FROM THE EDITORS

The Importance of Using Patient Experience to Direct Research

Does peritoneal rest (PR) facilitate recovery of the peritoneal membrane in patients who have developed ultrafiltration failure (UFF)? This question is explored through a 25-year retrospective analysis from Madrid (de Sousa *et al.*) that compared periods of PR used as treatment for UFF with episodes of PR mandated by other indications such as abdominal surgery. Raymond Krediet, in his excellent accompanying commentary, examines the significance of these observations, taking the opportunity to review the pathogenesis and clinical evaluation of UFF. The Madrid investigators found that PR may be beneficial early on in the development of UFF, but not once it has become established. They hypothesize that its use may interrupt the process of epidermal-mesenchymal transformation, considered to be important in the development of peritoneal membrane change, possibly allowing its reversal. Although no direct evidence for this is presented in the study, the reverse process is recognized as mesenchymal-epithelial transition and illustrates the inherent plasticity of the epithelial phenotype (1).

A large cohort study of 9,244 peritoneal dialysis (PD) patients linking the DaVita database to the US Renal Data System analyzes the relationship between both time-averaged serum alkaline phosphatase (ALP) and parathyroid hormone (PTH) and survival among PD patients (Rhee *et al.*). Importantly, higher ALP levels associate more closely with poorer survival in patients on PD than does PTH. Lamb and Delany (accompanying commentary) discuss the limitations of ALP as a bone marker since it exists in several isoforms, mostly unrelated to bone. At the same time, the role of PTH in the diagnosis of chronic kidney disease mineral bone disorder is questioned since its interpretation is complicated by multiple factors including difficulties with measurement. Bone specific ALP has the potential to relate much more closely to clinical outcome.

The relative costs of PD compared with HD vary considerably internationally, subject to a wide range of economic and health service-related factors. A recent comprehensive evaluation of this topic concluded that

PD is a more affordable modality in most health care systems, although a key factor is access to low-cost PD equipment, either through local production or low import duties (2). If PD utilization is to be effective, it generally requires governmental involvement to plan and promote the modality. In the US, Medicare implemented a bundled payment in 2011 in order to better manage dialysis costs and this has led to an increase in uptake of PD (3). A paper by Liu *et al.* in this issue of PDI uses a budget impact model to estimate the financial impact on Medicare of the changes in the distribution of dialysis modality selection under the new prospective payment system. Youssef and O'Donoghue discuss the difficulties of capturing true health care costs, observing that financial incentives in health care should be directed to improve patient outcomes, rather than simply focusing on reducing costs. However, the challenge is to identify measures that reflect true patient outcomes across the whole patient pathway. Increasing access to PD should be driven by evidence of its benefit to patient experience rather than primarily a desire to reduce costs.

It is therefore important that prominence should be given to the patient voice. In this issue of the journal, Helen Hurst and colleagues present work on the patient experience of living with encapsulating peritoneal sclerosis (EPS). They conducted interviews with 9 patients who had undergone peritoneal surgery for the condition at a specialist referral center, opening with the question, "Tell me about your experience of EPS." A key theme that emerged was the distress associated with "not being heard," during the commonly experienced diagnostic delay. Other aspects presented included: coming to terms with the diagnosis; the faith placed in the surgeon; and enduring the long period of post-operative recovery and rehabilitation.

Using patient experience to direct research allows priority to be given to topics that matter to patients, but that clinicians may not otherwise have prioritized. This principle is as important whether the research is on cellular processes, biochemical parameters, or macro-economic policy.

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