Review of predialysis education programs: a need for standardization

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Abstract: To make an informed decision on renal replacement therapy, patients should receive education about dialysis options in a structured program covering all modalities. Many patients do not receive such education, and there is disparity in the information they receive. This review aims to compile evidence on effective components of predialysis education programs as related to modality choice and outcomes. PubMed MEDLINE, Cochrane Library, and Ovid searches (from January 1, 1995 to December 31, 2013) with the main search terms of “predialysis”, “peritoneal dialysis”, “home dialysis”, “education”, “information”, and “decision” were performed. Of the 1,005 articles returned from the initial search, 110 were given full text reviews as they potentially met inclusion criteria (for example, they included adults or predialysis patients, or the details of an education program were reported). Only 29 out of the 110 studies met inclusion criteria. Ten out of 13 studies using a comparative design, showed an increase in home dialysis choice after predialysis education. Descriptions of the educational process varied and included individual and group education, multidisciplinary intervention, and varying duration and frequency of sessions. Problem-solving group sessions seem to be an effective component for enhancing the proportion of home dialysis choice. Evidence is lacking for many components, such as timing and staff competencies. There is a need for a standardized approach to evaluate the effect of predialysis educational interventions.

Keywords: dialysis, end-stage renal disease, informed decision, modality choice

Introduction

While in-center hemodialysis (HD) remains the most common treatment modality of end-stage renal disease, home dialysis with peritoneal dialysis (PD), such as automated PD and continuous ambulatory PD, and home HD are treatment options that can provide improved clinical and patient-reported outcomes. In addition, they can be less resource intensive and costly to the health care system.

There are some clinical factors that affect whether an individual patient is clinically suited for PD, but the majority (80%) of end-stage renal disease patients are capable of using home dialysis as their treatment.1

To date, there is no clear evidence that suggests better survival between PD and conventional three-times-per-week in-center HD, although some studies also report that PD is advantageous compared to in-center HD, with higher short-term survival rates and higher quality of life.2–4

All renal replacement therapies have different advantages and disadvantages, which may make them more or less appropriate for the patient depending on his or her clinical and personal situation. PD, which requires learning of technical skills by the patient, also requires a degree of responsibility and capability for self-care. However, it is advantageous in allowing the patient to remain independent, and to have more control over their own treatment and lifestyle. In-center HD is performed by trained nursing
staff within a health care setting but can be inconvenient with a rigid schedule of 4 hours treatment plus travel time three times weekly. Most commonly, clinical issues do not limit the treatment selection, and patient preference should be the deciding factor in the selection of treatment modality.\(^5\)

A growing body of research suggests that early referral to a nephrologist and patient education are associated with increased selection of PD among patients. When patients are presented with predialysis education clearly outlining the different treatment options, they are more likely to select a home dialysis modality.\(^6\) However, many patients do not receive predialysis education, and when they do, there is variation in what types of information they receive,\(^7\) as well as in the educational methods and system of delivery and support. As a consequence, overall rates of PD use remain much lower than those of in-center dialysis, with a global average of only approximately 11%. In-center HD remains the dominant renal replacement therapy, but the rate of PD varies greatly between countries\(^8\) and between centers within a country.\(^9\)

The present review aims to review evidence on effective components of predialysis education programs as related to modality choice and selected clinical outcomes. This aids clinical teams in setting up educational processes to ensure patients make informed decisions.

**Methods**

**Identification and screening**

PubMed MEDLINE and Ovid databases as well as the Cochrane Library were used to search the academic literature. A tailored search string was defined in order to maximize the number of relevant results. As we were interested in articles specifically addressing the subject of predialysis education, we built the search string in a way that those terms needed to be in the title or abstract of the article: (predialysis[tiab] or pre-dialysis[tiab] or peritoneal dialysis[tiab] or home dialysis[tiab]) and (education[tiab] or information[tiab] or decision[tiab]).

To ensure data was relatively current, a limit was imposed on the search, with inclusion of studies from January 1, 1995 to December 31, 2013. A second limit was added; only papers available in English were accepted. After applying the filters, the total number of search hits returned amounted to 1,005.

**Eligibility, inclusion, and exclusion**

Regarding the patient group the following inclusion criteria applied:

- Adults only (≥18 years old)
- Predialysis education for renal replacement therapy for chronic kidney disease (CKD) patients stage III, IV, and V
- Planned start patients, unplanned start patients, and patients on dialysis, ie, incident and prevalent patients.

With regard to the information presented on and the structure of the predialysis education programs, articles were only included if the following applied:

- A relatively detailed description of the program, such as number and content of sessions, and descriptions of educators
- Multiple sessions – a single session education was not considered a "program"
- Preferably, a duration greater than 1 month
- A multidisciplinary program involving physicians, nurses, dieticians, etc.

