



ESRD Brief: Patient Perspectives

The Problem From the Patient Perspective

Disease Management

A diagnosis of kidney failure (end-stage renal disease, ESRD) is a serious one for any individual who receives it. While the good news is that such failure can be treated successfully by life-sustaining dialysis (and, for some, kidney transplantation), the dialysis treatments themselves—let alone management of other conditions that may have led to kidney failure—are sufficiently demanding (3 days a week for 4 hours at a time). Without an end in sight, it can be both emotionally charged and life-changing for the individual as well as his/her family and/or caregivers and significant others. The physical and emotional burden is a heavy one.

In this setting, the dialysis care team, including the physicians, nurses, nursing assistants, technicians, social workers, dietitians, and others, become a critical part of the individual's world—and one on which he/she becomes very dependent for support, both for and beyond the treatments themselves. Maximizing the quality of this support, in particular that provided by the physician, must be the goal of any ESRD treatment model if the individual's ESRD journey is to be truly successful in terms of both health and quality of life.

Research has shown that education for patients and family members/caregivers is an integral part of treatment and enhancing quality of life. Not educating a patient and their care partner about their condition and treatment options leaves the patient at risk for complications as well as the possibility of not selecting a course of treatment best suited for them. Education is a simple and effective way to improve overall.

ESRD Treatment Options

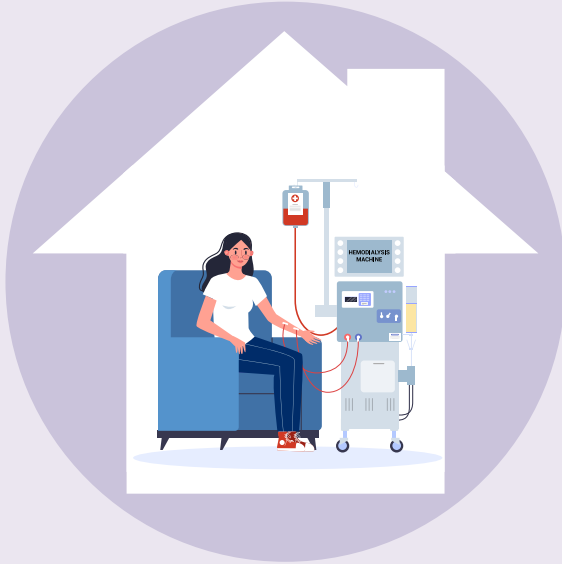
There are two main treatment options for ESRD patients: dialysis (hemodialysis and peritoneal) and kidney transplantation. Although a kidney transplant is the treatment of choice for many ESRD patients, the fact remains that such transplants are still quite limited, and so hemodialysis and peritoneal dialysis are the effective and practical treatment options available to most individuals with ESRD. Both treatments can substitute for the normal kidney's role as the remover of the toxic waste products that accumulate as part of normal body metabolism. Such dialysis can be done at a skilled treatment center or at home. The central issue is maximizing the dialysis experience for the patient and/or their caregiver, both from a health and quality-of-life point of view.



In recent years, a growing interest within reform initiatives in healthcare delivery is the emphasis on having a more prominent role for the patient voice. As the largest kidney patient consumer and advocacy organization in the nation, the American Association of Kidney Patients (AAKP) knows it is critical that the patient voice be included in all policy deliberations and patient care discussions and, in doing so, will always lead to a better understanding of patient values, and aspirations, care preferences, and decision making.

— American Association of Kidney Patients (AAKP)

In response to the Advancing American Kidney Health Executive Order in July 2019, the Centers for Medicare & Medicaid Services (CMS) launched five new CMS Center for Medicare and Medicaid Innovation (CMMI) payment models which aim to transform kidney care so that patients with chronic kidney disease have access to high-quality, coordinated care. The ESRD Treatment Choices (ETC) Model is one of the five models aimed to encourage greater use of home dialysis and kidney transplants for Medicare beneficiaries with ESRD. We believe that this model will have positive implications for both the ESRD field and more importantly individuals with ESRD.



ETC Model Implications for Patients

The ETC Model encourages greater use of home dialysis and kidney transplants. Home dialysis offers patients numerous benefits that, overall, provide patients with more flexibility and independence in their treatment support continued employment or a return to work as well as allow individuals to lead more productive lives, supporting their goals and aspirations. According to the AAKP, kidney patients who choose a home dialysis therapy as a treatment option experience:

- More energy after treatment
- Better control blood pressure
- Less stress on the heart
- Fewer diet and fluid restrictions
- Better mental and physical health
- You don't have to drive to and from the clinic
- Increased quality of life
- Can be done in many locations, making it easier to travel and work.
- Flexible schedule and increased independence.

Source: American Association of Kidney Patients. Retrieved from "Understanding Your Home Hemodialysis Options" and "Understanding Your Peritoneal Dialysis Options." <https://aakp.org/center-for-patient-research-and-education/dialysis-education/>.

