ORIGINAL INVESTIGATIONS

Dialysis Decision Making in Canada, the United Kingdom, and the United States

John K. McKenzie, MD, Alvin H. Moss, MD, Terry G. Feest, MD, Carol B. Stocking, PhD, and Mark Siegler, MD

• **This study was designed to determine the extent to which differences in criteria for dialysis patient selection and availability of financial resources cause the wide variation in acceptance rates for dialysis in Canada, the United Kingdom, and the United States. We also sought to determine whether there is agreement among nephrologists in the three countries on which patients should not be offered dialysis. We used a cross-sectional survey of all members of the Canadian Society of Nephrology and the Renal Association of Great Britain, and a randomized sample of 800 members of the American Society of Nephrology. Five case vignettes were presented asking for yes/no decisions on offering or not offering dialysis, together with ranking of factors considered important. We also inquired about dialysis resources and physician demographics. We compared responses by country. More nephrologists from the United Kingdom returned responses (83%) than Canadian (53%) or American (36%) nephrologists. American nephrologists offered dialysis more than Canadian or British nephrologists (three of five cases; $P < 0.04$ to $P < 0.001$) and ranked patient/family wishes (three of five cases; $P < 0.057$ to $P < 0.0001$) and fear of lawsuit ($P < 0.04$ to $P = 0.0012$) higher than British or Canadian nephrologists. Canadian and British nephrologists reported their perception of patients' quality of life as a reason to provide ($P = 0.0019$) or not provide ($P = 0.068$ to $P = 0.0026$) dialysis more often than their American counterparts. Despite these differences, nephrologists from each country did not differ by more than 30% on any decision and ranked factors almost identically. Ten percent and 12% of Canadian and British nephrologists, respectively, but only 2% of American nephrologists, reported refusing dialysis due to lack of resources ($P < 0.0001$). We conclude that the wide variation in dialysis acceptance rates in the three countries is somewhat influenced by differences in patient selection criteria and withholding of dialysis by nephrologists based on financial constraints, but that other factors, such as differences in rates of patient nonreferral for dialysis, contribute more significantly to the variation. Generally agreed on practice guidelines for dialysis patient selection appear possible.**

INDEX WORDS: Dialysis patient selection; patient/family wishes; fear of lawsuit; quality of life; allocation of scarce resources.

IN THE United Kingdom, 65 patients per million[1] population were accepted for dialysis in 1992, compared with 98 per million in Canada[1] and 212 per million in the United States.[2] Potential reasons for this threefold variation in acceptance rates (or treatment incidence rates as opposed to true incidence rates) are differences in the three countries in the following: incidence of end-stage renal disease (ESRD), availability of financial resources, criteria for dialysis patient acceptance, and referral rates of ESRD patients to nephrologists by primary care physicians.

The threefold variation cannot be explained by differences in the true incidence of ESRD in the respective countries. In 1988, the true incidence of ESRD in the United Kingdom was 148 patients per million population per year.[3] Comparable true incidence data for the United States are not available, but the highest estimate for 1988 is at most twice the UK rate.[2] Some of the variation is caused by higher incidences of ESRD in blacks in the United States and in native North Americans in the United States and Canada,[1,2] but large differences in the ESRD treatment incidence rates between Canada and the United States have been shown to persist after adjustment for race and age.[4]

From the Section of Nephrology, Department of Internal Medicine, the University of Manitoba, Winnipeg, Manitoba, Canada; the Section of Nephrology, Department of Medicine, Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, WV; the Richard Bright Renal Unit, Southmead General Hospital, Bristol, UK; and the MacLean Center for Clinical Medical Ethics, the University of Chicago Pritzker School of Medicine, Chicago, IL.

