What do we already know about home dialysis choice, continuation, and quality measurement?

The 2016 U.S. Renal Data Systems (USRDS) reports that there are 678,383 Americans with irreversible kidney failure, or end-stage renal disease (ESRD), and require dialysis or a kidney transplant to survive.\(^1\) Every year, across the country, more than 100,000 patients start dialysis due to kidney failure. Dialysis, a therapy that replaces the normal blood-filtering function of the kidney, can be completed in-center or at home. In-center dialysis usually conducted in an outpatient clinic, is where a nurse or technician performs the tasks required during treatment. In-center hemodialysis is usually done three times a week for about three to four hours or longer each session. In-center treatments are done at a pre-scheduled time. **Home dialysis (HD)** enables the patient, often assisted by a care partner, to carry out the treatment process in their own home. There are two (2) types of home dialysis. **Peritoneal dialysis (PD)** filters waste products from nearby blood vessels through an abdominal catheter, while **home hemodialysis (HHD)** is a process in which a patient connects to a hemodialysis machine to cleanse the blood directly. There are also various home hemodialysis schedules: conventional home hemodialysis, short daily home hemodialysis, and nocturnal home dialysis. The challenge for patients with kidney failure, their families and care providers, is to identify the dialysis type that best fits their needs and preferences.

Dialysis modality planning and decision-making is integral to the treatment process for many CKD patients, and home dialysis in particular has the potential to address some of the quality of life issues experienced by dialysis patients. While there is a growing body of research that suggests shorter and more frequent dialysis sessions at home has clinical benefits for blood pressure control, also provides better quality of life for patients who experience more independence, and decreased burden and time spent traveling to and from facilities, home dialysis is much less common in the United States than in other countries.\(^4,2,7\) Moreover, many patients who start dialysis at home end up switching to in-center dialysis within a short period.
The barriers to accessing home dialysis, and remaining on it, are largely known through published research. We are providing a summary of a brief literature review as background for our discussions.

Today we want to focus on potential solutions to these (and other) barriers to choosing and remaining on home dialysis modalities.

What are the barriers/facilitators to choosing and remaining on home dialysis?

**Barriers to Choosing Home Dialysis:**

- **Lack of modality choice at all** (often due to timing)
  - Often there is not enough time to make an informed decision before urgent start dialysis.\(^3\)
  - Providers simply do not offer the choice\(^4\)
  - Providers (in USA) may not have the confidence and knowledge to promote HD\(^5\)

- **Challenges to shared and informed decision-making**
  - Patients can lack “decisional power” (due to complexity of information, limited exposure to home dialysis, and no familiarity and knowledge of what it entails)\(^6\)
  - Lack of shared decision-making tools and resources for both patients and clinicians (2016 PCORI supported study)\(^7\)

- **Lack of patient understanding / knowledge of HD processes**
  - Lack of a satisfactory explanations of various techniques\(^6\)

- **Psychosocial factors preventing ability to learn and/or take on self-care responsibility**\(^9\)
  - General disinterest or lack of motivation of patient or family\(^10,11\)
  - Interpersonal Relationships (in which there is a strong opinion) e.g. family, clinicians (also a facilitator)
  - Fear
    - Isolation from medical and social support
    - Medical emergencies
    - Needle phobia, fear of cannulation\(^11\)
    - General lack of confidence\(^6,8\)
    - Fear of burdening family\(^12\)

- **Policy barriers:**
  - Limited and unmandated home dialysis training of nephrology fellows
  - Lack of synchronized education of ESRD care providers
  - Medicaid services’ poor reimbursement policies which dis-incentivize home based therapies\(^13\)

- **Miscellaneous**
  - Lack of storage space for equipment\(^8\)
  - Medical contraindications\(^10\)
    - Many older patients have contraindications to PD or barriers to self-care.\(^14\)
Facilitators to Choosing Home Dialysis:

- **Knowledge of potential benefits**
  (e.g. Reducing lifestyle disruption, sustaining employment, avoiding relocation, considering additional expenses, seeking flexible schedules, creating free time)\(^6\) and “Normalization of life less dominated by disease”\(^{15,16}\)
  - Access to other patients’ experiences\(^{15}\)
  - Completing a pre-dialysis education program\(^{17}\)

- **Gaining confidence in choice**
  - Overcoming fears of safety
  - Trust in professional certainty
  - Reassurance from peers\(^{18}\)
  - Patient motivation\(^{19}\)

- **Interpersonal Relationships** (in which there is a strong opinion) e.g. family, clinicians
  - Particularly family support (for elderly PD patients)\(^{14}\)

Barriers to Remaining on Home Dialysis:

- **(USA) Lack of known care team;** equipment support is often from external companies not local dialysis clinic\(^{20}\)
- Many similar barriers to those above for ‘choice’

Facilitators to Remaining on Home Dialysis:

- **Satisfaction with training** (Older patients in rural area)\(^{21}\)
- **(Potentially) telemedicine, remote monitoring**\(^{15,22}\)
- **Home care aids (for elderly patients on PD)\(^{23}\)**

Which patients (with which characteristics) do best on home dialysis?

- Rural patients may be slightly more likely to stay on home dialysis (authors’ hypothesize inconvenience of traveling to center)\(^5\)

- Minimizing central venous catheter (CVC) use and maximizing AV access use may improve HHD outcomes.\(^{24}\)

- Nocturnal home hemodialysis (NHD) - younger age and the absence of diabetes at onset of NHD may predict lower mortality risk.\(^{25}\)

- Patients with previous PD experience may have similar overall survival on HHD compared to those without PD experience.\(^{26}\)
What are the challenges to measuring the quality of home dialysis?

- Prevelance of HD is low compared to in-center
- Frequent switching from home to in-center treatment
- Few available or comparable studies (different patient samples and populations, between study cohorts broader ESRD population)
- Relatively healthier patient population leads to participants dropping out of studies due to reasons other than ESRD (e.g. geographical relocation)
- Different quality of life instruments provide different measurements across studies. e.g. “Measurement of patient preference for health states remains an appropriate method of estimating quality of life, further research is required to define the best method of eliciting such preferences in people with ESRD.”
- Lack of systematic research on patient selection and training for HHD.
- Studies comparing clinical outcomes between peritoneal dialysis and home hemodialysis have been very limited

Ideas study authors have suggested for future research

- HD technology design improvements
  “… to enhance the quality and safety of the patient experience include features to help patients manage their dialysis (e.g. providing timely reminders of next steps) and features to support communication between families and professionals (e.g. through remote monitoring).”
- Nephrologist education, training and support on alternative dialysis regimens
- Further characterization of the risk factors for, and causes of technique failure is needed to develop strategies to improve patient retention on home HD.
References


