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Matters of Life and Death: Why Do Older Patients Choose Conservative Management?

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Abstract

Background: Although many older patients with end-stage renal disease and limited prognoses prefer conservative management (CM), it is not widely offered in the United States. Moreover, there is a dearth of US-based literature reporting clinical experience with shared decision making regarding CM of advanced chronic kidney disease (CKD).

Methods: We describe the clinical experience of 13 patients who opted for CM at the University of Rochester Medical Center's CKD clinic during 2016–2017. Main outcomes include: (1) reason for choosing CM, (2) completion of advance directives, (3) location of death, and (4) utilization of hospice service. Patients' reasons for choosing CM were categorized into 4 broad categories based on a review of their electronic medical records. A retrospective chart review conducted by 2 reviewers determined the status of advance care planning, hospice referral, and place of death.

Results: The mean age of these patients was 81.8 years (SD 7.3). Their reasons for choosing CM included: poor prognoses; a wish to maintain their quality of life; their desire for a dignified life closure; and the intention to protect family members from having to see them suffer, based on their own memory of having witnessed a relative on dialysis previously. A total of 8 patients died: all received hospice services, 6 died at home, one at a nursing home, and one at a hospital. Advance care planning was completed in 100% of the cases. Symptoms were managed in collaboration with primary care physicians.

Conclusion: Patients' decisions to choose CM were influenced by their values and previous experience with dialysis, in addition to comorbidities and limited prognoses. Promoting the

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choice of CM in the United States will require training of clinicians in primary palliative care competencies, including communication and decision-making skills, as well as basic symptom management proficiencies.

Keywords

Chronic kidney disease; Medical management without dialysis; Conservative management; Older adults

Introduction

The Renal Physicians' Association and Kidney Disease Improving Global Outcomes have both endorsed conservative management (CM) as an acceptable treatment approach for older or frail patients with advanced chronic kidney disease (CKD) and poor prognoses [1, 2]. "Conservative care" is defined as planned holistic patient-centered care for patients with CKD stage-5 that includes the following: (1) interventions to delay progression of kidney disease and minimize risk of adverse events or complications, (2) shared decision making, (3) active symptom management, (4) detailed communication including advance care planning, (5) psychological support, (6) social and family support, and (7) cultural and spiritual domains of care [2]. Some studies have shown no difference in survival between dialysis and CM in older patients with multiple comorbidities. Rather, patients choosing CM maintain their functional status longer and have a fewer hospitalizations compared to those receiving dialysis [3–7]. CM is often preferred by patients when it is consistent with their values and goals [8]. However, despite national and international guidelines and the patient-centered value of CM, it is not widely available or offered as a choice in the United States; these practices limit informed decision making [9]. In one study, only 1% of US patients receiving dialysis remembered any discussions about CM [10]. In the United States, many barriers to discussing CM have been identified. Physician barriers include nephrologists' ambivalence regarding their role in offering and managing patients a CM pathway, a paternalistic style of decision making that pays little attention to patient preferences, discrepancies between patient and family's preferences, discomfort in discussing CM, end-of-life issues and prognoses, lack of institutional or a multidisciplinary team support, limited allotted time per patient visit, fear of disrupting an alliance with patients, hope of improving symptoms through dialysis, equating CM with capitulation, and lack of knowledge about CM outcomes [11–13]. Systems barriers include time constraints on patient visits, complexities associated with care coordination, lack of a supportive institutional culture, and an absence of appropriate financial reimbursement for CM in comparison to dialysis [12–15]. In contrast to these inhibiting factors, important factors that may lead a nephrologist to discuss CM is his/her moral distress when witnessing a patient suffering on dialysis and prognostic perceptions [12, 16].

