Abstract

Our first study was a systematic review that explored the relationship between patient-targeted educational interventions and the selection and use of PD. Of 3540 citations screened, 15 studies met our inclusion criteria. Patient targeted educational interventions were associated with a 2-fold increase in the odds of choosing PD. Our second study used data from this randomized trial to explore if the observed increased likelihood of choosing self-care dialysis resulted in increased likelihood of receiving self-care dialysis. In this clinical trial, seventy patients were randomized to receive either standard care or the educational intervention in 2003. The proportion of patients who received self-care dialysis as their first treatment in extended follow-up was not significantly different between the intervention group and the usual care group. In summary, this thesis work found a strong association between patient-targeted education interventions and the subsequent selection of PD, the most common form of self-care dialysis.
Preface

The following two manuscripts are based on work from this thesis and have been submitted or are in press. For both papers, Dan Devoe was involved in the conceptualization and design of the studies. He was also responsible for drafting the manuscripts, conducting the analysis and interpreting the data with guidance from his supervisors and thesis committee (Drs. Robert Quinn, Pietro Ravani, Matthew James, and Braden Manns). All authors contributed important intellectual content and critically reviewed the papers.


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To Jennette – your support was instrumental
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Epigraph

Imagination is the highest form of research.

~ Albert Einstein
CHAPTER 1. INTRODUCTION
1.1 Treatment Options for Patients with End Stage Renal Disease

Chronic kidney disease, defined as estimated glomerular filtration rate <60 ml/min/1.73 m² (a quantitative measure of kidney function) or presence of markers of kidney dysfunction, affects 13% of the adult population in North America¹. Individuals with end-stage renal disease (ESRD) make up 0.1% of the population, but are a vulnerable population with high rates of morbidity and mortality, as well as a reduced quality of life²-⁶. Caring for people with kidney failure is resource-intense and accounts for up to 7% of health care expenditures in developed countries⁷. While kidney transplantation is the preferred treatment for kidney failure⁶, the majority of people with kidney failure are treated with either hemodialysis (HD) or peritoneal dialysis (PD) therapy because of scarcity of organs from living or deceased donors².

PD requires the insertion of a dialysis catheter into the abdomen to exchange dialysis fluid 4 or more times per day; the patient performs PD at home. HD is typically performed in a hospital setting and requires access to the bloodstream to remove, clean and return the blood during three 4-hour sessions per week. While HD can be done at home, the complexity of the procedure restricts this choice to a more selected group of patients.

PD and HD are considered equivalent with regard to important clinical outcomes (e.g. survival, hospitalization, and quality of life)⁹-¹². However, PD has several important benefits over in-centre HD: the patient can be more independent; the therapy can be done while sleeping; it allows for a less restrictive diet (potassium and water intake); it makes travel much easier; it allows for a flexible schedule; and it costs an estimated $25,000 less per patient-year¹³. Thus, even small changes in the proportion of
patients treated with PD translate into the potential for large savings to the health care system, without compromising patient outcomes or quality of life.

1.2 Global Variability in PD Uptake

There is significant variability in the uptake of PD globally. PD use in the USA has declined by 8% since the 1980s\textsuperscript{14}. Today in the USA, PD is utilized among less than 7% of all patients with kidney failure\textsuperscript{15}. In recent years, the USA has implemented a bundled payment system, which has led to renewed growth in PD\textsuperscript{16}. Nevertheless, PD utilization in the USA is still behind Canada and other developed countries.

Over the years numerous patient level, care provider level, and system level factors have led to the decline of PD and an increase in HD utilization. Nephrologists’ experience with HD, the perceived superiority of HD, reimbursement incentives, and higher transplantation rates among patients initially treated with PD have all resulted in lower PD use \textsuperscript{14,17-19}. In contrast, in countries that have adopted a PD-first policy, PD accounts for \textsuperscript{>70\%} of renal replacement therapy\textsuperscript{15}. The PD-first policy implies that PD is offered as the initial dialysis modality over HD. However, a PD-first policy has not been adopted in many developed countries\textsuperscript{20}.

The reason for the lack of adoption of a PD-first policy is two-fold. First, the only randomized trial comparing PD and HD was unsuccessful and prematurely stopped\textsuperscript{21}. In an environment where both HD and PD are available, and in the absence of robust data suggesting the superiority of one method over the other, many believe patients should have a choice\textsuperscript{22}. Second, patient choice of treatment modality is influenced by the
nephrology teams perspective, which in turn may be affected by context and several barriers to PD uptake.

1.3 Barriers to PD Use in Canadian Context

PD is the most cost efficient treatment and increasing the appropriate use of PD has become a priority in many jurisdictions, including Alberta. There are subtle but important differences between the Canadian context and the USA. For example, physician level issues such as biased attitude against therapy, inexperience, and lack of proper training may be less common in Canada than in the USA. Availability of universal health care coverage may also be a contributing factor because the ability to pay for therapy is not an issue for Canadian patients.

Maximizing the use of PD is a complex process and most large-scale efforts to increase the number of patients treated with PD have been unsuccessful. There are three important barriers to increasing the use of PD: patient eligibility for PD; barriers to treating urgent cases with PD; and the need for self-care training and education. First, only about 75% of individuals are potentially eligible for PD therapy. The other 25% of patients have medical or social contraindications to treatment that are more common in a population that is older and has higher rates of comorbidities. Second, half of the patients initiating dialysis will start urgently in a hospital setting. In most centers, HD is the only available treatment for such patients and many will choose to continue with HD as their permanent dialysis treatment. Third, identifying, assessing, and educating patients about their treatment options and allowing them to make an informed choice requires lead-time and a coordinated, interdisciplinary approach involving nephrologists,
surgeons, dieticians, and nurses, that can be difficult to orchestrate and resource intensive. Educating patients about their treatment options, including those who start dialysis urgently with HD, is the only modifiable barrier and as such it merits further investigation.

1.4 Rationale for Studying Educational Interventions to Increase PD Use

Patient-directed interventions, such as educating patients about their treatment options may lead to increased use of PD. Prior to the start of dialysis, or after the initiation of dialysis in those who do not receive pre-dialysis care and receive HD as initial modality, patients can ideally be educated about treatment options available to them. They can be educated in order to make an informed decision regarding their preferred form of renal replacement therapy. The availability of modality education and the format in which modality education is provided (e.g. video tutorials, peer-to-peer, nurse led, etc.) may impact the proportion of patients who ultimately choose PD as a preferred form of renal replacement therapy. There is a great deal of variability in the design of the educational strategies and a summary of the components of a successful modality education program, such as the ideal person or persons to deliver the material, the structure of the intervention (one-to-one vs. small group sessions), the duration of the intervention (single-day vs. multiple days), and the format of material, is needed. To gain insight into dialysis modality education programs, in the first part of this thesis work we have systematically reviewed the totality of evidence on educational interventions to promote the use of PD.
1.5 A Distinction Between PD Choice and Receipt of PD

Studies examining the impact of patient-targeted educational strategies select either choice of PD or receipt of PD as their primary outcomes. PD choice is defined as whether an individual ‘intends’ to do PD once they commence renal replacement therapy. Receipt of PD is defined as an individual receiving PD as their treatment modality. There is a tendency to infer that patients choosing PD will ultimately receive it. However, PD choice does not always translate into receipt of PD for several reasons. PD choice at a particular point in time may not convert into receipt of PD because patients may change their views and perspectives, they may become ineligible for PD due to occurrence of adverse events or a deterioration in their clinical conditions, they may receive a transplant, or they may urgently start on HD after they made a decision but before they can actually use PD. Treating PD choice and receipt of PD as synonymous may lead us to overestimate the impact of interventions on the uptake of PD. As a consequence, it is important to measure the receipt of PD when evaluating the true impact of an educational intervention; this is addressed in the second study of this thesis work.

We conducted a systematic review and meta-analysis of educational interventions to increase PD to help determine how to effectively increase the appropriate use of PD. This systematic review will help inform clinical practice and policy regarding potential differences in educational interventions to increase PD utilization, and new research in this area to design new educational interventions and test them in clinical trials.
In the follow-up study we focused on the effect of education on receipt of self-care dialysis over a long period of time in order to understand the differences between receipt and choice of self-care modalities. This research can lead to a significant improvement in understanding patient decision-making and how health providers can maximize patient-centered educational services to adequately equip patients with chronic kidney disease to select the proper treatment.

1.6 Outline of Thesis Contents

This thesis examines the relationships between educational interventions and increased utilization of PD. Each chapter of this document is distinct and formatted for independent publication as part of a manuscript-based thesis. Each study addresses a specific research question, study cohort and methods. Three common questions are explored throughout the thesis: (1) Do educational interventions increase preference for PD?; (2) Do educational intervention increase utilization of PD?; (3) Are certain educational components more effective than others? These questions are linked by the common objective of improving patient understanding of treatment options so they can make an informed choice. Chapter 2 is comprised of a systematic review assessing the association between educational interventions and the choice of PD. Within this study, we also explore the components of the educational interventions employed in each study to understand the components of a successful modality education program. Chapter 3 extends the results of the first paper and explores the uptake of home therapies in patients previously enrolled in a randomized control study and examines the impact of an educational intervention as well as expressed preference for self-care dialysis on the
likelihood of receiving PD. Finally, Chapter 4 summarizes the findings of the thesis and discusses the strengths and limitations of the studies, clinical implications of our findings, and potential directions for future research.
CHAPTER 2. PATIENT EDUCATION AND SELECTION OF PERITONEAL DIALYSIS: A SYSTEMATIC REVIEW AND META-ANALYSIS OF COHORT STUDIES AND RANDOMIZED TRIAL
2.1 Abstract

Background: Educational interventions are increasingly used to promote peritoneal dialysis (PD), the most common form of home therapy for end-stage renal disease (ESRD). A systematic appraisal of the evidence in support of dialysis modality education is needed to inform the design of patient-targeted interventions to increase selection of PD. We performed a systematic review and meta-analysis to characterize the relationship between patient-targeted educational interventions and the selection and use of PD in adult patients with, or at risk of ESRD.

