COMMENTARY

REFLECTIONS ON EDUCATION INTERVENTIONS AND OPTIMAL DIALYSIS STARTS

The period of pre-dialysis care represents a valuable and unique window of opportunity within which to potentially improve patient outcomes. Education interventions provided to patients with stages 4–5 chronic kidney disease (CKD) have been associated with deferred initiation of dialysis (1), reduced use of catheters (2,3), and increased use of home-based dialysis therapies (4–7). Although studies of education interventions have shown promise, they have not been sufficiently conclusive, and many knowledge gaps remain. The current literature does, however, provide several insights that can guide clinical practice and inform future research prioritization and design. Important considerations include identifying knowledge gaps, handling bias in observational study designs, and standardizing outcome measures.

Randomized trials provide the least-biased estimates of treatment effects, and their reporting usually includes a detailed description of the candidate intervention. That description allows knowledge users to evaluate the generalizability of the study's findings to their own practice environments and, often, provides sufficient detail to allow the intervention to be replicated. A number of randomized clinical trials have evaluated the efficacy of education interventions in CKD patients across a wide range of outcomes.

A recent systematic review of such studies identified twenty-two reports (8). However, only two studies (reported across five publications) included pre-dialysis patients with stage 4 or 5 CKD not on dialysis. The first, by Manns *et al.*, evaluated the impact of a two-phase patient-centered education intervention (9). Patients who received the intervention were more likely to select self-care dialysis. A study by Devins *et al.* evaluated the impact of an intervention that included a 90-minute, interactive one-on-one slide-supported education session, a printed summary booklet, and supportive telephone calls every 3 weeks; the intervention was based on a "collaborative role-learning model" (1,10,11).

Among the 172 patients who received the intervention (compared with 163 control subjects), dialysis initiation was delayed, long-term knowledge retention was improved, and survival was better at 20 years. Although the findings of that single study have yet to be replicated in other populations, they can inform practice. Both of the foregoing studies provided sufficiently detailed descriptions of their interventions to facilitate dissemination and use of their research findings.

The paucity of published clinical trials in this area suggest that there are barriers (not themselves specifically studied) to undertaking or completing such studies. In the absence of such trials, observational designs can provide useful measures of treatment effects, provided that appropriate measures are taken to reduce the impact of bias. Given the relatively larger number of published observational studies of education interventions (3,6,12–15), the feasibility of such designs is an advantage over that of clinical trials. For example, in this issue of *Peritoneal Dialysis International*, Ribitsch and colleagues report that patients in Austria who chose to participate in an education program titled "INDIAL" had a greater propensity to choose PD than did patients who participated in no education program. This retrospective, nonrandomized, single-center cohort study addressed a question of great interest, but some of its limitations deserve comment.

It is worth first highlighting a problem inherent in many observational studies of patient education interventions in the late stages of CKD. At least 3 other overlapping processes interact with patient education to achieve optimal initiation of dialysis. They are

- early referral to a nephrologist,
- multidisciplinary team-based care, and
- empowerment of patients to make autonomous decisions.

Studies would ideally be designed to assess only one of those factors at a time, or else to enable the dissection

of the relative contribution of each of the four interacting factors. Unfortunately, observational studies in this area fail to consider those interactions, such that their conclusions about the education intervention are rarely clean.

In the study by Ribitsch *et al.*, timing of the referral and delivery of other aspects of multidisciplinary care were not directly measured. Matching patients on those and other important prognostic factors may have produced a less biased estimate of the effect of this group's education intervention. Alternatively, statistical adjustment for those factors would have been desirable, and failing that, the factors should be measured and reported so that qualitative judgments about their relative contributions can be made.

Ribitsch *et al.* attempted to mitigate the effect of late referral and emergency starts by excluding 233 patients who started dialysis with a central venous catheter (CVC). However, it has recently been shown that starting dialysis with a CVC is not a valid surrogate for the effects of late referral, lack of education, and emergency starts. In a recent Canadian study, a vast proportion of the patients followed by a nephrologist for more than 12 months who initiated hemodialysis (HD) started with a CVC (16). Similar results are reported by the US Renal Data System (17). Presumably, education efforts by North American nephrologists have been extended to many or most early-referred patients to empower good decisions and to facilitate creation of arteriovenous fistulae or grafts, but many patients start HD with a CVC nonetheless. Similarly, Ribitsch *et al.* showed that 46 of 116 patients in the education group (39.7%) started with a CVC, compared to 187 of 344 in the comparator group (54.4%). The authors did not reveal if the demographics of these two CVC groups are the same, no adjustments were made to the subsequent analysis, and whether the study cohorts remained comparable after eliminating the CVC starts was not reported. Indeed, the results of this Austrian education program are a mixed bag: more PD starts among those who received the INDIAL intervention, but still a high percentage of suboptimal starts in the group, despite lengthy and focused care by a highly motivated team.

