



The price and challenges of extraordinary success: treating end-stage renal failure in the next millennium

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According to projections published in this issue by Douglas E. Schaubel and colleagues,¹ the number of patients receiving treatment for end-stage renal disease in Canada will increase from 17 807 in 1996 to between 25 000 and 33 000 by the year 2005. This increase will be the result not of an inadequacy in the health care system, but of one of the most startling success stories in 20th-century medicine. Before the invention of dialysis treatment by Willem Koff in the 1940s,² the average survival of patients with chronic renal failure was approximately 2 weeks. With the current use of hemodialysis, peritoneal dialysis and transplantation, average survival is now approximately 5 years.³ The prevalence of any disease is determined by its incidence multiplied by its duration. By prolonging the survival of patients with kidney failure we have ensured that the prevalence of end-stage renal disease will continue to rise well into the next century. What implications does this have for our health care system?

1. In the United States it costs an estimated US\$47 400 to keep 1 patient with end-stage renal disease alive for 1 year.⁴ The costs in Canada are probably very similar. Health care budgets will have to absorb the increasing costs that come with the success of treatment. This needs to be planned for proactively. The current approach seems to be to hold back resources until the system is in crisis and health care workers are burnt out trying to cope with increased demands using resources designed for a smaller system. This is a classic case of not looking after what Stephen R. Covey calls "production capacity";⁵ it leads to deterioration both in the well-being of health care workers and in the quality of their work.

2. The treatment of end-stage renal disease is a dramatic technical success: many people are alive now who otherwise would have died. However, we need to make it an equally dramatic *human* success for patients. Hemodialysis, the backbone of treatment, consumes a lot of the patient's free time and involves onerous changes in lifestyle (particularly limits on fluid intake and dietary restrictions). The attempted control and surveillance of these patients by the medical system fits Michel Foucault's description of a "science of discipline."⁶ Peritoneal dialysis and transplantation involve different but equivalent challenges. The treatment

of kidney disease is not just a medical matter; it amounts to a way of life. We need more in-depth knowledge about the stages, characteristics, challenges and triumphs⁷ of this uniquely 20th-century lifestyle so that we can make it as satisfying and worthwhile as possible. Why spend such extensive resources to prolong suffering rather than add to the sum of human happiness?

3. Medicine is a hierarchical system with researchers and physicians at the top. We need the technological advances that come with biomedical research and medical expertise. However, hierarchical systems tend to underutilize the talent that is available to them.⁸ We need to encourage active participation and creativity in all parts of the system. To meet the many needs of patients with chronic kidney failure, a new model of care with an appropriate balance of teamwork and individual responsibility and hierarchy badly needs to be developed. Also, patients have direct experience of their disease and its treatment⁹ that health care workers cannot have. The system needs to be reoriented so that this knowledge can be transmitted and used for the benefit of other patients and the good of the system as a whole.

4. The delivery of treatment for end-stage renal disease is now, and will become even more, a major service industry. We need to acquire and to apply information and techniques that make such industries work effectively.¹⁰ The key point is that, for each patient, someone in the system needs to be responsible for the whole cycle of service from the point of entry onward. Otherwise, although individual elements of the service may be excellent, they might not add up to a worthwhile experience for the patient.

The increasing numbers of patients receiving treatment for end-stage renal disease envisaged by Schaubel and colleagues is real and is a sign of success. We need to handle this phenomenon well for its own sake and as a paradigm for other similar successes likely to arise as medicine continues its dramatic technological progress.

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Death provides renewed life for some, but ethical hazards for transplant teams

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There seems to be little doubt that the public is broadly in favour of organ and tissue transplantation. For end-stage disease of at least three organs (heart, kidney and liver), transplantation is now established as the norm of treatment. This creates an obligation for our health care system to provide organs, an obligation that has become more insistent with improved outcomes and rising public expectations. Are we doing all we can to provide this form of treatment? If not, are we shirking a duty? Is this a problem just for transplantation services, or for us all? At what point does failure to do everything possible to meet this obligation become negligence? Are we approaching that point now?

I believe we should increase efforts on a number of fronts to obtain more vital organs and tissues after death. These might include (a) a national procurement program (perhaps on the model of Spain¹), coordinated with new federal and provincial initiatives, such as those announced by BC for 1999² and recently reported by the Parliamentary Standing Committee on Health³ and (b) developing ways to obtain permission to use organs from those who have died from irreversible cardiopulmonary arrest — now termed non-heart-beating death — using the traditional criteria for the determination of death. Either of these options would allow us to avoid (c) legislation of “presumed consent,” which would make it necessary for those who do not wish their organs to be used at death to opt out in advance. In this issue, Drs. Graham Campbell and Francis Sutherland⁴ explore the possibilities of option b. Theirs is the second Canadian study⁵ to show evidence of a potential

source of organs from those who die in emergency departments and in intensive care or cardiac care units — the non-heart-beating source — to supplement the supply from brain-dead cadavers in which the heart is beating. In this non-heart-beating category are patients in whom resuscitation has failed or for whom life support has been deemed futile and discontinued with the agreement of family decision-makers. The non-heart-beating source remains essentially unused in North America (e.g., it accounts for less than 3% of kidney transplants)⁶ unlike in many parts of the United Kingdom and Europe, where in some centres it accounts for 40% of kidney transplants.⁷ The success rate of kidney transplants from a non-heart-beating source is comparable to that of transplants from a heart-beating source when the non-heart-beating source kidneys are further selected by tests carried out during ex-vivo machine perfusion before implantation.⁸

The exploration of new possibilities suggested by Campbell and Sutherland is also timely in light of the disturbing questions raised by Truog⁹ and others¹⁰⁻¹² about the criterion of “irreversible function of the whole brain and brain stem,” or so-called brain death. Although it is not the case that our use of the brain death diagnosis has led to patients being declared dead who had even the remotest chance of recovery, the issue of brain death is complex, one that involves philosophical concepts, physiological definitions, legal definitions and clinical criteria. Some commentators have pointed out that we often fail to wait for all the components of brain death to develop, such as accompanying diabetes insipidus, loss of all vasomotor tone, loss of