HEALTH POLICY

Dialysis in the Frail Elderly — A Current Ethical Problem, an Impending Ethical Crisis

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The current practice of hemodialysis for the frail elderly frequently ignores core bioethical principles. Lack of transparency and shared decision making coupled with financial incentives to treat have resulted in problems of overtreatment near the end of life. Imminent changes in reimbursement for hemodialysis will reverse the financial incentives to favor not treating high-risk patients. In this article, we describe what is empirically known about the approach to hemodialysis today, and how it violates four core ethical principles. We then discuss how the new financial system turns physician and organizational incentives upside down in ways that may exacerbate the ethical dilemmas, but in the opposite direction.

KEY WORDS: ethics; health policy; Medicare; renal disease; shared decision making.

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BACKGROUND

Since its development, hemodialysis (HD) has evolved from a scarce resource to a widely available standard of care. A *Life* magazine article in 1962 documented early days of rationing.¹ The ensuing public outrage resulted in the 1972 extension of Medicare to cover HD.² Today, HD remains the only life-extending treatment universally covered by public insurance.² Implicit HD rationing by age continued,³ but subsequently reversed under criticism of ageism.^{3–5} The oldest patients are now the fastest growing segment of the HD population,^{6,7} driven by apparent moral and technological imperatives to treat coupled with fee-for-service reimbursement. Overtreatment of elderly patients with end stage renal disease (ESRD) has gained attention in professional journals^{8,9} and the lay media,¹⁰ fuelled by disturbing outcome data.^{11–14}

In 2014, Medicare will change its payment structure for HD, with capitation of payment for all ESRD-related medical care of HD patients. This will bring financial incentives for cost avoidance and “cherry picking.” Below, we argue that today’s indiscriminate initiation of HD for frail elderly patients with ESRD¹⁵ loses sight of all four core principles of biomedical ethics: respect for autonomy, beneficence, non-maleficence, and justice (Table 1). Policies that shift incentives, combined with lack of ethical transparency, create a perfect storm of a return to implicit dialysis rationing.

RESPECT FOR AUTONOMY: PATIENTS ARE OFTEN PROVIDED NEITHER INFORMATION NOR CHOICE

In the US health care system, respect for patient autonomy has been consistently upheld by American jurisprudence.¹⁶ It plays out in daily medical practice through the process of informed consent. Despite the stated emphasis on patient autonomy and its corollary, shared decision making, studies show that HD patients frequently do not feel empowered to make an informed and autonomous choice¹⁷ and feel they have no choice but to start HD treatment.^{15,18}

According to surveys and interviews of patients with ESRD, many do not know their prognosis and do not recall alternatives being offered,^{17,19} despite preferring to receive detailed information.²⁰ Instead, patients recount being “rushed”²¹ and pressured¹⁷ into treatment at a time when they are too sick to process information and without a chance to discuss options with loved ones.²¹

Many physicians interpret “respect for patient autonomy” as presenting all available treatment options without recommendations and are reluctant to advocate for withholding treatment.²² This reluctance can obscure the life limiting reality of ESRD and the trade-offs those treatments present. Patients and families often perceive that they are given no choice but to continue aggressive treatment and are unprepared for the death of even the very old and very sick.²³ Patients and families may choose differently when goals of care are clearly articulated. They also may continue to opt for life extension irrespective of treatment burden and quality of

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Table 1. Ethical Challenges with Hemodialysis Initiation and Potential Solutions

