

## Caregiver Burden and Hemodialysis

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In the frenetic world of dialysis clinics, it is possible to occasionally forget that we are not treating individual patients but, rather, people who have families, friends, loved ones, and personal care attendants. The Frequent Hemodialysis Network (FHN) has underscored our commitment to patients while not overlooking those upon whom they rely.

The report by Suri *et al.* in this issue of *CJASN* (1) is a follow-up to their baseline analysis (2) about the degree of burden on unpaid caregivers as perceived by patients enrolled in the FHN trials. The authors had originally found a high degree of perceived caregiver burden (Cousineau score) among patients selected for the study, which was unrelated to demographic factors and comorbidity but was significantly associated with poorer self-reported health-related quality of life and depression. They then followed and contrasted during the course of a year the 65 of 120 patients randomized to daily in-center hemodialysis (6 days per week) and the 33 of 87 patients randomized to nocturnal home hemodialysis (6 nights per week) who reported having unpaid caregivers. The control groups consisted of 58 of 120 patients randomized for conventional in-center hemodialysis (3 days per week) and 32 of 42 patients randomized for home hemodialysis (3 times per week), respectively, who reported having unpaid caregivers. Suri *et al.* found no increase in perceived burden for the daily in-center group, and a trend toward greater burden among those randomized to home nocturnal hemodialysis. After correction for missing data, there was a significant and clinically meaningful difference in the nocturnal home versus the conventional home hemodialysis patients' Cousineau scores. A direct correlation was seen between changes in depressive symptoms and changes in perceived caregiver burden; an inverse correlation was seen in self-reported physical and mental health and the perceived caregiver burden.

By any standards, the FHN trial has been a landmark research investigation exploring the benchmark frequency of hemodialysis, which was set in 1965 at three times a week. Thrice-weekly hemodialysis is relied upon in most centers around the world, but it has always been recognized to be a compromise compared with a kidney's 24-hour, 7-days/week regulation of toxins and body-fluid volume (3).

The frequency was originally established through a combination of physiologic experiments, economic considerations, logistics, feasibility, and evaluations of pa-

tient acceptance. Numerous earlier studies suggested that increased dialysis frequency improved outcomes such as left ventricular hypertrophy, calcium and phosphorus metabolism, anemia, and health-related quality of life. However, the FHN trial is the first to be sufficiently powered and to have an adequate control group that meaningfully supports those conclusions (4).

FHN data suggest that frequent hemodialysis compared with conventional in-center hemodialysis is associated with favorable changes in the composite coprimary outcomes of death or 12-month change in left ventricular mass and death or 12-month change in the RAND-36 physical-health composite score (5).

Other findings are as follows: participants assigned to frequent compared with conventional in-center hemodialysis show no significant change over 12 months in adjusted mean Beck Depression Inventory scores, whereas they experience clinically significant improvements in adjusted mean mental health composite and emotional subscale scores (6). Executive function and global cognition are not improved, although enhanced performance was found on tests of memory and verbal fluency (7). Self-reported physical health and functioning were improved but had no significant effect on objective physical performance (8). The FHN Group also reported on cardiac function (9,10), anemia (11), residual kidney function (12), and nutrition (13).

Suri *et al.* are to be commended for studying caregiver burden, but they should also be faulted for limiting this investigation to perceived caregiver burden. Rather than survey the caregivers themselves or use an objective measure or surrogate measure of burden, the data were obtained from the patients. Although this is not necessarily inaccurate, it is the equivalent of asking caregivers whether patients have fevers instead of asking the patients directly (or even better, by pulling out a thermometer and taking their temperatures).

