

Dialysis: A paradigm case of rationing medical treatment

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Abstract

This article will follow the rationing of dialysis in parts of the English speaking world from the 1960s, when restrictions on treatment were overt and explicit, to the present day where, while in developed countries it may be argued it is a treatment that is accessible to all who 'need' it, this is not necessarily always the case.

The evolution of dialysis cannot be understood or separated from its history as a treatment which has always been, and in some ways still is, inherently rationed. This article will follow the rationing of dialysis in parts of the English speaking world from the 1960s, when restrictions on treatment were overt and explicit, to the present day where, while in developed countries it may be argued it is a treatment that is accessible to all who 'need' it that, this is not necessarily always the case.

In its relatively short history dialysis has managed to position itself as a paradigm case in which to discuss a myriad of ethical dilemmas: resource allocation; withdrawal of treatment; rescue medicine; advance directives; definitions of medical benefit and futility; and rationing.

Before providing a synopsis of the rationing history of dialysis I would like to highlight some facts about the cost of treatment and the demographic of those who receive it. Close to 80% of those people on dialysis around the world receive treatment in Europe, North America and Japan and yet these countries represent only 12% of the world population (Aviles-Gomez, Luquin-Arellano, Garcia-Garcia, Ibarra-Hernandez, & Briseno-Renteria, 2006 p. S2-70). In most developed countries, the

overall cost of renal replacement therapy accounts for about 2% of the national health budgets, which is spent on less than 0.1% of the total population (El Nahas & Bello, 2005; Jacobs, 2006).

Cost estimates in a developing country such as India where renal replacement therapy is not freely provided put the costs of dialysis for only 0.01% of the population (very conservative approximation of the number of ESKD patients) at 25% of the country's total health care budget (Kher, 2002). In 2005-2006 the single greatest reason for hospital admission in Australia was 'care involving dialysis' and this accounted for 12.1% of all hospital separations (Australian Institute of Health and Welfare, 2008) and yet in that same time period there were only 8,528 Australians actually undertaking dialysis (ANZDATA, 2006).

Dialysis is so costly that it is out of the reach of many developing/low income countries which are struggling to provide preventive and therapeutic measures for communicable diseases and basic needs such as sanitation and nutrition (Aviles-Gomez et al., 2006; Moosa & Kidd, 2006). For ESKD patients in economically advanced countries the focus is on increasing long term survival and improving quality of life. In contrast in developing countries the focus is on

short-term survival 'and the enormous costs of therapy that limit continuation of treatment in the majority of patients with ESKD' (Kher, 2002 p. 251). Less than 10% of ESKD patients in India receive renal replacement therapy and 70% of those starting dialysis die, or stop treatment, due to cost within the first three months (Sakhujia & Sud, 2003).

While dialysis is provided as part of mainstream health care in most developed countries it has not always been the case.

Early rationing of treatment

In the 1960s selection of people for dialysis treatment did not adhere to any generic rules or guidelines and often led to the use of inconsistent allocation criteria (Christensen & Moran, 1998). At that time there were approximately 40,000 people dying every year from ESKD in the United States (Kjellstrand, 1996). Programs differed markedly in scope, eligibility and criteria for selection (Schreiner, 2000). According to Schreiner (2000 p. S39) in the United States people with uraemia were '...migrating from state to state and from country to country...shopping for survival.'

The United States

In 1962 in Seattle, Washington in the United States a trial was undertaken at the Swedish Hospital to determine whether and how, the rugged and expensive new treatment of haemodialysis, at the cost of US\$15,000 a year per patient, could be made feasible on a mass, nationwide basis for ESKD (Alexander, 1962; Fox & Swazey, 1974).

