

## Deny Dialysis or “D-NI” Dialysis? The Case for “Do Not Initiate; Do Not Ignore” Orders

Rachel Carson

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The wave of interest in both palliative and geriatric care within the nephrology community is reflected by the number of publications and conference sessions focusing on these topics. Through work done by the American Society of Nephrology and the Renal Physicians Association, both geriatric care and palliative care are now included in the standard nephrology curriculum. Regardless of whether we call it maximum conservative care (MCM), supportive care, nondialysis care, or conservative kidney management (CKM), providing symptom-driven multidisciplinary care is essential to today’s clinical nephrology practice.

For the clinician, however, the difficulty lies in acting on clinical guidelines that recommend shared decision making. Few of us feel that we can predict how the individual will fare if dialysis were started. Without accurate information about survival and quality of life (QoL), both with and without dialysis, treatment planning discussions with patients and families are incomplete and possibly pointless. Consequently, the data reported by Da Silva-Gane and colleagues in this issue of *CJASN* are warmly welcomed. Their prospective cohort study followed 170 patients through a “low-clearance” clinic and sequentially measured QoL at 3-monthly intervals. Although their data show improved survival for those patients who started onto dialysis compared with those who opted for conservative management (41 versus 32 months unadjusted, 1245 days versus 974 days adjusted), it was at the expense of QoL (1).

Nephrologists expect that dialysis offers a survival advantage over conservative management. However, in economic terms, the literature reflects that past a certain level of comorbidity, there is a diminishing in return for each increment of investment (in this case, days on dialysis). For example, in this study, the estimated additional median survival was 404 days for hemodialysis patients versus those who elected for conservative kidney management. On the face of it, this may seem like a reasonable benefit; however, hemodialysis patients underwent treatment for a median of 326 (80%) of those 404 days. This is very similar to the proportion (78%) of additional survival days spent either hospitalized or attending an institution for dialysis reported previously (2). Lead-time bias is a methodologic problem inherent in describing outcomes for conservatively managed patients. This group and others have previously tried to reduce it by reporting

survival by starting the clock at a standardized estimated GFR (eGFR) threshold (<10–15 ml/min per 1.73 m<sup>2</sup>) (3,4). Unfortunately, in this paper, they have measured survival from the date of referral despite the increased prevalence of late referral (and therefore potential for late recruitment into the study) in the elderly, which renders the absolute survival difference somewhat difficult to interpret (5,6). However, it is unlikely that there will ever be a randomized blinded controlled trial using the gold standard “time zero” from which to measure survival for conservatively managed patients: the clinician’s decision that it is time to start dialysis.

The question we should ask is how patients feel on hemodialysis days? Caplin *et al.* have shown that a significant minority of hemodialysis patients experience post-treatment side effects, including fatigue, loss of appetite, and energy, that persist through the next morning (7). We must be transparent when counseling patients and explain that extra days survived while on hemodialysis may not allow them to participate in daily activities and interactions that matter most to them.

This paper’s finding of a lack of improvement in functional status after dialysis initiation in the Short Form 36 (SF-36) physical health scores in this paper should be emphasized because it strengthens the existing literature. Loss of functional status at the time of dialysis initiation has been previously reported (8,9). In a larger study in which they looked at nursing home residents, Kurella Tamura *et al.* found that there was a dramatic and sustained loss of function that appeared to be triggered by dialysis initiation. In contrast, previous studies of conservatively managed patients have demonstrated maintenance of functional status until quite close to death (10).

Perhaps more interesting is Da Silva-Gane’s finding of a detrimental effect of dialysis initiation on the Satisfaction with Life scale, although the wide individual variation reminds us how difficult it is to prospectively identify patients like those in this study who did have an improvement in their QoL. The older frail patient is more susceptible to emotional and functional decline with even the most minor disruption in his or her environment and so the observation that initiation of dialysis does not improve QoL should not be surprising. The question then is whether the decrement in QoL

Nanaimo Regional Hospital, Nanaimo, British Columbia, Canada

**Correspondence:**  
Dr. Rachel Carson,  
Nanaimo Regional Hospital, University of British Columbia,  
1200 Dufferin Crescent, Nanaimo, British Columbia, Canada V9S 2B7.  
Email: rachel.carson@viha.ca

seen at the time of dialysis could be prevented by doing more than just starting dialysis? One option is to supplement dialysis care some form of geriatric intervention (11–13). In Toronto, this sort of care is offered by way of inpatient rehabilitation. Nurses, physiotherapists, occupational therapists, and others help the patients adapt to a new lifestyle and restore their confidence in themselves. Although the published results are limited to improvements seen in the short term, unpublished data (S.V. Jassal, personal communication) suggest that these benefits are maintained over time in a substantial proportion of individuals.