Design, setting, participants, & measurements: We searched MEDLINE, EMBASE, CINAHL and EBMR in November 2013. We included observational studies and randomized trials of educational interventions designed to increase selection or use of PD. Pooled odds ratio were acquired using a random effects model.

Results: Of 2778 citations, 15 studies met our inclusion criteria, including one randomized trial. Patient-targeted educational interventions were associated with a 2-fold increase in the odds of choosing PD (pooled odds ratio [OR] 2.15; 95% CI, 1.07–4.32; I²=76.7%) based on results from 4 observational studies (N=7,653). In the single randomized trial (N=70), receipt of an educational intervention was associated with a more than 4-fold increase in the odds of choosing PD (OR 4.60; 95% CI, 1.19-17.74). Patient-targeted educational intervention was associated with a 3-fold increase in the odds of receiving PD as the initial treatment modality (OR 3.50; 95% CI: 2.82-4.35; I²=24.9%) based on results from 9 observational studies (N=8,229).
Conclusions: This systematic review supports the existence of a moderate association between patient-targeted education interventions and the subsequent selection and use of PD. Future comparative randomized trials (with well-defined education interventions and comparison groups) are required to determine the most effective components and structure of educational strategies.
2.2 Introduction

The prevalence of end-stage renal disease (ESRD) continues to rise (1). While patients with kidney failure constitute less than 0.1% of the adult population, they account for 5-7% of health care expenditures in high-income countries (2). This is largely driven by the cost of providing chronic dialysis, which, while life saving, is resource intensive (2). Conventional, in-center hemodialysis (HD) and home peritoneal dialysis (PD) are the two main treatment options for patients requiring dialysis. Although PD and HD are associated with comparable clinical outcomes and PD is much less expensive to provide (3,4), PD utilization is declining worldwide (1). This has led to renewed interest in understanding the determinants of PD utilization and designing interventions to maximize the safe and effective use of PD.

Patients with kidney failure should be educated about the treatment options available to them and allowed to make an informed decision regarding their preferred form of renal replacement therapy, unless they opt for conservative care. While a number of factors have likely played a role in the decline in PD utilization, the availability of modality education and the way in which modality education is provided may impact the proportion of patients who ultimately choose PD as their preferred treatment.

We conducted a systematic review of observational and experimental studies to evaluate the association between structured, patient-targeted, dialysis modality education interventions and the selection or use of PD in adults with chronic kidney disease (CKD).
2.3 Materials and Methods

We did a systematic review according to a pre-specified protocol (PROSPERO Number: CRD42014010017) and reported in accordance with published guidelines (10) (Table S3).

2.3.1 Search strategy

We searched MEDLINE, EMBASE, CINAHL, and EBMR in November 2013 (Supplementary material, Appendix 1). In addition, we reviewed abstracts from the annual meeting of the American Society of Nephrology between 2009 and 2013 and hand-searched reference lists of included articles for relevant citations. Each reviewer (B.W. and D.D.) independently performed title and abstract screening and the full text of any study considered relevant according to the selection criteria outlined below was retrieved for detailed review.

2.3.2 Selection criteria

Two reviewers (B.W. and D.D.) independently assessed the full text of each potentially relevant study for inclusion using predetermined eligibility criteria. Studies of adults (≥18 years) with CKD that reported patient-targeted education strategies about available dialysis modalities were included if they reported relevant outcomes (choice of PD or receipt of PD only, or choice/receipt of PD with home HD) and incorporated a standard care control group. We included both experimental and observational studies. Cross-sectional studies, case reports, review articles, and editorials without original data were excluded. Disagreements were resolved by a third co-investigator (M.J.).
2.3.3 Data extraction

All data were extracted in duplicate and included study characteristics (country, year, study design, sample size, and duration of study), patient characteristics (age, sex, mean estimated glomerular filtration rate (eGFR) at the time of education), and specific features of the education intervention (educators, diet, duration, discussion format, inclusion of family members, material mediums).

The primary outcome of interest was expressed modality choice. In other words, whether or not an individual intended to do PD, regardless of whether or not he/she ever received it. This was expressed as an odds ratio that represented the odds that a patient receiving targeted modality education chose PD divided by the odds that a patient receiving standard care chose PD. A secondary outcome of interest was receipt of PD. This captured whether or not an individual went on to receive PD and was calculated by dividing the odds of receiving PD in those receiving targeted modality education by the odds of receiving PD in those patients receiving standard care.

2.3.4 Risk of bias assessment

For randomized studies, we evaluated risk of bias using criteria adapted from Higgins et al (12). A risk of bias assessment tool based on the Ottawa-Newcastle criteria was applied to observational studies (13). Quality assessment did not influence the decision to include studies.
2.3.5 Data synthesis and analysis

Characteristics of the included studies were compiled in tabular form, according to the outcome of interest. The principal summary measures used were odds ratios. We compared the likelihood of choosing PD, or receiving PD, in participants who received educational intervention relative to the odds in those who did not receive educational interventions. Data were analyzed using Stata, version 13.1 (Stata Corp). Due to expected differences between studies due to study design, patient population, and the different education strategies, we combined results using a random effects model by DerSimonian and Laird (29). Statistical heterogeneity was quantified using the $I^2$ statistic. Stratified analyses and meta-regression were used to examine whether the association between educational intervention and outcomes was modified by the following variables defined a priori: geographical region in which the study was conducted (European, Asian, and North American studies), severity of kidney disease at the time of receipt of education (only Stage 5 CKD and ESRD patients vs. all CKD patients), and whether the study reported expressed choice or receipt of PD alone, or choice or receipt of PD and other self-care dialysis modalities combined. Publication bias was assessed using funnel plots and Begg’s test.

2.4 Results

2.4.1 Search yield

The search strategy generated 2778 unique citations; 2648 citations were excluded after reviewing title and abstract. The initial study eligibility agreement between reviewers for abstract and title screening was high ($\kappa=0.93$). A total of 130 articles were retrieved for
full-text review (Figure 1). Of these, 15 primary articles and abstracts were eligible for inclusion in our systematic review. Reasons for exclusion included: primary or secondary outcomes of interest not reported in the paper (n=37), not a report of original research (n=36), lack of a control group (n=16), intervention not clearly defined (n=14), and cross-sectional design (n=12) (Figure 1). Among the 15 included studies, 7 were before and after studies, 5 were cohort studies, two were case-control studies, and one was a randomized controlled trial (RCT). Of the 15 studies included in the systematic review, 2 could not be included in the meta-analysis due to missing information (14,15).

2.4.2 Study and participant characteristics

Attributes of the 15 studies included in the systematic review are outlined in Table 1. Of the 15 studies, 7 were from North America, 5 from Europe, and 3 from Asia. The number of participants included in the studies ranged from 63 to 21,302, for a total number of 31,653 participants. The mean age across studies ranged from 58 to 70.8, and the percentage of men ranged from 45% to 64.3%. The duration of follow-up across studies ranged from 12 months to 144 months. The mean eGFR ranged from less than or equal to 15 mL/min/1.73 m² to 20.4 mL/min/1.73 m². Two studies included only patients with Stage 5 CKD or ESRD (16,17). The majority of studies (13) reported choice of PD or receipt of PD only, while one study examined choice/receipt of PD or home HD (28), and one study examined receipt of PD, home HD, and transplant (16). All studies included patients considered eligible for PD.

2.4.3 Risk of bias assessment
Quality assessment of observational studies is reported in Table S1 (13). All observational studies had a clear indication of a patient group that received an educational intervention that was representative of the average exposed patient in the community, with the exception of one study (17). Only three observational studies performed a statistical analysis adjusted for important prognostic variables (16,18,19). For the single RCT (28), all quality indicators were met with the exception of blinding (Table S2).

2.4.4 Features of educational interventions

As expected, the nature of educational interventions varied greatly between studies. Full descriptions of the educational interventions are provided in Table 2. In two studies, a full description of the educational intervention was not provided (20,21). Specific components of each study educational intervention are highlighted in Table 3. Seven studies included a physician as an educator, while 10 included a nurse, and 4 included a multidisciplinary team. Eight studies carried out their educational intervention over a period of two or more days, and 5 studies included information on diet, which is less restrictive in PD patients compared to HD patients. In eight studies, the educational intervention was delivered as a group presentation, while 5 had one-on-one education sessions only, and two studies included both. As for the medium used for presentation, 6 used video, 7 used printed materials, while only one used website material. Finally, four of the studies included family members in the educational process.

2.4.5 Features of control groups
Only 6 of the 15 studies reported a description of the control intervention (2,9,16,18,19). Two of the 6 studies included standard education from a nephrologist (9,19), and two studies had standard education given by a multidisciplinary team (19,28).

2.4.6 Primary outcome: expressed choice of PD

A total of 6 studies reported the primary outcome, and 5 provided sufficient data for meta-analysis. Of these 5 studies, 4 were observational and one was a RCT (Figure 2). Based on 4 observational studies, including 7653 participants, patient-targeted educational intervention was associated with a 2-fold increase in the odds of choosing PD (pooled odds ratio [OR] 2.15; 95% CI, 1.07–4.32; $I^2=76.7\%$, Figure 2). In the single randomized trial, receipt of the educational intervention was associated with a more than 4-fold increase in the odds of choosing PD (OR 4.60; 95% CI, 1.19–17.74, Figure 2).

Stratified analyses and meta-regression were performed to further explore reasons for the heterogeneity among the observational studies. Geographical region in which the study was conducted was not significantly associated with choice of PD (p=0.14). There also did not appear to be a difference between studies examining the impact of modality education on choice of PD only versus studies reporting the impact of modality education on the choice of any self-care dialysis modalities (p=0.57).

2.4.7 Secondary outcome: receipt of PD

Ten observational studies reported on the receipt of PD as the initial dialysis modality; nine studies including 8,229 participants had sufficient data for meta-analysis (14)
Patient-targeted educational intervention was associated with a more than 3-fold increase in the odds of receiving PD (OR 3.50; 95% CI: 2.82-4.35; I^2=24.9%, Figure 3).