Regarding outcomes of the predialysis education, the scope of the literature review was broad. The following outcomes were included, if articles were available:

- Dialysis modality choice and the numbers of patients choosing each modality
- Any clinical outcome associated with predialysis education
- Health-related quality of life
- Measures associated with patient choice
- Financial impact of patients choosing more home therapies
- Patient satisfaction.

The literature was also reviewed for any information on processes, pathways, and organization of the predialysis education programs, such as:

- Patient decision making process
- Patient identification and enrolment
- Content, structure, and methodology of the predialysis education program.

Studies were excluded if the following applied:

- The study addressed practical dialysis technique training only (on PD for instance)
- Anecdotal stories on treatment option education only
- Education materials alone (ie, without process, resources, etc)
- CKD patients stage I–II;
- Patient support groups only (instead of education program)
- Too brief or unclear description of the predialysis education program.

**Web search**

In addition to the literature searches, a gray literature search was performed using Google. The web search was done on October 19, 2012 with the following search string: (–predialysis and [care or program or education or treatment option]).
Searching in the first ten pages provided relevant information related to CKD educational program. Nineteen links were found to be relevant; information varied between papers, guidelines, annual reports, survey results, web information resources on CKD, web-based program descriptions, and PowerPoint presentations.

Papers were excluded if they were already included in the literature search. An additional search on websites of nephrology and patient association was done. This included the following countries: Finland, Denmark, Norway, the Netherlands, UK, Canada, USA, Australia, and New Zealand. This search did not deliver data that was sufficiently detailed on the content, structure, and components of educational programs.

Results

Relevant papers

The literature searches yielded 29 relevant studies of which 19 had some sort of (quasi-) experimental design, and the others were mostly narrative reviews (Figure 1). The 19 studies were analyzed for effective components of predialysis education programs. Studies with their design and outcomes are summarized in Table 1. The Cochrane Library contained no directly relevant systematic reviews.

Predialysis education and clinical outcomes

Modality selection

While no quantitative analysis was conducted, studies reported more favorable outcomes for the patients attending a predialysis education program than those patients who did not attend a predialysis education program. Of nine studies reporting on dialysis modality selection using an intervention and control group, six noted a higher proportion of patients selecting home dialysis (PD or another home modality), while three found no significant difference in modality choice. Four studies with pre- and post- intervention (predialysis education) measurements showed higher levels of home dialysis use after the predialysis education intervention.

Patient knowledge

Four of 19 quasi-experimental studies reported on measures of patient knowledge. All reported higher levels of knowledge

Figure 1 Flowchart of literature selection.
Table 1: Studies evaluating predialysis education programs: design, outcome, and summary of results