In this paper, we describe our clinical experience with shared decision making in the cases of 13 patients who chose CM at the University of Rochester Medical Center, Rochester, NY, USA. All were under the clinical care of the first author (F.S.). We have grouped the reasons for their choice into 4 broad categories, and we exemplify each category by presenting an actual case using fictitious names, according to each patient's preference,

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followed by concise discussions. We argue that offering CM depends on the willingness of nephrologists to learn and use primary palliative care skills [17–19]. These skills include a willingness to listen to patients' preferences; clear communication of prognoses; ability to discuss treatment options with reference to patients' values, goals, and preferences; and basic symptom management [17–24]. While a multidisciplinary approach is ideal for a CM pathway, the absence of a multidisciplinary team should not preclude physicians from offering CM to their patients [10]. We describe our office-based approach to CM that is run by a single nephrologist trained in palliative care (F.S.) with occasional participation from nephrology fellows and residents.

Methods

We analyzed the electronic medical records of patients with CKD who had chosen a CM pathway during the year 2016–2017. These patients were cared for by the first author (F.S.). The second author (H.A.) participated in the CKD clinic as a renal fellow, and the senior author (R.M.E.) is a palliative care physician, an expert in communication and decision making, and mentor to the first author (F.S.) in both clinical and research-related matters. Independent chart reviews for patients 1–13 were performed by both the first and the second authors. Reasons for choosing CM were agreed upon by all 3 authors. Both clinical and personal factors that influenced decision making were considered in order to categorize the rationale behind each choice. Information about prognostic discussions, advance care planning, hospice use, and place of death was also extracted from the electronic medical record. The study was approved by Institutional Board Review at the University of Rochester.

Results

A total of 13 patients chose CM in the year studied (Table 1). The mean and median age of these patients were 81.8 years (SD 7.3) and 83 years (interquartile range 11), respectively. Nine were men; only 1 patient belonged to minority race status (Latino). All had a high burden of comorbid conditions. Six patients chose a CM pathway because they had poor prognoses resulting from a terminal nonrenal condition and they wished to maintain their current quality of life (QoL). Four patients chose CM in order to achieve a dignified closure to life and peace of mind. Two patients chose CM because they had previously witnessed the negative experience of a relative on dialysis. In 2 cases, the decision for CM was made by the surrogate decision-maker with the help of the physician (F.S.). Decision making was relatively simple and straight forward in 5 cases where patients had experience with dialysis or wished to choose CM for a dignified life closure, but it was complicated by patients' ambivalence as well as by emotions of anxiety and fear of death and abandonment in 8 cases when patients had limited life expectancy. In all cases, decisions were made slowly and deliberately over several visits. Advance directives were completed in all 13 cases, and the decision against dialysis was hand-written on the Medical Order for Life Sustaining Treatment (MOLST) form. Eight of 13 patients have died under hospice care: 6 at home, 1 at a nursing home, and 1 at a hospital. Pain and symptoms were managed with help from the primary care physician (PCP), except in one case where the first author (F.S.) managed

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symptoms because the patient mistrusted the PCP. None of the patients reversed their initial decision to pursue CM.

In this cohort, the main reasons for choosing CM were (1) limited life expectancy with or without dialysis, (2) poor expected QoL on dialysis, (3) dignified closure of life and peace of mind, and (4) previous experience of witnessing a relative suffers on dialysis. In the sections that follow, we address each of these themes with brief case reports (in the voice of the first author) and discussion of how we navigated the challenges of providing CM. We also briefly discuss issues of surrogate decision making for patients who lacked capacity to participate in discussions and advance care planning.

Limited Life Expectancy

"Henry (deceased) was a 75-year-old British immigrant who had decompensated liver disease, hypotension, and CKD stages 4–5. He lived with Betty, his wife of more than 40 years, who was in good health and very involved in Henry's health care. They had no children together; "he is all I got," Betty declared to me during a Friday morning clinic. Unfortunately, Henry was not a candidate for liver transplantation due to his other co-morbidities; he had previously undergone multiple hospitalizations, and now needed weekly paracenteses to maintain a more comfortable volume status. When Betty asked me if dialysis would help his liver disease and low blood pressure, I explained that it was unlikely that the liver disease would improve with dialysis, while expressing my concern that his low BP could complicate a dialysis course. After requesting their permission, we discussed Henry's survival prospects with or without dialysis. His primary goal was to be able to return to his garage and "build stuff," but it was improbable that dialysis would enable him to do so. Henry would choose dialysis during a state of hepatic encephalopathy, but refuse it when in a clear state of mind. After observing this consistent pattern over several visits, he and Betty ultimately chose CM with the help of the treating nephrologist. He died at home under hospice care."

