People over the age of 80 years are the fastest-growing segment of the population with stage 5 chronic kidney disease, which is dialysis initiation. We set out to describe the experiences of those elderly patients in initiating and being maintained on peritoneal dialysis.

We interviewed 4 patients (1 woman, 3 men; time on dialysis: 2 – 5 years) 75 – 88 years of age. A predetermined set of questions evaluating 7 domain topics were asked. The topics were initiating dialysis, dialysis knowledge, physical condition, social support, experience of dialysis, psychological support, and coordination of care. These in-depth interviews were analyzed in each category to determine common themes.

Within each domain, several themes were identified. The themes most important for physicians to understand to be able to deliver a high level of care to elderly patients on dialysis were

- the importance of peer and family influence on decision-making,
- the patient's support system,
- the patient's integration into the community, and
- the patient's increased perception of autonomy.

Patients in this age group on peritoneal dialysis have strong support systems and an increased perception of autonomy that allows them to be integrated into their community through hobbies and other social engagements.

Key words
Self care, aged, life experiences, social adjustment

Introduction
People more than 80 years of age constitute the fastest-growing segment of patients initiating dialysis (1,2). Dialysis for very old patients is a significant challenge for health care providers. These individuals are often referred to nephrologists in the later stages of their disease; they have shorter survival on chronic dialysis than younger patients do; and they have more comorbidities such as cardiovascular disease, malnutrition, and hearing and visual impairments (3,4). The debate over the costs and benefits of initiating dialysis for very old patients is growing (5). Some data suggest that outcomes are poor for very old patients (6,7), but elderly individuals may still obtain some enjoyment from life (5,8). Predicting the experience and quality of extended life that dialysis treatment will offer to these patients is difficult (8).

In that context, peritoneal dialysis (PD) offers several advantages over hemodialysis (HD), including better control of hypertension and cardiovascular stability and greater independence (9). Peritoneal dialysis is also more cost-efficient (10). The obstacles to PD are the drop-out rate and the increased comorbidities in the elderly population that make self care difficult (11).

Currently, there is no clear picture of the experiential process or lived experience as it unfolds over time for very old individuals on dialysis, especially patients on PD (12–14). The question posed in the present study was “How do elderly patients experience life on PD?”

Methods
As part of a larger study investigating the experience of dialysis among elderly patients, we interviewed 4 such patients on self-care PD. We conducted in-depth interviews to better understand the issues, opinions, concerns, and feelings from the patient’s perspective (15,16). A structured interview of approximately 1 hour covered 7 domain topics: initiating dialysis, knowledge of dialysis, physical condition, social support, psychological support, experience of dialysis, and communication and coordination between the nephrologist and the primary care physician. Health status information was also obtained from the patients using the Kidney Disease Quality of Life (KDQOL) instrument (17,18).
Interview data and field notes were transcribed and then analyzed by domain topic to identify common patterns and key themes about the patients’ experiences with PD (19). The KDQOL data for each patient were gathered from medical records.

Results
Respondents included 1 woman and 3 men. Their age ranged from 78 years to 87 years, and they had been on dialysis for an average of about 2 – 3 years. A brief background for each of the 4 patients follows.

Patient 1
This 79-year-old woman in her 5th month of continuous ambulatory PD (CAPD) resides in rural mid-Missouri. Her KDQOL effects score was 93.8. An active person, she is very self-sufficient. She currently lives alone, but keeps busy by spending time with her church family and her sisters (from whom she receives great support) and by quilting and reading. She learned much about dialysis by helping her husband with it. Her motto about dialysis is “Don’t let dialysis rule your life. You have to do it and make changes, but don’t let it be the thing you live for.”

Patient 2
This 78-year-old man has been using night cycling dialysis for 2 years. His KDQOL effects score was 90.6. He had worked as a physical education teacher and is considered by many to be a “health nut.” His wife had died 2 years before his interview, and he keeps busy by helping at church, playing dominos with neighbors, fishing, attending parties, and taking ladies to lunch. He said that his greatest support structure is his children (with whom he communicates daily). They had a great influence on his choice to dialyze. About dialysis he said, “My goal with PD [is] not to be restricted in the daytime.”

Patient 3
This 80-year-old man has been on CAPD for 3 years. His KDQOL effects score was 81.3. An active person, he still mows his yard weekly and takes his wife out to dinner every Friday. He attends church weekly on Sunday and is involved in his community, serving on the fire department board and the bank board. He receives much support from his wife and has learned much from his nurse (“I couldn’t do it without them”). He still travels and plans well ahead for meetings, saying, “I am loose in the daytime to do what I need to do.”

Patient 4
This 87-year-old man has been using CAPD for 5 years. His KDQOL effects score was 82.1. He learned about dialysis from a patient educator and is glad he is using PD because “it gives me flexibility.” He receives much support from his three children and wife, who frequently take him places, “sometimes [watching] me too close.” He serves on the library and water and light boards. He rides his stationary bicycle for 6 – 7 minutes daily. He has been on both HD and PD, and he says that “with PD you control your life more.”

Discussion
Within the study’s domain topics, several themes regarding the effects and experiences of dialysis were common among the patients we interviewed. Only the most important themes were extracted for discussion.