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Address reprint requests to John K. McKenzie, MD, 116-1 Snow St, Winnipeg, Manitoba, Canada R3T 2M4. E-mail: jmckenz@cc.umanitoba.ca

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The variation might be explained by differences in financing of dialysis in the three countries. In the United States, the ESRD program is financed by the federal Medicare program and covers 93% of patients who need dialysis or transplantation. In Canada and the United Kingdom, dialysis is financed from local budgets with much more limited funds.[5,6] Moreover, a major review of dialysis services in the United Kingdom has found large variations in dialysis acceptance rates, with a range of 19 to 128 patients per million population among districts and an association between districts with low levels of available dialysis services and low acceptance rates onto dialysis.[7]

Dialysis is an expensive medical therapy, costing approximately $47,000 per year per patient in the United States.[8] The cost of health care is straining the budgets of all three countries. Dialysis itself is associated with estimated yearly costs of £300 million in the United Kingdom[7] (US $9.5 billion[2]). The most widely used estimate of value of treatments incorporating considerations of cost is the quality-adjusted life-year, although its use remains controversial. By quality-adjusted life-year analysis, the acquired immunodeficiency syndrome (AIDS) has until recently been the most expensive disease receiving long-term therapy, especially considering the inevitable decline in quality of life. Dialysis has possibly been the next most expensive option. However, study of quality-adjusted life-year perceptions of ESRD patients in the United Kingdom showed that the majority perceived that they had a quality of life higher than other people may have believed, rendering dialysis more cost effective than commonly considered.[9] In terms of cost to the UK budget, the review of renal services in the United Kingdom suggests that to reach an annual acceptance rate of 80 patients per million population, half a billion pounds will be needed to finance this service annually (approximately US $900 million), an amount approximately 60% greater than the current expense for dialysis services.[7] An examination and comparison of how decisions are made to start patients on dialysis might be of considerable interest to health policy planners working with limited budgets. Such information also may be useful to nephrologists in the United Kingdom in advocating for more resources committed for dialysis or possibly may be a cause for concern for American nephrologists who might be found deficient in their stewardship of US health care resources, and also to be prolonging life inappropriately in some cases.

The limitations in funding in Canada and the United Kingdom have resulted in nonreferral of ESRD patients by primary care physicians to nephrologists.[4,10] Nonreferral of patients may account for most of the variation, but nephrologists in Canada and the United Kingdom also may have more stringent criteria for accepting patients for dialysis. Differences in criteria could result in patients in the United States being provided dialysis when the benefits are minimal or patients in Canada and the United Kingdom being denied dialysis of clear benefit or both. This British review admits that patients who would have benefited from dialysis have been denied it as recently as 1991 and calls for dialysis to be available for all ESRD patients who are likely to live at least 2 years after initiation.[7]

We conducted this study to determine to what extent differing criteria for patient acceptance to dialysis and availability of financial resources to pay for dialysis account for the variation in dialysis acceptance rates in the three countries and to determine whether there is general agreement among the nephrologists in the three countries about not offering dialysis to patients in certain clinical circumstances.

MATERIALS AND METHODS

Subject Identification and Solicitation

Questionnaires were mailed to all members of the Renal Association in Great Britain and of the Canadian Society of Nephrology in Canada, and to a random sample of 800 nephrologists selected from the membership list of the American Society of Nephrology in the United States. Nonrespondents were mailed a second questionnaire 4 weeks later. Follow-up phone calls to dialysis unit medical directors or their secretaries, encouraging a response, were made after the second mailing in Great Britain only. The net sample size in each country was reduced to adjust for those on mailing lists who were not caring for dialysis patients. Francophone Canadian nephrologists received the questionnaire after it had been professionally translated into French and reviewed by a Francophone nephrologist.

Questionnaire

The questionnaire contained 53 questions. It included sections questioning the management of five seriously ill patients, relevant factors in dialysis decision making, re-

sources for dialysis, and background information. The questionnaire was drafted by two of the authors (J.K.M. and A.H.M.) and was revised after pilot testing with nephrologists at the University of Chicago. (A copy of the questionnaire is available on request.)

To detect differences in dialysis decision making among nephrologists in the three countries, we used five cases drawn from our clinical experience of treating elderly and/or seriously ill patients with nonrenal medical problems in addition to ESRD. These cases are described below.

Patient 1 is a 68-year-old man with glomerulonephritis and hypertension requiring medical treatment who is now developing end-stage renal failure. He is otherwise physically healthy. During the last 2 years, before becoming uremic, he has become forgetful and cannot remember the day of the week or where he is for more than a few minutes; he has been diagnosed as having Alzheimer's disease. He consistently forgets his medication, but his daughter, with whom he lives, ensures that he gets it. He is cheerful and enjoys visiting, although he cannot find his way home. Several attempts to explain dialysis to him have been unsuccessful. His daughter (his nearest relative) would like him to have dialysis, although he has never expressed an opinion about it in the past, nor has he completed an advance directive.