In Henry's case, the critical aspect of shared decision making was the patient's, families, and nephrologist's willingness to discuss prognosis candidly. Such clarity involves addressing factors including renal prognosis, overall prognosis (life expectancy, and QoL), with and without dialysis. Henry's prognosis was determined on the basis of the nephrologist's clinical experience and the patient's previous trajectory of illness, aided by prognostic tools such as the Kidney failure risk calculator [25] MELD score [26], answer to the surprise question ("Would I be surprised if this patient died in the next year?") [27], the 6-month mortality predictor on dialysis [28], and functional status [29]. A recently published tool can also be used to determine prognosis [30]. Of decisive importance was the recognition that it was unlikely that dialysis would help him achieve the mental clarity or the physical strength to "build stuff." Prognostic uncertainty was discussed, and a fear of death was acknowledged. We talked about the dying process, and how it can be made less painful with opioids. The decision for CM was eventually reached in the course of several visits.

Like Henry, patients' 1–6 each had a life-limiting extrarenal illness, and none of them was a candidate for any curative therapies such as heart or liver transplant. Nonetheless, patients' preferences still played a major role in finalizing the decision for CM. For example, patients

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1, 5, and 6 chose against dialysis because a higher risk of decline in functional status was not acceptable to them [31, 32], while others were not content with their existing QoL and dialysis was unlikely to improve it. In these cases, particular attention was paid to managing symptoms with the help of PCPs.

Quality of Life

"Donald (alive) is a 95-year-old widowed nursing home resident with CKD stages 4–5 and congestive heart failure. He used to be an avid tennis player and was able to play until 2–3 years previously when neuropathy led to diminished balance. He was concerned about a difficulty with sleeping, anhedonia, and trouble swallowing solid food. He wanted to improve his functional status, including the goal of returning to tennis, but he was informed that it was improbable that dialysis would help him achieve that goal [32]. On the contrary, there was a significant chance that dialysis would lead to a further decline in his functional status [32], and Donald together with his son therefore decided against dialysis. He participated in physical therapy, and symptoms of insomnia and depression were managed successfully with Mirtazapine. An upper GI endoscopy revealed and treated Schatzki's rings leading to an improvement in his swallowing ability. He was diagnosed with monoclonal gammopathy, but he decided against a bone marrow biopsy. Now, he is approaching his 96th birthday, and is still on a CM pathway. It is interesting that although he was very forthcoming about choosing CM, he refused to openly engage in any discussion related to death and dying. Nonetheless, he completed his advance directives, stating a Do not Resuscitate and Do not Intubate Status. Currently, he enjoys socializing with other nursing home residents and hopes to find a female companion."

Donald preferred maintaining his QoL over life extension with dialysis, which could result in a functional status decline. He had not only quietly made peace with his mortality but also took actions to maintain or improve his QoL. Like many other patients, functional status was an important determinant of his QoL [33, 34]. He was frightened by the prospect of a decline in his functional status due to dialysis or even just a reduction in a chance at improved functionality [31, 32]. In one study, 40% of older adults experienced a decline in their functional status. Odds of such decline were higher in patients who were older and frail at baseline [31]. Many patients are willing to trade-off longevity for QoL and less functional dependence [35]. Other authors have reported that maintaining functioning was the top priority of older patients with CKD, followed by staying alive and pain reduction [36].

