Ethical Issues in the Care of Vulnerable Chronic Kidney Disease Patients: The Elderly, Cognitively Impaired, and Those From Different Cultural Backgrounds

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Numerous ethical issues such as the appropriate initiation or withdrawal of dialysis are inherent when one cares for patients with chronic kidney disease (CKD). Conflicts concerning decisions to withhold or withdraw dialysis often involve particularly vulnerable CKD patients such as the elderly, those with cognitive impairment, or those who come from different cultural backgrounds. Issues related to renal replacement therapy in vulnerable or special CKD populations will be explored within an ethical framework based on the principles of autonomy (self-determination), beneficence (to maximize good), nonmaleficence (to not cause harm), and justice (what is due or owed).

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Discussion

Ethical Issues With the Elderly and CKD

The elderly comprise the fastest growing segment of the dialysis population: octogenarians and nonagenarians beginning dialysis increased by 57% between 1996 and 2003. One-year mortality for the very elderly who initiated dialysis was 46% in a study of 13,577 patients. Older age, high numbers of comorbid conditions, and nonambulatory status were all predictors of death. Interestingly, a recent report of mortality among dialysis patients took the novel approach of examining excess mortality using standardized mortality ratios in years 1 to 5 after the first dialysis treatment. These investigators found that older ESRD patients, when compared with their age peers, actually had lower excess mortality than younger ESRD patients, especially in the first 3 years of dialysis. This analysis suggests that predicting and interpreting survival of ESRD patients is in part dependent...
on the method of analysis, emphasizing the importance of autonomy and beneficence in decision making about the initiation of dialysis. However, despite the vagaries of survival analysis among ESRD patients, ESRD clearly confers a relatively high mortality in the young and the old. Considering the principle of beneficence, is dialysis of benefit in the elderly with CKD?

There are few studies examining the survival of CKD patients on dialysis compared with those treated conservatively, but the available studies show that elderly CKD patients who begin dialysis live longer than those who do not. In a study of French octogenarians with CKD, survival was significantly better in those who began dialysis compared with those treated conservatively (median survival of 28.9 months in patients undergoing dialysis vs 8.9 months in the conservatively treated group, P < .0001). In this single-center cohort study of 146 consecutive octogenarians, independent predictors of death within 1 year on dialysis were poor nutritional status, late referral, and functional dependence. Interestingly, the burden of comorbid conditions was comparable in the dialyzed and conservatively treated groups, suggesting that comorbidity per se was either not primary in decision making or considered “pejoratively in the context of late referral, poor functional status, or social isolation.” A recent retrospective analysis of stage 5 CKD patients greater than 75 years of age also found significantly better survival among patients who started dialysis than those who were treated conservatively; the 1- and 2-year survival rate was 84% and 76% in the dialysis group (n = 52) compared with 68% and 47% in the conservatively treated group (n = 77). However, in contrast to the French study, the survival advantage was lost in patients with high comorbidity scores, especially when ischemic heart disease was present, leading the authors to conclude that comorbidity should be a major factor in advising patients to initiate or withhold dialysis. One small Italian study showed that a very low protein diet was safe and allowed postponement of dialysis in stage 5 CKD patients older than 70 years of age with a mortality rate equal to those who began dialysis.

Thus, like younger CKD patients, survival in the elderly is generally improved with the initiation of dialysis despite an overall high mortality for those on dialysis. Furthermore, like younger CKD patients, the survival of the elderly on dialysis is affected by nutritional and functional status as well as the presence of comorbid conditions. However, these factors may be weighed differently in dialysis decision making among the elderly compared with their younger cohorts. Should all CKD patients, therefore, be offered dialysis regardless of age and medical status? With the high and rising incidence of the elderly initiating dialysis, is withholding chronic dialysis from the elderly a rare event?

There are few studies to help answer these questions. One prospective study of referral of CKD patients for dialysis was performed in West Virginia by Sekkarie and Moss. Primary care providers withheld nephrology referral from 42 (22%) patients, and nephrologists withheld dialysis from 7% (25/332) of patients referred to them by primary care providers over a 1-year study period. Reasons for nonreferral to nephrology by primary care providers included old age, neurologic impairment, end-stage organ failure other than kidney (eg, heart, liver, or lung), metastatic cancer, the presence of multiple comorbid conditions, and patient or family refusal. Details on the effect of age on referral or nonreferral were not provided. Retrospective cohort studies and cross-sectional surveys of nephrologists from the 1990s have repeatedly found that neurologic impairment is the most often cited reason for withholding dialysis, but increasing patient age is a common factor.

The clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, provides evidence-based recommendations about withholding and withdrawing dialysis. In the guideline, appropriate criteria for withholding dialysis include patient or surrogate wishes, profound neurologic impairment, the presence of a non-renal terminal condition, or a medical condition that precludes the technical process of dialysis. Age, per se, is not listed as a criterion for withholding dialysis but clearly impacts patient survival and therefore is a factor...
It is reasonable to discuss estimated prognosis and time-limited trials of dialysis in order to provide informed consent to initiate dialysis. Patient age will, therefore, be a factor in decision making about dialysis initiation but should not be the sole criterion on which to base decisions to start dialysis, especially when survival is significantly better among elderly CKD patients who undergo dialysis compared with those who are treated conservatively. Because functional status and psychosocial factors affect an elderly CKD patient’s ability to adhere to dialysis treatments and influence his/her quality of life, time-limited trials of dialysis seem the most ethical and reasonable course to follow when faced with uncertainty about whether to initiate or withhold chronic dialysis from an elderly CKD patient. Strategies such as structured rehabilitation and short daily dialysis appear to be promising interventions to improve the health-related quality of life of elderly dialysis patients and to help them avoid placement in extended-care facilities. These deserve additional study in elderly CKD patients despite the issues of justice that arise when considering widespread availability of more expensive therapies.

Like factors affecting decisions to start dialysis, age is a risk factor for withdrawal from dialysis. As noted earlier, multiple factors may combine with age to increase the likelihood that a patient or a patient’s family will choose to stop dialysis. Social isolation, functional dependency, gender, ethnicity, and comorbid conditions all influence decisions to stop dialysis. With informed consent and shared decision making, withdrawal from dialysis is ethically and clinically acceptable; up to 20% of United States patients may withdraw from dialysis before death. It is incumbent on all providers caring for a patient contemplating withdrawal to address potentially remedial factors contributing to the decision to stop dialysis. Ongoing palliative care should also be provided.

The ethical principle of justice dictates that there is a societal obligation to allocate scarce resources equitably and appropriately. Although dialysis is an expensive therapy, it is generally paid for by society in developed countries and is therefore not a scarce resource. Thus, in the developed Western world, few are denied dialysis or withdrawn from dialysis simply because of age. However, deceased donor kidneys are a scarce resource, and thus the issue of transplanting the elderly deserves some consideration within this context. Using data from the Transplant Registry, elderly transplant recipients (age 70 and older) had a 41% lower overall risk of death compared with age-matched wait-listed candidates (relative risk = 0.59, \( P < .0001 \)). Similarly, recipients of expanded donor criteria allografts also had a lower mortality risk (relative risk = 0.75, \( P < .0001 \)). Single–transplant center reports have also described acceptable graft and patient survival in elderly transplant recipients, although the definition of elderly varies as does the importance of several risk factors. Transplant programs have criteria for excluding potential recipients, but age alone is generally not considered a contraindication to transplantation. Like with decisions to withhold or withdraw dialysis, the decision to transplant an elderly ESRD patient is best made via shared decision making, exploring prognosis, and balancing issues of beneficence with nonmaleficence and justice.

**Ethical Issues With CKD and the Cognitively Impaired**

Surveys and responses to hypothetical scenarios have repeatedly shown that a patient’s ability to relate and respond to the world is the most important factor in decisions to initiate and withdraw dialysis. One’s ability to understand starting or stopping a treatment like dialysis is inherent in the informed consent process and involves the principle of autonomy. Thus, cognitive awareness is an integral issue in dialysis decision making. The clinical practice guideline, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, identifies the persistent vegetative state as an appropriate condition in which to withhold or withdraw dialysis. The presence of advance directives and appropriate recommendations by the health care providers involved should facilitate appropriate decision making to withhold or withdraw dialysis in such cases.
However, the degree of cognitive impairment present may also influence decisions about dialysis and leave decision makers unsure about the appropriate plan of care. A recent study found that 73% of 338 chronic dialysis patients had either moderate or severe cognitive impairment on formal testing. Only 2.9% of the patients in this study had a prior documented history of cognitive impairment. Although there are some limitations of this study that may affect generalizability (common conditions that could affect cognitive function were not analyzed and the study participants were predominantly well educated and white), the findings raise important issues about the prevalence and recognition of cognitive impairment in dialysis patients. Additional studies of this area are needed.