Principle	Definition	Violation	Potential solutions
Respect for autonomy	Respect for patient autonomy requires acknowledging a patient's right to hold views, to make choices, and to act according to personal values and beliefs. Respect for autonomy plays out in practice through the doctrine of informed consent and open discussion of all options.	Failure to properly inform patients about their options. Failure to help patients and families anticipate the likely trajectory of their illness condition and future circumstances. Failure to elicit patients' goals of care. Failure to ensure that patients are free from coercion when making their choices. Failure to honor patients' advance directives and/or stated wishes.	Shared decision making. Describing patients' likely future circumstances, living conditions, etc., with and without dialysis. Eliciting patients' goals of care. Using prediction tools and decision aids. Respecting advanced directives and patients' stated wishes. Defending and empowering patients who are under pressure to make choices based on their goals of care.
Beneficence	The principle of beneficence refers to a moral obligation to act for the benefit of the patient. In medicine, we honor beneficence by providing treatments proven to either heal or comfort our patients.	Failure to consider benefits other than life extension and treatment efficacy. Failure to weigh benefits of treatment against the patients' goals of care.	Avoiding the assumption that life extension is the only benefit to be considered. Weighing expected treatment outcomes against patients' goals of care.
Nonmaleficence	Nonmaleficence is reflected by the Hippocratic maxim " <i>First do no harm.</i> " We honor the principle of nonmaleficence by not subjecting patients to potentially harmful treatments with little chance of benefit.	Subjecting patients who are unlikely to benefit from HD to the significant risks associated with treatment.	Employing clear and consistent criteria and prediction tools not to offer HD or to counsel against HD for those patients who are more likely to be harmed than to benefit. Refusing to dialyze a combative demented patient who is refusing treatment.
Justice	In health care, justice is most often taken to mean equitable access to health care for all.	Lack of coverage and access to treatment for other life-threatening illnesses. Factitious gatekeeping with financial incentives for HD providers. Risk of biased allocation in new Medicare reimbursement scheme.	Development of criteria for HD allocation based on clear and consistent measures of treatment benefit vs. risk. Lobbying for basic health care for all.

life. The prevailing ethical view in the US is that physicians should respect patient autonomy and either honor these wishes or transfer care. As a society, we cannot agree on futility criteria to support unilateral withholding or withdrawal of care.²⁴ Despite this, there is no ethical obligation to offer treatment that is ineffective, especially if there is significant risk of harm.²⁵

Often the rush to start HD can come at the expense of conversations about goals of care. While urgent initiation of HD may seem like the only option, timing is usually flexible. Early HD has failed to improve survival,^{26,27} and many patients may die before reaching the point of inevitable HD.²⁸ Peritoneal dialysis is a viable option for many²⁹ that is underutilized in the US.³⁰ It awards patients more control and possibly better quality of life.³¹

Finally, palliative care may be optimal for patients with ESRD whose symptom burden and mortality rivals that of cancer patients with or without HD.^{32,33} For the patients facing urgent decisions in the hospital setting, options are more limited and the stakes higher. Careful exploration of goals and values and honesty about the poor prognosis with

or without HD is imperative to bolster patient autonomy. In cases of ambiguity, time limited HD trials with pre-determined measures of success or failure could be undertaken. Palliative care should be considered in all patients with ESRD.

Respect for patient autonomy is also threatened by the tendency of physicians to choose life-extending therapy over supportive care when faced with conflicting goals of care within families.^{34,35} Physicians have reported giving preference to the wishes of family members over the patient's stated wishes both for competent^{35,36} and incompetent patients,³⁴ thus not respecting patients' autonomy despite explicitly stated wishes.^{35,37} Moreover, nephrologists feel ill prepared for these discussions.^{38,39} Newer frailty criteria⁴⁰ and prediction tools⁴¹ will hopefully guide providers and patients better in shared decision making, but will not eliminate these challenges.

Thus, the current practice of HD initiation often violates the principle of respect for autonomy by failing to properly inform patients about their options and by failing to ensure that patients' values are represented when those choices are made.

BENEFICENCE: DOES A NARROW DEFINITION OF BENEFIT DRIVE THE MORAL IMPERATIVE TO TREAT?