Dignified Life Closure and Peace of Mind

"Mr. Miller (alive) is an 87-year-old widowed man with late stage 3 CKD, and type 2 diabetes mellitus with neuropathy and hypertension. He is a retired pastor, and earlier in his life he had served in Africa as a missionary. He has a limited ability to walk because of severe pain from peripheral neuropathy. He has made a decision not to pursue dialysis should he become uremic. He has reflected on the meaning of life and discussed his own death and dying with his son, who is also a pastor. His goals at this age are to maintain dignity and avoid the invasion of his body with dialysis and other aggressive medical

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procedures. He made a choice to pursue CM for his and his family's peace of mind, and to preserve the dignity of his body and his soul."

Mr. Miller was not afraid of death or dying but worried instead about invasive procedures with tubes and needles during the last few years of his life. He believes in God and awaits his death to rejoin his wife. He decided on CM to achieve a dignified death [37, 38].

Previous Experience with a Family Member on Dialysis

"Ms. ID (alive) is an 88-year-old non-English speaking female from Puerto Rico with non-proteinuric stage 3 CKD, presumably from longstanding hypertension. She also has left-side breast cancer with left-side axillary lymph node involvement, and is being actively treated with oral chemotherapy. With her permission, favorable renal prognosis was discussed with her, but she remained worried. Her younger sister had previously been on dialysis and experienced poor QoL in addition to frequent hospitalizations. Ms. ID did not wish a similar experience for herself. She expressed her apprehension of losing control in healthcare settings, especially because she and her daughter could not speak English. She therefore insisted on documenting her wish to refrain from any dialysis treatment, and advance directives were completed to document a CM pathway. She wanted to maintain both her autonomy and her QoL. She has a favorable renal prognosis, but it is comforting for her to know that her wishes are documented and accessible to health care teams. In the renal clinic she displays a sense of humor, and has promised to bring back mangoes when she goes to Puerto Rico."

Patients 10–11 had seen their loved ones suffer on dialysis and feared a similar diminishment of their own QoL. Witnessing others' negative dialysis experiences appears to have influenced their current decision to choose CM [39, 40]. In our opinion, these patients were not only concerned about their own QoL but also wanted to protect their family members from the trauma of witnessing their suffering on dialysis. In such situations, we emphasize that the dialysis experience can be different for each individual patient. However, in the end, it is the obligation of the clinician to support patient autonomy and make a decision in accordance with the patient's preferences.

Other Issues Related to Dialysis Decision Making

Surrogate Decision Making—"John (deceased), was an 87-year-old man with CKD-5, poor functional status, and multiple comorbid conditions including severe dementia, severe pulmonary hypertension and advanced congestive heart failure. He had poor insight into his medical condition due to dementia. He spent most of his day sleeping, required assistance with feeding and bathing, needed 2 canes to walk. Based on John's wishes to receive cardiopulmonary resuscitation to keep him alive, Mary Lou, his wife of 60 years, thought that he would want to try dialysis if he were able to make a decision; she believed that he was still able to enjoy his time at a local casino. The treating nephrologist did not feel it was the right decision given John's advanced co-morbidities, severe dementia, expected poor prognosis and future course on dialysis. Despite these concerns, the family felt confident that John would like to try dialysis to keep enjoying his remaining time especially at the casino, so they decided to try dialysis for a month. Yet when Mary Lou attended a dialysis

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education class, she decided against dialysis because she knew that John would not like an AV fistula or a tube hanging out of his chest or abdomen. Moreover, she did not think that he would be able to sit for a long period of time for dialysis. Gaining more information about dialysis helped her make an informed decision to choose a CM pathway."

In cases 12–13, spouses made the decision, and in such cases, we try to learn about the patient's life, illness information, and his/her wishes. We encourage families to make a decision based on "what would that particular patient say in this situation?" It is also the nephrologists' duty to protect the patient from harm [41]. Dialysis decision making can evoke anxiety in surrogate decision makers, requiring support during and after the decision-making process [42, 43]. For example, the treating nephrologist thought that dialysis will cause more harm than benefit to John, so the situation caused him some moral distress. However, to resolve the conflict and to respect family's wishes, patient and family were referred for dialysis education, and this helped them to reach a decision to choose CM.

