

# The Provider's Role in Conservative Care and Advance Care Planning for Patients with ESRD

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Conservative care (CC), also known as conservative management, is being gradually recognized as a viable therapeutic alternative for patients with advanced CKD in the United States (1,2). The Renal Physician Association's clinical practice guideline on shared decision making in the appropriate initiation of and withdrawal from dialysis recommends to inform patients with stage 4 or 5 CKD and patients with ESRD about their prognosis and all treatment options, including CC (3). Although evidence is limited, current data suggest that patients with ESRD  $\geq 75$  years of age with high levels of comorbid conditions and/or poor functional status may not benefit from dialysis in survival and/or health-related quality of life. Indeed, hospitalization rates decrease and home deaths increase when these patients receive comprehensive CC compared with dialysis (4–7).

Despite its potential benefits, several caveats limit implementation of CC, including (1) lack of a precise definition, (2) poor characterization of the CKD population that might benefit from it, (3) limited observational evidence of its potential benefits, and (4) scarce data on patient-centered outcomes (8). A recent survey regarding practice patterns of CC in the United Kingdom highlighted some of these limitations (9). Despite that all but one of 67 (of a total of 71) adult renal units reported provision of CC, the absolute number of patients could not be calculated because of lack of agreement on when a patient is receiving CC. Indeed, terminology varied substantially among renal units, with conservative management being the most frequently used term (46%); 80% of units reported a need for better evidence comparing outcomes of CC versus dialysis, and 65% considered it appropriate to enter patients into a randomized trial. Interestingly, the majority of renal units (88%) provided primary care physicians (PCPs) with information/advice regarding CC.

Advance care planning (ACP) is essential to decision making regarding therapeutic options for patients with advanced CKD, including CC. ACP involves communicating information to the patient and family (or other caregiver) about the current clinical condition, prognosis, and treatment options within the context of the patient's values, goals, and preferences, which will ultimately guide shared decision making (3). The purpose of the latter is to align the treatment with patient and

family goals, values, and preferences. The team caring for patients with advanced CKD should become involved in ACP early in the illness and in a flexible manner, because the health status and patient and family goals may change over time (8). Unfortunately, current evidence suggests that discussions about prognosis and end of life care are uncommon and that decision making is integrated poorly into CKD care, which leads many patients and their families to be ill prepared for living with CKD or dealing with end of life decisions (10,11). Although still limited, current evidence suggests that ACP is associated with improved end of life care, reduced hospitalizations and inappropriate use of life-sustaining treatments, increased use of hospice and supportive care, and greater compliance with patients' end of life wishes (12,13).

In this issue of the *Clinical Journal of the American Society of Nephrology*, the results of two studies examining the provider's role in CC and ACP for patients with advanced CKD are reported (14,14).

In the first study, Parvez *et al.* (14) conducted a nationwide survey to examine nephrologists' and PCPs' practices, attitudes, and knowledge regarding CC in the United States.

Parvez *et al.* (14) reported confusion about terminology (*i.e.*, >40% of both nephrologists and PCPs believed that CC and palliative care were the same). Also, respondents had an underappreciation that pain is a common symptom (*i.e.*, <40% of both nephrologists and PCPs endorsed pain management), and there was a lack of knowledge about CC (*i.e.*, 20%–30% of nephrologists and PCPs responded that CC could serve as a bridge to kidney transplantation).

Although both nephrologists and PCPs reported similar practices about discussing CC with their patients with advanced CKD (61% versus 54.3%, respectively;  $P=0.17$ ), there were significant differences regarding barriers to discussing CC and knowledge of CC. Fewer nephrologists than PCPs reported as barriers difficulty in determining eligibility (14.3% versus 42.5%, respectively) and limited information about its effectiveness (24.5% and 49.6%, respectively). In contrast, nephrologists were more likely to endorse difficulty in determining whether a patient with CKD would benefit from CC than PCPs (52.8% versus 36.2%, respectively). As expected, nephrologists were more knowledgeable than PCPs about outcomes of CC

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versus dialysis and the Renal Physician Association's guidelines regarding withdrawal or withholding of dialysis.

The results of the work by Parvez *et al.* (14) should be interpreted in light of two significant limitations, namely a low response rate and likely selection bias. After inviting a simple random sample of 16,193 nephrologists and PCPs through three waves of emails, only 431 physicians responded to the survey (crude response rate of 2.7%). The majority of respondents were white men in their 30s and 40s, and nearly one half were in private practice. Also, close to two thirds were nephrologists, and of these, more were in academic practice compared with PCPs. Both the low response rate and the likely selection bias of the respondents limit the generalizability of the results. Indeed, most providers surprisingly reported that a discussion about CC was not difficult to initiate or time consuming and that they were not concerned how their patients would react after such a discussion.

In the second study, O'Hare *et al.* (15) conducted semi-structured interviews at the Veterans Affairs (VA) Puget Sound Healthcare System with 26 providers (74% of a total of 35 invited providers) from various disciplines and specializations who take care of patients with advanced CKD to evoke their perspectives on ACP. Among the 26 providers, there were 13 physicians (from cardiology, intensive care, nephrology, palliative care, psychiatry, and vascular surgery), six nurses (including nurses and nurse practitioners in palliative care, nephrology, and dialysis), three dialysis technicians, two dietitians, and two social workers.

O'Hare *et al.* (15) identified four overlapping themes: (1) a complex and fragmented medical care for this population across settings and providers and over time; (2) lack of a shared understanding and vision of ACP; (3) unclear definition of authority and responsibility for ACP; and (4) lack of collaboration and communication regarding ACP among all providers. Although the results reflected the practice of a small number of providers from a single center, they were consistent with published literature in other settings and populations. However, the single-center design limits their generalizability to settings other than the VA.

These two studies highlight several key points that strongly influence the provider's role in CC and ACP for patients with advanced CKD (14,15). First and foremost, they show confusion regarding terminology for CC. To address this issue, a recent Kidney Disease Improving Global Outcomes (KDIGO) Controversies Conference on Supportive Care in CKD defined CC as "planned holistic patient-centered care for patients with glomerular filtration rate category (G) 5 CKD, that includes interventions to delay progression of kidney disease and minimize risk of adverse events or complications, shared decision-making, active symptom management, detailed communication (including ACP), psychological support, social and family support, and cultural and spiritual domains of care" (8). The KDIGO definition explicitly states that comprehensive CC does not include dialysis (8).

Second, the studies point out the need for more evidence regarding optimal patient selection for CC and comparison of outcomes of CC versus dialysis (16). Although the latter is subject to lead time bias related to imprecisions with GFR estimation and difficulties with randomizing patients,

additional evidence will help address these barriers consistently identified by providers, individualize discussions with patients and families, and facilitate decision making. Third, they show the need to promote a shared vision of ACP and interdisciplinary collaboration among different providers involved in caring for patients with advanced CKD (2).

For the time, it seems reasonable to disseminate formal recommendations and guidelines regarding CC and ACP, particularly among PCPs (3). Also, information should be provided on a variety of tools and online resources, including skills-based training, to facilitate ACP for the health care team, patients, and family with CKD and ultimately, shared decision making (17–20). Additional research is needed to improve patient-centered care as a means of achieving better health outcomes and greater satisfaction among patients with advanced CKD (8).

#### Disclosures

None.

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See related articles, “Provider Knowledge, Attitudes, and Practices Surrounding Conservative Management for Patients with Advanced CKD,” and “Provider Perspectives on Advance Care Planning for Patients with Kidney Disease: Whose Job Is It Anyway?,” on pages 812–820 and 855–866, respectively.