REFLECTIONS ON SUPPLY–DEMAND MISMATCH IN DIALYSIS SERVICES IN ONTARIO

Nitaesh K. Choudhry; C. David Naylor, MD, DPhil, FRCPC

Abstract • Résumé

The population-based dialysis rate in Ontario more than doubled between 1981 and 1992, yet there is concern about over-loaded facilities, delayed treatment and denial of dialysis through non-referral and implicit rationing. A working party involving several stakeholders has been established in Ontario to address these issues. However, clinical policy making concerning dialysis services is impeded in all provinces by a lack of information. The causes of the moderately large variations in dialysis rates from province to province remain unclear. The exact extent and risks of delayed therapy have not been well defined. Dialysis protocols vary inexplicably among centres, and cost data on different methods of providing dialysis are limited. Many steps could be taken in Ontario and other provinces to generate a better information base for planning and managing dialysis services. Predialysis clinics with outreach programs could help to ensure equitable access to this life-sustaining therapy. Criteria for choosing modes and intensities of renal-replacement therapy must be reviewed. In areas of clear disagreement and uncertainty, patients could be randomly assigned to different protocols and outcomes studied. In areas of agreement, the criteria should be standardized. Advance directives may help ascertain patients’ wishes concerning the initiation or continuation of dialysis, and more accurate data on prognosis of different patient subgroups would aid in early identification of patients in a hopelessly deteriorating situation. Last, studies comparing the “output” (e.g., hours on hemodialysis) per dollar of different dialysis units and modalities are also needed to ensure that all facilities are operating efficiently without compromising patient outcomes.

Le taux de dialyse foncé sur la population en Ontario a plus que doublé entre 1981 et 1992, mais les installations surchargées, les traitements retardés et les dialyses refusées par non-présentation et rationnement implicite préoccupent. On a créé en Ontario un groupe de travail constitué de plusieurs intervenants et chargé d’étudier ces questions. Le manque d’information nuit toutefois à l’établissement de politiques sur les services de dialyse dans toutes les provinces. Les causes des variations moyennement importantes des taux de dialyse entre les provinces restent à préciser. On n’a pas bien défini l’étendue exacte et les risques liés au traitement retardé. Les protocoles de dialyse varient de façons inexplicables selon les centres et les données sur les coûts de méthodes différentes de dialyse sont limitées. L’Ontario et d’autres provinces pourraient prendre de nombreuses mesures pour créer une meilleure base d’information qui servirait à planifier et à gérer les services de dialyse. Des cliniques de prédialyse dotées de programmes d’extension pourraient aider à assurer un accès équitable à cette thérapie vitale. Il faut revoir les critères régissant le choix des modes et intensités de la transplantation rénale. Dans le domaine où il y a clairement désaccord et incertitude, on pourrait affecter les patients au hasard à différents protocoles et étudier les résultats. Dans les domaines où il y a entente, il faudrait normaliser les critères. Des directives préalables peuvent aider à déterminer les désirs des patients au sujet du début ou du maintien de la dialyse et des données plus précises sur le pronostic de divers groupes de patients aideraient à identifier rapidement les patients dont le cas se dégrade sans espoir. Enfin, des études permettant de comparer le «résultat» (p. ex., heures d’hémodyalise) par dollar selon les appareils et les modalités de dialyse s’imposent aussi si l’on veut assurer que toutes les installations fonctionnent de façon efficace sans compromettre des résultats pour les patients.

Dialysis has had a remarkable impact on both survival and quality of life for patients with end-stage renal disease (ESRD) since its introduction in the 1950s. Initially limited primarily to younger and healthier patients, dialysis can now be applied with technical success to almost any patient. The cost-effectiveness of dialysis, when compared with other therapeutic and preventive interventions (see Table 1), is recognized, although the cost-effectiveness of treating patients with a poor overall prognosis is less clear. None the less, one

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For prescribing information see page 709
indicator of the perceived value of this therapy is the creation, in 1972, of the End-Stage Renal Disease Program in the United States, the only US health care program in which entitlement is based on medical necessity rather than age or economic status.9 The number of people receiving dialysis is increasing steadily, both in Canada and the United States.9 In Ontario, the growth in supply is perceived to be lagging behind demand, leading to delayed therapy, waiting lists and denial of dialysis through nonreferral and other mechanisms.10,11 The Ontario Ministry of Health responded in 1994 by adding $20 million annually to the budget for dialysis in the province. However, appropriate levels of additional funding and distribution of these funds are unclear because the dimensions of supply—demand mismatch in dialysis services have been so poorly defined. This article accordingly aims first to identify for further study some factors that may contribute to the delay and denial of dialysis and, second, to propose steps to understand and address more effectively the supply—demand mismatch in dialysis services.