Advance Care Planning and Timing for Hospice Referral—We completed advance directives (MOLST and healthcare proxy forms) in all patients wishing to choose CM. We routinely discussed code status, feeding tube placement, and intubation decisions, and the decision about dialysis was usually written on a blank section in the MOLST form. Of the 8 of 13 patients who died, all were enrolled with hospice: 6 died at home, 1 at a nursing home, and 1 in a hospital under hospice care. Appropriate time for hospice referral is complicated because erythropoietin or IV iron infusion is usually not covered for patients under hospice care. In our practice, we manage these patients using the palliative care skills and delay hospice referral until the patient experiences an acute decline. However, an individual patient needs dictate the final decision.

Discussion

In this exploratory qualitative study, we identified 4 triggers that contribute to patient/family preferences for CM of older patients with advanced kidney disease: co-morbid conditions portending poor prognoses, wish to maintain QoL, desire for a dignified closure of life, and the memory of the previous suffering of a family member. Based on our clinical experience, we have addressed several key challenges to implementing CM in the United States and discovered examples of how those challenges (such as symptom management) can be overcome.

Shared decision making about renal replacement therapy involves ethical and moral considerations when a physician wishes to make the right decision for the patient while taking into account both clinical factors and patients' preferences and goals. While most of the nephrology literature has focused on the patient's and family's experience, values, and preferences, we argue that the values and experiences of nephrologists also play a significant role in the ability to offer CM and promote patient-centered decision making [44, 45]. For example, in the study by Ladin et al. [12], some nephrologists offered CM because of their moral distress at patient suffering, while in contrast, others viewed CM as ineffective and a capitulation. Evidently CM has different implications for diverse providers [12]. Several plausible explanations for this heterogeneity include: lack of knowledge and

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training in the communication and decision-making skills, a wish to do something for the patients and families and avoid disappointment, considering the CM approach as a medical failure, exposure to one's own mortality by talking about a limited prognosis, and an implicit bias to justify and promote dialysis in clinical settings in order to meet institutional financial goals [12, 14, 15, 46]. Self-reflection and self-monitoring are indispensable to becoming aware of one's own values and motivations and to engage in patient-centered decision making [45]. An important institutional approach is to include in nephrology fellowship training experiences in primary palliative care skills, such as communication, patient-centered decision making, and basic symptom management [17, 22, 47].

Symptom management is a critical component of delivering CM. In our clinic, although we always make a thorough review of symptoms, we usually refer symptom management to PCPs. In most cases, symptom management is uncomplicated: for example, most patients respond to low dose opioids if they need occasional opioids to control pain. We rarely prescribe nonrenal medications in the renal clinic, in order to reduce the burden on nephrologists uncomfortable with prescribing opioids who assist with overnight or weekend cross coverage. This experience of using opioids differs from that of patients with metastatic cancer who often require a more complicated opioid regime for effective pain treatment. Currently, however, we do not use any symptom assessment tool because we lack the formal infrastructure (support staff, etc.) to support such an initiative.

CM can and should be offered by any nephrologist. In our study, we identified ways in which CM might be promoted in the United States health-care system. A curriculum to educate providers on primary palliative care skills is needed [17]. Institutional support and implementation research can guide health-care institutions across the United System to create formal CM pathways and establish multidisciplinary teams for delivering CM. In the meantime, it is inappropriate to deprive patients of CM while we await an improved professional environment. Hence, we argue that nephrologists are obligated to consider the option of CM because of their expertise in kidney-related issues. Once the decision for CM has been made, the nephrologist should undertake advance care planning; advance care planning codes offer additional financial incentives to engage in such activities. The nephrologist should continue his/her efforts to delay the progression of CKD. Symptoms can be managed by the nephrologist, or with the help of PCPs; palliative care consultation can be obtained in more complex cases [17]. The timing of a hospice referral remains a challenge, due to the frequent inability of some hospice agencies to approve erythropoietin or intravenous iron, both of which can ameliorate symptoms of fatigue and shortness of breath. Policymakers should direct their attention to these patient-centered issues.