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Study design</th>
<th>Patient numbers</th>
<th>Patient characteristics</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agraharkar et al</td>
<td>2003</td>
<td>USA</td>
<td>Patient survey</td>
<td>136 (all received ed)</td>
<td>Age unknown, CKD IV-V, new patients on dialysis</td>
<td>Capture rate home dialysis (PD and HHD): 13% in 2001/2002, which is 1.17% growth as compared to 2000/2001.</td>
</tr>
<tr>
<td>Chanouzas et al</td>
<td>2012</td>
<td>UK</td>
<td>Retrospective cohort</td>
<td>118 (questionnaires returned, 49%)</td>
<td>CKD IV-V, incident predialysis patients Mean age 57.8 years, predialysis patients, eGFR 17.3 mL/min per 1.73 m²</td>
<td>20% of patients had chosen PD. 50% of patients choosing PD attended a formal education day vs 33% of HD patients. Intervention group had significantly less unplanned urgent dialysis (8.7% vs 24.2%); shortened hospital days (2.16 vs 5.05 days/patient per year), less cardiac events (2.7% vs 9.4%), and less infections (4.0% vs 12.1%). No difference in modality choice.</td>
</tr>
<tr>
<td>Cho et al</td>
<td>2012</td>
<td>Korea</td>
<td>Retrospective cohort</td>
<td>298 (149 in [intervention = education] and control group)</td>
<td>Mean age 61 years, 82% of patients had chosen PD. 50% of patients choosing PD attended a formal education day vs 33% of HD patients. Intervention group had significantly less unplanned urgent dialysis (8.7% vs 24.2%); shortened hospital days (2.16 vs 5.05 days/patient per year), less cardiac events (2.7% vs 9.4%), and less infections (4.0% vs 12.1%). No difference in modality choice.</td>
<td></td>
</tr>
<tr>
<td>Goovaerts et al</td>
<td>2005</td>
<td>Belgium</td>
<td>Multicenter patient survey</td>
<td>185 (all received predialysis education)</td>
<td>CKD IV-V, mean age 53 years</td>
<td>Eight patients preemptive transplantation, 177 on dialysis: 75 (40%) in-center HD, 102 patients self-care modality: 55 (31%) PD, 30 (16%) self-care dialysis in satellite unit, 17 (9%) home HD. Informed patients: 57% chose hemodialysis, 31.4% CAPD, 11.6% APD. Uninformed patients: 83% hemodialysis, 13.6% chose CAPD, 3.4% chose APD.</td>
</tr>
<tr>
<td>Gomez et al</td>
<td>1999</td>
<td>Spain</td>
<td>Multicenter patient survey</td>
<td>174 (86 informed, 88 uninformed patients)</td>
<td>Mean age 55.8 years, any patient in predialysis program</td>
<td>Significant change in PD selection: 30% preferred PD before the education, 46% selected PD after education. Significant knowledge gains. No significant changes in feelings of hope and fear. Significantly more patients in the intervention group stated that they had sufficient knowledge to participate in choosing dialysis modality. And they were significantly more informed in the post-education evaluation than in the pretest.</td>
</tr>
<tr>
<td>King et al</td>
<td>2008</td>
<td>USA</td>
<td>Patient survey</td>
<td>1.844 patients</td>
<td>Median age 61 years, 82% not yet on dialysis, CKD stage unknown</td>
<td>No significant differences in symptoms, duration of kidney disease, choice of dialysis treatment, cause of renal disease, symptoms, or overall health. The intervention group scored significantly better in terms of mood, less mobility problems, less functional disabilities, and lower levels of anxiety.</td>
</tr>
<tr>
<td>Klang et al</td>
<td>1999</td>
<td>Sweden</td>
<td>Intervention study. Pre-</td>
<td>56 (28 intervention, 28 control group)</td>
<td>CKD IV-V, mean age: 54 years treatment group, 58 years control group</td>
<td>No significant differences in symptoms, duration of kidney disease, choice of dialysis treatment, cause of renal disease, symptoms, or overall health. The intervention group scored significantly better in terms of mood, less mobility problems, less functional disabilities, and lower levels of anxiety.</td>
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</tr>
<tr>
<td>Lacson et al</td>
<td>2011</td>
<td>USA</td>
<td>Observational cohort</td>
<td>30,217 patients of which 3,165 exposed to educational program</td>
<td>Mean age 63 years, CKD III–V</td>
<td>Educational program group was significantly more likely to select PD (25.2% vs 4.1%; adjusted OR 5.13), and they had a significant better survival rate (adjusted HR 0.61).</td>
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<tr>
<td>Levin et al</td>
<td>1997</td>
<td>Canada</td>
<td>Prospective cohort study</td>
<td>76 (37 exposed to educational program, 39 standard care)</td>
<td>CKD III–V, age unknown</td>
<td>53% of the educational program group chose PD compared to 42% in the control group (not significant), and they had significantly less hospital days (6.5 vs 13.5). The educational-program group had better biochemical markers: blood pressure, calcium, phosphate, and anemia. 50.9% of patients educated/counseled before starting dialysis chose PD vs 34.8% of patients who received education after commencing dialysis.</td>
</tr>
<tr>
<td>Little et al</td>
<td>2001</td>
<td>UK</td>
<td>Patient survey</td>
<td>254 (165 counseled before commencing dialysis; 89 after)</td>
<td>CKD V, mean age 62.2 years, patients starting dialysis or just on dialysis</td>
<td>82.1% of the intervention group chose SCD vs 50% of the control group. There was no increase in patients choosing SCD after receiving books and video. The small group education session was the only statistically significant factor in selecting SCD.</td>
</tr>
<tr>
<td>Manns et al</td>
<td>2005</td>
<td>Canada</td>
<td>Randomized trial</td>
<td>70 randomized patients Two-phase patient-centered educational intervention vs standard care and education</td>
<td>CKD III–IV, median age 64 years</td>
<td>53% of the educational program group chose PD compared to 42% in the control group (not significant), and they had significantly less hospital days (6.5 vs 13.5). The educational-program group had better biochemical markers: blood pressure, calcium, phosphate, and anemia. 50.9% of patients educated/counseled before starting dialysis chose PD vs 34.8% of patients who received education after commencing dialysis.</td>
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</table>