DIALYSIS UTILIZATION PATTERNS

In Ontario, the prevalence of patients receiving dialysis increased from 145.2 per million population in 1981 to 301.3 in 1992.12 Similarly, the number of new patients entering dialysis per year increased from 56.1 per million population in 1981 to 108.1 in 1992.13 The preceding overall rates are not age-standardized, however, population aging would increase the rates by no more than 10% to 15%. Furthermore, there has been a definite demographic shift in the mean age of patients receiving hemodialysis, from 50 years of age in 1981 to 57 in 1992.14 This increase is clearly greater than would be expected as a result of the aging population alone. The most rapid growth was among patients 75 years of age and over, for whom the compound annual growth rate was 17.3%.15 These patients represented 5.0% of all new patients in 1982 and 13.5% of new patients in 1992.16 There were similar increases in the age of patients on dialysis nationally17 and in the United States.18

Dialysis rates vary within Ontario, among Canadian provinces and among countries. In 1992, Ontario rates ranged from 209.5 per million population in the northwest region of the province to 359.7 in the east region, with a mean of 301.31 (Fig. 1). Nationally, rates ranged from 235.7 per million population in British Columbia to 362.7 in Manitoba, with a national mean of 275.31 (Fig. 2). Internationally, there is an inexplicable range of dialysis rates; within this range, the dialysis rate in Canada falls in the middle, below that of the United States and Japan but higher than that of the United Kingdom and the former Czechoslovakia18 (Fig. 3). There are also unexplained sex differences in the use of dialysis modalities.19 Hence, it is impossible to use existing utilization figures to set a "correct" population-based dialysis rate at which supply matches needs.

DEMAND FOR DIALYSIS

Demand for dialysis is influenced by the number of new and existing cases of renal disease, the number of patients brought to medical attention, the criteria used to select patients for dialysis and the number of patients no longer receiving dialysis as a result of death, withdrawal of treatment or kidney transplantation.

PREVALENCE AND INCIDENCE OF RENAL DISEASE

In Canada, the total number of patients with ESRD increased from 5576 in 1981 to 14 211 in 1992.20 It is

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**Table 1: Cost-effectiveness of dialysis, renal transplantation and other treatments**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Cost per life-year gained, $*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home dialysis†</td>
<td>39 100</td>
</tr>
<tr>
<td>In-centre dialysis‡</td>
<td>49 100</td>
</tr>
<tr>
<td>Kidney transplant from a living, related donor‡</td>
<td>30 400</td>
</tr>
<tr>
<td>Kidney transplant from a cadaver‡</td>
<td>41 500</td>
</tr>
<tr>
<td>Treatment of hyperlipidemia with cholestyramine‡</td>
<td>171 900</td>
</tr>
<tr>
<td>Coronary care for a patient with a low probability of having a myocardial infarction‡</td>
<td>239 900</td>
</tr>
<tr>
<td>Liver transplant†</td>
<td>50 100</td>
</tr>
<tr>
<td>Heart transplant†</td>
<td>31 000</td>
</tr>
</tbody>
</table>

*All costs are in constant 1993 US dollars, calculated with the use of the Consumer Price Index. Costs reported in the studies cited may be based on different methodologic assumptions.

†Based on the mean of high and low estimates of survival probabilities and earnings.

