

# Palliation Versus Dialysis for End-Stage Renal Disease in the Oldest Old: What are the Considerations?

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**ABSTRACT:** As the US population continues to age, new cases of end-stage renal disease (ESRD) in individuals, aged 85 years or older (the oldest old), are increasing. Many patients who begin hemodialysis despite questionable benefit may struggle with high symptom burden and rapid functional decline. This article reviews the history regarding the funding and development of the Medicare ESRD program, reviews current approaches to the oldest old with ESRD, and considers strategies to improve the management approach of this vulnerable population.

**KEYWORDS:** End-stage renal disease, hemodialysis, renal replacement therapy, palliative care, Medicare

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## Introduction

The world's population is aging rapidly, and the United States is no exception. As of 2014, the US population, aged 65 years or older, was estimated to be roughly 46 million persons, and this number is expected to rise to 98 million by 2060.<sup>1</sup> The population of adults aged 85 years or older is expected to almost triple by 2040 to 14.6 million. This population of adults, aged 85 years and older, is known collectively as the "oldest old" and constitutes about 14% of all persons in the United States.<sup>2</sup> According to the Centers for Medicare & Medicaid Services (CMS), about 60% of the oldest old are living with at least 2 chronic medical conditions, and one-quarter of this population have 6 or more chronic illnesses including life-limiting diseases such as heart failure, emphysema, end-stage renal disease (ESRD), and dementia.<sup>3</sup> The oldest old are among the most rapidly growing population receiving dialysis for ESRD.<sup>4</sup>

In the United States, hemodialysis (HD) is offered regularly as life-prolonging therapy over maximum conservative therapies for ESRD with patients regardless of age, comorbidities, prognosis, or decision-making capacity.<sup>5–8</sup> Of the estimated 428 558 patients on HD in the United States, more than 91 000 of those were in the age group of 75 years or older, and this age group

accounted for 26 125 new HD starts in 2014 (almost 25% of new starts).<sup>9</sup> Among the oldest old, although some may experience improved quality of life with HD, those with multiple comorbidities appear to be at *increased risk* of hospitalizations, worsening of functional decline, and reduction in overall quality of life compared with management with maximum conservative therapies without HD.<sup>10</sup> As a result of the tendency to offer HD to all eligible patients, palliative care often remains underused for the oldest old with ESRD despite its documented benefits to patients, value-added care, and advocacy by multiple professional organizations.<sup>11,12</sup> This perspective highlights some of the significant clinical and societal conundrums faced by clinicians and patients when considering HD among the oldest old and seeks to review evidence that supports the benefits of shared decision making and palliative care in this group.

## Background

When Medicare established its End Stage Renal Disease Program in 1972,<sup>13,14</sup> based on the recommendations of the Gottschalk Committee,<sup>15</sup> the program's expectation was to provide care to healthier patients with ESRD, aged 54 years or younger, who were considered to be essentially disabled by their chronic illness but with a reasonable hope for rehabilitation by treatment with recovery of normal baseline functional status.<sup>16</sup> Today, nearly half (49%) of those starting HD are older than 65 years of age, many of whom have multiple comorbidities in

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addition to ESRD.<sup>17</sup> Although therapy with HD may extend life expectancy for many patients with ESRD, the median survival for those, aged 85 to 89 years, after initiating HD is estimated to be 11.6 months, and only 8.4 months for those above 90 years of age.<sup>18</sup> Unfortunately, HD does not promise restored health or function for those with multimorbidity. Rather, in older and frail populations, initiation of HD can lead to functional decline, cognitive impairment, decreased quality of life, and increased overall burden on caregivers.<sup>19–22</sup> Furthermore, patients with a diagnosis of dementia before initiation of dialysis have a higher risk of death compared with those who do not.<sup>23</sup>

Prior to the enactment of the ESRD legislation in 1972, many older and sicker patients with ESRD would have been ineligible to start dialysis and were likely to succumb to their renal failure. Now, despite distinct differences in the pathophysiology and natural history of chronic kidney disease in older versus younger individuals, as well as reported differences in personal goals of care between these age groups, management of ESRD is often performed in a “one-size-fits-all” manner.<sup>10</sup> Much of this has to do with the improved efficiency and availability of HD as well as financial incentives. This may also be associated with society’s propensity to follow the *rule of rescue*. Daniels postulated that for patients who face life-and-death situations, there is a propensity to use technology that may reasonably alter the course of that disease.<sup>24,25</sup> However, although the technology is readily available in the United States, recent data question whether HD is associated with improved outcomes, including survival for the oldest old despite the technical ability to offer the procedure.<sup>20,21</sup>