Note: CKD = Chronic Kidney Disease, PD = Peritoneal Dialysis, HHD = Home Hemodialysis, APD = Automated Peritoneal Dialysis, SCD = Sustainable Compliance Dialysis.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Year</th>
<th>Country</th>
<th>Study Design</th>
<th>Study Period</th>
<th>Sample Size</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>McLaughlin et al.</td>
<td>2008</td>
<td>Canada</td>
<td>Randomized trial</td>
<td>2003 (same as previous study)</td>
<td>70 randomized patients</td>
<td>Freedom, lifestyle, and control were identified as three reasons to engage in SCD. Patients who received the educational intervention were more likely to perceive freedom and control as advantages and were more likely to select SCD.</td>
</tr>
<tr>
<td>Pagels et al.</td>
<td>2000</td>
<td>Sweden</td>
<td>Observational cohort</td>
<td>2004</td>
<td>223 (70 exposed to nurse-led clinics, 153 comparison group)</td>
<td>52% (n=11) of the nurse-led clinics group initiated home dialysis (HHD: n=4, PD: n=7) as compared to 33% in the comparison group.</td>
</tr>
<tr>
<td>Piccoli</td>
<td>2006</td>
<td>Italy</td>
<td>Questionnaire</td>
<td>1999</td>
<td>50 (18 followed educational program)</td>
<td>12 of 18 patients (66%) who followed the education program chose home dialysis. Of another 31 patients who started dialysis in the center, 13 (42%) chose PD, 3 (10%) HHD, and 15 (48%) chose hospital dialysis.</td>
</tr>
<tr>
<td>Rasgon et al.</td>
<td>1996</td>
<td>USA</td>
<td>Patient records review</td>
<td>1995</td>
<td>30 patients on home dialysis (2 HHD, 28 CAPD)</td>
<td>74% (14 out of 19) of employed patients maintained their employment status after initiating home RRT.</td>
</tr>
<tr>
<td>Ribitsch et al.</td>
<td>2013</td>
<td>Austria</td>
<td>Retrospective cohort study</td>
<td>2004–2008</td>
<td>227 patients (70 received predialysis education, 152 did not)</td>
<td>In the group receiving education, 54.3% started with PD vs 28% in the comparison group; in the education group, 45.7% started with HD vs 72% among the standard-care comparators.</td>
</tr>
<tr>
<td>Rioux et al.</td>
<td>2011</td>
<td>Canada</td>
<td>Retrospective observational cohort</td>
<td>2005–2009</td>
<td>228 patients (all receiving multimedia education)</td>
<td>35% of all acute starters adopted home dialysis after the implementation of the in-hospital education program vs 13% before the program.</td>
</tr>
<tr>
<td>Watson</td>
<td>2008</td>
<td>Canada</td>
<td>Observational study: pre- and post- comparison advanced practice nurse</td>
<td>2008-2009</td>
<td>119 on chronic dialysis</td>
<td>The proportion of patients on in-center dialysis was reduced from 87% to 33% after the intervention, and the proportion of patients on home dialysis increased from 13% to 67%.</td>
</tr>
</tbody>
</table>

**Abbreviations:** APD, automated PD; CAPD, continuous ambulatory PD; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; HD, hemodialysis; HHD, home HD; HR, hazard ratio; PD, peritoneal dialysis; OR, odds ratio; RRT, renal replacement therapy; SCD, self-care dialysis.
of end-stage renal disease and of different treatment options for patients receiving predialysis education.12,36,40

Mortality and morbidity
Two studies reported on length of hospital stay, which was lower for the education groups (6.5 versus 13.5 total hospital days; 2.2 versus 5.1 hospital days/patient per year),36,57 thus leading to cost savings.36 Eight studies reported on mortality and morbidity (including biochemical indicators, cardiovascular incidents, infection rates, emotional status).31,35,37,46,58,59 All studies reported better rates for the treatment group.

 Costs
 Watson47 found a reduction of in-center dialysis from 87% to 33% due to the introduction of an advanced practice nurse with an educating/counseling role. They calculated a theoretical cost saving of $1,328,000 over a 2.5-year period as opposed to the situation without this reduction.

 Components of predialysis education programs
 The articles retrieved from the literature and gray literature search addressed a wide range of aspects of predialysis education programs.

 Multidisciplinary education
 Predialysis care is delivered by a multidisciplinary team including, most of the time, a nephrologist, a nurse, a dietitian, and a social worker.10,12,14,16,18,19,24,25,27,28,60 A multidisciplinary team can also include: a pharmacist who explains information on the medicines needs;21,22 a psychologist, who could be a specialized nurse for emotional support when needed;10,24 a case manager;25 representatives from the local patient kidney support group; and other patients established on maintenance dialysis.27 It is often not clear from the literature whether the members of the multidisciplinary care team are also the main educators for the patient. Of course there will be knowledge transfer during a patient’s visit to a nephrologist or dietitian. It is, however, most of the time not known whether this was in the setting of an educational program with defined cognitive and functional goals.

