally satisfied with their current dialysis modality; only two were planning a change of modality.

The relatives considered it important that the family was involved in the decision making, as the dialysis would fill a large part of their lives as well, whether it occurred in the home or at the hospital (due to the patient’s absence from the home). ‘My husband has to be able to accept it [HHD]. If he can’t, then we won’t do it’ (woman on CAPD wishing to change to HHD). ‘It is important to include the relatives in the decision, even if the patient seems very independent or doesn’t want the spouse to be involved’ (wife of a CAPD patient). The relatives wished to have the opportunity to meet and talk with other dialysis patients and their relatives before choosing dialysis modality.

Both the patients and relatives thought it would be useful for relatives to have a forum where they could meet to share experiences and discuss anxieties and decisions. ‘It is important that we relatives talk with others in the same position . . . I can easily tell other people that we have started on HHD, but they don’t even know there is something called dialysis’ (husband to HHD patient). ‘The balance of power in a relationship can change when something like dialysis happens . . . it would be good to discuss with other dialysis spouses how I could tackle this’ (wife of a man about to start dialysis).

Discussion

The focus group interviews revealed that all dialysis modalities have both advantages and disadvantages and that no modality offers the optimal lifestyle for all patients. This concurs with the literature on patients’ physical, social and psychological functioning, where there is no strong evidence for differences in health-related quality of life between dialysis modalities. Comparative studies have primarily involved HD (either CHD or HHD) and PD (CAPD or APD) patients, while a few smaller studies have compared different HD modalities or PD modalities. In most cases, no significant differences have been found between HD and PD patients [7–11], although better physical and psychological functioning has been reported for PD patients, even after the adjustment for differences in age, education, marital and employment status [12]. The conclusions from comparative studies need to be carefully assessed, however, as sociodemographic and clinical variables can vary between dialysis groups [11]. Furthermore, CHD patients have typically participated in questionnaires on dialysis days—when they may be feeling worse than on days between dialysis sessions [7,12–14].

Maintenance of a normal life

The literature supports the findings from the focus groups that becoming a dialysis patient is a major life event that impacts not only the life of the patient, but also that of family members [15–17]. Qualitative studies have found that end-stage renal disease and dialysis treatment lead to changes of great significance for personal identity as well as body image and autonomy [18–23]. Dialysis treatment leads to a new awareness of the body and its functions, physical changes that often represent a decline in ability and functioning and the start of time-consuming life-long treatment that maintains the person in a sick role. It becomes important for the patient to appear normal while at the same time recognizing and somewhat accepting the new circumstances [18–24]. The focus group participants expressed a need to live a normal life despite their chronic illness and had developed a range of coping strategies, e.g. by avoiding the hospital and the sick role, by differentiating between days with and without dialysis or by incorporating the dialysis into their everyday life.

Involvement in the choice of modality

Some focus group patients felt that they had not been given a real choice of dialysis modality; this is supported by the literature [25–27]. About 36% of patients with end-stage renal disease may have contraindications to either HD or PD, mainly related to PD and often due to social reasons e.g. older age, living alone or physical or mental disability [28–30]. Approximately two-thirds of patients should thus have a real choice of dialysis modality, a proportion which even may be increased through better communication between the health professionals and the patient about the patient’s wishes, perceived and real abilities and about options for improving the patient’s chances of coping with self-care through education, support and, especially for the older patient, an option for professional assistance in the home [2,3,28,30–32]. A cohort study showed that half of the patients who could freely choose dialysis modality chose PD and the other half chose HHD [29].

Choice of dialysis modality

The choice of dialysis modality is influenced by clinical factors, recommendations from health professionals and other patients, as well as preferences of patients and their families [33]. While professional advice is probably strongly influenced by clinical effectiveness, familiarity with modality and perception of the patient’s social and physical functioning, both the focus group interviews and the literature indicate that patients’ preferences are heavily influenced by a wish for as near normal a life as possible [34] and that the choice of treatment should consider patients’ preferences and their current lifestyle [35,36]. The pre-dialysis patients interviewed felt it was important to know and weigh up the advantages and disadvantages of each dialysis modality. Main considerations mentioned were bringing dialysis
home, long hours away from home and integrating dialysis into the previous daily life by dialysing at times not spent on other things of importance.