### Funding History and Challenges

When the Medicare program expanded to include the End Stage Renal Disease Program, patients with ESRD were covered for unlimited HD treatment as long as they were eligible for Social Security. At the time when Congress and President Nixon passed this law, the number of patients undergoing HD was approximately 10 000, and the estimated annual cost at the time was US \$280 million.<sup>14,26</sup> Adjusted for inflation in 2017, this would equal roughly US \$1.63 billion. However, the indications for dialysis have broadened with increasing availability, and the US population has grown and aged concurrently. Thus, most of the HD recipients are older and sicker than initially was expected. Consequently, Medicare covers 90% of all patients receiving HD in the United States, as well as care for those receiving kidney transplant services and peritoneal dialysis.<sup>17</sup> Medicare expenditures in 2013 totaled US \$437 billion, of which US \$30.9 billion were from ESRD costs. The US Renal Data System’s 2015 annual report estimated that Medicare spent US \$26.1 billion to provide HD to approximately 400 000 individuals.<sup>9,17</sup> In aggregate, despite comprising less than 1% of the total Medicare population, those with ESRD receive 7.1% of total Medicare dollars annually.<sup>9</sup>

**Table 1.** Centers for Medicare and Medicaid Services ESRD Quality Incentive Program for payment year 2016.<sup>27</sup>

A. Clinical measures
<ol style="list-style-type: none"> <li>1. Hemoglobin &gt; 12 g/dL<sup>a</sup></li> <li>2. Vascular access type measure topic (arteriovenous fistula, catheter)</li> <li>3. Kt/V dialysis adequacy measure topic (hemodialysis, peritoneal dialysis, pediatric hemodialysis)</li> <li>4. National Healthcare Safety Network bloodstream infection in hemodialysis outpatients</li> <li>5. Hypercalcemia</li> </ol>
B. Reporting measures
<ol style="list-style-type: none"> <li>1. In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS)</li> <li>2. Mineral metabolism</li> <li>3. Anemia management</li> </ol>

Abbreviation: ESRD, end-stage renal disease.

<sup>a</sup>Replaced by Standardized Readmission Ratio in payment year 2017.

In addition to funding HD, CMS also oversees quality standards through the Medicare ESRD Quality Incentive Program, which is updated yearly. In 2016, the program included 8 clinical measures and 3 reporting measures, encompassing anemia management, dialysis adequacy, vascular access type, patient experience of care, infections, hospital readmissions, and mineral metabolism (see Table 1). These quality measures are monitored and updated annually and have been established to ensure that all patients receiving HD in the United States are being treated as uniformly and safely as possible across practice settings.<sup>27</sup>

That being said, because clinicians are incentivized to follow these guidelines, it is plausible that some components of these guideline lead to overtreatment.<sup>28</sup> For example, it has been suggested that elderly patients receiving earlier arteriovenous fistulas may not be the most cost-effective option for patients with a limited prognosis, and the surgical risks and subsequent complications are not inconsequential.<sup>29</sup> At this time, however, there are no specific quality measures regarding appropriate selection of patients for HD, participation in shared decision making prior to HD initiation, or accounting for appropriateness of these quality measures based on an individual’s goals of care. At this point, it is interesting to note that The Gottschalk Committee report recommended a government-sponsored program to offer dialysis through the Medicare ESRD program, similar to that previously established by the Department of Veterans Affairs.<sup>16</sup> However, the Medicare End Stage Renal Disease program ultimately offered a fee-for-service model providing payments to independent providers and incentivizing the rise in for-profit facilities which currently make up most of the dialysis providers.<sup>16</sup>

We anticipate that the process of shared decision making, as proposed in the Renal Physicians Association Guideline,<sup>30</sup> will be increasingly emphasized in future compliance monitoring,<sup>31</sup> and current calls for advancing research priorities

**Table 2.** Recommendation summary of the Renal Physicians Association's Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis (for Adults), Clinical Practice Guideline, Second Edition, 2010.<sup>30</sup>