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Selection for haemodialysis was made by a committee formally known as the 'The Admissions and Policies Committee of the Seattle Artificial Kidney Center' or less formally, as the 'God' Committee (Alexander, 1962 p. 106; Fox & Swazey, 1974; McCormick, 1993). This Committee was made up of a lawyer, a minister, a banker, a housewife, an official of state government, a labour leader and a surgeon (Alexander, 1962 p. 107). The Seattle Committee was not the only lay committee who had to decide who received treatment and who did not (Fox & Swazey, 1974 p. 254-255) but it was the one that was given the most media coverage.

All prospective candidates for dialysis were pre-screened by a board of physicians who acted as gate keepers and decided whether they were medically or psychiatrically suitable prior to being presented to the 'God' Committee. This initial 'medical' screening selected those who were: co-operative and without severe hypertension (Cameron, 2002 p. 209); between 25 and 45 years of age (Alexander, 1962 p. 106; Cameron, 2002 p. 209); preferably had some residual renal function; and lived within reasonable distance of the dialysis unit (Cameron, 2002). According to the doctors undertaking the screening, older patients (i.e. over 45 years of age) were too apt

to develop other serious complications (Alexander, 1962 p. 106).

Psychological suitability involved the successful candidate being able to: take an active role in their own well-being; have potential for rehabilitation (which meant a satisfactory, useful life by the patient's own standards or those of the community); and able to tolerate the 'frequent and recurring stressful situations that accompany dialysis' (Fox & Swazey, 1974 p. 250-251). Rehabilitation or restoration of useful life from a medical perspective meant the return to pre-dialysis occupation, school or household duties (Blagg, Hickman, Eschbach, & Scribner, 1970;


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Bluemle, 1968; Dawborn, Adam, & Royle, 1971). Those people who were deemed medically and psychiatrically suitable were then referred to the 'God' Committee who weighted the following factors for their selection of successful candidates: age; gender; marital status; number of dependents; income; net worth; emotional stability with particular regard to the potential patient's capacity to accept the treatment; educational background; nature of occupation; past performance and future potential; and the people put up as referees. Alexander (1962 p. 109) reports on a conversation amongst the God Committee in which the decision about who would be selected for dialysis was discussed relative to the likelihood of the remarriage of the patient's wife should the patient be refused treatment:

For the children's sake, we've got to reckon with the surviving parent's opportunity to remarry, and a woman with three children has a better chance to find a husband than a very young widow with six children.

Selection for dialysis was seen as necessary because of the past failure of some patients to be rehabilitated to an employable condition (Cole, Blagg, Hegstrom, & Scribner, 1986). Hegstrom et al (1961 p.142) provided the following criteria and reasons for patient selection in 1961.

Selection of patients for long-term haemodialysis poses important moral, ethical and socioeconomic problems. However, if the goal of treatment is to be complete rehabilitation and restoration of the patient to a happy and useful life, the following characteristics would seem to be important in choosing patients for therapy:

1. The patient should be a young adult, preferably under 35 years of age who is no longer able to work because of symptoms of uremia.

2. There should be no evidence of hypertensive cardiovascular disease. Hypertension, if present, should be mild or if severe should be of recent onset.
3. Renal function should be stable or slowly progressive since any residual function as represented by a creatinine clearance greater than 1.5 ml per minute greatly simplifies the therapeutic problem. Those patients with polycystic renal disease would seem to be especially suitable candidates.
4. 'The patient should be emotionally stable and mature'

Schupak et al (1967 p. 713) elaborated further on dialysis selection with his experience in a New York hospital where 'the uninformed, the indigent, the poorly motivated, the dull, and the unreliable patient to a large extent' were deferred from consideration for treatment.

In these early days of dialysis it was very obvious that the 'old', in this context meaning over 45 years of age, had no chance of being treated for ESKD (Moss, 1994). It must also be acknowledged however, that at this time children were also not likely to receive treatment (Cameron, 2002). Bluemle (1968 p. 751) noted that 'few children have been treated by chronic dialysis, presumably because they are prone to frequent medical complications and find it difficult to adjust psychologically.' An early renal transplant, often from a parent was thought to be the optimal treatment for children as especially for pre-adolescents, it was thought that on dialysis growth failure would persist, and physical, psychological and social development would be inhibited (Nevins & Kjellstrand, 1983).