 Seven articles retrieved from the scientific literature review described multidisciplinary education program,29,30,35,36,40,41 which consists of multiple education sessions where patients are educated by three or more health care professionals such as nephrologist, nurse, dietitian, social worker, home-dialysis coordinator, pharmacist, technician, or by other dialysis patients. An Australian survey revealed that although with multidisciplinary education patients are educated by three or more health care professionals, a high proportion of the education is done by the nurse specialist, as nephrologists have limited time for one-on-one education.61 Others see an important role of the nurse as a case manager in planning, implementing, and evaluating educational programs.22

 Delivery style
 The education delivery style can either be one-on-one sessions or class room teaching style. But in general, a mix of one-on-one and group sessions is advocated. Educational programs should contain individualized one-on-one counseling sessions with a member/members of the multidisciplinary team. This can be a physician, nephrologist, nurse, dietician, social worker, etc.39,41,55 In addition to those small group discussions, peer counseling and problem-solving or “brainstorming” sessions have been described wherein patients discuss treatment modalities, as well as barriers and benefits, and troubleshooting of possible problems with other patients (or facilitators).7,40,41 The group sessions can have a variety of formats such as group lectures, interactive workshops, or open forum sessions.

 In the national Australian survey on predialysis education, most participating units combined group and one-on-one sessions. Group education sessions seemed to affect the choice of home dialysis; home dialysis rates increased from 20% to 38%.19

 The most ideal design for investigating the effect of certain components of a predialysis education program would be a head-to-head comparison of two programs that differ in a single aspect, while patients are randomly assigned to one of the programs. There was only one study making a head-to-head comparison of two “programs”40 using randomization. In this study, standard care was compared to a group of patients who received standard care plus two-phase education. The standard care consisted of receiving teaching about kidney disease, including dietary instructions, and detailed information about the different modalities of renal replacement therapy. This occurred via an initial 3-hour one-on-one session where patients were seen by a nurse, dietician, and social worker. Patients were then followed by their nephrologist and the multidisciplinary care team every 3–6 months. The two-phase additional education consisted of phase 1, in which patients received four written manuals and a video, and phase 2, which consisted of a 90-minute problem solving group session. The small-group education (phase 2) turned out to be effective in enhancing the proportion of
patients choosing self-care dialysis (including home- and self-care HD and PD) from 50% to 82%.

Frequency and duration
The number of sessions and duration per session varies by educational program. There are reports of six individual sessions of 1 hour; four sessions, 1 night a week for 2 hours; or at least four to five interviews. Table 2 contains a description of the educational programs retrieved from the scientific literature.

In the national Australian survey, educators were asked to fill out how much time each new patient spends receiving information regarding treatment options. Thirteen percent of units (n=4) spent on average less than 1 hour providing education. Thirteen units were educating for 1–2 hours and 13 units for over 2 hours. The rate of home dialysis was 36% in the units offering the longest education hours (>3 hours) compared to 20% in the units averaging less than 1 hour’s education.

Timing
Timing of education was seen as important to the patient and health care professional, but the studies did not allow firm conclusions to be reached over timing vs dialysis start. The more time a patient has to acquire knowledge prior to commencing dialysis, the better their clinical outcomes and the more likely they are to select a home dialysis modality. An estimated glomerular filtration rate of less than 30 mL/min (stage IV CKD) has been reported as ideal for referral to CKD clinic. Others recommend that patients should be referred as early as possible to renal education (>6 months).

Learning theory
Basing the educational program on the principles of adult learning ensures the appropriateness of delivery of educational materials and content in a manner best understood by this patient population and can help expedite the process of adult learning. One study tested a new PD home training program based on adult learning theory in a quasi-experimental prospective study using a nonstandardized conventional training group as controls. The adult-learning-based program incorporated the different domains of learning and accommodated different perceptual styles (eg, visual and auditory). The new training program improved patient outcomes (eg, less exit-site infections, less dropout to HD after infection, better fluid balance scores, and better compliance scores). Although this study focused on patients who had already chosen PD, it is a good example of the benefits of a well-designed educational program.

Discussion
Weak evidence base
Unfortunately, the findings presented in the previous section are not based on a strong evidence base since there are a number of limitations found within the studies available for analysis. The study quality was often poor; experimental studies often lacked a control group, as well as pre- and postintervention measures. In some instances, data was presented in comparison to other reports or to previous findings of modality rates rather than in comparison to a control group of patients. Some studies used a quasi-experimental design but did not provide dialysis modality measures, again limiting full analysis.

Two studies reported rates of “self-care dialysis” but neglected to differentiate between home dialysis (PD or home HD) and self-care HD performed in a satellite unit.