The Impact of Cross-Cultural Differences on the Ethical Framework

The field of medical ethics has been invaluable in providing a framework within which we can examine the numerous ethical challenges such as withholding or withdrawing dialysis inherent in providing care to patients with CKD, especially for those who may gain limited benefit from dialysis such as the elderly, those with significant comorbidity, and those who have substantial cognitive impairment. However, the field of medical ethics is a product of Western culture, and as such, is unavoidably bound to the perspectives of that culture. As a result, many of the assumptions implicit in a Western autonomy-based approach to bioethical deliberation will not be shared by people with different cultural backgrounds. The effectiveness, therefore, of our current ethical framework may be limited, and at times completely insufficient in the face of issues that are closely linked to different cultural perspectives.

Cross-Cultural Issues Relating to Autonomy and Decision Making

The concept of autonomy best highlights the contrast between Western and many non-Western cultures. The Western principle of autonomy implies that every person has the right to self-determination. However, many cultures are characterized by strong communal values and social harmony in which the person is viewed as a “relational-self,” a self for whom social relationships, rather than individualism, provide the basis for moral judgments. From this perspective, an insistence on self-determination erodes the value placed on personal interconnectedness and challenges the assumption that the patient should make his/her own medical decisions. Although Western ethics promote the patient as the best person to make health care decisions, there are tremendous cross-cultural differences in decision-making models (often reflecting underlying differences in the importance or interpretation of “autonomy”). For example, Korean Americans and Mexican Americans tend to operate within a more family-centered model of decision making than European Americans and blacks. Because “relational autonomy” is valued in traditional Chinese culture, the family functions as both the collective decision maker and the conduit for moral, religious, and social norms. In a similar manner, Hindu and Sikh bioethics is primarily duty based; the person is not seen as autonomous but rather as intimately integrated with his/her extended family, community, and environment. Aboriginal people believe that all are entitled to make their own decisions but offer yet another approach to autonomy. The aboriginal concept of “autonomy” includes respect for interpersonal relationships and noninterference. This high degree of respect for personal dependence means that advising, persuading, or instructing is “undesirable behavior.” Yet, despite the importance of noninterference, the value placed on interpersonal relationships causes most Aboriginal patients to prefer that immediate and extended family members be involved in medical decision making. Consequently, health care providers must recognize that many patients, particularly from non-Western cultures, may prefer the family or community receive and disclose information before the initiation or withdrawal of dialysis, make decisions, and coordinate patient care, even when they themselves are competent.
Aboriginal and Asian cultures prohibit explicit references to dying based on an interpretative framework in which language has the capacity to create reality. Positive thinking is believed to promote health, whereas truth telling (of bad news) is viewed as disrespectful because it could shorten the life of the patient. This can make it difficult to discuss survival and natural history of the illness, and, in fact, family members may discourage physicians or interpreters from delivering bad news and instead communicate prognostic information themselves in such a way as to “balance” hope with the bad news. Health care providers need to understand that in some contexts, this may be appropriate.

Cross-Cultural Issues Relating to Advance Care Planning and Demands for “Inappropriate” Dialysis

Cross-cultural variations in the concept of autonomy, decision-making models, and the meaning of illness have implications for tools such as advance care planning. Although advance care planning is promoted by medical ethicists and widely accepted in the medical profession, its value reflects the great importance Western culture places on self-determination (autonomy). For cultures that do not value self-determination and individualism or view disclosure of “bad news” as dangerous to the patient, advance care planning may be perceived as a violation of traditional values and would impede an ethical approach to end-of-life care. Given the high prevalence of CKD in many ethnic minority groups, the clinical implication is that many dialysis patients will not have discussed end-of-life care preferences and will not have advance directives; their end-of-life care wishes will be unknown.

