



# Home Dialyzors United

Home Dialyzors United (HDU) is pleased to offer The University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) comments concerning its upcoming report to CMS which investigates avenues for acquiring the evidence, data and infrastructure necessary to implement ESRD patient-driven measures. We understand that UM-KECC is soliciting comments about patient reported outcomes (PROs) quality of life; patient centered outcomes (PCOs) and experience of care. HDU would like to comment on these and suggest patient driven measures.

HDU, a 501(c)(3) non-profit organization, is the only dialysis patient group dedicated to home dialysis. Our mission is to inspire, inform, and advocate for an extraordinary quality of life for the home dialyzer community. We know from personal experience that, with the right dialysis treatment, patients with ESRD (and their families and care partners) can lead a normal life, enjoying family and friends, and pursuing employment, education, volunteer, and leisure activities. We also know that studies have repeatedly shown that patients who dialyze at home have better treatment outcomes.

Despite these findings, 90% of patients who need dialysis are treated in-center, most spending three to four hours, three times per week, connected to a dialysis machine. The treatment itself can be disabling, stressing the heart and other vital organs and may contribute to premature death. Although some centers offer treatment shifts that start after 5:00 P.M., most patients must undergo their in-center treatments during the day, making it difficult to work or engage in other life activities. Patients are often discouraged from being active partners in their care. With conventional dialysis treatments, many patients live to dialyze, rather than dialyzing to live.

Bearing in mind those ideas, we would like to suggest possible new measures and to comment on several studies which can be used as a basis for implementing those measures that are meaningful to patients and health care providers.

## **Recovery Time after Dialysis**

HDU feels that recovery time after dialysis, sometimes called post-dialysis fatigue (PDF), should be considered as a patient-centered measure. We feel strongly that this measure would drive improvement in many other areas of patients' lives.

A recent study in the American Journal of Kidney Diseases (AJKD), entitled "Patient and Caregiver Priorities for Outcomes in Hemodialysis:



# Home Dialyzors United

An International Nominal Group Technique Study,”<sup>1</sup> aimed to identify and rank outcomes that are important to patients. Whereas investigators tend to choose clinical outcomes that they feel are important to maximizing life expectancy and minimizing morbidity, those priorities are seldom the same as those that patients consider to be important. The study found that while biochemical markers are simple to measure, patients are more concerned with outcomes that have an impact on their day-to-day lives and well-being.

The aforementioned AJKD study ranked the highest patient and caregiver priorities as follows:

- 1) Fatigue/energy
- 2) Resilience/coping
- 3) Travel
- 4) Dialysis free time
- 5) Impact on family
- 6) Ability to work
- 7) Sleep
- 8) Anxiety/stress

When clustered into domains, the main themes elicited are:

- 1) Maximizing the capacity to function
- 2) Being normal

---

<sup>1</sup> Urquhart-Secord R, Craig JC, Hemmelgarn B, Tam-Tham H, Manns B, Howell M, Polkinghorne KR, Kerr PG, Harris DC, Thompson S, Schick-Makaroff K, Wheeler DC, van Biesen W, Winkelmayer WC, Johnson DW, Howard K, Evangelidis N, Tong A. Patient and Caregiver Priorities for Outcomes in Hemodialysis: An International Nominal Group Technique Study. *Am J Kidney Dis.* doi:10.1053/j.ajkd.2016.02.037.



# Home Dialyzors United

Long PDF is a vivid example of deficiencies in both of these themes. Inability to function (or even stay awake) for multiple hours after each dialysis session is abnormal and clearly prevents persons with ESRD from engaging in activities of daily living at home, at work, and elsewhere. Unfortunately, long PDF is common. One survey of 550 patients found that 40% had not recovered until bedtime.<sup>2</sup> In a larger study of over 6000 patients who participated in the Dialysis Outcomes and Practice Patterns Study (DOPPS), 68% of patients required more than 2 hours to recover after treatment and 27% required more than 6 hours.<sup>3</sup>

Furthermore, PDF is a cross-cutting outcome, because it is associated not only with poor quality of life, but also with poor clinical outcomes. In the aforementioned DOPPS cohort, each additional hour of post-dialysis recovery time was associated with 5% increased risk of death and 3% increased risk of hospitalization. This strengthens the argument that recovery time after dialysis ought to be significant to clinicians, as well. After all, serum phosphorus is universally considered to be clinically significant, but that is primarily because of observational studies that show an association of phosphorus with clinical outcomes.