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**Fig. 1: Dialysis rates in regions of Ontario and Ontario as a whole in 1992.**12
unclear whether this is due to an increase in disease, detection or survival of patients undergoing dialysis or transplantation. We could locate no data that rigorously establish whether the age-specific incidence of ESRD has changed. Trend data involve only patients who receive dialysis or transplantation, and little is known about trends in the number of patients with ESRD who are never referred for renal-replacement therapy. More generally, differences in the incidence or prevalence of a disease seldom have much explanatory power in examining variations in service provision within or among jurisdictions.29 Thus, although demand must be influenced by the incidence of renal disease and the prevalence of terminal uremia, variable utilization rates likely reflect differences in the criteria for referral and selection of patients as well.30

REFERRAL FOR RENAL ASSESSMENT

Independent of shifts in true prevalence or incidence or both, demand may be driven up by increased referrals to dialysis centres. This increase is unlikely to result from an increased rate of detection of ESRD, since the benchmarks for diagnosis — tests of blood urea nitrogen and serum creatinine levels — have been available for 30 years. Referral patterns probably reflect shifts in knowledge (e.g., referring physicians' awareness of the increased technical feasibility of dialysis) and attitudes (e.g., toward more aggressive treatment of very elderly patients or those with multiple medical problems).

An increase in referrals does not preclude the possibility that some patients who may benefit are still not being referred, as has been observed in the United Kingdom.29 A recent survey suggested that "nonreferral" occurs in Ontario, with family physicians and internists undertaking implicit rationing of dialysis on the basis of both age and coexisting disease.31 However, this study had a low response rate and relied on physician self-reporting to describe practice patterns. Little is known about actual referral practices.

ACCEPTANCE OF PATIENTS FOR AND APPROPRIATENESS OF DIALYSIS

Preferential selection of younger and healthier patients for transplantation does occur,32 but it does not explain the growth in the utilization of dialysis among elderly patients. Even when rates of dialysis and transplantation (i.e., all renal-replacement therapies) are combined, elderly patients remain the fastest growing segment of patients with ESRD. Although no data are available for Canada, patients of all ages receiving renal-replacement therapies in the United States now show an increased prevalence of comorbid conditions.38 The increased age and poorer health of these patients clearly reflect less restrictive criteria for acceptance for dialysis — a trend in keeping with the growing technical feasibility of dialysis.3

Is this apparent shift in case selection appropriate? Rand Corporation researchers have defined a service as appropriate when "the benefits of performing the procedure outweigh the risks by a sufficient margin that it is worth doing and the procedure is preferable to other alternatives, including no treatment."39 In keeping with this definition, practitioners have suggested that dialysis not be provided to patients who cannot benefit from treatment.30-32 One author has designated "between 10% and 20% of patients as inappropriate selections with minimal hope of rehabilitation or participation in work, school, or home life."34 However, no formal study of the quality of case selection for dialysis has been conducted. Patients' perceptions of risks and benefits clearly require special consideration in this context.

SURVIVAL OF DIALYSIS PATIENTS

In Canada, 12.1% of patients died within 1 year after the initiation of treatment (dialysis or a transplant) in

Fig. 2: Dialysis rates in Canadian provinces and Canada as a whole in 1992.36

Fig. 3: Dialysis rates in Canada and a selection of seven other countries in 1992.39
1981, whereas only 4.4% of such patients died within 1 year in 1991. Whether this improvement in survival is attributable primarily to improvements in dialysis technology, greater use of transplantation or both is unknown. Improved survival of patients receiving dialysis has contributed to, but obviously does not fully explain, the rising demand for this service. Early or prophylactic dialysis has been shown to yield better outcomes than initiating dialysis only when the patient has terminal uremia. Thus, any growth in waiting lists may have unintended effects on longer-term survival and eventual demand for services.

SUCCESSFUL RENAL TRANSPLANTATION

The advantages of renal transplantation over dialysis include less functional impairment, better quality of life, and lower long-term costs. The transplantation rate in Canada has increased from 20.0 per million population in 1981, peaking at 34.8 in 1988 and declining to 27.5 in 1992. However, this increase has not kept pace with the growth in the prevalence of patients with ESRD. This phenomenon may be partly explained by the fact that the population of patients with ESRD is aging, and older ESRD patients have comorbid conditions that make them less suitable candidates for transplantation. However a supply-demand mismatch in transplantation, over and above the effect of aging, is evinced by the increase in the rate of patients waiting for a transplant, from 59.5 per million population to 69.5 over 3 years from 1991 to 1993 alone. In addition, waiting times for a transplant seem to have increased: in the first year after renal-failure treatment was initiated, the proportion of patients who had received a transplant decreased from a peak of 22.7% in 1985 to 14.2% in 1991. Graft-failure rates among transplanted organs have remained relatively constant. The rate-limiting factor in renal transplantation is the number of organs available for transplantation.