Meta-regression was performed to explore reasons for between-study heterogeneity. Meta-regressions for both the geographical region in which the study was conducted (P=0.12, 5 European, 2 Asian, and 2 North American studies) and the distinction between studies that reported PD only versus those that included all dialysis modalities (P=0.91, 9 PD only studies, and one PD + other modalities study) failed to show statistical significance. Furthermore, potential effect difference among those with varying severity of kidney disease (only Stage 5 CKD and ESRD patients vs. all CKD patients) at the time of receipt of education failed to show statistical significance (P=0.96, 7 Stage 5 and ESRD patients studies, and 7 all CKD patients studies).

2.4.8 Publication bias

Visual inspection of funnel plots for symmetry indicated the absence of small study effects for both the primary and secondary outcomes (Figures S1, S2). The absence of small study effects was corroborated by a non-significant Begg’s test for both expressed PD choice (p-value: 0.80) and receipt of PD (p-value: 0.34).

2.5 Discussion

In this review of 15 studies we found that, when compared to standard care, patient-targeted modality education was associated with a 2.1-fold increase in the odds of
choosing PD in observational studies, a 4.6-fold increase in the odds of choosing PD in
the lone RCT, and a 3.5-fold increase in the odds of patients receiving PD as their initial
dialysis therapy. In addition, we observed a large degree of statistical heterogeneity for
our primary outcome, PD choice that was not explained by geographical region where the
study was conducted, whether outcomes included choice/receipt of PD versus PD plus
other modalities.

We recently described a six-step framework for understanding the drivers of PD uptake
in incident ESRD patients (31). This framework helps to clarify the potential impact of
targeted modality education on incident PD utilization in environments where patients are
free to make an informed choice. Patients must be identified, assessed for PD eligibility,
offered the therapy if they are candidates, choose PD, and then programs must be
successful in getting them on the treatment. Each step is equally important in terms of
the impact on PD uptake. A 1% change in the proportion of patients making it through
any of these steps has an equal impact on incident PD utilization. Targeted modality
education specifically addresses modality choice and based on our results, appears to be
effective. The expected impact on incident PD utilization is likely dependent on the
baseline choice rate in a program and may exhibit a ceiling effect. Our work, and that of
others, indicates that patients who are educated about their treatment options will choose
PD 50%-60% of the time (31, 32).

Although this review demonstrates that patient-targeted education appears to be strongly
associated with PD choice and receipt of PD, the variability in the design of the
educational strategies identified, and the variability in strength of association across studies highlights remaining questions about when and how educational interventions should be delivered. The interventions varied greatly between studies and were not reported in two. The approach to modality education in the single RCT included physician and nurse educators, was conducted over a period of more than 2 days, included detailed dietary information, had one-on-one and group discussions, used video and printed material, and included family members (28). The standard care group did not receive these interventions. Interestingly, it was only after receiving phase two of the educational intervention (small groups including family members) that the authors demonstrated a significant increase in the proportion of patients planning to start self-care dialysis (23/28 (82.1%) in intervention group vs. 17/34 (50.0%); p-value: 0.015) (28). This suggested that small group sessions, the inclusion of family members in educational interventions, and delivering educational interventions over multiple days were potentially important elements of modality education.

Timing of modality education may also be an important consideration. Most modality education programs direct their efforts to patients with advanced CKD prior to dialysis initiation, but approximately 50% of patients will start urgently in hospital (30). Our findings suggest that the relative impact of modality education on the likelihood of choosing PD is similar in patients who have already started on HD. This subset of patients typically starts dialysis on HD via a catheter, even though some centers offer acute PD starts, and may not be targeted for modality education. This represents a
missed opportunity, as high-performing centers convert a significant number of such patients to PD in the first 6 months of therapy (31).

We made a distinction between PD choice and receipt of PD for the purposes of our review. This was done because expressed choice at a particular point in time may not translate into receipt of PD because patients change their minds, they may no longer be eligible for PD due to occurrence of adverse events or a deterioration in their clinical conditions, or the occurrence of transplantation. The difference in heterogeneity observed in choice of PD and receipt of PD may reflect this fact. The stronger association of patient-targeted education with PD use than PD choice may simply be a consequence of the different education strategies among the different complement of studies included in each analysis and the different study populations.

There is an interest in increasing PD penetrance in many jurisdictions worldwide. Regional, national, and international bodies have identified increasing PD utilization as a strategic priority. While modality education targets one, specific step in the process of care that determines PD utilization, it appears to be effective. However, making clear recommendations based on the current literature about how best to implement modality education is challenging for the reasons articulated above. Further work to help elucidate the critical components of a successful modality education program with respect to timing of intervention, the ideal person or persons to deliver the material, the nature of the intervention (one-to-one vs. small group sessions), and the duration of the intervention (single-day vs. multiple days) is required. Understanding the cost of such
interventions and the resources required to implement them would help to clarify the cost-effectiveness. This may vary according to baseline rates of PD utilization. For example, in an area where PD penetration is low, modality education may lead to a significant increase in PD use. In programs where PD utilization is higher at baseline, there may very well be an attenuated effect. Based on our review, we can recommend the intervention described in the single RCT, as the evidence of efficacy is the strongest.

Our study has important limitations. First, there is a relative paucity of high quality literature on the effectiveness of patient education and PD uptake. The majority of studies identified were observational and only one was an RCT. The design of observational studies can establish an association between education and PD choice and PD use, but does not establish causality. We also observed a large degree of statistical heterogeneity for our primary outcome, PD choice. This is likely explained by differences in study populations and the educational interventions evaluated. In addition, the standard care group in most studies was poorly defined and it is not clear if much of the benefit of the interventions tested related to simply making people aware of a treatment choice that they might not otherwise have heard about (33). Finally, given the limited number of available studies and limited statistical power, meta-regression was not able to identify the features of educational interventions that may explain variability in effectiveness.

2.6 Conclusions

In conclusion, this systematic review establishes the strong associations between patient-targeted dialysis modality education and PD choice and use. The variability in the design
of the educational strategies identified and the strength of association across studies
highlights the uncertainty about and when and how educational interventions should be
delivered, as well as the likelihood of impact according to baseline PD penetration.

2.7 Acknowledgments

None

2.8 Statement of Competing Financial Interests

None
### Table 2.1. Study and Patient Characteristics of Included Studies

<table>
<thead>
<tr>
<th>Primary author, Year</th>
<th>Design of study</th>
<th>Country</th>
<th>Study era</th>
<th>N</th>
<th>Mean age (years)</th>
<th>% Male</th>
<th>Mean MDRD eGFR (mL/min/1.73 m²)</th>
<th>Duration of follow-up (months)</th>
<th>Outcome(s) evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agraharkar, 2003 (14)</td>
<td>prospective before-after</td>
<td>USA</td>
<td>2001 - 2002</td>
<td>136</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>16</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Gadallah, 2001 (15)</td>
<td>prospective before-after</td>
<td>USA</td>
<td>nr</td>
<td>436 (201 pre-intervention, 235 post-intervention)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>48</td>
<td>PD choice, PD prevalence</td>
</tr>
<tr>
<td>Gomez, 1999 (22)</td>
<td>prospective before-after</td>
<td>Spain</td>
<td>1996 to 1997</td>
<td>174 (86 intervention, 88 control)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>13</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Hanko, 2011 (16)</td>
<td>retrospective cohort</td>
<td>Canada</td>
<td>2005 - 2008</td>
<td>78 (36 seen by nurse, 42 not seen by nurse)</td>
<td>58.0 (seen by nurse), 60.2 (not seen by nurse)</td>
<td>63.9% (seen by nurse), 61.9% (not seen by nurse)</td>
<td>not applicable; all patients already on HD</td>
<td>48</td>
<td>Incidence of independent renal replacement therapy (PD, HHD, transplant) among patients already on HD</td>
</tr>
<tr>
<td>King, 2008 (26)</td>
<td>retrospective before-after</td>
<td>USA</td>
<td>1994 - 2006</td>
<td>1844</td>
<td>median 61</td>
<td>51%</td>
<td>NR</td>
<td>144</td>
<td>PD choice</td>
</tr>
<tr>
<td>Authors, Year</td>
<td>Study Type</td>
<td>Location</td>
<td>Year</td>
<td>Sample Size</td>
<td>Education Status</td>
<td>Mean Age</td>
<td>Mortality</td>
<td>Mean Survival</td>
<td>Follow-Up</td>
</tr>
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<tr>
<td>Lacson, 2011 (18)</td>
<td>prospective cohort</td>
<td>USA</td>
<td>2008</td>
<td>5600 (2800 educated patients, 2800 matched non-educated patients)</td>
<td>63.4 (educated), 63.5 (non-educated)</td>
<td>56.6</td>
<td>NR</td>
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<td>PD choice, Receipt of PD at 90 days among patients already on HD</td>
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<tr>
<td>Manns, 2005 (28)</td>
<td>RCT</td>
<td>Canada</td>
<td>2003</td>
<td>70 (35 intervention, 35 control)</td>
<td>mean 65.2 (intervention), 63.6 (control)</td>
<td>60% (intervention), 48.6% (control)</td>
<td>mean 20.4 (intervention), 20.3 (control)</td>
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<td>PD choice</td>
</tr>
<tr>
<td>Marron, 2005 (20)</td>
<td>case-control</td>
<td>Spain</td>
<td>2002</td>
<td>621 (232 intervention, 389 control)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>12</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Marron, 2006 (21)</td>
<td>case-control</td>
<td>Spain</td>
<td>2003</td>
<td>1153 (928 intervention, 225 control)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>12</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Ohno, 2006 (27)</td>
<td>before-after</td>
<td>Japan</td>
<td>2001 - 2004</td>
<td>77 (37 pre-intervention, 40 post-intervention)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>48</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Okada, 2012 (23)</td>
<td>before-after</td>
<td>Japan</td>
<td>2009 - 2010</td>
<td>63</td>
<td>69.1</td>
<td>51%</td>
<td>38.4</td>
<td>24</td>
<td>PD choice</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Country</td>
<td>Duration</td>
<td>Sample Size</td>
<td>PD Choice</td>
<td>PD Initiation</td>
<td>Outcome</td>
<td>Follow-up</td>
<td>Effect Size</td>
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<tr>
<td>Proenzano, 2009 (33)</td>
<td>cohort</td>
<td>USA</td>
<td>2008-2009</td>
<td>21302 (304 intervention, 20998 control)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>12</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Ravani, 2003 (19)</td>
<td>prospective before-after</td>
<td>Italy</td>
<td>1999-2002</td>
<td>145 (52 traditional, 93 formal pre-dialysis education program)</td>
<td>70.8 (traditional), 65.2 (pre-dialysis education program), p=0.019</td>
<td>55.8% (traditional), 59.1% (pre-dialysis education program)</td>
<td>NR</td>
<td>42</td>
<td>PD choice</td>
</tr>
<tr>
<td>Ribitsch, 2013 (17)</td>
<td>retrospective cohort</td>
<td>Austria</td>
<td>2004-2008</td>
<td>227 (70 intervention, 157 control)</td>
<td>median 57.5 (intervention), 56 (control)</td>
<td>64.3% (intervention), 66.2% (control)</td>
<td>&lt;= 15 mL/min; all Stage 5 CKD patients</td>
<td>48</td>
<td>Receipt of PD</td>
</tr>
<tr>
<td>Wu, 2009 (9)</td>
<td>prospective cohort</td>
<td>Taiwan</td>
<td>2006-2008</td>
<td>163 (123 non-educated, 40 educated)</td>
<td>61.2 (non-educated), 65.5 (educated), p=0.048</td>
<td>55.9% (non-educated), 45.3% (educated)</td>
<td>23.4 (non-educated), 24.2 (educated)</td>
<td>11.7 ± 0.9</td>
<td>Receipt of PD</td>
</tr>
</tbody>
</table>

