

The Conversation: A Vital Element of Nephrology Care for Older Americans Who Are Medically Complex

Candice Halinski, MBA, MHCDS, MSN, NP-C, Regina Roofeh, MPH, and Tara Liberman, DO

CE 1.2 contact hours

The U.S. population is aging. By 2030, projections indicate that over 20% of the U.S. population will be 65 years old or older (U.S. Census Bureau, 2019). This aging has been supported, in part, by the continued development of life-prolonging medical therapies and technologies. These innovations, including kidney replacement therapy, have been effective in providing additional options to patients facing serious illness, but they have also introduced a new level of complexity in the provider assessment of treatment for these patients. Health care providers are being tasked to decide what medical care is appropriate for an aging and medically complex population.

The availability of kidney replacement therapies and the co-existing belief that physicians have an absolute duty of fidelity to their patients has been the cause of considerable ethical debate in the United States (Butler et al., 2016). As part of the 1972 Amendments to the Social Security Act (PL 92-603), Medicare was expanded to cover individuals with kidney failure (KF, formally recognized as end stage renal disease [ESRD] or end stage kidney disease [ESKD]) who qualified for Social Security (or were the spouse or dependent of someone who qualified) (Centers for Medicare and Medicaid Services [CMS], 2012). As this technology has improved, costs of care have increased concurrently, causing significant debate among health care providers (Gabbay et al., 2010). The opinions of health care professionals regarding dialysis in the older adult population have fluctuated as the KF population and health care landscape in the United States have changed (Butler

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The U.S. population is aging, supported in part by continued development of life-prolonging medical therapies and technologies. These innovations, including kidney replacement therapies, have been effective in providing additional options to patients facing serious illness, but they have also introduced a new level of complexity in the provider assessment of treatment for these patients. Health care providers are being tasked to decide if medical care is appropriate for an aging and medically complex population, a decision complicated by a variety of factors. Patient-focused conversations surrounding goals of care, prognosis, medical futility, and quality of life need to become part of the routine practice pattern for nephrology care in the United States.

Key Words:

Conservative care, hemodialysis and the elderly, treatment options, advance care planning.

et al., 2016). These discussions will continue and expand as the population of older adults with KF continues to grow. Conversations regarding individual patient goals of care and shared decision-making procedures may help to guide health care professionals toward the most appropriate levels of care.

The Epidemiology of Chronic Kidney Disease and Kidney Failure in the United States

The early identification and recognition of chronic kidney disease (CKD) enables physicians to proactively manage the patient disease burden to delay or avoid transition to KF. In the United States, it is estimated that on average,

Candice Halinski, MBA, MHCDS, MSN, NP-C, is the Clinical Director: Service Line, Northwell Health, Great Neck, NY, and a member of ANNA's Long Island Chapter.