There was only one study presenting a head-to-head comparison of educational programs showing that problemsolving group sessions were instrumental in modality choice. There were no Cochrane Library systematic reviews that related directly to educational programs for dialysis options. One more-recent Cochrane systematic review compared studies examining early or late referral to renal units in terms of clinical outcomes including initial dialysis modality. The review did not examine educational programs but did note that studies show early referral results in greater use of PD. The overall better preparation for dialysis in early-referred patients probably relates in part to the education delivered at this time, but the evidence review did not allow for that conclusion.

Need for standardization
Because of the lack of studies comparing detailed components of educational programs, this literature review employed a qualitative rather than quantitative design. The data extraction was conducted with a quasi-systematic method. Keywords and phrases describing content were compared and grouped across studies. However, there is little standardization in the description of intervention (in this case, educational content). For this reason, studies may describe the same content in very different ways or use the same terms to describe very different methods and content. For example, when a program describes a patient’s “case worker”, they could be referring to an individual who meets with the patients to offer support and counseling, but they could also be referring to the role of a health care professional who manages the patient’s interactions between members of the nephrology team (ie, ensuring that the patient is seen

Table 2 contains a description of the components of educational programs, this literature review

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Table 2 Summary description of predialysis educational programs evaluated in (quasi-) experimental or observational studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Educational program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agraharkar et al</td>
<td>2003</td>
<td>USA</td>
<td>Predialysis option education:</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Meet with nephrologist, options explained.</td>
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<td></td>
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<td></td>
<td>• Dialysis education by home dialysis coordinator (includes demonstration of PD on mannequin), video provided.</td>
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<td></td>
<td>• Meeting with current home dialysis patients.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Disposition meeting with multidisciplinary group for patient and family.</td>
</tr>
<tr>
<td>Chanouzas et al</td>
<td>2012</td>
<td>UK</td>
<td>Standard pre-dialysis education program:</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• When GFR &lt;25 mL/min, meeting with the kidney failure support team. Home visit is arranged.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Home visit: visual, verbal, and written formats (leaflets, booklets, and DVDs). All modalities are described in detail. Visits typically last 2–4 hours. Interpreter present if needed and family advised to be present.</td>
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<tr>
<td></td>
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<td></td>
<td>• Further education is offered at home if the patient is still uncertain.</td>
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<td></td>
<td></td>
<td></td>
<td>• Invitations to PD and HD unit to meet patients and nurses. Option to meet expert patients.</td>
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<td></td>
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<td></td>
<td>• A formal education day every 3 months: half-day workshop on lifestyle and dietary modifications for each modality.</td>
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<td></td>
<td></td>
<td></td>
<td>• All patients seen within 4 weeks to discuss modality choice, and encouraged to come to a decision within 3 months.</td>
</tr>
<tr>
<td>Cho et al</td>
<td>2012</td>
<td>Korea</td>
<td>Multidisciplinary predialysis education:</td>
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<td></td>
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<td></td>
<td>• Group session by multidisciplinary team (2 hours). Education on: normal kidney function; pathophysiological alterations in CKD; nutritional and medical treatment; and RRT options. Multidisciplinary team.</td>
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<td>• Individual session by nurse and dietician (1.5–2 hours): patient and family; slide presentation on diet and RRT options (benefits, complications, and outcomes); video on different RRT choices. Dietician prescribes diet, take home booklets.</td>
</tr>
<tr>
<td>Goovaerts et al</td>
<td>2005</td>
<td>Belgium</td>
<td>Predialysis education program for all patients with a GFR of &lt;25 mL/min:</td>
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<td>• PDEP run by a team of eight nurses. Patients are informed on an individual basis.</td>
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<td>• Watch three in-house videos (one on each, HD, CAPD, and APD) (60 minutes in total).</td>
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<td>• Patients receive a brochure summarizing key points, are invited to speak with other patients on the different RRTs, and can visit centers if they wish.</td>
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<td></td>
<td>• Contact with a social worker and dietician is arranged.</td>
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<tr>
<td>Gomez et al</td>
<td>1999</td>
<td>Spain</td>
<td>Standardized information package from Baxter Healthcare:</td>
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<td>• First appointment. Flip chart explaining treatment options is shown. Patient is given guidebook to read at home.</td>
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<td>• Second appointment. Starts by discussing and clarifying doubts the patient may have, answering questions. Video is shown. It is also recommended that the patient sees how the various techniques of dialysis are carried out in practice.</td>
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<tr>
<td>King et al</td>
<td>2008</td>
<td>USA</td>
<td>Statewide kidney education program. Multidisciplinary education to patients prior to starting dialysis as well as to patients who wish to switch modality:</td>
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<td>• Six classes of 60–75 minutes each on the following topics: 1) introduction to kidney disease; 2) diet and kidney disease; 3) financing and coping with kidney disease; 4) hemodialysis; 5) peritoneal dialysis; and 6) kidney transplant.</td>
</tr>
<tr>
<td>Klang et al</td>
<td>1999</td>
<td>Sweden</td>
<td>Specific educational salutogenic program based on relationship between health, stress and coping.</td>
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<tr>
<td></td>
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<td>• Four sessions (2 hours each) of group teaching with a classroom approach, covering one theme per session.</td>
</tr>
<tr>
<td>Klang et al</td>
<td>1998</td>
<td>Sweden</td>
<td>Themes: renal disease and dietary management; active renal replacement therapies; physical exercise training; and possible impact of renal failure on finances, family, and social life.</td>
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<td>For each series, 5–7 patients (of similar age) were invited to attend along with a relative. Patients were divided into three groups based on age: 1) young adults; 2) middle-aged; and 3) elderly. Throughout the program, the patients and their relatives had established contact with the nephrology team, consisting of a physician, a specialist-nurse, a clinical nutritionist, a physiotherapist, and a clinical social worker.</td>
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<td>Same as the above.</td>
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Lacson et al\textsuperscript{37} 2011 USA