GFR: glomerular filtration rate; PD: peritoneal dialysis; HD: hemodialysis NR: not reported
| Primary author, year | Description of education intervention                                                                                                                                                                                                                                                                                                                                                                           | Description of control intervention |}
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Agraharkar, 2003 (14)</td>
<td>The attending nephrologist explained all of the available dialysis modalities, including ICHD, HHD, and PD (and the various forms of PD), and their advantages and disadvantages to the patient and the patient's immediate family members. They were then introduced to the home dialysis coordinator, who demonstrated the technique of PD on a mannequin. An educational video that demonstrates all the available RRTs was then shown to the patient and family members. New patients were encouraged to meet with pre-existing PD patients. The disposition team (physician, nurse, social worker, technician, coordinator, and dietician) met collectively with the patient and the family, who were encouraged to express their expectations and concerns, if any, and the patient was thus accepted into the program.</td>
<td>NR</td>
</tr>
<tr>
<td>Gadallah, 2001 (15)</td>
<td>Patients were invited to visit both HD and PD units and to discuss with dialysis patients the details of dialysis. Patients were given the opportunity to converse freely with current dialysis patients and to ask questions regarding placement and complications of dialysis access, feelings of well-being, social freedom, dialysis scheduling, and a variety of quality-of-life issues. Patients were given commercially available booklets and ESRD education films to review and discuss with their families before making a modality choice. Patients were subsequently given the opportunity to ask the nephrologist more detailed questions regarding the modality of dialysis.</td>
<td>NR</td>
</tr>
<tr>
<td>Gomez, 1999 (22)</td>
<td>Materials used in the standard information package include: Flip Chart [(Treatment Options in Renal Therapy, Baxter Healthcare Corporation, 1995) shown to the patient on the visit. This chart gives a general idea of ESRD and the treatment options available, using short phrases and illustrations]. Guidebook [(Getting to Know the Renal Replacement Treatment Options, Baxter Healthcare Corporation, 1995)] given to the patient on the first visit, to be read before the following visit. This guidebook briefly explains the most important aspects of ESRD and its</td>
<td>NR</td>
</tr>
</tbody>
</table>
The patient was advised to refresh his/her knowledge by reading the guidebook the day before the second visit, Video [(End Stage Renal Disease and its Treatment, Baxter Healthcare Corporation, 1995) that is watched by clinic staff and the patient together, on the second visit], and Handbook [(Questions and Answers, Baxter Healthcare Corporation, 1995) for use by the “patient educator” so that he/she can give a standard answer to any frequently-asked question. It can also be given to the patient at an appropriate time]. During the first appointment, the flip chart is shown and the patient is given the Guidebook to read at home. In the second appointment, 7 to 30 days later, any doubts the patient may have are discussed and clarified, and answered according to the recommendations set in the handbook. The video is then shown. It is also recommended that the patient see how the various techniques of dialysis are carried out in practice.

Hanko, 2011 (16)

The RTN usually met with patients during their scheduled treatments in the hospital-based HD unit. On occasion, further discussion was arranged outside of the patient’s regular dialysis time, either in person or by telephone. The RTN assessed and educated the patients as follows: 1) Initial assessment: chart review; interview(s) with patient and, if relevant, next-of-kin/caregivers; and review of the assessments of other team members (e.g. assessment of home life by the social worker). 2) Suitability for independent modalities: advantages, potential barriers and contraindications to independent RRT modalities were identified using standardized criteria including the Match-D tool (designed specifically to aid assessment of suitability for home dialysis modalities). 3) Education: during face-to-face meetings, the RTN assessed the patient’s preferred learning style taking into account the patient’s language, literacy, education and their expressed preferences (e.g. web-based information versus reading material). Education was then tailored to the individual with resources including individual counseling, written material, audio/visual material, web browsing and group discussions. Most resource materials were obtained from Baxter Healthcare, the United States National Kidney Foundation and the Kidney Foundation of Canada. In addition, all patients

Patients with suboptimal HD starts who were not educated by the RTN.
were given the opportunity to watch a DVD produced by the BCPRA entitled ‘Patient-to-Patient: Kidney Care in BC’. The DVD outlines RRT modalities and is available in English, Cantonese, Mandarin, Punjabi and Tagalog. 4) Modality choice: if no contraindications or significant barriers were identified, patients were encouraged to consider independent modalities of RRT. The RTN initiated referral for PD catheter insertion, permanent HD vascular access creation, HHD assessment and/or kidney transplant assessment as appropriate and in consultation with the nephrologist. 5) Follow-up: the RTN followed the patient until a long-term plan for RRT was established. The RTN spent a median education time of 5.6 h (IQR 1.5–9.2 h) over a median of 8 visits (IQR 3–8 visits) per patient.

<table>
<thead>
<tr>
<th>King, 2008 (26)</th>
<th>The patients are enrolled in 6 classes, each 60 to 75 minutes, being held during one weekend or over a two-week period. The entire series of classes is moderated by a social worker with a master's degree in social work. 3/6 classes focus on treatment modalities (1 each on HD, PD, tx), each presented by a different registered nurse with expertise in that particular area. There are also patient presenters, who are sometimes accompanied by family members, for the treatment option classes. The other 3 classes cover introduction to kidney disease, diet and kidney disease, and financing and coping with kidney disease.</th>
</tr>
</thead>
<tbody>
<tr>
<td>NR</td>
<td>In 2006, a nationwide treatment options education program (TOPs) was initiated by Fresenius Medical Care, North American. Patient teaching materials were selected regionally in consultation with local nephrologists from standardized readily available materials. The TOPs is intended to be a multiple-touch program with initial education completed in a single group class session, then, 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. TOPs patient education is to be provided by using the 2008 FMS “Treatment Options Program, For People with Chronic Kidney Disease” PowerPoint presentation. This educational tool is also available in flipchart form. A non-TOP educated patients; specifics not reported</td>
</tr>
</tbody>
</table>
TOPs DVD is available and consists of three primary components: a) A five minute preview of the primary treatment options b) The twenty-five minute full length review of CKD and the primary treatment options c) Nine individual treatment option chapters. In addition, concept reinforcement handouts have been created to supplement the information presented in the PowerPoint presentation. These handouts include: Following up with your Doctor, CKD, Access Options, Transplant Option, Hemodialysis Option, Peritoneal Dialysis Option.

| Manns, 2005 (28) | Educational intervention consists of 2 phases. Phase 1 included handing out 4 educational manuals and a 15-minute video on self-care dialysis: The first manual, entitled “Choosing the type of dialysis best suited to you,” described the different types of dialysis, including the potential advantages to self-care dialysis, such as flexibility in scheduling dialysis (home/self-care hemodialysis and PD), easier travel planning (PD), and more flexibility with diet and fluid intake (PD). The other 3 written manuals described the 3 forms of self-care dialysis (peritoneal dialysis, home, and self-care hemodialysis) in more detail. In addition, patients received a 15-minute video entitled “Choosing the type of dialysis best suited to you,” produced locally, which detailed visually the different types of dialysis and the potential advantages and disadvantages of self-care dialysis, including patient testimonials that described the impact of the different modalities on everyday life. The second component of the education, which occurred 2 weeks after the educational material was given to patients, involved a 90-minute small group interactive session involving 3 to 6 patients (plus family members), a nephrologist, and a predialysis nurse. The main teaching format was problem-based learning in small groups focused around cases that were representative of the local population. The session began with a brainstorming session in which the participants described the advantages and disadvantages of self-care dialysis based on their current knowledge. Following this, the participants separated into 2 smaller groups where they “problem-solved” a “dialysis scenario,” which involved them finding solutions to overcome some of the barriers to self-care dialysis. Each small | There is a multidisciplinary CKD clinic where patients are case managed by a renal nurse clinician. Patients receive teaching about kidney disease, including dietary instructions and detailed information about the different modalities of renal replacement therapy. This occurs via an initial 3-hour one-on-one session where a nurse, dietician, and social worker see patients. Patients are then followed by their nephrologist and the multidisciplinary care team every 3 to 6 months. |
group then presented their solution to the larger group, including reasons for their choices. Finally, participants were shown selected portions of the “Self-care dialysis” video.