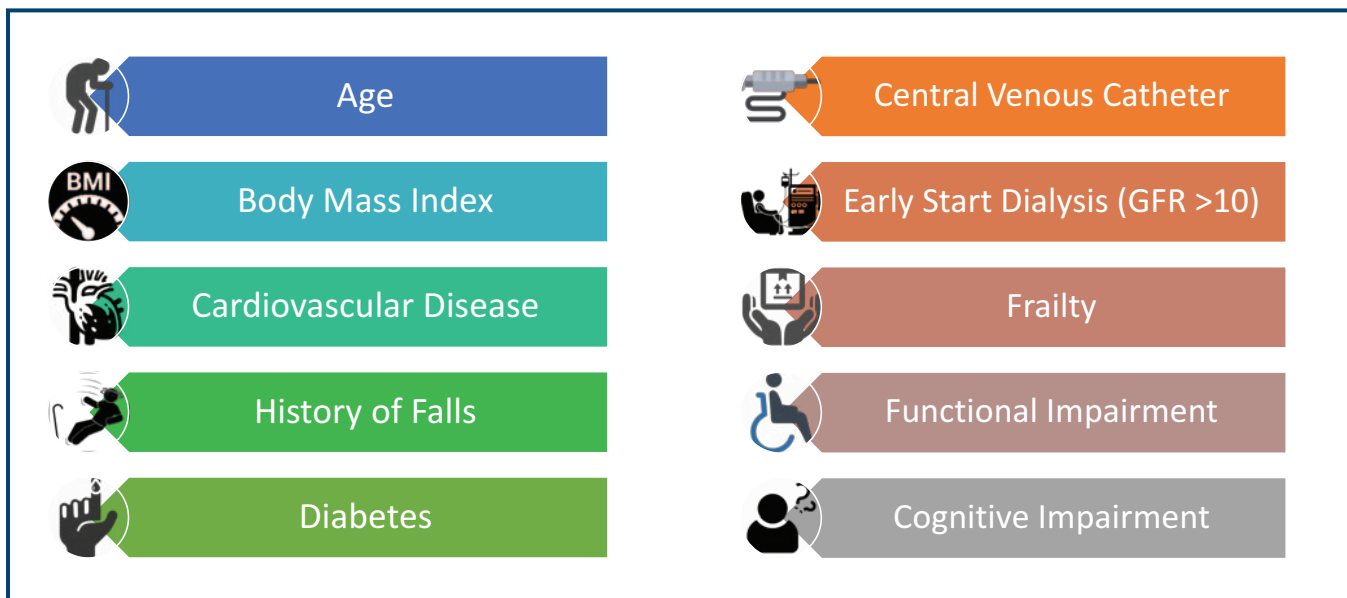
Regina Roofeh, MPH, is the Senior Program Manager, Department of Medicine, Northwell Health, Great Neck, NY.

Tara Liberman, DO, is the Associate Chief, Department of Medicine, Geriatrics & Palliative Care, Northwell Health, Great Neck, NY.

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Figure 1
Associated Risk Factors for Mortality in the Elderly Dialysis Population



15% of the general population (about 37 million people) are living with CKD Stages 1-5, with variable prevalence across age, racial, and ethnic groups (Centers for Disease Control and Prevention [CDC], 2019). For example, the percentage of individuals living with CKD rises to 38% for the population over 65 years.

Despite the importance of early identification, there remains a lack of preventative screening processes, which can lead to delayed detection and poor disease management. Patient awareness of disease presence remains low through Stages 1-3, with increasing awareness at Stage 4, when clear symptoms begin to present (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2016). CKD is often called a ‘silent disease’ because the early stages frequently present with no symptoms, and the disease remains undetected until it has advanced (NIDDK, 2016).

Although there have been widespread improvements in the treatment of CKD and KF, mortality in older adult patients who pursue kidney replacement therapies remains equivocally high. A systematic review of 28 individual studies by Song and colleagues (2020) found that advanced age alone is associated with increased mortality rates for older adult patients on dialysis. When associated risk factors (see Figure 1) were examined, mortality rates increased with a 95% CI in all categories.

The Emergence of Medical Technologies

Advances in medical technology and innovative nursing care have given health care providers the opportunity to treat illnesses that would have been considered fatal in

