The present study was undertaken to examine the experience of younger dialysis patients with end-stage renal disease (ESRD) care. Structured tape-recorded interviews focusing on perceptions of ESRD care and how that care could be improved were initially conducted with 25 dialysis patients [16 on conventional hemodialysis (HD), 6 on nocturnal in-center HD, 2 on home peritoneal dialysis (PD), and 1 on home HD]. The mean age of the patients was 43.8 ± 12.2 years, and their mean dialysis duration was 4.6 ± 3.0 years. Five important domains were identified from the interviews. Based on those findings, a questionnaire was developed and distributed to 62 ESRD patients (49 on HD, 13 on PD). Several domains were identified that provide insight into how the patients thought their care could be improved. Our results suggest that certain changes in ESRD care might improve the experience of younger dialysis patients.

Key words
ESRD, hemodialysis, patient experiences, young adults, patient-centered care

Introduction
Nearly 400,000 patients are maintained on dialysis in the United States for the treatment of end-stage renal disease (ESRD) (1). Considerable attention has been focused on elderly patients starting dialysis, particularly because the ESRD incidence rate is so much higher in patients more than 65 years of age than in younger patients (1–4). Studies have focused on the concerns, problems, and perceptions of ESRD care among elderly patients (2–4). Less attention has been paid to the perspectives of younger patients concerning delivery of ESRD care, which is in many ways surprising, given that younger patients likely have needs and concerns different from those of elderly patients.

Of particular note are recent studies suggesting that young adults transitioning from pediatric to adult nephrology care have very particular and special needs (5,6). For example, one study conducted in the United Kingdom, focusing on young renal transplant patients during the time of transition to adult care from pediatric care, showed that their compliance with immunosuppression medications was significantly jeopardized during that period (5). The authors hypothesized that the difference in health care delivery between the pediatric and the adult groups played a significant role. When certain changes were introduced into the system, including the institution of social groups for this subset of patients and of common clinic visits with both adult and pediatric caregiver teams, the rate of noncompliance was significantly reduced (5).

The purpose of the present study was to try to better understand the perception of the dialysis experience by younger adult patients and to see if their expectations for care were being met. We hope that the results of our study will help caregivers to improve the ESRD experience of the younger adult with ESRD.

Methods
Our study was conducted in a home dialysis unit [including continuous ambulatory peritoneal dialysis (CAPD) and home hemodialysis (HD) patients] and in four HD units located in the greater New Haven area. The Hospital of Saint Raphael Review Board approved the study.

All patients who had been on dialysis for at least 3 months, who were medically stable without hospitalizations in the preceding 3 months, and who were less than 65 years of age were eligible to participate.

In the first part of the study, audio-recorded interviews of 25 dialysis patients were conducted by
4 trained investigators after informed consent had been obtained from the patients. Of the 25 patients interviewed, 16 were being treated with conventional HD; 6, with nocturnal 3-times-weekly in-center HD; 2, with home PD; and 1, with home HD. Each interview lasted for 20 – 30 minutes and was intended to explore the dialysis care experience of a younger dialysis patient, particularly focusing on how that experience might be improved. The questions that were asked were exploratory and open-ended, eliciting spontaneous responses concerning dialysis treatment, patient satisfaction with care, and how care might be improved. Cues were given as needed to encourage patients to report and elaborate on all aspects of patient factors that could potentially be changed to enhance the experience. Although the data were gathered and analyzed for the HD and PD patients separately, all results were combined, given that no significant differences were observed between the groups.

Two investigators (HBY, SHF) independently reviewed the 25 tapes and identified the important domains cited by the patients. Five such domains were noted (see the Results section). Based on the audio interviews and the five key domains identified, a questionnaire that elaborated on the various aspects of care in each of the domains was developed. Most of the questions were answered on a 1 – 10 Likert scale (negative to positive). To increase the sensitivity of the questionnaire to differences between patients undergoing different types of dialysis, different questions for HD and PD patients were included. The questionnaire was intended to be self-administered or administered with interviewer assistance and to take approximately 20 minutes to complete. Based on patient preference, the questionnaire was administered either during a PD clinic visit or during a HD session, or it was completed by the patient at home. The questionnaire was completed by 62 patients (49 on HD, 13 on PD).

The questionnaire was pretested for comprehensibility and understanding on a small sample of subjects. Those subjects were then asked to comment on the wording and clarity of questions. Members of the clinical staff (nephrologists, social workers, and dialysis nurses) were asked to assess whether the instrument was appropriately phrased, logical, patient-centered, and easily understandable. Appropriate changes were made and incorporated into the final questionnaire based on the pretesting results.