In summary, patients and families choose CM due to various reasons including medical, value based, and existential. Policy level changes are needed to address nephrologists' workforce training needs in palliative care, communication, and decision-making skills and to create financial incentives to encourage choice of CM. Lack of such policies should not deprive older adults with advanced CKD from receiving their preferred treatment.

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Table 1.

An overview of clinical- and patient-related factors in decision making for CM and the subsequent end-of-life course

Factors influencing decision-making	Clinical situation	Patients'/caregivers' factors	Hospice referral	Place of death
Life expectancy and QoL				
Patient-1 (86-year-old Caucasian male) CKD-4	End-stage CHF; difficulty with walking	Patient decided against dialysis due to low likelihood of improving functional status	Yes	Home
Patient-2 (67-year-old Caucasian male) CKD-4	S/p liver transplant now decompensated liver cirrhosis; nursing-home resident; CHF inability to walk	Patient decided against dialysis because of low likelihood of improving already unsatisfactory QoL	Yes	Nursing home
Patient-3 (85-year-old Caucasian male) stage 4 CKD	Advanced CHF; cardiorenal syndrome	He was not content with his QoL and decided against dialysis for QoL reasons	Yes	Hospital, he was admitted for pneumonia; did not receive dialysis
Patient-4 (77-year-old Caucasian male) CKD-4	Stage 4 chronic lymphocytic lymphoma; NASH cirrhosis; recurrent GI bleedings	Decided against dialysis for QoL reasons	No	Alive
Patient-5 (94-year-old Caucasian male) CKD-5	CHF walks with a walker	He decided against dialysis because of its potential impact on functional status and QoL	No active palliative management	Alive
Patient-6 (83-year-old Caucasian male) CKD-4	Cardiorenal syndrome; multiple myeloma; inability to walk	Decided against dialysis with the help of his wife, as it was unlikely to improve his functional status	Yes	Home
Dignified closure of life and peace of mind				
Patient-7 (73-year-old Caucasian female) CKD-4	Lifelong ulcerative colitis status post multiple surgeries	Despite good renal prognosis, patient wanted to document decision against dialysis for peace of mind and a dignified life closure	No	Alive
Patient-8 (87-year-old Caucasian male) stage 3 CKD	Diabetic nephropathy	Patient chose a dignified closure of life without any artificial life support	No	Alive
Patient-9 (82-year-old Caucasian female) stage 4 CKD	Ulcerative colitis; sjogren syndrome	She made the decision against dialysis for QoL reasons and wished a dignified closure of life. Later she was diagnosed with cholangiocarcinoma	yes	Home
Patient-10 (79-year-old Caucasian female) stage 4	Aortic stenosis; multiple myeloma	She wanted a dignified closure of life and had previously witnessed her husband suffer during his illness	Yes	Home
Previous experience of watching someone on dialysis				
Patient-11 (88 years old Latino female) CKD-3	Active breast cancer (on chemo)	She decided against dialysis based on her knowledge of her sister's life on dialysis and for QoL reasons	Not yet	Alive
Decisions made by the surrogate				
Patient-12 (87-year-old Caucasian male) CKD-5	Severe dementia; wheelchair bound with very limited ability to walk; extremely limited ADL and IADL	Spouse made the decision based on her knowledge that the patient would not tolerate any dialysis catheter or AV fistula on his body	Yes	Home

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Factors influencing decision-making	**Clinical situation**	**Patients'/caregivers' factors**	**Hospice referral**	**Place of death**
Patient-13 (75-year-old Caucasian male) stage 4 CKD	Hepatorenal syndrome encephalopathy	Wife made the decision for CM because of husband's poor prognosis	Yes	Home

CM, conservative management; CKD, chronic kidney disease; QoL, quality of life; CHF, congestive heart failure; NASH, nonalcoholic steatohepatitis; ADL, activities of daily living; IADL, instrumental ADL.