Management of Cystinuric Patients in a Dedicated Stone Clinic Decreases Stone Events

Introduction and Objective: Patients with cystinuria frequently undergo multiple surgical procedures throughout their lifetime, with potential loss of renal function and attendant morbidity. We investigate whether referral to a dedicated stone clinic, with emphasis on minimizing surgical morbidity, and comprehensive dietary and medical therapy, can decrease stone events and preserve renal function.

Materials and Methods: A total of 41 consecutive cystinuric patients were treated over a 12-year time period. Patients were followed semiannually with renal sonograms, 24-hour urine collections and clinic visits with an endourologist and nephrologist with a special interest in treating cystinuria. Surgical intervention, when indicated, utilized flexible ureteropyeloscopy preferentially to percutaneous procedures, except for complete staghorn or infectious calculi. Stone-free status was defined as absence of stones or asymptomatic stones up to 4 mm on post-procedural sonography, and stability of disease was defined as having achieved stone free status or maintaining stable, asymptomatic renal stones at last follow-up.

Results: Our 41 patients had a mean age of diagnosis of cystinuria of 21 years (range 4 to 44). At referral, 6 (15%) patients had a nonfunctioning or surgically absent kidney as a result of prior procedures. During mean 67 month follow-up (range 1 to 172), our patients underwent 101 procedures for 80 stone events, 15 of which were for bilateral stones. Under our care, operative interventions were more likely to consist of ureteroscopy (used in 76% of patients), as opposed to percutaneous procedures (used in 24%). Our patients experienced decreased frequency of stone events and subsequent surgical procedures, undergoing one surgery every 38 months as opposed to every 27 months prior to referral. Mean stone size was 34 mm (range 20 to 70 mm), and we achieved overall stone clearance of 84%, with no difference noted between ureteroscopy or percutaneous procedures (Table 1). Renal function remained stable during follow-up, and stability of disease was achieved in 36 (88%) of patients. **Conclusions:** For cystinuric patients, a dedicated stone clinic emphasizing careful surveillance, medical management, and surgical intervention minimizing renal trauma effectively reduces stone events and their associated morbidity.