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Description</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marron, 2005</td>
<td>dialysis education; specifics not reported</td>
<td>NR</td>
</tr>
<tr>
<td>Marron, 2006</td>
<td>dialysis education; specifics not reported</td>
<td>NR</td>
</tr>
<tr>
<td>Ohno, 2006</td>
<td>As a new patient reaches the stage of requiring dialysis, a specially trained Dialysis Education nurse presents the advantages and disadvantages of HD and PD and our experience with these modalities. Especially, they always follow PD patients from initiation to withdrawal of PD. In addition, we assure the patients that we are available to handle any PD complication, including peritonitis, and that they can transfer to HD whenever the need arises. PD is recommended to patients with severe cardiovascular disease, except where there is a history of extensive operative scarring on the abdomen. Eventually, patients choose the mode of dialysis that suits their own lifestyle.</td>
<td>NR</td>
</tr>
<tr>
<td>Okada, 2012</td>
<td>In 2007, The Kidney Disease Therapy Society (KDTS) was created with the aim to improving the QoL of CKD patients with respect to patient decision-making. The KDTS conducts a PD promotion program by issuing pamphlets, providing predialysis education, and giving public lectures.</td>
<td>NR</td>
</tr>
<tr>
<td>Provenzano, 2009</td>
<td>DaVita’s EMPOWER™ program is a general educational tool for patients with CKD. Monthly classroom educational sessions are offered on co-morbidities, steps to help preserve renal function, tools to improve quality of life and dialysis modality selection.</td>
<td>NR</td>
</tr>
<tr>
<td>Ravani, 2003</td>
<td>All patients with eCrCl (as per Cockcroft-Gault) were invited to participate in the formal pre-dialysis follow-up program (PEP), which included full-time physicians and nurses who devoted approximately one-third of their work time to the program. They were responsible for the organization of pre-ordered laboratory testing, the application of recommended diagnostic and interventional strategies, information and education concerning ESRD, with a progressively intense follow-up protocol, according to kidney function. The same experienced nephrologist saw all patients in a traditional outpatient clinic. Patients received dialysis orientation from the physician in charge, and by the PEP team, but close to the dialysis start date. The average duration of each</td>
<td>NR</td>
</tr>
<tr>
<td>Source</td>
<td>Description</td>
<td></td>
</tr>
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<td>--------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>Ribitsch, 2013 (17)</td>
<td>On 2 consecutive days, groups of patients (maximum 6) and their relatives receive information concerning the basic pathophysiologic principles of CKD and RRTs including HD, PD, and kidney transplantation. The interactive program is presented by a multidisciplinary team, including nurses, dieticians, and nephrologists. In a 2-hour session on the first day, patients are given basic information about medical, dietary, and lifestyle issues. The 2-hour session on the second day features practical demonstrations of HD and PD. Patients did not receive structured education; specifics not reported.</td>
<td></td>
</tr>
</tbody>
</table>
| Wu, 2009 (9) | The MPE team comprised a nurse for case management, social workers, dietitians, HD and PD patient volunteers and 10 nephrologists. The program consisted of an integrated course involving individual lectures on renal health, delivered by the case-management nurse, according to the guidelines in a standardized instruction booklet. The lectures focused on nutrition, lifestyle, nephrotoxin avoidance, dietary principles and pharmacological regimens. Further, the case-management nurse contacted the patients to ensure timely follow-up. Standardized interactive educational sessions were periodically conducted wherein all patients were interviewed depending on their CKD stage, determined earlier using the NKF/DOQI guidelines: Stage III or IV CKD patients were followed up every 3 months, and stage V CKD patients were followed up on a monthly basis. For stage III CKD patients, the program consisted of lectures on healthy renal function, clinical presentation of uremia, risk factors and complications associated with renal progression and an introduction to the various RRTs (i.e. HD, PD and renal transplantation). For stage IV CKD patients, the program included discussions on the management of complications associated with CKD, indications of RRT and evaluation of vascular or peritoneal access. Patients with stage V CKD were monitored for timely initiation of RRT, care of vascular or peritoneal access, dialysis-associated complications and the same group of nephrologists instructed all participants regarding the renal function, evaluation of laboratory data and the clinical indicators of chronic renal failure as well as strategies for its management and treatment. Furthermore, the nephrologists explained the general principles of HD and PD when the patients exhibited an eGFR of <30 mL/min/1.73 m2 (stage IV CKD). All patients were provided with written instructions. The nephrologists evaluated the comorbidity factors influencing each patient’s condition before referral to a nurse specializing in HD or PD. The nursing staff provided instructions for daily living and explained the criteria used for the
All patients received dietary counseling biannually from a dietitian. Additionally, the case-management nurse often contacted the participants via telephone to encourage them to inform their nephrologists of their symptoms and to reinforce the importance of medical visits. The MPE program was discontinued once RRT was initiated for these patients.
## Table 2.3 Components of educational interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>Educator</th>
<th>Duration (Days)</th>
<th>Diet</th>
<th>Discussion Format</th>
<th>Medium</th>
<th>Family Members Involved</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Physician</td>
<td>Nurse</td>
<td>Multidisciplinary</td>
<td>1 Day</td>
<td>2 or more days</td>
<td>Diet</td>
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<td>✔</td>
<td>✔</td>
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<td>✔</td>
<td>✔</td>
<td>✔</td>
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<td>✔</td>
<td>✔</td>
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<td>✔</td>
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<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>Gómez</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Hanko</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>King</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Lacson</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Wu</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>

*NR: not reported
Table 2.4 Quality Assessment of Observational Studies Included in the Analysis

<p>| Quality measure | Type of study         | Was selection of exposed and non-exposed cohorts drawn from the same population? | Is the group receiving intervention representative of the average exposed patient in the community? | Did the study match exposed and unexposed cohorts for all variables that are associated with the outcome of interest? | Can we be confident in the assessment of the presence or absence of prognostic factors, or did the statistical analysis adjust for these prognostic variables? | Can we be confident that the outcome of interest was not present at start of study? | Can we be confident in the assessment of outcome? | Is the same method of assessing outcome applied to both groups? | Are co-interventions similar between groups, length of follow up is adequate for outcome to occur, and number lost to follow-up does not affect our conclusion about the effect of the intervention on the outcome? | Were the reasons for drop out identified and similar across groups? |
|-----------------|-----------------------|---------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Agraharkar, 2003 (14) | Prospective before-after | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Unknown                                                                                                                                         | Unknown                                                                                                                                         |
| Gadallah, 2001 (15) | Prospective before-after | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Unknown                                                                                                                                         | Unknown                                                                                                                                         |
| Gomez, 1999 (22) | Prospective before-after | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                                | Unknown                                                                                                                                         |
| Hanko, 2011 (16) | Retrospective cohort    | Yes                                                                               | Yes                                                                                                          | No                                                                                                                                         | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                                | Yes                                                                                                                                                |
| King, 2008 (26)  | Retrospective before-after | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Unknown                                                                                                                                         | Unknown                                                                                                                                         |
| Lacson, 2011 (18) | Prospective cohort      | Unknown                                                                           | Yes                                                                                                          | Yes                                                                                                                                         | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Unknown                                                                                                                                         | Unknown                                                                                                                                         |
| Marron, 2005 (20) | Case-control            | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Not applicable                                                                                                                                               | Not applicable                                                                                                                                 | Not applicable                                                                                                                                 | Not applicable                                                                                                                                     |
| Marron, 2006 (21) | Case-control            | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Not applicable                                                                                                                                               | Not applicable                                                                                                                                 | Not applicable                                                                                                                                 | Not applicable                                                                                                                                     |
| Ohno, 2006 (27)  | Before-after            | Not applicable                                                                   | Yes                                                                                                          | Not applicable                                                                                                                                                                                             | No                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Yes                                                                                                                                  | Unknown                                                                                                                                         | Unknown                                                                                                                                         |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Before-after</th>
<th>Not applicable</th>
<th>Yes</th>
<th>Not applicable</th>
<th>No</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Unknown</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Okada, 2012 (23)</td>
<td>Prospective</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Ravani, 2003 (19)</td>
<td>Before-after</td>
<td>Not applicable</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Ribitsch, 2013 (17)</td>
<td>Retrospective</td>
<td>Unknown</td>
<td>Unknown</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Wu, 2009 (9)</td>
<td>Prospective</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
</tbody>
</table>
Table 2.5 Quality Assessment of Randomized Controlled Trials Included in the Analysis

<table>
<thead>
<tr>
<th>Quality measure</th>
<th>Manns, 2005 (28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was there adequate sequence generation?</td>
<td>Yes</td>
</tr>
<tr>
<td>Was allocation adequately concealed?</td>
<td>Yes</td>
</tr>
<tr>
<td>Was blinding maintained among study participants, attending nurses and physicians, data collectors, outcome adjudicators, and data analysts?</td>
<td>No</td>
</tr>
<tr>
<td>Were incomplete outcome data adequately addressed?</td>
<td>Yes</td>
</tr>
<tr>
<td>Were reports of the study free of suggestion of selective outcome reporting?</td>
<td>Yes</td>
</tr>
<tr>
<td>Was the study apparently free of other problems that could put it at a risk of bias?</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Table 2.6 Prisma Checklist

<table>
<thead>
<tr>
<th>Title</th>
<th>ABSTRACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>1</td>
</tr>
</tbody>
</table>

| Structured summary | 2 |
| Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | 1 |

| INTRODUCTION | 3 |
| Rationale | Describe the rationale for the review in the context of what is already known. | 1-2 |
| Objectives | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | 2 |

| METHODS | 3 |
| Protocol and registration | 5 |
| Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | PROSPERO, Registration Number: CRD42014010017 |
| Eligibility criteria | 6 |
| Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | 3 |
| Information sources | 7 |
| Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | 3 |
| Search | 8 |
| Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | 3, pages 8-9 |
| Study selection | 9 |
| State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | 3 |
| Data collection process | 10 |
| Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | 3-4 |
| Data items | 11 |
| List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | 3-4 |
| Risk of bias in individual studies | 12 |
| Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | 3 |
| Summary measures | 13 |
| State the principal summary measures (e.g., risk ratio, difference in means). | 4 |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I²) for each meta-analysis. | 4 |
Figure 2.1 Study selection flowchart.
Figure 2.2 Forrest plot for impact of patient-targeted education on odds of choosing PD, stratified by study type.
### Figure 2.3 Forrest plot for impact of patient-targeted education on odds of receiving PD.