Caregiver burden has not been well studied in home dialysis populations. Perhaps this is because home dialysis patients rely so heavily on unpaid caregivers that exposing the burden of those caregivers might create a controversy and have a negative effect on the use of home dialysis. There are also subtleties and ambiguities, as well as seismic forces exposed when one tackles caregiver burden. These are incredibly difficult to conceptualize, describe, or research. For example, the authors allude to Ganzini's study of people from Oregon who sought physician aid in dying through the state's Death with Dignity Act; more than half of the

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small sample endorsed that their decision was prompted in part by an inability to continue caring for themselves combined with not wanting others to provide the care (14). In other words, they did not wish to become a greater burden upon loved ones. Some readers have reacted to this finding by becoming enraged that society has not offered sufficient resources and services to severely ill members, thereby “compelling” them to take advantage of a protocol to end their lives. Others applaud the altruism and honesty of people who highly value their own independence and are not prepared to accept increasing sacrifices from families in order to stay alive (or prolong their dying). This subject defies reduction to a correct or incorrect answer.

In the 1960s and 1970s, when dialysis machines were a rare commodity, we appreciated the complexity of whether to initiate treatment, and clinicians turned to the cumulative wisdom of committees in order to make those torturous decisions (Christopher Blagg, personal communication). It was only when Medicare coverage was extended that dialysis facilities proliferated and the patient population mushroomed. Access to unlimited funding and plentiful clinical resources obviated the need to make these tough decisions.

Four decades later, we understand that this was a temporary solution. The dialysis population has swollen in numbers, has become elderly, is rife with comorbid progressive disorders, and continues to have elevated mortality rates. Although guidelines for the initiation and discontinuation of dialysis are available (15), geriatric and palliative medicine innovations are being explored, and patient-centered communication and care is being fostered (16), these are difficult innovations to integrate into practice. However, the changing economic, demographic, and political landscape is demanding modifications in nephrology and forcing us to attend to the inherent complexities and bioethical conundrums of our specialty.

Caregiver burden is one of those challenging and frustrating topics that should now be examined. Although it is obvious that people require tremendous support to undergo these therapies, we can no longer take for granted that necessary resources are present in their homes. We would like to believe that people exist in a loving milieu that is prepared to shoulder any burden. The reality is that many patients fly solo, live alone, and are estranged from or may lack helpful families. When patients are among the fortunate ones to have caregivers at home, these caregivers are usually spouses—as Suri *et al.* found. Because our population is elderly, we are talking about equally aged partners, many of whom have their own physical ailments, lack community connections, and have limited financial reserves.

If we accept that home dialysis—be it hemo or peritoneal—offers advantages to patient health and results in better “value” (quality divided by cost), it would seem obvious that home dialysis should be the treatment of choice for most patients. Why then do <5% of patients in the United States receive home dialysis? Patients can do home peritoneal (and some hemo) dialysis themselves, but our increasingly debilitated and elderly dialysis population requires assistance. Although the US Centers for Medicare and Medicaid Services had successful pilot projects with paid patient-assisted home dialysis (17), and for many years the University of Washington had a successful program using paid assistance (Christopher Blagg, personal communication), the US Government has hitherto chosen not to

subsidize home dialysis assistance. In the United Kingdom, France, and other countries, paid home dialysis assistance is available and provides value (18–20). When paid assistance is available, caregiver burden may decrease; however, to our knowledge, this has not been studied.

Finally, here are a couple of thoughts to ponder. If you or a loved one develops renal failure and a transplant is not an option, you may not want to undergo any form of dialysis. But if you accept dialysis, would you want it delivered in-center or at home? A number of surveys show that nephrologists overwhelmingly would want home hemodialysis (21). After digesting the FHN findings, would you prefer the conventional or high frequency of treatments? Finally, would you want to rely on your spouse or children as the caregivers?

Suri *et al.* have carefully refrained from extrapolating their data and making any specific policy recommendations about caregivers—paid or otherwise. In a commentary, we are not subject to similar restraints, and we believe that the practice of RRT is facing a paradigmatic change. It is an opportunity to seriously explore how to make home dialysis more readily available to our patients and this will require subsidized home dialysis assistance.

#### Disclosures

None.

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See related article, “Effects of Frequent Hemodialysis on Perceived Caregiver Burden in the Frequent Hemodialysis Network Trials,” on pages 936–942.