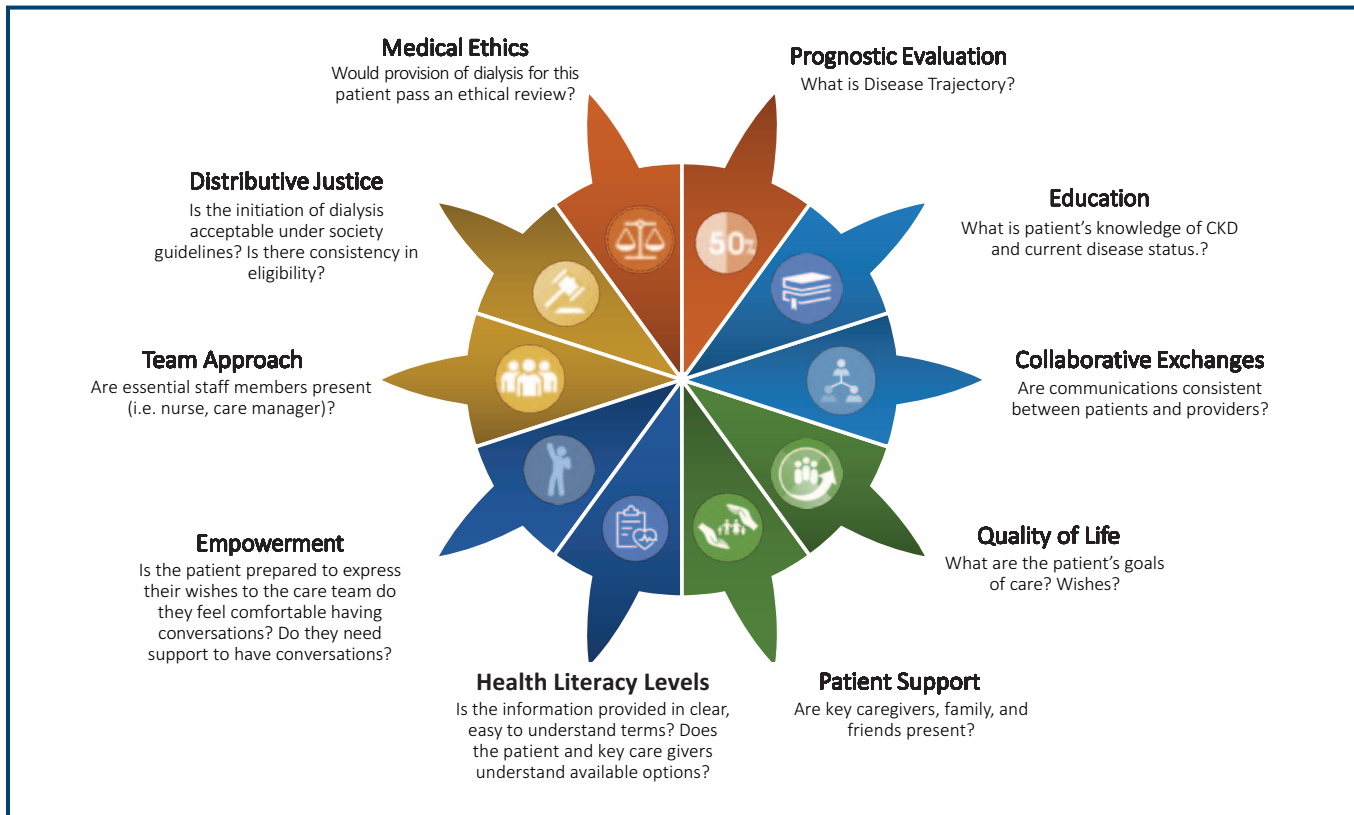
past years. Kidney replacement therapies in particular have changed vastly from their early infancy. Current dialysis therapies that are now considered routine and streamlined were once cumbersome and fraught with complications and suboptimal outcomes.

These advances have challenged many underlying medical and ethical principles and changed the way in which we view the appropriation of resources. Issues of medical futility, access to care, beneficence, non-maleficence, and distributive justice all weigh heavily around the decision to initiate dialysis. Patient-centered prognostic conversations should include elements that consider important core components (see Figure 2). The principles of beneficence and non-maleficence remind us that dialysis should only be provided when it has potential to contribute to outcomes that are clinically meaningful, improve patient outcomes, and contribute to quality of life, while at the same time, avoiding harm. Decisions are further complicated by the technological success of dialysis treatments and widespread availability of treatment options. This has the potential to cause conflict when providers fail to differentiate between the obligation to save a life and the opportunity to treat KF effectively (Schmidt, 2012).