Patient 2 is a 72-year-old widow with known diabetes who has been on insulin for 27 years. She is blind and has severe renal failure, autonomic neuropathy with diarrhea, and peripheral neuropathy. She has had a below-knee amputation on one side and has recently developed a penetrating ulcer on the other foot that is not healing. She requires oral morphine frequently for pain due to ischemia in her hands and legs. She is recently breathless and unable to walk more than a few steps on crutches. Her home is poorly wheelchair accessible. She describes her life as a burden, but wants dialysis so that she can provide a home for her disabled son who lives with her.

Patient 3, a 29-year-old male heroin addict, has AIDS and renal failure. He is noncompliant with diet and medication, and usually does not come for appointments. He has had two episodes of bacterial endocarditis, has had a mitral valve replacement, and takes anticoagulants irregularly.

Patient 4, a 68-year-old woman, was resuscitated from a cardiac arrest of unknown duration in her hospital room while recovering from pneumonia. She now has reasonable cardiac function and has been weaned from the respirator. She had abnormal renal function initially and has drifted into end-stage renal failure. All consultants agree that she is in a persistent vegetative state (PVS). Her wishes for future care are unknown.

Patient 5, a 19-year-old man with Duchenne's muscular dystrophy, is confined to a wheelchair and cannot easily dress himself. He can feed himself with difficulty, is able to operate a computer-assisted education program, and relates well to family, friends, and hospital staff, although he says he does have periods when ''life is not worth living.'' He does not yet require respirator assistance. He has developed glomerulonephritis and end-stage renal failure.

There were three advantages to using standardized cases: the clinical circumstances could be structured to examine the issues of offering and withdrawing dialysis, the cases would be identical for all respondents, and variation in decision making among physicians could be readily identified.[11] Respondents were asked to indicate (yes or no) whether they would offer dialysis and then to rank a list of possible reasons for their choice in order of importance. Reasons for offering dialysis included patient request, family request, dialysis sustains life, adequate quality of life, fear of lawsuit, and other. Reasons for not offering dialysis included poor quality of life, limited survival, inability to comply, unacceptable lifestyle, and other. In four of the vignettes, additional information and questions were provided to manipulate the case to determine whether patient (or family) requests or noncompliant, abusive patient behavior might cause nephrologists to change their initial decision about offering dialysis.

Respondents also were asked to rank nine factors in order of importance in making dialysis decisions in their practice: age, lifestyle of the patient, previous medical compliance, ability to pay, life expectancy, expected quality of life, other medical conditions, mental status, and available social supports from family, friends, etc.

A single question was asked about resources: ''Are dialysis resources so scarce in any of the units you work in that dialysis has been withheld from any patient because of lack of funding?''

Respondents indicated their age, gender, year of commencing practice, country, and profit or not-for-profit status of the dialysis unit where they treated most of their patients.

Comparisons of population proportions were done using chi-squared analysis. One-way analysis of variance was used to compare responses in the clinical vignettes, and the Bonferonni *t*-test was used to compare the mean values of these rankings between countries.

This research study was approved by the University of Chicago Division of Biological Sciences Institutional Review Board for the Protection of Human Subjects.

RESULTS

Respondent Characteristics

One hundred forty-four of 171 (84%) British nephrologists, 116 of 219 (53%) Canadian nephrologists, and 273 of 765 (36%) American nephrologists returned questionnaires. Over 65% of the British nephrologists responded without telephone prompting. The mean age (47 years) and the year of starting nephrology practice did not differ for respondents from the three countries.