Once on a dialysis modality, patients are seldom inclined to change modality [25,37]. It is debatable, however, whether these preferences reflect decision-making strategies that are successful in identifying the modality best suited to the individual patient [37] or whether they are more a reflection of the life-saving nature of dialysis, a lack of knowledge about alternative modalities, the sense of security obtained from familiarity or the general demanding nature of dialysis that makes it seem insuperable to the patient to change modality and daily routines.

Pre-dialysis education

The general acceptance of current treatment modality means that a move towards greater numbers of patients on out-of-centre dialysis requires greater focus on pre-dialysis patients. Provision of information about alternative modalities is important for the choice of out-of-centre dialysis [29,31,38,39], and counselling was found to be an independent predictor for choosing PD over CHD [31]. Referral to a specialist nephrology centre must therefore occur early enough for the patient and nearest relatives to be offered pre-dialysis education, including wide-ranging information on the advantages and disadvantages of different modalities. Dialysis education is associated with a planned start [39], however, and many patients start dialysis acutely [39]—usually on CHD [31]—thus receiving little information until after dialysis is established.

Timing of dialysis education is important. The focus group participants noted that it takes time to adjust to being a dialysis patient and to find one’s own way of handling a chronic disease and a time-consuming and restrictive treatment. Timing and level of education in relation to the stage of chronic kidney disease are likely to influence the effectiveness and acceptability of self-care interventions and initiatives [35,40]. Self-care practices take time to learn, and dialysis patients need to develop confidence in their ability to care for their own dialysis needs. Health professionals need to be aware of the possibility that the present dialysis modality may no longer be the best for the patient, perhaps not due to clinical reasons, but due to changes in the patient’s physical status or social circumstances.

Limitations to the study

Convenience samples were used for the focus group interviews, and the relatively small number of participating patients and relatives may not be representative of dialysis patients as a whole. For practical reasons, the patients in each focus group were recruited from the same hospital. There can be considerable national and local differences in the way an out-of-centre modality is organized and the extent to which the patient is involved. The design of the study does not enable analysis of how factors such as age, gender, renal disease, comorbidity and organization of dialysis modality affect patients’ experiences and the choice of modality. It is likely that younger patients still in the workforce and with children at home have rather different needs and wishes regarding dialysis compared to elderly patients with greater comorbidity. Some of these differences emerge in this study, but could be investigated more thoroughly in different age groups. The interview with CHD patients took place immediately after their treatment and they were clearly tired and less active in the discussion than the participants in some of the other groups. The aAPD patients were older people and generally less outspoken, while their significant others were more active in the discussion.

The conclusion from the current study is that, in the absence of absolute clinical contraindications, the question should be which dialysis modality best suits the patient’s own expectations and wishes regarding daily life and lifestyle. It is neither possible nor relevant for all patients to choose out-of-centre dialysis, but it might be possible to take greater account of patients’ preferences when choosing dialysis modality. It would seem that a real possibility of a choice and the involvement of patients in the choice of dialysis modality influences which modality is chosen. Not all the participants in the focus group had had a choice and for some it had been difficult or so far impossible to obtain their choices.

Dialysis centres need to provide a genuine offer of out-of-centre dialysis. This is likely to require facilities for self-care CHD, the possibility of setting up and maintaining dialysis machines and water supply in private homes, APD machines for night dialysis, possibility for aAPD and easy access to health professional advice and technical support.

Acknowledgements. The authors thank the dialysis patients and their close ones for taking part in the focus group interviews and the staff at six dialysis units for their assistance in recruiting patients and the practical arrangement of the interviews. They also thank the students Martin Nielsen and Martin Toft Sorensen for their help with the focus group interviews.

Conflict of interest statement. JVP has received an unrestricted research grant, consulting fees and lecture fees from Baxter HealthCare.

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Received for publication: 21.5.08
Accepted in revised form: 6.6.08