<table>
<thead>
<tr>
<th>Study</th>
<th>Odds Ratio (95% CI)</th>
<th>% Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gomez</td>
<td>3.67 (1.74, 7.97)</td>
<td>6.98</td>
</tr>
<tr>
<td>Hanko</td>
<td>3.75 (1.08, 13.05)</td>
<td>2.87</td>
</tr>
<tr>
<td>Lacson</td>
<td>4.69 (3.24, 6.79)</td>
<td>20.00</td>
</tr>
<tr>
<td>Marron, year 2005</td>
<td>5.02 (3.12, 8.19)</td>
<td>14.24</td>
</tr>
<tr>
<td>Marron, year 2006</td>
<td>3.83 (2.30, 6.74)</td>
<td>12.18</td>
</tr>
<tr>
<td>Ohno</td>
<td>2.30 (0.78, 6.97)</td>
<td>3.65</td>
</tr>
<tr>
<td>Provenzano</td>
<td>2.55 (1.86, 3.44)</td>
<td>24.36</td>
</tr>
<tr>
<td>Ribitsch</td>
<td>3.35 (1.82, 6.14)</td>
<td>10.09</td>
</tr>
<tr>
<td>Wu</td>
<td>2.11 (0.88, 4.92)</td>
<td>5.64</td>
</tr>
<tr>
<td>Overall (I-squared = 24.9%, p = 0.222)</td>
<td>3.50 (2.82, 4.35)</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**NOTE:** Weights are from random effects analysis.
Figure 2.4 Funnel plot assessing for publication bias in studies assessing PD choice as an outcome (S.E Standard Error, OR Odds Ratio, PD Peritoneal Dialysis).
Figure 2.5 Funnel plot assessing for publication bias in studies assessing receipt of PD as an outcome (S.E Standard Error, OR Odds Ratio, PD Peritoneal Dialysis).
Figure 2.6 Search Strategies

MEDLINE <1946 to 2013 November 08>
1502 results

1  patient education.mp. or exp Patient Education as Topic/ (80424)
2  Health Education/ (52909)
3  education/ or teaching/ (59701)
4  treatment information.mp. (780)
5  1 or 2 or 3 or 4 (188363)
6  chronic renal insufficiency.mp. or exp Renal Insufficiency, Chronic/ (84532)
7  chronic kidney disease.mp. (19422)
8  chronic kidney failure.mp. (993)
9  end-stage renal disease.mp. (20615)
10  end-stage kidney disease.mp. (1063)
11  6 or 7 or 8 or 9 or 10 (101603)
12  peritoneal dialysis.mp. or exp Peritoneal Dialysis/ (26754)
13  11 or 12 (117491)
14  5 and 13 (1502)

EMBASE <1974 to 2013 November 08>
1813 results

1  patient education.mp. or exp patient education/ (91067)
2  health education.mp. or health education/ (94517)
3  treatment information.mp. (1093)
4  1 or 2 or 3 (181983)
5  chronic kidney failure.mp. or exp chronic kidney failure/ (58648)
6  chronic kidney disease.mp. or exp chronic kidney disease/ (35795)
7  chronic renal insufficiency.mp. (5869)
8  end-stage renal disease.mp. (26576)
9  end-stage kidney disease.mp. (1453)
10  5 or 6 or 7 or 8 or 9 (111254)
11  peritoneal dialysis.mp. or exp peritoneal dialysis/ (35650)
12  10 or 11 (136281)
13  4 and 12 (1813)
All EBM Reviews <2005 to September 2013>
142 results

1 patient education.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (7195)
2 health education.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (4576)
3 teaching.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (7172)
4 education.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (25665)
5 treatment information.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (135)
6 1 or 2 or 3 or 4 or 5 (30312)
7 chronic renal insufficiency.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (309)
8 chronic kidney disease.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (1258)
9 chronic kidney failure.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (134)
10 end-stage renal disease.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (1252)
11 end-stage kidney disease.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (172)
12 7 or 8 or 9 or 10 or 11 (2853)
13 peritoneal dialysis.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw] (1283)
14 12 or 13 (3913)
15 6 and 14 (142)

CINAHL – Ebsco 1937 – November 8, 2013
904 results

(MH "Patient Education+") OR "patient education"
(MH "Health Education+") OR "health education"
"treatment information"
(MH "Teaching") OR "teaching"
s1 or s2 or s3 or s4
(MH "Renal Insufficiency, Chronic+") OR "chronic renal insufficiency"
(MH "Kidney Failure, Chronic+") OR "chronic kidney failure"
"chronic kidney disease"
"end-stage renal disease"
"end-stage kidney disease"
s6 or s7 or s8 or s9 or s10
(MH "Peritoneal Dialysis+") OR "peritoneal dialysis"
s11 or s12
s5 and s13
References


CHAPTER 3. EFFECT OF PATIENT CHOICE ON THE RECEIPT OF SELF-CARE
DIALYSIS: EXTENDED FOLLOW-UP OF A RANDOMIZED TRIAL.
3.1 Abstract

Background: Educational interventions may increase the likelihood that a patient will choose self-care dialysis. However, whether patients who choose self-care dialysis after educational interventions ultimately go on to receive it is uncertain.

Aim: We conducted a 12-year follow-up study of patients randomized to a pre-dialysis education intervention or usual care to determine if a patient’s choice to do self-care dialysis led to increased receipt of self-care dialysis. We sought to determine if patients who had initially decided to choose self-care dialysis (outcome of the original trial) were more likely to receive it, and to examine the impact of the educational intervention on the likelihood of receiving self-care dialysis.

Method: Pre-dialysis patients in Southern Alberta Renal Program (SARP) renal care clinic, which includes all end stage renal disease patients and patients with advanced CKD, were enrolled. The primary exposure was “choice” or “non-choice” of self-care dialysis. Choice was assigned following the educational intervention in 2003. The primary outcome was initial receipt of self-care dialysis (PD, HHD) versus in-center dialysis (HD). We used Fisher’s exact test to compare proportions.

Results: Seventy patients were randomized to either standard care or an educational intervention in 2003. Six patients did not indicate whether or not they would choose self-care dialysis because they died (n=1), were transplanted (n=1), went on dialysis before they could complete the trial
(n=2), or did not complete the post-intervention survey (n=2). The patients who chose self-care dialysis following the intervention period were no more likely to receive it than those who did not choose a self-care modality [14/42 (33.3%) vs. 3/22 (21.4%); p-value=0.137]. Restricting the analysis to only those individuals who subsequently went on to receive dialysis, 14/20 (70.0%) in the choice group received self-care dialysis compared to just 3/13 (23%) among those who did not choose self-care dialysis (p-value: 0.013). In the secondary analysis the proportion of patients who received self-care dialysis as their first treatment was not significantly different between groups [11/35 (31.4%) for the educational intervention vs. 9/35 (25.7%) for the usual care arm; p=0.791].

Conclusions: Educational interventions designed to promote self-care dialysis may increase the choice of self-care dialysis, but this expressed choice may not translate into an increased number of patients receiving self-care dialysis. In patients who ultimately went on to require dialysis, a significantly higher proportion of patients who chose self-care modalities received them. However, there was no association between a patient-targeted educational intervention and the receipt of self-care dialysis over an extended duration of follow-up.
3.2 Introduction

Self-care dialysis [peritoneal dialysis (PD) or home hemodialysis (HHD)] is less expensive to provide than traditional, in-center hemodialysis (HD)\(^1\). While self-care dialysis and traditional in-center HD are associated with comparable clinical outcomes\(^2-5\), self-care dialysis has several important potential benefits: the patient can be more independent, it can be performed while sleeping, makes travel easier (PD only), and allows for a more flexible schedule\(^6\). However, self-care therapies are underutilized due to a number of patient, provider, and system factors\(^7\). Many feel that it is important to provide structured education around treatment options for patients with end stage kidney disease, and that education might influence patient treatment preferences (patient choice) and the likelihood they will go on to be treated with a self-care modality.

Prior studies examining the impact of patient-targeted educational strategies have used the choice of self-care dialysis as their primary outcome\(^8-13\). Choice of self-care dialysis is defined as the intent to do PD or HHD for renal replacement therapy. Receipt of self-care dialysis refers to whether the patient goes on to be treated with PD or HHD. There is a tendency to infer that patients choosing PD or HHD will ultimately receive it\(^9,12\). However, choice does not always translate into receipt because patients may change their views and perspectives, or become ineligible due to occurrence of adverse events or deterioration in their clinical conditions. Also, patients may receive a transplant, or they may need to start dialysis urgently with HD (the most commonly used method for urgent dialysis) and choose to stay on it, even after they have made a decision to pursue self-care dialysis. Thus, assuming that choice of self-care dialysis and the receipt of self-care dialysis are synonymous may be misleading, as
Interventions that lead to an increased choice of self-care dialysis may not actually impact PD utilization (receipt) – the desired outcome.

In a recent systematic review we found only one randomized control trial (RCT) looking at an educational intervention to increase the number of patients who chose self-care dialysis. The study demonstrated that an educational intervention was associated with more than a 4-fold increase in the odds of choosing self-care dialysis (OR 4.60; 95% CI, 1.19-17.74)\textsuperscript{9,14}. However, the original trial did not assess the receipt of self-care dialysis\textsuperscript{9}. To address this, we used long-term follow-up data from this study to determine if patient choice translated into receipt of self-care dialysis.

3.3 Materials and Methods

We analyzed long-term, follow-up data from 70 patients randomized to receive either a two-phase pre-dialysis educational intervention (n=35) or standard care (n=35) defined as teaching about the dialytic modality choices in 2003. The educational intervention consisted of 2 phases. Phase 1 included handing out four educational manuals and a 15-minute video on self-care dialysis. Phase 2 occurred two weeks after the educational material was given to patients and involved a 90-minute group brainstorming session with 3 to 6 patients (plus family members), a nephrologist, and a pre-dialysis nurse. The control patients received standard care.