Dialysis Decision Making in Clinical Vignettes

Significantly more American nephrologists would offer dialysis than British or Canadian nephrologists; this was demonstrated in three of the five cases: the demented patient ($P < 0.001$), the diabetic patient ($P < 0.001$), and the PVS patient ($P < 0.04$) (Table 1). In all five cases, the British and Canadian nephrologists did not dif-

Table 1. Percentage of Nephrologists Offering Dialysis According to Country of Practice

Clinical Vignette	Canada (n = 116)	UK (n = 144)	US (n = 273)	*P* Value
Demented patient	67	68	82	<0.001
Diabetic patient	57	63	80	<0.001
Heroin addict	49	50	56	NS
PVS patient	2	3	7	<0.04
Muscular dystrophy patient	92	96	95	NS

fer. Except for the patient in the PVS, a majority of nephrologists would offer dialysis in each scenario.

The reasons given for offering or not offering dialysis varied among the nephrologists. The American nephrologists more often cited respect for the patient or family request as the most important reason to offer dialysis (Table 2). Canadian and British nephrologists were more influenced by their perceptions of quality of life in the various cases. For example, they cited adequate quality of life as a reason to offer dialysis to the patient with muscular dystrophy more often than the Americans (Canadians 21% *v* British 17% *v* Americans 8%; $P = 0.0019$). The Canadian and British nephrologists also selected poor quality of life more often than the Americans as a reason not to offer dialysis (diabetic patient: Canadians 18% *v* British 19% *v* Americans 11%, $P = 0.068$; PVS patient: Canadians 62% *v* British 74% *v* Americans 56%, $P = 0.0026$). Nephrologists' major reason not to offer dialysis to the patient who was the heroin addict was inability to comply (Canadians 21% *v* British 19% *v* American 20%; P = NS). The American nephrologists also ranked fear of lawsuit higher as a reason to offer dialysis and differed significantly ($P < 0.05$) from the British on this factor in three of the five cases.

Table 2. Percentage Ranking Patient or Family Request First Among Reasons to Offer Dialysis

Clinical Vignette	Canada (n = 116)	UK (n = 144)	US (n = 273)	*P* Value
Demented patient	36	38	47	0.057
Diabetic patient	53	57	75	<0.0001
Heroin addict	31	33	28	NS
PVS patient	0	0	3	NS
Muscular dystrophy patient	48	61	70	<0.0004

The manipulation of the cases allowed us to demonstrate that American nephrologists viewed patient and family requests and fear of a lawsuit as more important in making dialysis decisions than did the Canadians and British. For example, in the demented patient case, there were three manipulations. If the patient, who had commenced dialysis, became unhappy and asked to stop dialysis, had repeated ''accidents'' on dialysis necessitating restraints, or developed uncontrollable heart failure, 97% to 98% of nephrologists from all three countries would stop dialysis if the family agreed. However, if the family did not agree to stop, in all three circumstances fewer American nephrologists (35% to 39%) would stop compared with Canadian and British nephrologists (50% to 71%; $P < 0.0001$ for all three circumstances). Similarly, in the case of the PVS patient, only a few nephrologists would offer dialysis, but if the family insisted on it, more Americans than Canadians or British would provide it (Canadians 30% *v* British 16% *v* Americans 45%; $P < 0.0001$). In the case of the noncompliant heroin addict, if the patient refused to come for dialysis more than once a week and often had to be dialyzed emergently, a similar percentage of nephrologists would continue dialysis (Canadians 44% *v* British 51% *v* Americans 47%; P = NS), but a higher proportion of American nephrologists ranked fear of lawsuit as one of the top four reasons to continue dialysis in this case than did the Canadians or British (Canadians 24% *v* British 36% *v* Americans 56%; $P = 0.0003$). In the case of the patient with muscular dystrophy, if the patient refused dialysis and had decision-making capacity, nearly all nephrologists (Canadians 94% *v* British 98% *v* Americans 95%) would respect his refusal.