Older Adults and the Medically Complex: An Expanding Population

The aging population is expanding both nationally and globally (CDC, 2019; United Nations – Department of Economy and Social Affairs, 2019). This is driven by a variety of confounding factors that can include medical and technological advancements, socioeconomic development,

Figure 2
Conversation Considerations



and increased prosperity. It is estimated that by 2034, there will be about 77 million persons over the age of 65 in the United States (U.S. Census Bureau, 2019). The most recent report from the U.S. Renal Data System (USRDS) (2020) notes the prevalence of CKD in U.S. adults age 65 and over as 38.6%.

The risk of developing CKD increases considerably with advancing age, which can be a key predictor in the emergence of the disease. In addition to age as a non-modifiable risk factor, patients often present with conditions, such as diabetes mellitus, obesity, and cardiovascular disease (USRDS, 2020). These factors alone would traditionally complicate treatment and care planning issues; however, advancing age further complicates care because older adults are also faced with issues of frailty, decreased quality of life, and limited life expectancy (Mallappallil et al., 2014). This further complicates treatment options and provider decisions surrounding provision of renal replacement therapies.

The Treatment of Kidney Failure with the Older Adult Population

As disease state and symptomology progress, nephrology professionals are forced to navigate many complex

issues, especially as it pertains to kidney replacement therapies in late-stage CKD and KF. The progression of kidney disease is further complicated when age is a confounding factor. Currently, there is no consensus on how to manage older adult patients in late-stage CKD. In addition, once kidney replacement therapy begins, it is unclear as to whether or not the dialysis treatment should be modified for age (Canaud et al., 2011). Additionally, limitations in prognostic tools and limited training on prognostic conversations make it difficult for nephrologists to discuss and provide conservative management as a treatment option (Davison, 2020). Dialysis treatment prescriptions for older adults are not exclusively influenced by disease status, but rather, involve a combination of factors, such as cultural influence, family dynamics, socioeconomic status, patient treatment adherence, and patient wishes.

The practice of dialysis initiation currently involves an age-neutral approach; however, this may need to be reconsidered for individuals over 75 years. While it is reasonable to assume dialysis is warranted for patients with KF who are symptomatic, the decision to dialyze older adults may need to be modified. Although laboratory testing can confirm the presence of CKD, practitioners must consider that the rate of decline in eGFR is dramatically different in

older adults (Rosansky et al., 2017). Older adults lose their kidney function at a considerably slower rate than their younger counterparts. In addition, their first-year mortality rate is complicated by the presence of multiple comorbidities. In such cases, it is likely these patients will die as a result of disease-related complications other than KF (Rosansky et al., 2017).

Previous practice patterns in the United States allowed for ‘early start’ dialysis with an eGFR greater than 10mL/min/1.73m² (Rosansky et al., 2017). In the late 2000s, this practice pattern began to change, and nephrologists began to initiate treatment based on a combination of laboratory values and symptomatology. While there is consensus among providers about initiating treatment based on this combination, laboratory values still remain a primary factor in initiating treatment. For older adults, this equates to treatment despite the absence of non-life-threatening symptoms and treatment of symptoms that may have been able to be managed medically (Rosansky et al., 2017).

The Need for Advance Care Planning for Elderly Persons with CKD

With all the advancement in health care, patients need a way to communicate their needs or wants regarding treatment. In 1967, the Euthanasia Society of America proposed a law that became the precursor for advance directives as we know them today. Kutner (1969) noted that premises of common and constitution law supported that patients should not be subjected to treatment without their consent. This provided a meaningful beginning to help patients make choices, but another dilemma was created. What do you do when a patient is no longer able to make health care decisions? The answer from Kutner was a document called a ‘living will’ (Kutner, 1975). This document would allow people to indicate in writing ahead of time what their wishes were regarding treatments.