3.3.1 Patient population

Patients were enrolled through the Southern Alberta Renal Program (SARP) renal care clinic. This regional clinic includes patients with advanced CKD. Patients in SARP who had seen
more than one multidisciplinary team member and had a GFR <30 mL/min/1.73m² were eligible for enrolment. Patients with cognitive dysfunction, non–English-speaking patients, patients not considered independent by nurse assessment, patients currently on dialysis, and patients unwilling or unable to provide consent were excluded. Following the intervention patients were asked to indicate their modality choice (HD, PD, HHD) by filling out a survey.

3.3.2 Study protocol

The Conjoint Health Research Ethics Board at The University of Calgary approved this follow-up study. Our primary objective was to examine if patient choice of self-care dialysis translated into receipt of self-care dialysis. Our secondary objective was to determine the effectiveness of a pre-dialysis modality educational intervention in increasing the receipt of self-care dialysis.

3.3.3 Exposure and outcomes

The primary exposure was choice of self-care dialysis and patients were classified as “choice” or “non-choice” of a self-care dialysis modality. Choice was assigned following the educational intervention in 2003 (Figure 3.1). Baseline characteristics were reported for both groups and included age, gender, marital status, employment status, comorbidities, and the number of months a patient was followed in a pre-dialysis clinic. The primary outcome was initial receipt of self-care dialysis, or receipt of PD or HHD within 6 months of starting dialysis. For example, individuals who received urgent HD for 4 weeks and then switched to PD were considered to have received self-care dialysis. For our secondary analysis, the exposure of interest was the receipt of the educational intervention during the clinical trial. Patients were
classified according to whether they had received the intervention or not, and followed to see if they went on to receive self-care dialysis. We extended patient follow-up to July 2nd, 2015 for the occurrence of death, transplantation, and switching to a different dialysis modality. Outcome data was retrieved from the electronic medical records software Patient-based Renal Information System (PARIS). Information in PARIS was retrieved from the nurses’ notes, patient’s timeline, and Canadian Organ Replacement Register (CORR) forms.

3.3.4 Statistical analysis

We used Fisher’s exact test to compare the proportions of patients who received self-care dialysis, according to the patient’s expressed choice following the completion of the educational intervention (main analysis) and by randomized group (secondary analysis). All statistical tests were 2-sided with a $P<0.05$ defining statistical significance. We used Stata, Version 14 for all analyses (StataCorp, USA).

3.4 Results

Forty-two patients chose self-care dialysis and twenty-two patients chose traditional, in-center HD or were unable to make a choice. There was no difference in age, gender, or employment status between the choice and non-choice groups (Table 3.1). As of July 2015, 20 of 42 patients in the choice group and 13 of 22 patients in the non-choice group, had received dialysis. In the choice group, four patients received a transplant prior to receiving dialysis, ten died prior to receiving dialysis, and eight patients never required dialysis. In the non-choice group, nine patients died prior to receiving dialysis (Figure 3.2).
3.4.1 Patient choice and receipt of self-care dialysis

Patients who chose self-care dialysis were not more likely to receive it than those who did not [14/42 (33.3%) vs. 3/22 (21.4%); p-value=0.137]. If the analysis was restricted to individuals who subsequently went on to receive dialysis, 14/20 (70.0%) in the choice group received self-care dialysis compared to just 3/13 (23%) among those who did not choose self-care dialysis (p-value: 0.013).

3.4.2 Education and receipt of self-care dialysis

The proportion of patients who received self-care dialysis as their treatment within 6 months dialysis treatment was not significantly different between those who received the educational intervention and those who did not [11/35 (31.4%) for the educational intervention vs. 9/35 (25.7%) for the usual care arm; p=0.791].

3.4.3 Long-term outcomes

As of July 2015, patients had been followed for approximately 12 years since study enrolment. Death occurred in 26 of 42 (61.9%) patients in the choice group and 15 of 22 (68.2%) patients in the non-choice group (Table 3.2). In the choice group, 10 (23.8%) patients received a kidney transplant versus 5 (22.7%) in the non-choice group. Of the 14 patients in the choice group who received PD, three (21.4%) patients switched to HD in the choice group due to peritonitis and four (28.6%) switched to HD due to other reasons (abdominal complications, social reasons). Of the 3 patients in the non-choice group who received PD, one patient switched to HD in the non-choice group due to peritonitis and two switched to HD due to patient preference and social reasons.
3.5 Discussion

This follow-up study suggests that patients who expressed intent to do self-care dialysis may not be more likely to receive it. Further, while the educational intervention increased the likelihood of choosing self-care dialysis in the original trial, choice did not appear to translate into an increase in the proportion of patients treated with self-care dialysis. However, when the analysis was restricted to patients who ultimately went on to require dialysis, a significantly higher proportion received self-care modalities if they had chosen them.

Considering that both HD and PD are available in most renal programs, and in the absence of robust data suggesting the superiority of one method over the other, many believe patients should have a choice \(^{15-17}\), but there is pressure to grow the PD population. There is a general feeling that pre-dialysis modality education may increase the number of patients who choose self-care dialysis. We recently performed a systematic review and meta-analysis and found that, when compared to standard care, patient-targeted modality education was associated with a 2.1-fold increase in the odds of choosing PD in observational studies\(^ {14}\). This literature review confirmed that modality education is seen as a way to increase PD choice. However, choice of self-care dialysis does not necessarily translate into receipt of a self-care modality. Patients may change their minds, may become ineligible for self-care dialysis due to occurrence of adverse events and deterioration in their health status, or may not need dialysis because they die before they reach end-stage kidney failure, or receive a kidney transplant. Our findings suggest that choice may not be a reliable surrogate for receipt of self-care dialysis, so it is likely advisable to focus on the receipt of self-care dialysis in studies evaluating interventions designed
to increase the use of these therapies, where possible. Thus, receipt is a better outcome to assess interventions and is a better performance measure of a program.

Our study has also limitations, largely related to the single-center nature of original study and its relatively small sample size that may have limited our power to detect a difference. Another limitation is that this is an observational study although the choice (vs. non-choice) cannot be randomly assigned in a trial. While the original study was powered to test the hypothesis that educational intervention increases the choice of self-care dialysis, a larger study would be necessary to test the impact of educational interventions on the utilization of self-care dialysis.

Our recent systematic review demonstrated that patient-targeted educational interventions were associated with a 3-fold increase in the odds of receiving PD as the initial treatment modality based on results from 9 observational studies\textsuperscript{14}. Liebman et al showed that 50\% of patients who express a choice for home dialysis in the pre-dialysis period received it\textsuperscript{18}, compared to 33\% in the present analysis. The discrepancy may be related to the fact that our data were captured prospectively as part of a clinical trial, where the intervention and control groups were well defined, and choice was prospectively documented. Alternatively, a true difference may exist and we are simply underpowered to detect it. It is interesting to note that if the analysis is restricted to those who went on to receive dialysis, 70\% in the choice group received self-care dialysis. This highlights the importance of capturing the entire denominator of all patients who were targeted with the intervention to appropriately assess its effectiveness. Thus, applying education to a larger pool of patients may be worth while even if only a small percentage go on
to receive dialysis, because in those who require dialysis, they are more likely to receive home therapies, if educated. However, more research is needed to know more about patients who do not go on to require dialysis, allowing us to minimize the number of patients we educate and create potential savings of limited healthcare resources (time and finances). Potentially, the proportion of people that we educate and subsequently do not start dialysis could be minimized by implementing educational strategies in combination with the most appropriate timing (e.g. only educate about choice in patients who reach a stage four eGFR of 15-29).

The findings from our study have important implications. While education about modality choices is important to provide informed consent, our findings would suggest it might not increase the utilization of self-care dialysis. This highlights the importance of measuring self-care dialysis utilization explicitly, rather than relying on choice as a surrogate. A number of barriers to increasing self-care dialysis utilization have been identified and may be specific to the local environment or program. A systematic approach to understanding local barriers to maximizing the use of self-care dialysis is helpful to facilitate the identification of areas that require attention and the interventions that might be of benefit. These interventions may include overcoming obstacles that prevent patients from receiving PD such as improving home conditions and providing home care assistance; improving the outcomes of PD catheter insertion; the prevention of catheter-related complications; and social and family support systems. It is likely that a comprehensive program that includes proper training of patients, the provision of home care or assistance as needed, and monitoring of important PD outcomes may be required to maximize the use of self-care dialysis.

Our study suggests that patient choice to initiate a self-care dialysis treatment does not necessarily translate into receipt of self-care dialysis. Furthermore, there was no association
between a patient-targeted educational intervention and the receipt of self-care dialysis over an extended duration of follow-up. Utilizing choice as a surrogate for receipt may not be appropriate and may lead to inappropriate or misleading conclusions. Thus, it is important to measure the receipt of self-care dialysis directly in studies that explore the impact of interventions designed to increase the use of self-care dialysis.