Patient self-selection for the education intervention represents another major source of bias that is not unique to this observational study by Ribitsch *et al.* It would seem rather plausible that the more highly-motivated patients who choose to undergo modality education are also likely to choose a form of independent dialysis. Hence, it would be equally valid to conclude that patients who are willing to undergo modality education are more likely to choose PD. Given the study design, we cannot

confidently conclude that there is a causal link between undergoing modality education and selection of PD. Unfortunately, this problem can be fully addressed only by random treatment assignment.

An additional difficulty in interpreting the study pertains to measurement of the primary outcome. As simple and sensible metrics that can be used to characterize dialysis initiation, the terms "optimal start" and "suboptimal start" have only recently been coined (18). By definition, a suboptimal start occurs when a patient initiates dialysis with a CVC or as an inpatient in a hospital (or both). Suboptimal starts are a cause for alarm, because they are associated with a doubling of the risk for death, hospitalization, and transfusion (16). Ribitsch *et al.* disclose that, by policy, all patients at their center start dialysis as inpatients; hence, the authors were unable to use the new metric. In our opinion, there is no reason why a well-prepared, healthy, and stable patient should ever need to start dialysis as an inpatient. Indeed, there is no clinical or economic advantage to an inpatient start, especially if it is clinically unnecessary. Furthermore, the authors' center does not offer home HD, and as a result, the generalizability of their results to centers that offer and promote both home HD and PD is limited. Finally, and most importantly, without a well-defined and agreed-upon metric, future studies of education interventions will be difficult to interpret and compare.

The identified limitations notwithstanding, we are firm believers in patient education and empowerment of patient choice (19). We also acknowledge that not all research questions pertaining to the efficacy of education interventions can be subjected to the rigors of clinical trials. Education interventions are an essential prerequisite for informed decision-making. Given the complexity of modality and access planning, it should be considered every patient's undeniable right to have access to the education required to make informed choices. Despite the support of nephrologists for this paradigm, effective implementation across the globe is surprisingly uncommon. Several barriers are likely operational at various levels and are worth considering systematically, because they point the way to priorities for future research.

A recent survey of US nephrologist group practices suggested that only 82 of 137 randomly sampled dialysis programs (60%) made use of funding resources for CKD education made available through the *Medicare Improvement for Patients and Providers Act* (20). Characteristics of nephrologist practices, such as small size and lack of suitable personnel, may represent significant barriers to the availability of education programs. In

some instances, a lack of access to independent dialysis modalities or vascular and body access infrastructure (or both) are barriers to optimal initiation of dialysis, even if education were to be provided. Physician biases and practices are likely major determinants of modality choice and account for considerable variability in PD utilization, even within a given group practice (21).

Finally, a better understanding of the factors that determine the effectiveness of education interventions is needed. The dissociation between measured and perceived knowledge of CKD and modalities has been documented, and highlights the need for innovative and effective education strategies (22). To that end, it is worth considering the patient-level barriers to effective learning and optimization of health literacy. It is clear not only that health literacy varies, but also that a dissociation exists between the perceived and measured literacy of patients. These sobering observations speak to the complexity of CKD knowledge and perhaps also to the need for individualized education programs. Considering the aforementioned barriers to knowledge use by patients, high-priority research questions might include these:

- Among patients with stage 4 – 5 CKD, does an individualized education program, compared with non-individualized or group education, result in a greater rate of optimal starts?
- Which theories of health education (for example, adult learning theory, theory of planned behavior, others) are best suited to the CKD population and the decisions they face?
- What are the relative benefits and disadvantages of providing education interventions over multiple compared with single sessions?
- What is the role of the family or informal caregiver in the education process? How can this person's involvement be leveraged to optimize decision-making and outcomes?
- Do earlier education interventions—for example, at stage 3 rather than the routine stage 4 practice—lead to a higher rate of preemptive transplantation and optimal initiation of dialysis?
- Which targets for individualization of education interventions lead to the best outcomes at the most reasonable cost? Health literacy level, cultural and language considerations, stage of CKD, current CKD knowledge level, or choice of medium (group discussion or focus group, individual interview, written materials, audio, video)?
- Do written or electronic (for example, web-based) clinical decision support tools lead to better decision-making and outcomes?
- Which additional strategies are needed to target vulnerable populations and to reduce disparities in access to patient education?
- How do we overcome patient-related delay and indecision that occurs after appropriate educational efforts (23)?

Despite important knowledge gaps in the design and implementation of education strategies, it is encouraging that awareness, interest, and availability of resources have generally improved across the developed world. A logical and essential next step is a shift in focus from “if” to “how,” so as to offer interventions that lead to better-informed decisions and better outcomes. Above all else, the end users, our patients, should be active participants in future research prioritization and planning endeavors. Where clinical trials are not feasible, investigators should implement measures to reduce the impact of selection bias and other major confounders, and should use metrics that are practical and comparable across studies. Additionally, successful interventions should be described in sufficient detail so that new knowledge can be more effectively driven into practice. Practitioners should understand that important and modifiable opportunities for promoting optimal dialysis starts are available and that application of these currently known strategies, and future research, are priorities.

DISCLOSURES

The authors have no financial conflicts of interest to declare.

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