In 1976, the living will became a standardized tool for patients, allowing an individual to express wishes regarding life-sustaining treatment (Sabatino, 2010). The use of living wills proliferated, but as technology continued to advance, so did the increase in challenging situations for applicability of a living will. Policy makers realized something needed to change, and another tool emerged – the health care proxy. Health care proxies allow an individual to authorize another individual of their choosing to act on their behalf if they become incapacitated (Hollander, 1991).

Both of these tools helped clear up confusion for patients regarding to their health care wishes. Over time, it felt cumbersome to have two separate documents addressing health care wishes. In the 1990s, New Jersey was the first state to pass legislation combining aspects from the two documents into one document known as ‘advance directives’ for health care (Sabatino, 2010). Other states recognized the usefulness of such a document and began adopting laws to use advance directives. The federal government also recognized the importance of advance direc-

tives and enacted the Patient Self Determination Act. Hospitals receiving Medicaid or Medicare reimbursement were mandated to educate patients about the need to make wishes known through advance directives (Sabatino, 2010).

At the same time, the nephrology community and associations, such as the Renal Physicians Association (RPA), quickly ascertained that these patients were medically complicated and had numerous complex requirements for care. As a result of this realization, the RPA convened a multidisciplinary group to address and discuss the sensitive issue of advance directives in this special population. In 2000, the RPA published “Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis,” which was updated in 2010 (Levine, 2001; RPA 2010). The RPA guidelines were developed to help practitioners work with patients and their families in making the best choices. While national associations such as the RPA endorse the concept of shared decision-making, there are several clinical, social, and technical barriers which impede advance care planning conversations for patients with CKD and KF (Senteio & Callahan, 2020). This leaves much room for interpretation when health care providers are attempting to initiate or facilitate conversations with their patients.

The Importance of ‘The Conversation’

In nephrology practice, conversations surrounding the care of patients with CKD and KF often involve diagnosis, prognosis, and medical management. Attempts at shared decision-making revolve around the application of medical treatment and technologies. Treatment is provided with much emphasis on the patient’s medical conditions or disease state. Conversations surrounding medical futility, quality of life, and advance care planning are often limited. Mandel and colleagues (2017) found that 90% of patients on dialysis desired having such conversations; however, less than 10% report having done so. Furthermore, less than 50% of patients on dialysis have completed an advance directive. Of the directives that are complete, they rarely address preferences regarding dialysis therapies (Mandel et al., 2017). In the USRDS Study of Treatment Preferences, 40.6% of participants were not sure of their prognosis, and only 37.5% had treatment preferences documented (USRDS, 2020). Under such circumstances, the default becomes dialysis, and the conversation surrounding advance care planning is often omitted for a variety of reasons.

The increased availability of health care information has changed the dynamics of health care, and patients are now ‘consumers,’ who expect they are offered every treatment possible. The default in nephrology can include the provision of dialysis with little regard to patient condition, quality of life, treatment goals, and patient expectations.

In treating older adults with KF, the need to reflect upon treatment plans and expectations is just as important as the administration of treatments and medications. The critical path step in deciding whether to offer and pursue kidney replacement therapies in older adults should

include carefully planned conversations that incorporate key elements (see Figure 2) and mutual exchanges between the patient, family, and care team.

Practice patterns that include concepts, such as shared decision-making and patient empowerment, can help reduce the initiation of dialysis as a treatment for those who will not benefit. In order to reduce missed opportunities to educate patients and families about the importance of advance directives, the nephrology community should continue to pursue case studies and root cause analysis. These are the most effective means of learning by example.

Initiatives, such as The Conversation Project, remind the health care team that the omission of conversations surrounding goals of care, prognosis, and treatment options result in the delivery of care that may fail to honor a patient's wishes (The Conversation Project, n.d.). A survey by The Conversation Project in 2018 found that 92% of Americans said it was important to discuss their wishes for end-of-life care and 95% said they would like to talk about it, but only 32% had had that discussion (The Conversation Project, 2020).