Results

Interviews

Table I shows the demographic data for the 25 patients who completed the interviews.

The 5 domains identified from the interviews based on the independent reviews were these:

- Significant distress during initiation of dialysis or transition in care was expressed by 68% of the patients (50% reported distress during initiation of dialysis, and 32% during changes in treatment modality).
- Interest in seeking guidance from other patients who had similar experiences was expressed by 60% of patients, who felt that such conversations could alleviate fear of the unknown and help in problem-solving; 60% were interested in a "mentor" system, identifying a "buddy" to share their common concerns and to explore ways of effectively coping with adversities.
- Interest in social interactions with other patients, family, and health care staff to support care management was expressed by 64% of patients. Within this group, 65% were interested in organized social activities either within or outside the dialysis units, or in support groups (or both).
- The idea of special HD shifts or PD clinics for youthful adults was endorsed by 50% of patients.
- A future with a kidney graft was envisioned by 70% of patients; 64% preferred to obtain first-hand information from patients who had already received a graft to help them navigate the complex system of transplantation evaluation.

Questionnaires

Table I shows demographic data for the 62 patients who completed the questionnaire.

More than 70% of patients (34/49 on HD and 10/13 on PD) would like to talk with someone on dialysis before starting dialysis. About 72% (36/49 on HD and 9/13 on PD) would like their family to receive more support or information about their condition. While on dialysis, 53% (26/49 on HD) felt bored, and 61% (30/49 on HD) were uncomfortable. Half the patients (24/49 on HD and 7/13 on PD) would like to have a better understanding of their treatment. Half the patients (23/49 on HD and 8/13 on PD) would like to have more relationships with young people on
dialysis; 55% (27/49 on HD and 7/13 on PD) would like to participate in social activities outside of the unit with other patients. Participation in support groups would be appreciated by 55% (24/49 on HD and 8/13 on PD). And about 50% would like more information about diet, blood work, weight management, and medications.

Interest in transplantation was expressed by 94% of HD patients (37/39) and by 77% of PD patients (10/13). More information about transplantation was wanted by 57% of HD patients (28/49) and 85% of PD patients (11/13). More than 50% of patients (29/49 on HD and 6/13 on PD) were worried about transplantation. Almost 60% of patients (30/49 on HD and 6/13 on PD) would like to speak with someone who has received a kidney graft.

**Discussion**

Our study was designed to examine the perceptions of younger ESRD patients concerning their experience with dialysis treatment. The incidence of ESRD is much greater in elderly patients. The experience of elderly patients on dialysis has recently been investigated in several studies (2–4), but much less literature is available about the experience of dialysis among younger patients. With more emphasis being placed on patient-centered care and an understanding of the patient experience (7–9), we tried to better understand the concerns of the under-65 age group on dialysis and the ways in which we might improve their experience of dialysis.

Analysis of 25 patient interviews led to the identification of 5 major themes (outlined in Table II), which were then developed into a questionnaire that was completed by 62 PD and HD patients. The themes expressed by the patients concerning their care were very clear and consistent. We feel that these themes can inform us as caregivers about how the care of this patient population can be modified to improve the patient experience.

Most patients would have wanted to talk to someone on dialysis before starting ESRD therapy. In our current system of chronic kidney disease education, this area seems to be one that can clearly be improved. Interestingly, many of the patients in our study volunteered to be mentors. Most patients wanted further family support and involvement. Given that family involvement has an important role in supporting the patient, particularly for home dialysis patients, this area seems important to focus on. It is perhaps surprising that, despite focused staff involvement with the patients in our units (especially the PD unit), half of the patients (both PD and HD) wanted to have a better understanding of their treatment. That finding makes us wonder whether additional studies are needed to clarify the optimal way to communicate information to patients about their care. About half the patients were interested in having contact with patients of similar age and were enthusiastic about support groups and social groups outside the dialysis units. A multidisciplinary approach to identify practical ways to implement such contacts might be an important area to develop. Nearly all patients were interested in pursuing renal transplantation, but would like additional information and the opportunity to talk with someone who has already received a graft.

**Conclusions**

Our study suggests that, from a patient perspective, improvements could be made in several domains of...
care for ESRD patients. It is important to see if these results are similar in other dialysis units and other regions in the country. If our results are reproducible, they would provide the community of ESRD caretakers with important information for implementing changes in their current strategies of patient care.

Disclosures
None of the author have relevant relationships to disclose that represent a financial conflict of interest.

References

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