Initiating dialysis
One of the more interesting themes expressed by patients in our sample was how they approached initiating dialysis, which typically began with experiences they had had earlier with friends, family, or a patient educator (“I wasn’t scared about doing it. It helped a lot going into it knowing what it was, because my husband had already done it”). Other patients discussed what they had seen when friends went through dialysis, and they decided to handle their decision in different ways (“I was talking to people in the [HD] clinic one day, and they said they felt [terrible] the next day[, and] then the next day they’d feel better; then they’d feel bad again. One advantage is that I feel about the same every day”).

Previous work has shown that organized peer support helps dialysis patients to better adapt to treatment and the new lifestyle demanded by dialysis (20,21). Similarly, we have noted that, for many patients, the choice of the way to receive dialysis is largely influenced by earlier experiences. This is a resounding theme, especially with this population of elderly patients who frequently cited the experiences of friends or other family members. When discussing dialysis with a patient, it seems that discussing the patient’s prior exposures to dialysis will largely influence their decisions. As a clinician, working through the barriers is an essential part of helping patients to select the best treatment option.
Knowledge of dialysis

“I didn’t think it would be that complicated when we started, but my wife is a big help.”

For many patients, the process can be difficult. In this age group, the simplicity of a treatment option or the availability of assistance seems to lead to better adherence (“I talk to [patient educator] on the phone if I need help”). Other patients remark, “I get good support. I am lucky enough to have three of my children live here in town.”

A large proportion of patients are estimated to switch from PD to HD, with rates of up to 35% being reported (11). As one patient explained, the complexity of the treatment can lead to a change in modality. Of the patients we interviewed, all cited support systems. For some, the support may come from family; for others, the ability to speak with a patient educator or nurse may be important. It also seems that, in this elderly population, a full and detailed description of the treatment before it starts is important if patients are to achieve a real understanding of what they should expect. Such measures might perhaps ameliorate the PD drop-out rate.

Experience of dialysis

According to McLaughlin et al., one prominent reason that patients choose PD is the freedom and lifestyle benefit that they identify (10). One important theme described by our patients was the ability to remain active and autonomous (“It’s flexible; I can do it when I want to”). Other patients said that “my goal was not to be restricted in the daytime.” Patients frequently mentioned the ability to continue to travel, to attend board meetings, to work at church, and to meet with friends as benefits of PD. Having the ability to choose to do those things seemed to be a source of happiness for many of these patients (“I’m glad I did it because it is much more convenient for me”).

Several of our patients had experienced both forms of treatment (PD and HD), and one patient said that “life didn’t change much with PD, but in hemo, the tail wags the dog.” A resounding theme was that “with PD you control your life more.” It is obvious that autonomy was important to our patients, allowing them to stay engaged in the community. Certainly, clinicians should find it helpful to understand that these advantages need to be in the forefront of the discussion as factors that help promote PD over HD.

Distance to the clinic is another big reason patients choose PD. Our patient population includes rural patients. A clinician’s awareness of the effects of distance should make that topic one to be discussed during patient encounters. It seemed to be the deciding factor for 2 of the 4 patients we interviewed.

Social and psychological support

Social engagement—whether provided by family, friends, or other groups—is recognized to increase the sense of physical and cognitive health in patients (22). The patients seemed to find that PD provides increased flexibility, but they are all still very motivated to be involved in the lives of their families and to remain integrated in society. All of the patients interviewed cited specific examples of things that they continue to do besides deal with end-stage renal disease (“I go to church, play dominoes, fish a lot, go to parties, and take ladies out to lunch”). Patients on PD seemed to remain very active in organizations, hobbies, and activities (“I’m still on the bank board. You tell me when there is a meeting, and I’ll be there”), expressing a sense of satisfaction about life.

Previous research by Tentori et al. and Takhreem (23,24) demonstrated that, for dialysis patients, activity has far-reaching positive benefits (“We go out to dinner quite often. We belong to one or two organizations”). It seems that patients have more autonomy on PD, enabling them to be more active, which correlates with increased overall well-being for the patient.

Study limitations

Although we used recommended research techniques, our study has limitations. First, its qualitative nature limited the sample size. However, what is lost in generalization is made up in having a more thorough in-depth understanding of the experience of dialysis in an elderly population. Second, the sample was confined primarily to rural U.S. Midwest communities; it would be of interest to replicate this study in a more urban community. Third, our patient sample was purposely selected, and it is possible that patients who refused to participate in the study had notably different attitudes and experiences. Yet despite that limitation, there was a remarkable consistency between the interviewed patients.
Our study identified themes within conceptual domains that can help to generate hypotheses for quantitative evaluation in future studies with larger, more representative samples.

Conclusions
Elderly patients on dialysis face many issues. Peers and family influence their perceptions about dialysis, a factor that must be taken into consideration. A strong support system was mentioned by all our patients, which is perhaps a reason for their continued success with PD. Perceived autonomy is also an important factor when dealing with patients deciding to pursue PD.

The PD modality also perhaps offers a possibility of increased social engagements. Our patients were well integrated into the community. The greater flexibility and increased activity that PD allows patients can increase a patient’s overall health—as the KDQOL evidence and other data show. Although not statistically significant, the KDQOL disease score for our patients averaged 86.95/100, and the Deyo–Charlson Index score averaged 62.5/100 (higher scores are better).

Disclosures
The authors have no financial conflicts of interest to declare.

References

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