Treatment option education: a multiple-touch program.
- Initial education completed in a single group class session.
- With patient consent, followed up by contact at 30, 90, and 180 days thereafter to: 1) review treatment options; 2) inquire about each patient's kidney function/status and, if appropriate, dialysis access planning; and 3) provide feedback to the referring physician.

Levin et al\textsuperscript{38} 1997 Canada

All patients were referred for a formal orientation to dialysis sessions of 2–3 hours delivered by a nurse educator and social worker. Session consisted of an educational video; a standardized discussion of RRT options; demonstration of PD and HD techniques; and discussion of no treatment. In addition, the educational group following the multidisciplinary predialysis care clinic for CKD patients followed a predialysis clinic which included: discussions about renal function, blood pressure, bone disease, and diet therapy, delivered in a stepwise fashion over the course of multiple visits.

Frequency of visits and lab tests determined by CKD stage and severity.
Initial visit lasted 3 hours, after that, visits are 1.5 hours, every 2, 3, or 6 months depending on CKD stage.

Little et al\textsuperscript{39} 2001 UK

Modality-choice education program of Birmingham dialysis center:
- At initial interview written information on CAPD and HD.
- At follow-up: more detailed counseling and assessment. Lasts 1–2 hours. Video package is provided in addition to verbal and written materials.
- Patients given tour of HD unit and invited to discuss dialysis with HD and CAPD patients.
- Patient's initial modality choice recorded and a follow-up telephone call scheduled. Additional follow-up and counseling arranged as required.

Manns et al\textsuperscript{40} 2005 Canada

In addition to multidisciplinary care, two-phase education: phase 1: education materials, phase 2: small group problem solving education session.
Timetable phase 2:
- (10 minutes) introductions, overview, and goals of the course (nurse facilitator).
- (10 minutes) introduction of topic: self-care dialysis (physician facilitator).
- (20 minutes) brainstorming session (physician facilitator).
- (20 minutes) what type of dialysis (patients discuss in small groups).
- (10 minutes) group presentations (patient presenters).
- (10 minutes) video presentation (nurse).
- Feedback for the course and close (physician).

McLaughlin et al\textsuperscript{41} 2008 Canada

Same as the above.

Pagels et al\textsuperscript{42} 2008 Sweden

Nurse-led educational clinics (duration, approximately 1 hour) in conjunction with physician outpatient care: the content of each visit was determined largely by each individual patient's questions and wishes. Focus was on:
- discussions aimed at motivating, guiding, and supporting the patient;
- education (ie, kidney function, symptoms, test results, medication, treatment alternatives);
- self-care (diet, controlling edema);
- daily life with chronic illness;
- well-being and quality of life; and
- on health check-ups.

Piccoli 2000 Italy

A multistep education program that follows patients along the extended path from chronic renal failure to dialysis. Monthly 2-hour lessons on the main aspects of ESRD (dialysis, transplantation, diet, drugs, etc). Subjects are chosen in consultation with patients. Lessons consist of informal discussions held by the familiar caregivers, with the occasional help of experts.