Another intervention is to simply help patients navigate through the process of dialysis in a more personalized way. In a program designed to reduce illness intrusiveness, Devins *et al.* reported a survival benefit in patients who were coached by a nonrenally trained educator (14). In the RightStart program, Wingard *et al.* assigned a personal coordinator to each patient in the intervention group who was charged with ensuring early correction of anemia and bone mineral disturbances, as well as providing dialysis education and streamlining vascular access care (15). The results showed improved survival at 1 year in the intervention group. Conservative management patients potentially receive more assistance or services for QoL-related issues than their dialyzing counterparts. The cross-sectional QoL study by Yong *et al.* hinted at this by showing that even in a country with nearly 50% peritoneal dialysis prevalence, dialysis patients' symptom intensity and SF-36 scores were, if anything, worse than patients' in a "palliative care" group (16). Ellam *et al.* also showed a difference in survival between early and late referred conservative management patients (17), suggesting that whatever conservative management is, it is not "nothing" and does have a quantifiable effect. This is also consistent with the beneficial effect of early referral on QoL seen for patients on a dialysis care pathway (18,19).

Even the language we use is problematic. We describe "withholding" rather than "choosing" a care pathway (20), which implies that dialysis is somehow the best therapy and the patients managed conservatively are being deprived of benefit. As studies start to appear suggesting survival benefit from early palliative care referral in other specialties (21–23), one wonders if we will someday talk about "withholding conservative care," rather than withholding dialysis. There is established support for inclusion of a conservative management choice in ESRD decision making (16,24–27). However, psychology theory tells us that people tend to select the option that is presented as the default choice. For example, countries with "opt-out" consent policies around organ donation have exploited "inertia bias" and increased donation rates by changing the default to presumed consent. A recent article advocated taking advantage of inertia bias as part of a behavioral economic approach to increase advance care planning (29).

For ESRD patients with a heavy burden of comorbid illness, we should consider the radical notion of presenting "planned conservative management" as the default choice (perhaps with peritoneal dialysis as a second choice) unless the patient expresses an active interest in hemodialysis care. Lest this sound like a case for rationing services, the reality

is that there is a significant, if poorly quantified, risk of shortened survival when unplanned trials of hemodialysis are used. It is particularly valid to default away from hemodialysis, even if frail patients have not yet made a firm commitment to conservative management, when the benefits of a trial of hemodialysis are so unclear. In fact, the trial period is also the period during which the patient will experience the highest morbidity and mortality risk. Complications from vascular access, iatrogenic, or hospital acquired disease and mortality are highest in the initial 90 days. This disproportionate up-front risk is further amplified by the loss of residual renal function such that the conservative care door closes, and classic palliative/terminal care becomes the only realistic option.

### Future Directions

Research from the United Kingdom, including the study by Da Silva-Gane reported here, forms the bulk of published evidence around conservative management in ESRD. Including these patients in multiple national registry databases would offer a broader, international perspective and the opportunity for much-needed research in this area. Patients with ESRD choosing conservative management should also have access to the same benefit programs as comparable patients on dialysis. For example, in British Columbia, Canada, government "dialysis formulary" medication benefits are being extended to patients with ESRD (eGFR  $\leq 10$ ) who choose conservative management; they had previously been excluded from these benefits despite having a similar burden of renal disease (30). Within the United States, conservative care programs are doomed to fail until universal Federal Medicaid insurance laws are modified. Currently, full coverage is only available to those on dialysis (31). Finally, prognostication for patients choosing conservative management in the modern era of renal replacement therapy, although vastly better informed than a decade ago, is still based on small cohort studies. However, the number of potential conservative management patients is significant. For example, in Australia, it was recently estimated that one in seven patients referred to nephrologists plans not to dialyze (32). Data from a noteworthy large Canadian community-based cohort study recently published by Hemmelgarn *et al.* showed that for every patient over 75 with baseline stage 4 chronic kidney disease and outpatient progression who started dialysis, there were between 2- and 10-fold more who did not (33). Therefore, it is time for us to do three things: D-NI (*do not initiate* dialysis by default and *do not ignore* the additional rehabilitation and social needs of all ESRD patients); *identify* conservative management (MCM, NDC, CKM) as a "fourth modality" in ESRD care; and finally, *include* patients with ESRD who choose not to dialyze in national registry databases and benefit programs.

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None.

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See related article, “Quality of Life and Survival in Patients with Advanced Kidney Failure Managed Conservatively or by Dialysis” on pages 2002–2009.