In 1968 Bluemle (p. 754) wrote that if it was desirable to invest limited dialysis resources in those patients who tended to respond most favourably then age had

to be taken into account. In 1968, in a survey in the United States, eight out of 11 dialysis centres considered age as one of the determining factors as to whether patients were accepted onto a regular dialysis program (Abram & Wadlington, 1968 cited in Rathaus & Bernheim, 1978). Even by 1972 in Seattle where it was reported that it was possible to accept all patients who were referred for treatment so that the selection committees were no longer needed, very few people with diabetes were treated and only 10% of patients were 56 years or older (Scribner, Cole, Ahmad, & Blagg, 2004).

The moral repugnance of the God Committee's processes caused such an outcry that it ignited a prominent and public debate in American medical ethics (Churchill, Torrance, & Taylor, 1987; Cohen, Steinman, & Robinson, 2004; Stanton, 1999 p.1170). The objections were about the use of standards that were influenced by the value systems of those selecting or rejecting potential candidates (Fox & Swazey, 1974 p. 269). Some commentators have credited this ethical outcry (Schneiderman & Jecker, 1995 p. 44) as contributing to the passage of Public Law 92-603 in 1972 in the United States. This law guaranteed that there is special federal coverage for the costs of treatment for all persons with ESKD. The passage of this law raised questions as to why ESKD had been singled out for coverage whereas other catastrophic diseases had not (Fox & Swazey, 1974; Peitzman, 2001). Lobbying from interest groups was very strong and a patient was wheeled in front of the Senate Committee and dialysed by his wife. The dilemma of the 'identified' life was far more compelling than that of 'statistical' lives. This was not the case for other diseases (Gordon, 2006; Kutner & Brogan, 1985). When this law was enacted and the ESKD program established, Congress stipulated that

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patients should be screened for their appropriateness for dialysis but there was no definition of what this actually meant (Moss, 2003; Moss, Rettig, & Cassel, 1993). The passage of this law opened up access to dialysis for older people and those with diabetes in the United States (Blagg, 2005). It has been suggested however, that because of the universal health care coverage of dialysis in the United States under Medicare, therapy is excessively or inappropriately available to older patients (Mulkerrin, 2000). This assertion was reflected in a study that found that American nephrologists would offer dialysis more often to people with co-morbid conditions such as dementia or complicated diabetes mellitus than their colleagues in Canada and Britain (McKenzie, Moss, Feest, Stocking, & Siegler, 1998).

Britain

In Britain between 1963 and 1966 those selected for dialysis treatment had to be mature and stable adults, aged between 20 and 50 years of age, and without any other serious complicating diseases (Compy, 1966 cited in Stanton 1999 p. 1181). Those who were married, had children and a stable home environment were given preference. The imminence of death and whether the illness had rendered the person unable to work were also indicators for selection for dialysis. It was also thought that, while patients did not need to be highly intelligent, they did need to be able to understand the rules for care of their access device and be extremely co-operative over their diet. Unlike the United States, Britain did not change its criteria for dialysis access in the 1970s. According to Stanton (1999 p. 1170) the funding system in Britain in 1973 meant that access was still virtually restricted to those aged between 18 and 50 years of age. This 'rationing' was achieved in two ways:

Firstly, there was 'resource allocation' rationing by the centre curtailing central funds earmarked for a special purpose; by the centre imposing limits on regional budgets; and by regions deciding to place limits on the funding of a given treatment... Secondly, there was 'point of service' rationing by individual doctors or clinical teams. Since resources were limited, these 'gatekeepers' had to choose which patients should receive treatment and which to turn away (Stanton, 1999 p. 1172).