1. Develop a physician-patient relationship for shared decision making
2. Fully inform patients with AKI, stage 4 and 5 CKD, and ESRD about their diagnosis, prognosis, and all treatment options
3. Give all patients with AKI, stage 5 CKD, or ESRD an estimate of prognosis specific to their overall condition
4. Institute advance care planning
5. If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD, or ESRD in certain, well-defined situations
6. Consider forgoing dialysis for patients with AKI, CKD, or ESRD who have a very poor prognosis or for whom dialysis cannot be provided safely
7. Consider a time-limited trial of dialysis for patients requiring dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached about providing dialysis
8. Establish a systematic due process approach for conflict resolution if there is disagreement about what decision should be made regarding dialysis
9. To improve patient-centered outcomes, offer palliative care services and interventions to all patients with AKI, CKD, and ESRD who have burdens of their disease
10. Use a systematic approach to communicate about diagnosis, prognosis, treatment options, and goals of care

Abbreviations: AKI, acute kidney injury; CKD, chronic kidney disease; ESRD, end-stage renal disease.

that will improve overall care for this population have recently outlined strategies to promote this increasingly.<sup>32</sup>

### Translating Policy Issues to Clinical Practice

Dialysis remains a vital, life-saving therapy for many individuals with ESRD, but as outlined above, there are many challenges when it comes to weighing the benefits and burdens of dialysis for frail elderly patients and for those with dementia. Notwithstanding these findings, CMS continues to fund HD for *all* patients, regardless of other factors such as age, comorbidity, and goals of care—which collectively may affect outcomes.

We highlight 3 initiatives to improve quality, reduce overall costs and, moreover, promote goal-concordant plans of care for individuals over 85 years of age with ESRD. These initiatives can further incentivize shared decision making for patients diagnosed with ESRD. The goal would be to raise the quality of care and improve patient-centered outcomes for this vulnerable population, all while promoting increased patient and provider satisfaction with goals of care discussions.

First, to provide incentives for providers to take the time to have these conversations, CMS could create accurate billing codes to capture these discussions or as a means of measuring the quality of these discussions from a monitoring perspective. Beyond documentation, reimbursement mechanisms for engaging in the process of shared decision making in ESRD, similar to advance care planning reimbursement codes is one option.<sup>33</sup> There are, however, multiple barriers to providers having such goals of care discussions with their patients. For example, it has been reported that many providers still believe that they lack the necessary time and training to have lengthy and difficult shared decision-making conversations with patients about treatment options for ESRD.<sup>34</sup> Nevertheless, when these conversations do occur prior to starting dialysis, studies suggest that patients, caregivers, and providers voice frustrations about the conversations.<sup>7,35</sup> Such conversations often happen during a difficult time when patients are diagnosed initially or when feeling ill due to

progression of ESRD; thus, many believe this is an area where improvements can be made.<sup>34</sup>

Nephrology trainees report inadequate comfort with approaching end-of-life situation and believe more should be done to prepare them during their postgraduate training fellowship.<sup>36</sup> The result is that many patients with ESRD believe that they were not given sufficient information about their disease or the treatment options at time of diagnosis.<sup>37,38</sup> Overall, studies vary on the amount of decisional regret patients report after opting to begin dialysis.<sup>38–40</sup> This combined with a cultural perception in US health care that aggressive treatment is obligatory regardless of age or prognosis, which may be a major reason why most of the elderly patients diagnosed with ESRD begin HD rather than pursuing maximal conservative therapies without HD. Similar to general advance care planning in the setting, the ESRD shared decision-making service could be provided by a physician, advanced clinical practitioner, or licensed social worker.<sup>30</sup>

Two major sources of education and information are recommended to educate and empower renal providers with stronger communication skill set. The Renal Physicians Association has developed its “Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis” Clinical Practice Guideline most recently updated in 2010.<sup>30</sup> The goals of this resource are to bring principles of shared decision making and goal-concordant care into the awareness of dialysis providers and to improve such discussion when considering HD in populations that may be at risk for suboptimal outcomes.<sup>30</sup> These recommendations are summarized in Table 2. Also, palliative care and nephrology experts have developed *NephroTalk*, an educational program focused on improving physician comfort with communication, modeled after similar successful models in oncology.<sup>41,42</sup>

More recently, Moss<sup>43</sup> published a primer for palliative medicine clinicians to improve the integration of supportive care into ESRD treatment decisions. Geared for palliative medicine providers, this piece emphasizes the challenges faced when patients are considering dialysis, with an innovative emphasis on how to approach patients with acute kidney injury



who may not have had sufficient preparation to weigh the pros and cons of renal replacement therapy.