WITHDRAWAL FROM DIALYSIS

In Ontario, 13.9% of the deaths of ESRD patients receiving renal-replacement therapy (dialysis or a transplant) in 1992 were due to "social causes," including refusal of further treatment, suicide or discontinuation of therapy for "any other reason." For patients receiving continuous ambulatory peritoneal dialysis (CAPD), the reason for discontinuation was given as "patient's request" in 3.2% of cases, "family's request" in 0.5% and "patient unable to cope" in 4.6%; another 6.2% of patients receiving CAPD discontinued dialysis for "other" reasons, for a total of 14.5% cases in which discontinuation may have involved elements of patient choice. It is unknown whether these proportions reflected cases in which patients made appropriately informed choices and what proportion of cases were related to irreversible, multisystem medical problems. (The distinction between "terminal" and "preterminal" discontinuation of dialysis is discussed later.)

SUPPLY ISSUES

The potential implications of inadequate funding of dialysis services are clear. Overloaded programs may delay dialysis unduly. Implicit rationing may occur, through selective nonreferral and rejection of elderly patients or those with multiple comorbid conditions. Quality of care within programs may be compromised by reduced staff time per patient and shortened times for dialysis treatment. It is even possible that the proportion of withdrawals will increase if pressures on dialysis services affect the quality of psychosocial support available for patients and families. However, speculation about the toll exacted by inadequate funding raises the question of whether existing funds are well spent.

Ontario's renal-dialysis capacity rests in 12 teaching and 10 community hospitals that serve as regional referral centres, 3 pediatric programs, 3 free-standing self-care hemodialysis units, 1 chronic care facility that offers in-centre full-care hemodialysis and peritoneal dialysis, 13 satellite units that provide full-care or self-care hemodialysis and 1 government-funded independent health facility (Janet Bick, provincial advocacy coordinator [Ontario], The Kidney Foundation of Canada, Toronto: personal communication, 1994). These facilities are supported by funds from several sources, including global operating budgets for hospitals, the Life Support Program, expansion funding and private donations. Capital funding is provided through separate capital allocations to the hospitals. As a result of the complexity of dialysis funding, it is difficult to establish program costs.

A British study concluded that, given enough staff, the renal units surveyed could support almost twice the number of hemodialysis patients without any capital expenditure. Obviously, hiring more staff requires additional operating resources. Unfortunately, there is very limited information on the comparative efficiency of dialysis programs, the actual allocations of money to dialysis services or the cost (and outcome) implications of variations in the use of hemodialysis versus peritoneal dialysis.

AN APPROACH TO THE PROBLEM

We suggest several concrete steps that could lead to a better understanding of and response to the issue of supply-demand mismatch in dialysis services.
First, information about the epidemiologic features of renal disease, service use and costs is too limited. For example, we need better information about variations in intraprovincial dialysis rates, including adjustments for, and analysis of the impact of, age, sex, race, incidence of renal disease, comorbidity and other variables. Explanations for intraprovincial variations in dialysis use should be sought, since these regional differences may be markers for inequitable access to necessary services. Also needed are economic evaluations of programs and practice patterns, with a focus on minimizing costs yet maintaining quality of care. For example, studies comparing the "output" per dollar spent of dialysis units could be used to ensure that all facilities are operating efficiently without compromising patient outcomes. In this regard, nephrologists in Toronto have created a utilization index that determines the actual activity of a hemodialysis unit in relation to its budgeted capacity.\(^1\)

Second, any variations among centres in criteria for acceptance of new patients for dialysis should be reviewed. A diagnosis of ESRD implies that dialysis or transplantation is required for survival, whereas a diagnosis of "chronic renal failure" (CRF) indicates renal insufficiency in which the patient does not yet (and may never) require dialysis or transplantation. As CRF worsens, a judgment must be made about when the burden of the disease outweighs the burden of dialysis. Symptom severity is therefore part of the equation.