Services expanded in Britain and selection criteria relaxed, to some extent, by the 1980s, but there was still a shortage of hospital haemodialysis for those who were not suitable for home dialysis or transplantation. This meant that older patients in particular, did not receive treatment (Stanton, 1999). According to Stanton (1999 p. 1173) it was not that patients were blatantly being turned away by nephrologists, but 'many sicker or older patients were not put forward by their doctors for acceptance onto dialysis programmes.' It has been suggested that general practitioners and local physicians may have thought that some of these people were not suitable for treatment and therefore did not refer them to specialist centres (Challah, Wing, Bauer, & Morris, 1984). The expansion of continuous ambulatory peritoneal dialysis (CAPD), as a viable, successful treatment after 1979, opened up possibilities for people who may not have been offered treatment prior to this. My own personal experience in the early 1980s, working clinically in a large renal unit in Britain, supported the fact that, in that unit at least, there were still not many people over 50 years of age on haemodialysis, and there were very few people with diabetes who received treatment. Also at that time, there were great regional discrepancies in Britain in dialysis services (Rothenberg, 1992; Stanton, 1999).

Australia

There is very little in the literature about the early years of dialysis in Australia. In 1968 however, a report published by the Ad-Hoc Committee on the Rationalization of Facilities for Organ Transplantation and Renal Dialysis (Anonymous, 1968 p. 1201) stated that recurrent haemodialysis should be restricted to patients awaiting transplantation. If patients were not seen as potential candidates for transplantation, then the majority of these people were also not 'offered' dialysis. It was thought that only a small number of patients unsuitable for transplantation required haemodialysis as a definitive form of treatment. The Report also stated that patients should be selected on medical grounds. The commonly accepted criteria for selection, and the indicators for transplantation and therefore haemodialysis, were cited as follows:

1. The presence of irreversible renal failure which cannot be managed adequately by rigorous conservative measures.
2. The understanding and acceptance by the patient of the implications of his selection on to the programme.
3. Age in the range of 15-55 years with marginal variations in particular patients.

Criteria against selection include:

1. The presence of such intellectual or psychological factors as would prevent a patient from either (a) understanding fully the implications of his selection, or (b) enjoying the benefits of successful dialysis and transplantation, or (c) cooperating in those areas of his total management where this is essential to success.

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2. The presence of intractable complicating disease which could either (a) seriously interfere with the programme of dialysis, transplantation or postoperative immunosuppression, or (b) significantly reduce the prospects of a successful outcome. (Anonymous, 1968 p. 1205).

While not explicitly discussing the rationing of dialysis therapy, the above criteria do suggest that: the old; those with co-morbidities; and those who could not be involved or compliant with their treatment regime and make the most of their 'selection' (whatever that may mean), were not seen as 'ideal' candidates for transplantation and, if this were the case, then they were also not considered for dialysis.

In Australia in 1971 Dawborn et al (1971) asserted that dialysis services were limited and in the early 1970s home haemodialysis patients had to pay for their own machine and its installation (Evans, 1980). In 1985 one major teaching hospital in Australia (at the very least) did not offer dialysis to those over 60 years of age (Fraenkel, 2006). Up until 1989 Melbourne was the only city in the state of Victoria that provided institutional dialysis. This treatment was not even available in the major regional centres of the state.

The end of rationing?

In the 21st century, in most of the developed world, dialysis treatment is a part of mainstream health care systems. While there are many factors which contribute to the increasing age of the dialysis population it is interesting to note the changes in the age demographics over the years. In Australia in 1979 approximately 11% of the dialysis population were aged over 60 years (Australian and New Zealand Dialysis and Transplant Registry,

1979) whereas by 2007 46% of people receiving dialysis were 65 years or older (ANZDATA, 2008).