Factors Used in Decision Making

Of the nine factors provided, the nephrologists from the three countries agreed on the rank ordering of seven (Table 3). British nephrologists placed life expectancy second, while Canadian and American nephrologists placed it third, with the reverse for mental status. Using Kruskal-Wallis mean rank testing, there were significant differences ($P \leq 0.05$) among the three countries for mental status; it was considered much less important in the United Kingdom than in Canada

Table 3. Ranking of Factors Used in Dialysis Decision Making According to Country of Practice

	Canada (n = 116)	UK (n = 144)	US (n = 273)
Quality of life	1.95* (1)	1.80 (1)	2.04 (1)
Mental status	3.58 (2)	3.85 (3)	3.32 (2)
Life expectancy	3.79 (3)	3.70 (2)	4.12 (3)
Other medical conditions	3.99 (4)	4.18 (4)	4.15 (4)
Compliance (with previous medical regimens)	4.82 (5)	4.77 (5)	4.66 (5)
Social support	5.34 (6)	5.82 (6)	5.52 (6)
Lifestyle (unacceptable)	6.29 (7)	5.86 (7)	5.88 (7)
Age	6.85 (8)	6.53 (8)	6.97 (8)
Ability to pay	8.31 (9)	8.5 (9)	8.31 (9)

*Mean value for factor (1 = most important, 9 = least important).

or the United States. Similarly, ability to pay was rated lowest by the nephrologists in all countries, but mean rank was lowest in the United Kingdom ($P \leq 0.05$).

Resource Scarcity

Twelve percent of British, 10% of Canadian, and 2% of US nephrologists ($P < 0.0001$) said they had withheld dialysis from at least one patient because of insufficient funding to cover the cost of dialysis. Forty-five percent of American nephrologists dialyzed most of their patients in for-profit dialysis units compared with 1% of Canadian and no British nephrologists. However, there were no differences in responses to clinical vignettes, ranking of factors for dialysis decision making, or demographics between the American nephrologists who mainly cared for patients in for-profit dialysis units and those who did not.

DISCUSSION

Because dialysis is a treatment that can sustain patients' lives for years and because it is so expensive, it has raised two of the most difficult ethical dilemmas of our time: how much in the way of scarce health care resources should be committed to funding its availability and how should patients be selected to receive it?[12] Although the British had previously discriminated against the elderly in the dialysis selection process,[13] they are now beginning to catch up to other countries in accepting older patients for dialysis.[14,15] Nonetheless, there is still a wide variation in patient acceptance rates for dialysis in the three countries. To our knowledge, this study examines for the first time the attitudes and reported practices of Canadian, British, and American nephrologists in dialysis patient selection. It demonstrates both clear differences and areas of general agreement in dialysis decision making.

Not surprisingly, a significantly greater percentage of American nephrologists than Canadian or British nephrologists indicated they would offer dialysis to the patients described in our questionnaire. However, there was never more than a 30% difference in the responses among the nephrologists from the three countries. There were important distinctions, however, in the reasons given by the nephrologists to justify offering dialysis. Our results suggest that the American nephrologists were more motivated by patient and family requests for treatment and fear of lawsuits, whereas the British and Canadian nephrologists were more influenced by their perceptions of patient quality of life in the various cases. Our findings support those from a previous study in which some American nephrologists indicated they would provide dialysis even if they thought it was inappropriate if the family would not agree to have dialysis withheld or withdrawn.[16]

These differences were particularly striking in the responses to the manipulations of the cases of the PVS and demented patients. While over 90% of all nephrologists, including American nephrologists, thought that dialysis should not be offered to a PVS patient, almost half of the American nephrologists (and 30% of the Canadian and 16% of the British nephrologists) would provide it if the family insisted on it. Similarly, over 95% of nephrologists from the three countries would stop dialysis of the demented patient if he became unhappy on dialysis, required restraints to complete a treatment, or developed uncontrollable heart failure, and if the family agreed to stop. Whereas 50% of British and Canadian nephrologists would stop dialysis if the family disagreed, only a minority of American nephrologists would stop dialysis. The responses of the American nephrologists are similar to those reported previously by Singer.[17]

Because the American nephrologists also ranked fear of lawsuit higher than their Canadian and British colleagues, it may be that part of their motivation to honor the family request was not

only a belief that they were ethically required to honor a surrogate's decision, but also a concern for their being sued if they did not. American case law contains legal decisions not involving dialysis patients finding in favor of the family's wishes when they request the initiation or continuation of life-sustaining treatment even in permanently unconscious patients[18] or anencephalic infants.[19] American nephrologists have previously indicated that their dialysis decision making is strongly affected by legal considerations,[16] and many may not know that nephrologists can refuse to dialyze patients when they do not think dialysis is in the patients' best interests.[20] Moreover, McCrary et al[21] have noted that physicians make treatment decisions primarily based on perceived rather than real constraints from the legal system; this may have severe consequences for patients, particularly in the form of overtreatment. They observe that inappropriate use of scarce medical resources and unnecessary suffering of patients and families may result from such instances, two ethical concerns raised by inappropriate overacceptance of patients for dialysis.