Although the Renal Physicians Association Guideline and Moss' supportive nephrology primer give expert guidance on promoting shared decision making with ESRD, they are unable to incentivize the process in a way other quality metrics do.

Next, palliative medicine services could be more frequently involved in shared decision-making conversations, for at least those who are at highest risk.<sup>12</sup>

The barriers to goals of care discussions are pervasive and far-reaching. Efforts through policy and guidelines to mitigate the difficulty of addressing complex goals of care and quality of life issues with this specific population have been slow to occur. We anticipate that changes will not improve quickly, opening the door to subspecialty palliative medicine clinicians to support providers and patients along the way. Subspecialty palliative medicine focuses on symptom relief throughout a serious, life-threatening illness, by treating the whole patient and family and devoting appropriate attention to the psychosocial and spiritual components of suffering. Evidence has suggested that palliative care reduces health care costs and improves quality, without decreasing survival.<sup>12,44</sup> Given the overall poor prognosis among the oldest old with ESRD, combined with the complexity of decision making regarding management with HD versus optimal conservative therapies without HD, palliative care specialists could offer tremendous value-added service for this population. At the time of diagnosis of ESRD, it is imperative that patients be offered palliative medicine services to discuss ALL treatment options as is promoted in the Renal Physicians Association Guideline and other society guidelines.<sup>30</sup>

Finally, understanding that subspecialty palliative care services are not available to all persons or locations at the same level, we support the Center to Advance Palliative Care's recommendations to include palliative care measures in the ESRD Quality Incentive Program.<sup>45</sup> As noted above, the current measures focus on the quality of the HD being performed, without regard for appropriateness of initiating or maintaining therapy. To be formally included in the ESRD Quality Incentive Program, a quality measure must be supported by the National Quality Forum, which has previously endorsed several measures related to palliative care that could be appropriate for the ESRD Quality Incentive Program. Herein, the goal would be to align more consistently with the health care provider's recommendations for management of ESRD with the patients' goals of care. Of course, implementing such quality measures will require considerable deliberation and strategy to improve the value and quality of care provided without becoming unduly burdensome to providers. However, it is our belief that current practice and reimbursement models have not kept pace with the changing population and evolutions in public health and health care technology. As such, it is time to reevaluate the Medicare ESRD Program to ensure that all patients with ESRD receive informed consent and the best care consistent with their values and goals.

## Conclusions

In the United States, the median age of those starting HD for ESRD is approximately 65 years old and continues to rise annually. This trend also affects the oldest old, with a reported 57% age-adjusted increase in HD for octogenarians and nonagenarians in the United States from 1996 to 2003. This population can experience decreased quality of life and increased rate of functional decline after initiating HD, which needs to be considered and discussed as part of the informed consent process. Excellent resources from the Renal Physicians Association and others are available to guide clinicians through best practices in this regard. Current quality metrics and financial incentives, coupled with the US cultural imperative to treat aggressively, steer many individuals with ESRD toward HD, regardless of age, comorbidities, or overall prognosis. To improve care for individuals aged 85 years or older with ESRD, it is strongly recommended that shared decision making be encouraged, incentivized, and monitored via the ESRD Quality Incentive Program of CMS. Making sure that patients are receiving adequate dialytic treatment will always remain important, but assuring that patients are receiving adequate informed consent and treatments consistent with their goals, preferences, and values should be more formally emphasized.

## Author Contributions

LSW, GDS, and TS conceived and designed the experiments. LSW, GDS, BT, and KMS analyzed the data; contributed to the writing of the manuscript; jointly developed the structure and arguments for the paper; and made critical revisions and approved final version. LSW and GDS wrote the first draft of the manuscript. LSW, GDS, TS, BT, and KMS agree with manuscript results and conclusions and reviewed and approved the final manuscript.

## Disclosures and Ethics

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