An Additional Benefit of Dialysis at Home - Reduced COVID-19 Exposure

A more recent benefit of home dialysis for patients and the ESRD field would be reducing patient's possible exposure to COVID-19. As many reports have shown, people who have underlying medical conditions such as ESRD are at higher risk for COVID-19 complications due to immune system deficiency.

According to Hsu and Weiner (2020), ESRD patients are disproportionately being affected by COVID-19 and are experiencing higher deaths rates compared to non-ESRD patients. Patients who receive in-center dialysis are at higher risk for contracting COVID-19 due to the inability to properly distance patients from one another. Therefore, focusing efforts to shift in-center dialysis treatments to home dialysis is necessary for individuals where home treatment is a very viable option.

Source: Hsu, C. M., & Weiner, D. E. (2020, October 13). COVID-19 in dialysis patients: Outlasting and outsmarting a pandemic. *Kidney International*, 98(6), 1402–1404. Retrieved from [https://www.kidney-international.org/article/S0085-2538\(20\)31203-5/fulltext](https://www.kidney-international.org/article/S0085-2538(20)31203-5/fulltext).



USRDS Data

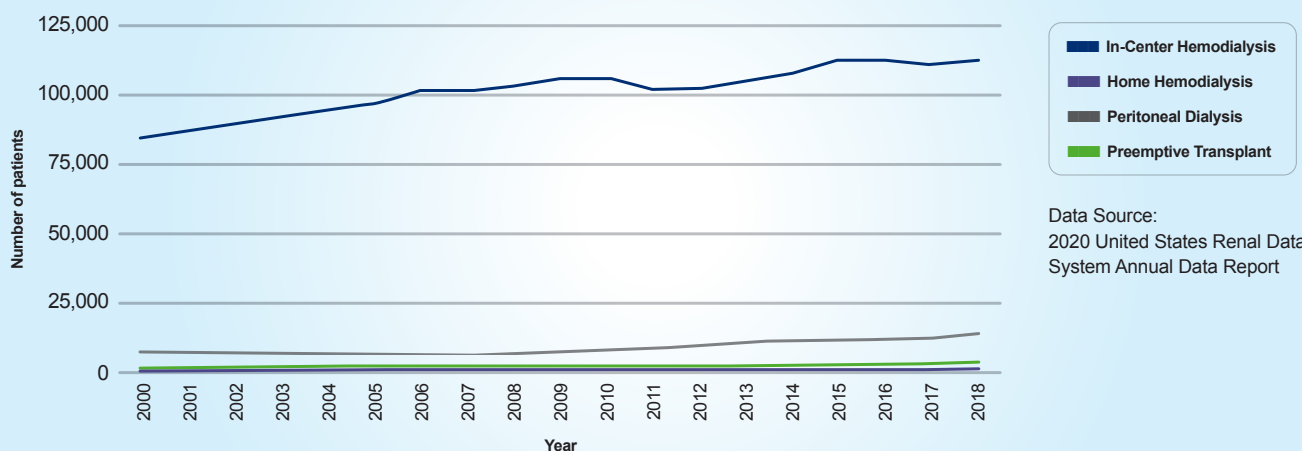
Each year, the United States Renal Data System (USRDS) Annual Data Report (ADR) is updated with the most recent public and private kidney disease data in the United States. The report is used in support of public policy initiatives and to improve care for individuals with acute kidney injury, chronic kidney disease, and ESRD. Several key data points reflect ESRD treatment choices and demonstrate a significant shift in program goals to increase the utilization of home modalities and preemptive transplants among Medicare beneficiaries. These goals are in keeping with the national kidney care priorities set forth in the July 2019 Executive Order on Advancing American Kidney Health and in CMS' ESRD Treatment Choices Payment Model.

In 2020, more than 110,000 patients initiated in-center hemodialysis compared to fewer than 450 patients who initiated home hemodialysis during the same period. The decades-long relatively flat growth in the use of home dialysis is disappointing, as many technological advancements in home dialysis technologies have strong evidence for improving the lives and health status of ESRD patients. More promising is the recent trend for preemptive transplants elected by 3,854 Medicare patients in 2018, a 2.9-percent increase over 2017.

Patient Choice and Patient Voice

AAKP has been a vocal advocate for the principle of increased patient consumer care choice through access to safe and innovative treatment options. AAKP believes advancements in treatments and technologies are among the strongest tools to help transcend the current, outdated brick-and-mortar status quo kidney dialysis care delivery system while increasing patient health outcomes. AAKP has been a staunch defender of the kidney patient voice informing care choice and defines quality kidney care as a treatment that best aligns with patient aspirations, including the ability to work full or part time and have a career, to start a family, own a home, and retire securely. Survey insights from AAKP's Center for Patient Education and Research demonstrate that the patient voice must be respected and understood as a major factor that determines treatment choice and risk acceptance. It is important to understand that a patient's voice is not unilateral and may include a variety of influencing factors that are as important to that individual as their own thoughts, including family, friends, care partners, faith/religion, and cultural/community considerations.

Figure 1.1 Number of incident ESRD patients, by modality, 2000–2018



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