One of the common misconceptions about persons with ESRD is that their disease is so disabling that they cannot continue working at their current employment, and must either find alternate employment that is less demanding or stop working entirely and rely on disability benefits. However, the Medicare statute contemplates that persons with ESRD may be able to work and should be supported in their efforts to do so. Specifically, the statute says:

*(6) It is the intent of the Congress that . . . the maximum practical number of patients who are suitable candidates for vocational rehabilitation services be given access to such services and encouraged to return to gainful employment. SSA Section 1881(c)(1)(A)(i)(6)*

Although it is true that persons with ESRD *may have disabilities*, it does not follow that they are, in fact, *disabled*. Unfortunately, it is too often the treatment modality that is disabling. First of all, it is difficult to work during normal business hours if the person has to go to in-center treatment

---

<sup>2</sup> Caplin B, Kumar S, Davenport A. Patients' perspective of haemodialysis-associated symptoms. *Nephrol Dial Transplant Off Publ Eur Dial Transpl Assoc - Eur Ren Assoc.* 2011;26(8):2656-2663. doi:10.1093/ndt/gfq763.

<sup>3</sup> Rayner HC, Zepel L, Fuller DS, et al. Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis Off J Natl Kidney Found.* 2014;64(1):86-94. doi:10.1053/j.ajkd.2014.01.014.



# Home Dialyzors United

three times a week. As delineated above, often the traditional treatment is sufficiently intense that the post-treatment recovery may take hours. In fact, the Social Security Administration recognizes ESRD requiring frequent dialysis as a possible qualifying condition for Social Security Disability Insurance (SSDI).

HDU would argue forcefully that initiating a measure of recovery time after dialysis/post dialysis fatigue would address not only employment and sleep but also the other top patient priorities. Patients who are not fatigued following treatment are able to travel, interact with family and work and are less anxious and depressed. In addition, the dialysis-free time is available for patients to lead a normal life, rather than spending that free time simply recuperating from dialysis. “Post Dialysis Fatigue: A Frequent and Debilitating Symptom,” a recent review in by Maurizio Bossola and Luigi Tazza in *Seminars in Dialysis*, also addressed the decreased quality of life in the vast number of patients who experience PDF. The review concluded that PDF is one of the most common and most debilitating problems associated with short thrice-weekly dialysis.

Measuring recovery time after dialysis would also be simple and take relatively little effort thereby minimizing staff burden. DOPPS has demonstrated that a very simple question can generate answers that correlate strongly with clinical outcomes and QOL. “How long does it take you to recover from dialysis?” has been shown to be easily interpreted, to elicit clear and simple answers, and to have stability?

## **Recommendations and Conclusion**

HDU recognizes that the addition of too many quality measures may dilute the intent of the QIP. Therefore, we recommend that any measures that are topped out or ones that are no longer effective be replaced by measures that truly matter to patients.

HDU supports the proposals in the QIP to continue including pain assessment and depression screening as reporting measures. However, we continue to believe that these measures need to be further developed, to ensure that the assessment looks at the psychosocial and quality of life issues that may contribute to the patient’s depression or pain, and that appropriate follow-up steps are taken to help relieve the depression and pain. Because home dialysis has been shown to improve patient scores in these areas, it is critical that follow-up include an assessment of the patient’s interest in home dialysis and assistance with moving to home dialysis if that is the patient’s wish. Presently, the QIP is still a long way from ensuring that patients get high quality care that provides them with an optimal quality of life, based on their values.



# Home Dialyzors United

In conclusion, HDU would make a recommendation to investigate the use of the following patient centered outcome:

Adoption of a recovery time after dialysis measure would hopefully encourage centers to offer lifestyle friendly modalities that allow patients and their families to live normal lives.

Home Dialyzors United is available at any time to offer further input to the UM-KECC and thanks the Center for the opportunity to provide these comments.

Sincerely,

Home Dialyzors United

Denise Eilers, BSN, RN (& former HHD care partner)

President, HDU Board of Directors

## References

- [1] Urquhart-Secord R, Craig JC, Hemmelgarn B, Tam-Tham H, Manns B, Howell M, Polkinghorne KR, Kerr PG, Harris DC, Thompson S, Schick-Makaroff K, Wheeler DC, van Biesen W, Winkelmayer WC, Johnson DW, Howard K, Evangelidis N, Tong A. Patient and Caregiver Priorities for Outcomes in Hemodialysis: An International Nominal Group Technique Study. *Am J Kidney Dis*. doi: 10.1053/j.ajkd.2016.02.037.
- [2] Caplin B, Kumar S, Davenport A. Patients' perspective of haemodialysis-associated symptoms. *Nephrol Dial Transplant Off Publ Eur Dial Transpl Assoc - Eur Ren Assoc*. 2011;26(8):2656-2663. doi:10.1093/ndt/gfq763.
- [3] Rayner HC, Zepel L, Fuller DS, et al. Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis Off J Natl Kidney Found*. 2014;64(1):86-94. doi:10.1053/j.ajkd.2014.01.014.
- [4] Bossola M, Tazza L. Postdialysis Fatigue: A Frequent and Debilitating Symptom. *Semin Dial*. 2016;29(3):222-227. doi:10.1111/sdi.12468.