Mostly, symptoms of nausea, pruritus, restless legs, anemia, neuropathy, pericarditis, fatigue and "gut feelings" govern the manner in which most nephrologists prescribe dialysis.\(^5\)

However, there is a "grey zone" in which practitioners disagree on the merits of initiating dialysis.\(^6\) Moss, Retting and Cassel\(^6\) have suggested that variations in prescribing of dialysis may be attributable to "professional uncertainty, lack of knowledge, and differences in individual physician decision-making." Practice guidelines may help by laying out explicit criteria as the basis for the allocation of scarce dialysis resources, in contrast to the implicit standards now used.\(^5\)

Third, data on waiting lists, including numbers of patients waiting, their clinical characteristics, time from registration to dialysis and sequential quality-of-life measures, should be gathered.\(^2\) Definitions of waiting times are not straightforward, since the severity of symptoms can differ among patients with similar serum creatinine or blood urea nitrogen levels. Current concerns about delayed dialysis may be reduced if waiting lists actually consist largely of persons receiving expectant management until the burden of ESRD symptoms clearly outweighs the burden of regular dialysis. Waiting times could instead be defined as beginning when the physician and patient agree that regular dialysis is appropriate. However, since preliminary evidence suggests that earlier dialysis leads to better longer-term outcomes,\(^7\) researchers must establish the nature and size of the "penalty" (if any) for deferred dialysis as a function of time. For example, patients could be randomly assigned to wait for different lengths of time before beginning dialysis once they meet predetermined biochemical and clinical criteria.

Fourth, a more organized system of predialysis clinics could mitigate queuing and ensure equitable access to this life-prolonging therapy. The clinical, biochemical and quality-of-life characteristics of patients registered at predialysis clinics in different regions could be compared to determine whether the threshold for initiating dialysis varies unduly. This system could also promote the use of guidelines for initiating dialysis, ensure that patients are aware of their treatment options and offer all patients starting dialysis the opportunity to make advance directives. However, even a registry of predialysis patients will not include patients who present with previously undiagnosed ESRD and those who die without ESRD having been diagnosed or without having been referred. The numbers of patients in these categories should also be ascertained for planning purposes.

Fifth, it is important to determine how many patients would choose dialysis if they were given full information and a choice. Owing to a reluctance to record withdrawal from dialysis as a cause of death, the reported rates of withdrawal may be an underestimate.\(^5\) Physicians may feel uncomfortable in making decisions for incompetent patients whose wishes for their future care are unclear, and, as a result, their management of such patients may vary.\(^6\) Advance directives may aid in ascertaining patients' wishes concerning the withdrawal of dialysis and help ensure treatment in accordance with patient preferences.\(^5\)

Mendelsohn suggests that a distinction be made between "nonterminal" and "terminal" withdrawal of dialysis. (Dr. David C. Mendelsohn, Division of Nephrology, Toronto Hospital: personal communication, 1994) Nonterminal withdrawal is rare and terminal withdrawal, although more common, has a limited impact because the patients involved are at a very high risk of death even if dialysis were continued. An important step, advocated by Parfrey,\(^7\) is more accurate prognosis, so that patients in a hopelessly deteriorating situation can be identified earlier.

Sixth, the comparative advantages of different intensities and modes of dialysis have been poorly delineated. Inadequate dialysis likely contributes to impaired quality of life and reduces life expectancy. However, Parfrey's recent review\(^8\) highlights the need for these options to be tested in major randomized clinical trials. In areas of
clear disagreement among practitioners and resulting uncertainty, patients should be randomly assigned to different protocols and outcomes studied. In areas of agreement, the criteria should be standardized in the interests of fairness and efficient use of resources.

A working party involving several stakeholders has recently been established in Ontario to address some of the issues raised in this article; the extensive involvement of clinical nephrologists in the province is anticipated. Although our discussion has focused on Ontario, imbalances between dialysis demand and supply have been observed across Canada. Our proposed framework may therefore be applicable to other provinces as they consider ways to tackle this growing problem.

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