Even within a Western ethical framework, the principle of respect for autonomy has been challenged by demands from patients and families for medical interventions believed by the health care team to be inappropriate. A Western ethical approach would claim that the initiation or continued provision of inappropriate or “futile” dialysis violates the ethical principles of beneficence and nonmaleficence, violates medical practice standards and professional integrity, and imposes unjustified financial burdens on health care systems. The concept of medical futility was devised to take “precedence over” patient autonomy and would permit physicians to withhold or withdraw treatments such as dialysis deemed to be inappropriate without subjecting such a decision to patient approval. However, the concept of “futility” confounds the morally distinct cases of demands for treatment unlikely to work and demands for effective treatment supporting a controversial end (e.g., permanent unconsciousness). Although appeals for ineffective treatment may be dismissed because such treatment falls outside the bounds of standard care, treatment that supports a controversial end typically involves substantial value disagreements in which the concept of “futility” is meaningless. Conflicts over withholding or withdrawing dialysis typically fall into the second category. Although most patients and their families would not choose to prolong life and initiate or continue dialysis in a profoundly diminished state, some have very good reasons for doing so, and these reasons often involve cultural considerations.

For some religions, referring to dialysis as “futile” may represent a lack of faith in divine intervention. Alternatively, demands for “inappropriate” dialysis may reflect role obligation such as an opportunity to fulfill an obligation as a good wife. The wife may understand and be accepting of her husband’s poor outcome, but these facts may be unimportant relative to how she should act as a good wife. A good wife always asks that everything be done for her husband. Although she may not want her husband to suffer, she may accept suffering as an unavoidable part of the cycle of birth and death. Another example would be the moral perspective of traditional China, which is influenced primarily by Confucianism. In Confucian teaching, death is evaluated in terms of accomplishment in this world. A death is “good” only when most, if not all, of one’s moral duties in life have been fulfilled. Resistance to foregoing dialysis despite perceived limited benefit to the patient may reflect a patient’s desire to extend life in order to fulfill moral duties. It does not necessarily reflect denial for their serious situation or unrealistic
expectations for care. Children may be reluctant to withdraw dialysis of a parent for reasons of filial piety. In Confucian thought, filial piety is considered a virtue that can only be expressed when a parent is alive; to extend a parent’s life is to extend the opportunity to show filial piety.

The recent experience in Thailand regarding the use of ventilators has been instrumental in showing how none of the fundamental principles of Western bioethics (autonomy, beneficence, nonmaleficence, truth telling, or justice) sufficiently guide decisions to withdraw life-sustaining therapy in incompetent patients within a Buddhist ethical framework. The first precept of Buddhism forbids killing. By withdrawing life-sustaining treatment, the physician or decision maker creates “ill will” or “repugnance” in their mind, putting their karma at stake. Karma is a moral law central to Thai Buddhism in which actions generate either merit or demerit, and the balance of these 2 determines one’s spiritual future. Suffering during the dying event may at times be perceived as an opportunity to atone for one’s bad deeds and improve karma to secure a better spiritual future. Decisions to withdraw treatment are not based on the patient’s prior wishes because the self is seen as different from moment to moment (in this context, it becomes clearer why advance care planning is perceived as ludicrous; How could a person know what he/she would want years later, in a different state of consciousness?). Decisions are also not based on the patient’s best interests, truth telling, or what is good for society as a whole (social justice). Nor is it sufficient to say that these situations represent self-interest dilemmas in which the best interests (ie, the spiritual well-being of the decision makers and health care providers) are in conflict with the best interests of the patient. Putting one’s interests ahead of the patient would also be perceived as “ill will” toward the patient and would thus generate a demerit. Self-interest and ethical duty are so intertwined as to be indistinguishable. In a Buddhist ethical framework, it is impossible to withdraw life-sustaining treatment with beneficial intent.

Cultural variations in end-of-life preferences have been noted since the 1990s. For example, there is a consistent tendency toward preference for more aggressive end-of-life interventions among blacks. In recent years, institutions have attempted to develop guidelines that grant considerable latitude for professional discretion in decisions to withhold or withdraw treatments considered nonbeneficial for the patient. The impact of such policies would fall disproportionately on cultures that prefer aggressive end-of-life interventions, violating the obligation to respect the wishes and values of the patient, and might constitute discrimination against those with different value systems. It is clear that in a multicultural society, very different value systems may be at work in medical decision making. Although decisions to initiate or continue dialysis in patients in whom benefit is perceived to be minimal may be made clearer to the health care team when considered in the context of different value systems.