3.6 Acknowledgments

None

3.7 Statement of Competing Financial Interests

None
### Table 3.1: Baseline characteristics

<table>
<thead>
<tr>
<th></th>
<th>Choice (N= 42)</th>
<th>Non-Choice (N=22)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, years (sd)</strong></td>
<td>64.5 (15.5)</td>
<td>66.7 (14.5)</td>
<td>0.58</td>
</tr>
<tr>
<td><strong>Age, years (range)</strong></td>
<td>27-84</td>
<td>35-88</td>
<td></td>
</tr>
<tr>
<td><strong>Gender (% male)</strong></td>
<td>26 (61.9%)</td>
<td>10 (45.5%)</td>
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</tr>
<tr>
<td><strong>Married</strong></td>
<td>33 (78.6%)</td>
<td>15 (68.2%)</td>
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<tr>
<td><strong>Employment</strong></td>
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<tr>
<td>• Employed</td>
<td>10 (23.8%)</td>
<td>4 (18.2%)</td>
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</tr>
<tr>
<td>• Unemployed</td>
<td>5 (11.9%)</td>
<td>3 (13.6%)</td>
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</tr>
<tr>
<td>• Retired</td>
<td>23 (54.8%)</td>
<td>12 (54.5%)</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Coronary heart disease</strong></td>
<td>11 (26.2%)</td>
<td>7 (31.8%)</td>
<td>0.77</td>
</tr>
<tr>
<td><strong>Congestive heart failure</strong></td>
<td>2 (4.8%)</td>
<td>5 (22.7%)</td>
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<tr>
<td><strong>Peripheral vascular disease</strong></td>
<td>6 (14.3%)</td>
<td>6 (27.3%)</td>
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<td><strong>Previous stroke</strong></td>
<td>4 (9.5%)</td>
<td>1 (4.5%)</td>
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<td><strong>Lung disease</strong></td>
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<tr>
<td><strong>Diabetes</strong></td>
<td>26 (62.9%)</td>
<td>8 (36.4%)</td>
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<td><strong>Duration of pre-dialysis care</strong></td>
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<td>• &lt;3 months</td>
<td>4 (9.5%)</td>
<td>3 (13.6%)</td>
<td>0.68</td>
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<tr>
<td>• 3–12 months</td>
<td>2 (4.8%)</td>
<td>3 (13.6%)</td>
<td>0.33</td>
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<td>• &gt;12 months</td>
<td>10 (23.8%)</td>
<td>12 (54.5%)</td>
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<tr>
<td></td>
<td>Choice Group (n=42)</td>
<td>Non-Choice Group (n=22)</td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------------------</td>
<td>------------------------</td>
<td></td>
</tr>
<tr>
<td>Death (n/%)</td>
<td>26 (61.9%)</td>
<td>15 (68.2%)</td>
<td></td>
</tr>
<tr>
<td>Kidney Transplant</td>
<td>10 (23.8%)</td>
<td>5 (22.7%)</td>
<td></td>
</tr>
<tr>
<td>Patients switched to HD due to peritonitis</td>
<td>3 (21.4%)</td>
<td>1 (33.3%)</td>
<td></td>
</tr>
<tr>
<td>Patients switched to HD due to other reasons (abdominal complications, social reasons, preference).</td>
<td>5 (28.6%)</td>
<td>2 (66.7%)</td>
<td></td>
</tr>
</tbody>
</table>
Figure 3.1: Follow-up of patients enrolled in original randomized controlled trial from January 2003 until modality choice was made in December 2003.
Figure 3.2: Long-term follow-up of patients enrolled in the original RCT from January, 2003 until July, 2015.
References


CHAPTER 4. SUMMARY
4.1 Summary of Objectives and Findings

The overall objective of this thesis was to better understand the role of pre-dialysis education and its impact on the choice and receipt of home therapies. To address this objective, we conducted a systematic review and meta-analysis to characterize the relationship between patient-targeted educational interventions and the selection and use of PD in adult patients with, or at risk of ESRD. Patient-targeted educational interventions were associated with a 2-fold increase in the odds of choosing PD and a 3-fold increase in the odds of receiving PD as the initial treatment modality. This systematic review demonstrated a strong association between patient-targeted educational interventions and the subsequent selection and use of PD.

The second study explored whether patients who had initially chosen self-care dialysis were more likely to receive it, and examined the impact of the educational intervention on the likelihood of receiving self-care dialysis, using data from a randomized trial. This study revealed that patient choice might not translate into an increased number of patients receiving self-care dialysis. However, when the analysis was restricted to patients who ultimately went on to receive dialysis, a significantly higher proportion of patients who chose self-care modalities received them. There was no association between the patient-targeted educational intervention and the receipt of self-care dialysis during long-term follow-up.

4.2 Systematic Review and Meta-Analysis of Patient Education and Selection of Peritoneal Dialysis

The findings from our systematic review and meta-analysis have important implications. Pre-dialysis patient-targeted modality education was found to increase both the choice of PD and the receipt of PD.
There was a great deal of heterogeneity in the educational strategies employed by investigators in the studies reviewed, which highlighted the need to better understand the impact of the timing of educational interventions, as well as the medium used to deliver the education. Unfortunately, there are few data available to help us understand what the critical elements of a successful educational program are in this population, although conducting such a study or the series of studies required would be challenging. The approach to modality education in the single RCT was based on principles of adult education and grounded in education theory. The educational sessions included physician and nurse educators, was conducted over a period of more than 2 days, included detailed dietary information, had one-on-one and group discussions, used video and printed material, and included family members. This suggested that small group sessions, the inclusion of family members in educational interventions, and delivering educational interventions over multiple days were potentially important elements of modality education. The above-mentioned educational strategies may serve as a practical guide to follow for clinicians looking to carry out a well-rounded pre-dialysis education program.

A related issue is that most modality education programs direct their efforts to patients with advanced CKD and deliver the program prior to the start of dialysis. However, many patients will start urgently on HD and will not have had any modality education, as a consequence. It is likely important to identify this group of patients and target them for modality education so that they understand the treatment options available to them. Addressing this gap could result in the transition of HD patients to PD who might otherwise have continued on HD by default. Future work could look specifically at this group of patients who start dialysis urgently to determine if an educational intervention is effective in this population.
There is a relative paucity of high quality literature on the effectiveness of patient education and PD uptake. The majority of studies identified were observational and only one was an RCT. The design of observational studies can establish an association between education and PD choice and PD use, but they do not establish a causal link. Ultimately, this review highlights the importance of designing an effective educational program that focuses on both pre-dialysis education and modality education in urgent starts. Future studies should address the variability in the design of the educational strategies and seek to identify the most effective timing (i.e., level of residual kidney function and speed of kidney function deterioration) and mediums for education.

4.3 Effect of Patient Choice on the Receipt of Self-Care Dialysis

Increasing the PD population has become an increasing area of interest in many jurisdictions worldwide. PD is underutilized in the US\textsuperscript{15}. However in recent years, a bundled payment system has been implemented, which has led to renewed interest in growing the PD population\textsuperscript{16}. This may stimulate providers to seek out interventions that will successfully grow local PD populations. To date, there are very few interventions in the literature that have received as much interest as pre-dialysis modality education.

However, clinicians should be weary of implementing an educational program in hopes of PD growth unless it serves to address a clearly defined, local barrier to increasing utilization. It is important to understand what local barriers are, have a systematic approach to measuring them, and then target interventions to eliminate specific barriers to PD uptake\textsuperscript{22}. Blake et al recently described a six-step framework for understanding the drivers of PD uptake in incident ESRD patients. This framework helps to clarify the potential impact of targeted modality
education on incident PD utilization in environments where patients are free to make an informed choice. Patients must be identified, educated, assessed for PD eligibility, offered the therapy if they are candidates, choose PD, and then programs must be successful in getting them on the treatment. Each step is equally important in terms of the impact on PD uptake. A 1% change in the proportion of patients making it through any of these steps has an equal impact on incident PD utilization. A program that incorporates proper execution of the six steps and alleviates barriers to uptake may increase both the incidence and prevalence of PD populations. Thus, stakeholders such as healthcare providers and clinicians need to understand how these and other factors influence PD in the local context and to implement interventions that target areas of need. Indeed the implementation of a modality educational program appears to be of benefit in situations where the proportion of patients choosing PD is low, but may not lead to an increase in PD prevalence in situations where choice rates are not an issue. In that setting, revamping modality education may not result in an increase in PD numbers and may be an inefficient use of resources.

Historically, a patient’s expressed choice of self-care dialysis has been considered a reliable surrogate for the likelihood that they will go on to receive self-care dialysis. However, this study raised some doubt as to whether or not patient choice ultimately translates into an increased number of patients receiving PD. The numbers of patients were studied and with the potential limitations in mind, there are several potential explanations for our findings if they are indeed true. First, patients may change their minds for a variety of reasons (social circumstances, changes in their ability to function independently, loss of a caregiver, etc.). Second, they may even become ineligible for PD because of adverse events or a decline in their health. Finally, patients might receive a transplant or die and never require dialysis. For the
time being, it is likely advisable to measure the receipt of PD directly when evaluating new interventions designed to increase the use of PD population or at least be cognizant of the fact that educational interventions are likely to increase choice rate, but may not translate into increased PD numbers.

When we restricted our analysis to patients who ultimately went on to require dialysis, a significantly higher proportion of patients who chose self-care modalities received them. However, there was no association between a patient-targeted educational intervention and the receipt of self-care dialysis over an extended duration of follow-up for all patients. It becomes important to look at use of self-care dialysis as a percentage of all patients educated because of the attrition rates prior to dialysis. If the majority of patients dies, receives transplant, or never requires dialysis then local programs must consider the implications with through a cost-effectiveness lens. It is important to understand how much a local educational intervention will cost, how many patients it will be applied to, how much staff and patient time it will require, and most importantly, how many patients will likely go on to receive self-care dialysis. This will aid clinicians and healthcare policy makers in understanding if pre-dialysis education is truly a good investment of limited resources. It may be that it is still worth the resources and effort to educate a proportion of patients who will never required treatment, given the potential cost-savings realized by those that do go on to require dialysis. Our findings would suggest that if patients do require dialysis, they appear to be more likely to be treated with self-care dialysis.

4.3 Future work

Further work to help elucidate the critical components of a successful modality education program with respect to timing of intervention, the ideal person or persons to deliver the material
(competence and skills of the educator), the nature of the intervention (one-to-one vs. small group sessions), and the duration of the intervention (single-day vs. multiple days) is required. Future comparative randomized trials (with well-defined educational interventions and comparison groups) are required to determine the most effective components and how best to structure educational strategies and their impact on PD utilization.

4.4 Conclusions

Our systematic review demonstrates a strong association between patient-targeted educational interventions and the subsequent selection and use of PD. The follow-up study suggests that although patient-targeted educational intervention increased patient choice of self-care dialysis, it did not lead to increased receipt of self-care dialysis over long-term follow-up. Furthermore, patients who chose self-care dialysis were not more likely to ultimately receive it.
References