When it comes to beneficence, the situation is no better. The “biomedicalization of old age” has made it difficult for physicians not to offer, and for patients not to accept, life-extending interventions regardless of age and regardless of the likely benefit.^{15,42} Routine medical care overshadows choice, and the technological imperative⁴³ has been implicitly transformed to a moral imperative.⁴⁴ For the oldest and sickest patients, the imperative to treat is not well supported by the literature. The overall quality of evidence supporting a modest survival benefit with HD in the very elderly is very low due to methodological limitations of the studies and heterogeneity of the comparison groups.⁴⁵ High comorbidity scores adversely impact survival.⁴⁶ Symptom burden is high for patients with advanced, chronic kidney disease⁴⁷ as well as those on HD¹⁴ and supportive care,⁴⁸ with limited ability to compare quality of life between groups.^{45,48}

Many patients’ views of their own welfare seem to surround being able to maintain their lifestyle and social interactions more than life extension.^{21,49} Patients vary greatly in their personal approach to life, suffering, and death²¹ and can have multiple goals of care that influence what beneficence toward them might mean.⁵⁰ While these goals should shape how beneficence is applied in the dialysis decision-making process, they rarely do.¹⁸ Patients also care deeply about their loved ones.²¹ The current practice blinds patients and families to high mortality for acutely ill frail elders.⁵¹ Being unprepared for the death of a loved one and having to make treatment decisions for them has been shown to have significant negative emotional consequences.^{52–54} Irrespective of whether HD is likely to have life-extending benefits for an individual patient, determinations of benefit ought to be based on his or her goals, values,⁵⁵ and current state of health. The physiological efficacy of HD may not necessarily translate to a personal benefit from treatment if the patient perceives the balance of burdens and benefits as unfavorable. Treatment efficacy and survival benefit are not always primary factors for patients.

Thus, the principle of beneficence is violated when a narrow definition of treatment benefit, which centers on life extension, fails to take into account other benefits that may be more consistent with the patient’s goals of care.

NONMALEFICENCE: THE HARMS OF HEMODIALYSIS OFTEN OUTWEIGH ITS BENEFITS IN THE FRAIL ELDERLY PATIENT

A similar story arises with the principle of nonmaleficence. For the frail elderly patients, HD may do more harm than good. In nursing home and community-dwelling elders,

the onset of HD seems to bring rapid functional decline.^{12,13} While there is no direct comparison available, patients on supportive care alone seem more likely to maintain a stable functional status trajectory throughout most of the terminal year with a precipitous drop-off only in the last 1–2 months before death.⁵⁶ Many older HD patients regret having started HD.^{17,19} The symptom burden in the elderly HD patient is heavy and rivals that of cancer,¹⁴ yet palliative care is underutilized, even in patients who withdraw from HD.⁵⁷ Death associated with discontinuation of HD has increased from 14 % of patients 65 and older in 1989–1991⁵⁸ to 23 % in 65 to 74-year-old patients and 34 % of those ≥ 85 years in 2005–2006.⁵⁹

Survival of elderly patients on HD is poor.⁶ A recent push toward earlier initiation of HD has failed to improve survival.^{26,27} Best supportive care for elderly ESRD patients has achieved a 1-year overall survival of 65 %, which rivals survival on HD. Of those patients, 71 % died at home⁶⁰—a central goal for many patients.^{61,62} Similarly, elderly patients with dementia have particularly poor survival on HD.⁶³ Disruption in their routine can prompt fear and agitation. Continuing HD in patients with agitation can cause moral distress for caregivers who may feel that they are violating the patient’s right to bodily integrity and freedom from trespass (*personal experience*).

The harm of HD in many patient populations, especially frail older patients, may outweigh the benefits with respect to the outcomes many patients care most about, thus violating the principle of nonmaleficence.