Rasgon et al\textsuperscript{44} 1996 USA

Multidisciplinary predialysis education program:
- Psychosocial assessment by LCSW.
- Education about dialysis and choices of modalities by LCSW and/or renal nurse educator.
- Orientation to dialysis unit and counseling sessions with patient and family members by LCSW.
- Peer counseling facilitated by LCSW and/or renal nurse educator.
Table 2 (Continued)

<table>
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<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Educational program</th>
</tr>
</thead>
</table>
| Ribitsch et al  | 2013 | Austria | Multidisciplinary predialysis education program:  
  - Two consecutive days, small groups (maximum 6 patients plus relatives).  
  - Multidisciplinary team: nurse, dietician, nephrologist.  
  - First day, 2-hour session: basic information on medical, dietary, and lifestyle issues.  
  - Second day, 2-hour session: practical demonstration HD and PD.                                                                                                                                                                                                                   |
| Rioux et al    | 2011 | Canada  | Multidisciplinary education program:  
  - Advanced nurse practitioner provides multimedia education on dialysis modalities to patients using manuals, flipcharts, pamphlets, and DVDs.  
  - In-hospital education occurs over 3–5 appointments. Family encouraged to attend.  
  - Attempt is made to assess and match patient’s values, abilities, and lifestyle to their RRT modality needs.  
  - Discharge plan of RRT is discussed. Different modalities are discussed, including benefits and barriers.  
  - Patients invited to visit HHD and PD units.                                                                                                                                                                                                                                      |
| Watson         | 2008 | Canada  | Advanced practice nurses were hired to intervene on unplanned dialysis-start patients, to give them “predialysis education” after they had begun dialysis. Number of sessions not specified; flexible to patient’s needs. Topics covered among others:  
  - Social situation (home? employed?).  
  - Values and lifestyle (independence?).  
  - Educate the basics (fundamental renal function, RRT).  
  - Find education medium that suits patient learning style (video, written).  
  - Discuss modalities (positive and negative aspects).  
  - Tours of dialysis facilities.  
  - Assess patient coping styles (helps determine modality and give patient strength).                                                                                                                                                                                                 |

Abbreviations: APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; CKD, chronic kidney disease; ESRD, end-stage renal disease; GFR, glomerular filtration rate; HD, hemodialysis; HHD, home HD; LCSW, licensed social worker; PD, peritoneal dialysis; PDEP, PD education program; RRT, renal replacement therapy.
by the nephrologist, arranging appointments with dieticians and social workers as needed), or referring to something else entirely. Likewise, many papers do not use educational theory to describe the selection or design of the educational programs. Much of the creation and description of the educational programs and their content is left to the discretion of the study authors, with no standardized method to describe this across the field.

This lack of standardization of education programs is also acknowledged by professionals in the field of predialysis education. The Provincial PD Joint Initiative in Ontario, Canada, acknowledges that standardized predialysis education supports patients in understanding their options but notes there are no recommendations as to its components or content.22

The development of effective interventions is hampered by the absence of a nomenclature to specify and report their content. This limits the possibility of replicating effective interventions, synthesizing evidence, and understanding the causal mechanisms underlying behavior change. In contrast, biomedical interventions are precisely specified (eg, the pharmacological “ingredients” of prescribed drugs, their dose and frequency of administration). For most complex interventions, the precise “ingredients” are unknown; descriptions (eg, “behavioral counseling”) can mean different things to different researchers or implementers. The lack of a method for specifying complex interventions undermines the precision of the methodology to review evidence and synthesise its effectiveness, posing a problem for secondary as well as primary research.63

The UK Medical Research Council’s guidance for developing and evaluating complex interventions acknowledges the need for improved methods of specifying and reporting intervention content. The CONSORT statement for randomized trials of nonpharmacologic interventions calls for precise details of the intervention, including a description of the different intervention components.64 For example, this issue of unspecified intervention content is found in other areas of chronic disease, not only renal education programs. For example, researchers have been found to report low confidence in their ability to replicate highly effective interventions for diabetes prevention.65

For the development of a taxonomy of education content and regulations for describing this taxonomy to be developed and promoted in the world of renal education, we could learn from other academic fields, such as a taxonomy of behavior change techniques and the use of theory in behavior change intervention design, which are two models that could be expanded and adapted to the field of predialysis education.65,66

Educating patients about dialysis options is important to allow informed decision making, but clinical evidence is lacking concerning the most effective educational methods and staff competencies to develop the education. There is a need for a standardized approach built on best evidence from CKD and also from other clinical conditions and existing knowledge on the evaluation of complex interventions to ensure formal evaluation of predialysis education programs, and their effects on clinical outcomes and modality choice.

Acknowledgment

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Disclosure

Peter A Rutherford was an employee of Baxter Healthcare at the time of performing this research. The authors report no conflicts of interest in this work.

References

8. ERA-EDTA Registry. ERA-EDTA Registry Annual Report 2011. Amsterdam: Academic Medical Center, Department of Medical Informatics; 2013.