Another difference noted was that almost no American nephrologists reported that lack of funding had caused them to withhold dialysis from patients, whereas 10% of Canadian and British nephrologists acknowledged this problem. Thus, patients who would have benefited from dialysis did not receive it; this fiscal constraint may contribute to the underacceptance of patients for dialysis in Canada and the United Kingdom.

Despite these differences, there was considerable agreement among the nephrologists of the three countries regarding dialysis decision making. The mean ranking of seven of the nine factors relating to offering dialysis was the same, and the ranking for the other two factors only differed by one. More than 90% of nephrologists from all three countries agreed that dialysis should not be offered to the PVS patient, and more than 95% concurred that the muscular dystrophy patient with decision-making capacity should be allowed to refuse dialysis if that were his choice.

Given this level of consensus on many aspects of dialysis decision making, it seems likely that practice guidelines can be developed that would be helpful to nephrologists and patients in all three countries. These guidelines could specify patients for whom dialysis is not appropriate, and criteria on which a decision to offer dialysis ought to be based.[22] American nephrologists, for example, could use these guidelines to justify not offering dialysis to an incompetent patient whose family requested it. In using such guidelines, American nephrologists would be practicing according to the standard of care, and consequently their concerns about legal liability would be greatly reduced. Canadian and British nephrologists could use these guidelines to educate nonspecialists about which patients should be referred for a dialysis evaluation.

There are several limitations to this study. First, the response rates of the nephrologists in the three countries differed. The British response rate was modestly increased by the phone calls made to nonrespondents. These phone calls were not part of the original study design. They were made because of the interest of the British nephrologists in the results, because renal services in the United Kingdom were under review[7] at the time of this study. It is unclear what bias in the results may have been introduced by the higher British response rates. Other studies of nephrologists with response rates in the range of the Canadian and American ones for this study (35% to 50%), however, have found meaningful results that have been subsequently validated.[23] Furthermore, the lower American response rate may reflect the fact that they assign less importance to the topic of dialysis decision making, because they are rarely constrained by resources and largely do what the patient or family requests. Nonetheless, because there is a possibility of bias in the results of our study, we determined whether there were significant differences between the American respondents and the nonrespondents by comparing their age, academic affiliation, location, and gender. There were no differences in any of these demographics except age. The respondents were slightly younger (48.7 years *v* 50.6 years; $P < 0.01$) than the nonrespondents. In Canada, there was no difference in gender or geographic distribution between respondents and nonrespondents. Respondents commenced practice 2.7 years later than nonrespondents and were presumably younger. Since the American and Canadian respondents were younger than the nonrespondents, we analyzed the responses by age greater than and less than 50 years and found no consistent

differences. We believe the study results are valid despite the variation in response rates. Second, the results presented are reported decisions in response to questionnaire cases as opposed to actual practice. A review of actual cases may have provided somewhat different data, but such cases may not have been comparable enough to allow conclusions to be drawn about dialysis practices.

In this study, we were interested in examining the reasons for the wide variation in dialysis acceptance rates in the three countries. Differences in patient selection criteria for dialysis used by the nephrologists in the three countries do not come close to accounting for the threefold variation. According to the nephrologists in Canada and the United Kingdom, differences in resource availability in these countries have played a minor role in their withholding dialysis from patients who would have benefited from it. The major cause for the discrepancy in dialysis acceptance rates seems more likely to be the nonreferral of ESRD patients to nephrologists by nonspecialists, a practice that has been recently well documented, both in Canada and in the United Kingdom.[4,7] This documentation also suggests that the nonreferral by primary care physicians in these countries is motivated by a belief that resources for dialysis are limited and that rationing of dialysis is necessary because there are insufficient resources to fund it for all patients who might benefit from it.

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