JUSTICE: PATIENTS’ RIGHTS AND DISTRIBUTIVE JUSTICE

The principle of justice encompasses both individual rights and societal concerns. People hold widely disparate views of what constitutes just allocation of resources; i.e., to each according to need, merit, age, ability to pay, and contribution to society, among other metrics.⁶⁴ In health care, justice is most often taken to mean equitable access to health care for all. Many societies consider access to health care to be a basic human right. While the right to health care is not yet reality in the US, HD is an exception as it is covered for the entire population through Medicare. In this sense, there is an unfair culture of “dialysis exceptionalism.” Medicare is publicly financed and subject to fiscal constraints. In addition to rapidly aging demographics, there has also been increasing intensity of care for the elderly and terminally ill in the past decades.^{65,66} Between 1997 and 2003, there was a 57 % age-adjusted increase of HD initiation in octogenarians and nonagenarians.⁷ This trend

contributes to runaway costs that threaten the solvency of Medicare. Currently patients on HD consume over 6 % of the total Medicare budget.⁶

Concerns for justice could prompt limits, however rationing of health care does not seem acceptable to the US public. US physicians also oppose bedside rationing (J. C. Tilburt, MD, MPH, et al., unpublished data, January 2013). Attempts to provide ethical justification for rationing of care have largely failed, be it on the basis of age^{67,68} or futility.²⁴ However, there seems to be a tacit societal acceptance of withholding of care based on inability to pay (HD being an exception). Likewise, payment models with incentives shown to influence care provision are widely accepted. The current financing of HD is thus not morally neutral. Arguably the current financing of HD has created incentives for too much of a good thing. The current system incentivizes “factitious gatekeeping”⁶⁹—a dynamic in which physicians steer patients toward revenue generating therapies. The majority of HD is provided by for-profit entities.⁷⁰ In this setting, financial incentives have been shown to adversely affect treatment recommendations for ESRD with increased rates of in-center HD and less referral for transplantation or other less lucrative therapy options.⁷¹ Dialysis providers also perceive “cherry picking” in the current system.⁷² Physicians have also been shown to be subject to subconscious bias in their recommendations,⁷³ and their clinical decision making does not always match up with their a priori perceptions of what they believe guides their recommendations.⁷⁴

In light of the above, it is concerning that once the incentives shift with bundled HD payment, withholding HD could result in financial profit. This dynamic, known as “restrictive gatekeeping,”⁶⁹ was the object of outrage during the 1990’s debate over managed care. Some have argued that negative and positive gatekeeping could create a moral stress test, potentially jeopardizing the primacy of patient welfare.⁷⁵ If systems of transparency and accountability are not in place prior to the pending 2014 Medicare reimbursement scheme, implicit, nontransparent, and potentially-biased decisions about HD could evolve. If so, the ethical problems described above may reverse, bringing a new set of ethical concerns from the opposite direction.

Justice is violated by the current dialysis exceptionalism that threatens the fiscal solvency of Medicare and contributes to the technological imperative in end-of-life care. The pending reimbursement rules for HD pose an even greater threat to justice in health care by creating incentives for implicit rationing of HD based on bias, ageism, and replacement of the current financial incentive to treat, with financial incentives not to treat. We are ill-prepared to handle such a scenario.

CONCLUSION

The current situation of offering HD indiscriminately to patients has resulted in a situation where a significant number of frail elderly patients are potentially harmed from overly aggressive treatment near the end of life. An earlier generation’s worry about ageism and “playing foul” has been replaced by an equally paternalistic failure to offer or discuss risks, benefits, and alternatives to HD. This undermines patient autonomy and hampers patients’ ability to weigh life extension against other life goals. Respect for autonomy demands that health care providers elicit and respect patients’ preferences and adhere to their expressed wishes, even if this involves difficult negotiations with families. Without structures of transparency, the new policies for HD reimbursement, slated for 2014, may tempt physicians to withhold HD based on financial disincentive. Giving HD providers a vocabulary, guidelines, and protocols rooted in patient welfare, as well as using explicit criteria, could minimize ad hoc withholding of therapy based on subconscious bias. This is a unique opportunity for an open public debate on how to defend this important societal benefit without adversely affecting access to other important public goods, including basic health care for all.

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