

Patient Experiences with Home Dialysis

James Myers

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Introduction

The number of patients with kidney disease utilizing home dialysis has been growing rapidly, and it appears that it will continue to grow in the immediate future. Although there are scientific metrics to quantify the quality of care and actual patient experience with in-center hemodialysis, there are no corresponding scientific metrics to quantify the quality of home dialysis modalities for patients on home dialysis. How patients with kidney disease feel about their experiences with home dialysis has not been deduced to a quantifiable, uniform, and verifiable set of scientific terms.

One purpose of the article by Rivara *et al.* (1), appearing in this issue of *CJASN*, was to identify some repeatable, objective domains to help define how patients on home dialysis feel about their home dialysis experiences. The authors used a “mixed method multiple stakeholder approach” to create the Home Dialysis Care Experience (Home-DCE), a 26-item patient-reported experience measure for use in peritoneal dialysis and home hemodialysis.

As a result of a literature review, interviews, focus groups, and a prioritization exercise, Rivara *et al.* (1) were able to create 15 domains of home dialysis care experience in six areas: (1) communication and education of patients, (2) concern and helpfulness of the care team, (3) proficiency of the care team, (4) patient-centered care, (5) care coordination, and (6) amenities and environment. Focus group results showed that patients thought the following were most important: patient education and communication, care coordination, and personalization of care.

With verifiable, quantifiable results, these findings will definitely affect patient care as a result of patient input.

Communication and Education of Patients

Patients chose the “patient education and communication” evaluation category as their first priority. With the onset of initial dialysis, anxiety follows. For peritoneal dialysis, for example, patients must complete some training before they are allowed to begin treatment at home. With home dialysis, a caretaker or partner may be involved to assist the patient, but many new patients have been allowed to “go it alone.”

All of these new, sometimes sudden, and unexpected changes can raise fears in the patient, which

can be overcome by communication, training, and experience. In this way, the patient and caregiver can feel confident that they can handle the procedures, anticipate problems, and overcome obstacles.

Communication is a two-way street. The great advantage of patient-reported communication is that the medical professional and the manufacturing industry can obtain feedback from the patient. What experiences were positive? What experiences were negative? Where is there room for improvement? Patient feedback results in adjustments that not only benefit the patient but also the medical and manufacturing elements. We can make the patient experience better by adjusting these issues, resulting in improvements to the dialysis product.

This feedback also has the advantage of taking into account racial, ethnic, regional, and individual differences in patients. A one-size-fits-all approach may cause the patient to feel neglected, whereas an approach that takes individual differences into account may lead to greater acceptance and increased patient adherence. If the idea here is to improve and maintain patient kidney health, success can be best obtained with patient acceptance.

Concern and Helpfulness of the Care Team

This criterion was highlighted by the patients as important as well. Concerns initiate an open discussion of issues and problems and an exchange of ideas. The staff member, caretaker, or partner showing genuine concern for the well-being and comfort of the patient often raises patient confidence and adherence. This extends not only to physical comfort but also mental well-being. This consideration, in turn, leads to satisfaction with the experience and product, lending itself to the adherence needed to successfully lead to better kidney health. Issues raised by the staff members’ and caretakers’ concern and helpfulness can result in adjustments that benefit both the patient and the researcher. Personalization of care is critical here. This is the most important aspect of quantifying individual preferences and concerns raised by the patient.

Patient-Centered Care

In any form of medical or commercial discourse, the emphasis should be on the ultimate user or consumer

American Association
of Kidney Patients,
Indiana

Correspondence:
James Myers,
American Association
of Kidney Patients, 940
Kenwood Street, Apt.
426, Hammond, IN
46320. Email:
kidneystories@
hotmail.com

to be truly accepted within the limits of scientific development. The patient is suffering from kidney failure, so for KRT to be appropriate, the care must revolve around the best result obtainable for the patient. Patient-focused care results in patient satisfaction and better health results.

In this study, individual patients' needs are elements highly rated by the patients themselves. Personalization of care was a touchstone here.

Care Coordination

Coordination of care occurs at the juncture where patient preference meets medical necessity. There are certain medical and scientific objectives to dialysis that must be met in order to obtain a proper cleansing of the blood. In this study, the patients agreed that taking patient preferences combined with standard medically accepted practices results in a correct end result for home dialysis success. The desired clearance must be obtained with patient health in mind.

Effect on Future Research

Accounting for patient concerns and preferences has had an effect on research and will continue to do so in the future. As the patient is the ultimate consumer of both the service and the product, patient-reported experience becomes invaluable to aid in innovative adjustments and invention made to improve both the product and the experience. Research is at its best when taking into account the experiences of the patient.

Recently, I read a couple of articles concerning patient satisfaction with home dialysis (2,3). Rubin *et al.* (2) concluded that, "[a]fter several weeks of initiating dialysis, patients receiving peritoneal dialysis rated their care higher than those receiving hemodialysis. These findings indicate that clinicians should give patients more information about the option of peritoneal dialysis." The suggested changes came about from interviewing thousands of patients connected with dialysis centers supervising and training patients

on peritoneal dialysis. This is a very good example of how patient input has influenced research into the use and preference for home dialysis.

Rivara *et al.* (1) accomplished their goal in developing an objective, scientific method to quantify patients' home dialysis experience. The Home-DCE instrument represents the first of its kind for the assessment of patient-reported experience of care in home dialysis.

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