Ethical Issues in the Provision of Culturally Appropriate (End-of-Life) Care

Health professional cultural sensitivity is particularly important in delivering end-of-life care. Given the high mortality rate, end-of-life care is relevant for CKD patients. All cultures generate explanatory models that attempt to account for the phenomenon of illness and its place in human existence to define what a disease is, how it occurs, what measures can prevent or control it, and why some people and not others are affected. In Western medicine, the primary explanatory model of illness focuses on abnormalities in the structure of bodily organs and systems. On the other hand, many non-Western cultures such as Traditional Chinese medicine view the body, soul, and spirit as an integrated whole in the context of strong interpersonal relationships and may require access to a traditional healer (which may be viewed as similar to access to a hospital chaplain in a Western context). Complex cultural relationship rules also determine who should and who should not be directly involved in providing physical care, with many cultures strongly preferring that family be directly involved.
Recent research indicates that people from rural and remote areas wish to die at home, connected to land and family for strong cultural reasons. Yet many are relocated for end-of-life care. For indigenous people, relocation at the end of life is an extremely frightening experience. This highlights the strong need to provide local palliative care services and raises significant questions about the cultural appropriateness of relocation during the end of life. Culture also plays a role in the expression of suffering and grief. Many cultures are reluctant to complain of pain, particularly men who do not want to appear weak by expressing their pain. Others are not comfortable with frank, direct styles of communication. Patients may not express grief overtly because this may be seen as inappropriate. Emotional containment does not mean indifference. Health care providers should be cognizant of such cultural influences.

Ethics and Culture in Policy Development for CKD

A Western bioethical framework places importance on justice that dictates that there is a societal obligation to allocate resources equitably and appropriately. However, registry data report racial differences in CKD care, with ethnic minorities at a disadvantage. For reasons that are not well understood, ethnic minorities such as blacks, Aboriginal people, and East Asian and Indo Asian patients have significantly lower rates of kidney transplantation compared with white patients after adjusting for potential confounders including blood type and remote location of residence. This disparity is the greatest for transplants from living donors, which is important because this inequity is potentially amenable to intervention. Blacks are less likely to discuss organ donation within the family, have less knowledge about organ donation, are less likely to sign a donor card, and have a higher level of mistrust of the health system. East Asian and Indo Asian people may be less likely to donate kidneys because of reticence of family members to make a decision about donation on behalf of a deceased relative. None of the major Asian religions forbid organ donation, and a 1995 fatwa (edict) from the Muslim Law Council specifically states that organ donation is acceptable. However, studies have shown that many United Kingdom Muslims are unaware of the fatwa, which if confirmed in other populations would suggest that community-based initiatives involving religious leaders may be useful for increasing donation. Second, language barriers provide significant obstacles to ensuring equal access to care, especially for treatments such as transplantation that require substantial patient education.

Peritoneal dialysis may have potential advantages for certain cultural groups. Clinical experience suggests that peritoneal dialysis may be particularly suitable for patients who prefer that care be delivered by family or for patients who reside in rural locations because it obviates the need to relocate to a region that is served by a hemodialysis unit. Thus, social and cultural networks are preserved by treating patients in their own community, a high priority for many Aboriginal people. However, Aboriginal patients are significantly less likely to initiate therapy on peritoneal dialysis compared with white patients. The reasons for this discrepancy in practice and presumed cultural preference are unclear but deserve additional study.

The clinical implication of these findings is that, as a profession, nephrology has an ethical and moral obligation to develop initiatives and policies that address the inequities in the delivery of CKD care.

Summary

In Western society in which dialysis resources are unlimited, patient and family desire (autonomy) and medical benefit (beneficence) versus risk (nonmaleficence) is operative, and dialysis, often using the practice of time-limited trials, is appropriate with informed consent. As with any CKD patient, risk factors affecting patient survival will need to be considered on an individual basis for the elderly and cognitively impaired as with any CKD patient. The ethical principle of justice may raise additional considerations when transplantation or less widely available and more expensive procedures like daily dialysis are contemplated in elderly CKD patients.
However, Western and non-Western cultures may hold sharply divergent views about health, disease, and medical care. A Western ethic should include cultural sensitivity and respect that recognizes that cultural and moral perspectives influence an individual’s attitudes toward and choices about health care. Health professionals need to recognize the diversity of beliefs and practices within cultural groups; this may be complicated by the process of acculturating to Western life and many will hold blended cultural perspectives. Health professionals, therefore, must be careful not to use information about preferences by cultural group to assume the preferences of an individual. When health care workers are uncertain about how a patient or family perceives a situation, it is best to simply ask. Ethical approaches to decision making and the provision of care must encompass diversity in values and integrate these into clinical policies so all patients, regardless of cultural background, will have equal access to quality care within societal values.

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