

## Advance Care Planning for Patients with Advanced CKD: A Need to Move Forward

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For well over a decade, we have known that dialysis patients and their families and friends desire opportunities to engage in advance care planning with their nephrologist and dialysis teams (1–3). Clinical practice guidelines have recommended advance care planning as central tenets of dialysis care and CKD management (4) and prominent nephrology societies have embraced this aspect of clinical nephrology as a priority, recommending that practitioners “do not initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physicians” (5). In their well conducted qualitative study of advance care planning in 13 dialysis patients and nine families/friends, Goff *et al.* identified three major themes: (1) lack of experience in advance care planning with nephrologists and/or dialysis team members, (2) life and dialysis experiences as well as patient traits and relationships with family and friends influence advance care planning, and (3) patients want nephrologists to lead advance care planning discussions and peer mentorship through this process would be welcome (6). Goff *et al.* also provide interesting patient reflections and information on perceived disenfranchisement among patients with less education and lower socioeconomic status. Each of these themes confirms prior work in CKD (1–3) and is consistent with a recent systematic review of the contextual factors influencing the uptake of advance care planning in general palliative care (7).

The work by Goff *et al.* should be commended as a key element in end-user/stakeholder engagement at the local level necessary for the development and implementation of a successful advance care planning program. Such engagement will also need to extend to staff, advance care planning facilitators, and administrators to ensure that advance care planning initiatives are responsive to specific site-identified needs. Clearly, to enhance the implementation of advance care planning, local contextual factors influencing its uptake need to be understood. However, the focus of future research needs to be on establishing frameworks for implementing and evaluating advance care planning among patients with advanced CKD.

Goff *et al.* suggest that patient experience with death or severe illness in a family member may facilitate advance care planning (6). A study of 43 in-center hemodialysis patients in the 1990s failed to show that experience with potentially life-threatening illness in the patient or a family member influenced completion of advance directives, a surrogate end point of successful advance care planning (3).

However, in the 1990s, Perry *et al.* identified personal experience with death as a factor increasing the comfort of dialysis healthcare providers (nurses, social workers, physicians) with advance care planning discussions (8). Thus, although personal experience might encourage staff to engage in advance care planning, we lack evidence showing that such experiences result in positive outcomes. This disconnect holds true for many of the perceived facilitators and barriers to advance care planning and reflects uncertainty as to how programs can best operationalize advance care planning programs to capitalize on facilitators or mitigate barriers. Moreover, there is no consensus on a comprehensive evaluative strategy of advance care planning.

Patients believe that nephrologists should lead advance care planning discussions, but most dialysis patients report never engaging in such discussions with their nephrologists (1,3,6). In 2006, only 39% of surveyed American and Canadian nephrologists reported feeling very well prepared to make end-of-life decisions with patients (9). Most nephrology trainees report little education in palliative care topics like advance care planning (10,11) and few have been observed leading patient-family meetings where such issues are discussed (10,11). Opportunities now exist to train nephrologists in the communication skills that enhance advance care planning discussions (12). However, if an individual nephrologist recognizes the importance and need for such skills, shouldn't he or she independently seek to acquire those skills or develop a process whereby someone in the dialysis unit who is interested and capable leads efforts in this clinical area of care? It is difficult to believe that nephrologists remain unconvinced about the importance of engaging in advance care planning with their dialysis patients. We need studies of successful ways to implement effective, ongoing advance care planning for dialysis patients.

It is time to study the implementation and effectiveness of advance care planning in CKD patients and their families and loved ones. How can we more effectively make advance care planning part of routine care in dialysis units? Are peer mentors the answer for some units, as demonstrated by Perry *et al.* 10 years ago (13)? Can dialysis unit nurses or social workers assume the role of trained facilitators, a method shown to be effective for increasing advance care planning (14)? Although nephrologists are integral members of the team in the advance care planning process, if they have done an effective job,

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advance care planning topics would have been introduced and discussed in most cases during the course of CKD management, long before dialysis was initiated. As again demonstrated by the participants in the study by Goff *et al.*, dialysis patients believe that advance care planning should be started early in the course of CKD and revisited at intervals (6). Interestingly, Goff *et al.* report that several of their patients had engaged in advance care planning discussions with their primary care physicians. Why have nephrologists and dialysis units not investigated the link between combined advance care planning by dialysis units and primary care providers?

Because elderly individuals are the fastest growing group of dialysis patients (15) and because the prognosis for survival and maintaining functional status in elderly individuals on dialysis is poor (15–18), advance care planning, particularly in terms of initiating dialysis, is advocated (4,5). Thus, as patients and families have requested, nephrology input is essential early in CKD management and dialysis modality selection, including the decision not to begin dialysis. We know little about the methods of implementing advance care planning among such patients. Only a few centers have reported their experience with GFR category 5 CKD patients choosing not to begin dialysis and the aspects of palliative care received by these patients (19). Additional study of the process of implementing advance care planning discussions in such patients, the effectiveness of the palliative care subsequently provided, and the compliance with the advance care planning choices made would be helpful, and indeed are essential, in developing clinical models that could be implemented widely. Although there may be differences among patient groups in terms of acceptance for advance care planning, we need to move beyond the current literature into the realm of implementation and effectiveness in order to provide optimum care for our patients and their families. Barriers to and facilitators of advance care planning have been well defined by studies like the one by Goff *et al.* (1–3,6). Future research needs to focus on the healthcare structures and processes as well as clinically relevant outcomes (*i.e.*, those that are meaningful to patients and their families and friends), when implementing and evaluating advance care planning programs. Issues of sustainability and cost also need to be addressed. One recent study of a single dialysis center's outcomes of advance care planning demonstrated increased hospice use and reduced in-hospital deaths among dialysis patients (20). We need similar reports of successful programs.

We know from the general population as well as from those with cancer and those with chronic disease that advance care planning can enhance communication among patients and care providers ensuring that end-of-life care wishes are known, reduce unwanted and aggressive treatments at the end of life, improve patient and family/loved one satisfaction with care, and reduce stress, anxiety, and depression in surviving relatives (21,22). We also know that dialysis patients, more than those with congestive heart failure or cancer, die in intensive care units undergoing expensive treatments inconsistent with their wishes (23,24). The key to reversing these unacceptable situations is to promote effective, early, flexible, and recurring advance care planning with dialysis patients and their loved ones throughout the course of CKD. We clearly recognize the need for advance care planning. Goff *et al.* once again bring this need to our attention. The nephrology community would benefit greatly from well conducted clinical studies of the implementation and

effectiveness of advance care planning programs. It is time to stop discussing the need for such clinical processes and to start exploring ways to make it work. It is hoped that Goff *et al.* and others will continue work in this area of clinical nephrology with a shift in focus to examining effective processes for ensuring that medical care provided is in keeping with patients' wishes for end-of-life care, that advance care planning leads to reduced unwanted interventions near the end of life, and that dialysis patients and their families are satisfied with the care provided. It is time for nephrologists to assume responsibility for this aspect of dialysis care and to facilitate processes leading to advance care planning discussions with their dialysis patients. Leadership of dialysis unit companies and dialysis payers should also assist in this move forward toward better patient care.

#### Disclosures

None.

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See related article, “Advance Care Planning: A Qualitative Study of Dialysis Patients and Families,” on pages 390–400.