An Examination of the Conversation: Where Could We Improve?

In older adults, the progression of CKD may be slower, and in some cases, it is more likely they may die from complications of comorbidity (usually of cardiovascular disease) rather than KF. Older adult patients with CKD are at greater risk of complications and increased mortality as a result of comorbid complications (Levey et al., 2015). In addition, in persons over age 75 years, dialysis may not offer significant survival advantage (Ladin et al., 2018). This does not eliminate the obligation of the health care team to initiate conversations surrounding goals of care. While conservative management theories and principles have gained acceptance in the nephrology community, many patients still report feeling like the initiation of dialysis treatment is not a choice (Ladin et al., 2018). The combination of advancing age and CKD may lead providers to a false sense of security surrounding the likelihood of progression to KF.

Operating under this pretense allows for a 'misdiagnosis' in which patient goals and preferences are excluded from the conversations. Here, providers are engaging in a paternalistic realm and patients are passive recipients of care.

Conversations regarding prognosis and treatment of KF for older adults should focus upon a patient's wishes and the ability to uphold the expressed wishes of the patient. Failure to engage in prognostic conversations have profound implications, especially as it relates to engagement in end-of-life discussions, care preferences (USRDS, 2020), and treatment pathways. Of significant importance is that those with limited knowledge regarding prognosis are reported less likely to have a surrogate decision-maker or to have thought about end-of-life considerations, such as withdrawal from dialysis because their prognostic expectation may be more optimistic. This can have considerable long-term consequences when patients without realistic prognos-

Resources

The Conversation Project

<https://theconversationproject.org/>

Goal: To have every person's wishes for end-of-life care expressed and respected

Resources

- Starter Kits
 - What Matters to Me
 - The Conversation Starter Kit (in multiple languages; Kit, Coaching Guide, slide presentation, etc.)
 - Being Prepared in the Time of COVID (English and Spanish)
 - Health Care Proxy Kit: Who Will Speak for You?
- Blog
- Videos
- Newsletter
- Conversation Champions Discussion Group

Institute for Healthcare Improvement

White Paper: "Conversation ready": A framework for improving end-of-life care (2nd ed.). <http://www.ihl.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx>

tic expectations pursue life prolongation over relief of discomfort or symptom burdens (Li et al., 2018; USRDS, 2020).

How one goes about having this conversation can be daunting, and breaking bad news to a patient about dialysis decision-making can be stressful. This makes it necessary to develop a focused and goal-oriented approach that can be beneficial to both patient and provider.

Proposal for Action

Unlike many treatments and interventions in medicine, discussions around advance care planning, prognosis, quality of life, and treatment futility do not follow formal care pathways or standards of care. As health care providers, we need to remove the paternalistic approach to treatment and offer our patients the right to participate fully in their care and co-create their future. This process is patient-centered and invites friends, family, and team members to participate. It involves a deep sense of engagement and an unwavering commitment to the collaborative creation of realistic, patient-centered goals.

While we acknowledge the importance of shared decision-making and informed patient consent, we also recognize that health care providers need to be empowered and provided with the appropriate tools to facilitate such care. This process begins with changing how we deliver 'routine' nephrology care and creating pathways, processes, and organizational cultures that:

- Teach providers how to conduct the conversation.
- Provide tools that facilitate the conversation.
- Provide infrastructure that supports the inclusion of the conversation.
- Reimburse those who have the conversation.
- Support and uphold delivery of “the conversation” as routine nephrology care.

Conclusion

The challenge for this generation of health care is to leverage principles of patient-centered care and truly engage with patients as active participants in creating their personal vision for the delivery of health care as their kidney disease progresses. Advance directives and the alignment of patient goals with the delivery of nephrology care should be at the foundation of every treatment conversation for older adults with advanced CKD and KF. Will you take the challenge?

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