The previous explicit rationing and exclusion of certain ESKD patients from treatment is generally claimed to be a thing of the past. However, despite this claim, some of the language used, both in the literature and by clinicians suggests that patients must 'qualify' for dialysis treatment and do not necessarily have an unlimited right to it. The process of qualification is neither standardised nor objective. While in the literature patient choice is encouraged and argued for, along with the importance of autonomous decisions and informed consent, language is also used that can only be seen as restricting choices based on whether 'someone' considers the person/patient or group of people/patients as 'eligible' for treatment. Patients are 'offered' or 'selected for' treatment and they are 'accepted onto programs'. They may be 'candidates' for treatment if they meet certain criteria. Treatment is 'withheld', 'limited' or 'withdrawn'. The use of such language suggests that the patients are passive in the process of treatment decision-making. According to Lowance (2002 p. 88) such language implies unilateral action on the part of the caregiver and is therefore paternalistic in concept. A study in Ireland found that even among nephrologists, who worked together as a team, there was substantial variation in both their propensity to offer dialysis and their perceptions of the benefits of dialysis for patients (Kee et al., 2000).

According to Russ et al (2005) advanced age should no longer be a factor in the withholding of dialysis. The existence of co-morbidities, and their associated severity and impact on the patient's life, has now emerged as the criteria most likely to be used for withholding treatment. As it is older ESKD patients

who typically have greater systemic illness and poorer prognosis for rehabilitation and survival they are still the ones for whom the appropriateness and duration of dialysis is likely to be questioned (Russ et al., 2005).

Few countries admit that rationing of dialysis services may currently take place (Dor, Pauly, Eichleay, & Held, 2007). Although overt explicit rationing rarely takes place 'lower levels of response commitment can lead to bottlenecks in ancillary services, resulting in delays and long waiting lists' (Dor et al., 2007 p. 99). In Canada, Japan, the United Kingdom and Spain it has been reported that a shortage of surgeons and operating room time has led to waiting lists for the creation of vascular access devices (Dor et al., 2007).

There is a disparity in overall acceptance rates of older people for dialysis between some countries such as Britain and the United States and Canada when measured by persons per million population (pmp). This could be explained partially by the higher incidence of ESKD in the United States and Canada or alternatively, by the fact that dialysis is excessively or inappropriately available to older people in the United States without considering whether there will be a health or social benefit to the individual patient (Mulkerrin, 2000 p. 253). It may also be the case that older patients with ESKD in Britain continue to be denied access to dialysis based on their chronological age as it has been suggested that some degree of age-related referral bias may still persist (Hamel et al., 1999; Krishnan, Lok, & Jassal, 2002). The suggestion that rationing of dialysis is still a reality in Britain (Lamping et al., 2000) is also supported by the percentage of gross domestic product spent on health care, the number of nephrologists per head of population, and the proximity of patients

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to their local renal unit in some areas (Watson, 2005). In Britain according to Dor et al (2007) and Nicholson and Roderick (2007), there is anecdotal evidence of capacity limits because of lack of facilities at some dialysis centres. In 2001 there were a few local health authorities in Britain who still did not fund thrice weekly haemodialysis or Erythropoietin (Cameron, 2002 p.235).

Research has shown in New Zealand that the minor differences in the acceptance rates of people onto renal replacement therapy across the country cannot be explained by medical morbidity and are likely to be determined by differences in allocation and availability of treatment facilities and access and (Dor et al., 2007) renal replacement therapy resources (Ashton & Marshall, 2007; Collins, 1998; Collins & Metcalf, 2003). According to Ashton and Marshall (2007) the high use of peritoneal dialysis in New Zealand (48.1% in 2002) may not necessarily be a reflection of choice but the result of a shortage of dialysis facilities capable of providing the alternative haemodialysis.

Two studies in Canada (Manns, Mendelssohn, & Taub, 2007; Mendelssohn, Kua, & Singer, 1995) found that many patients who could benefit from ESKD care were not being referred for such care and that there was a shortage of dialysis stations in some Canadian centres.

Selection committees to assess the suitability of patients with ESKD for renal replacement treatment still exist in the 21st century. A recent South African study (Moosa & Kidd, 2006) reviewed the decisions made by the Assessment Committee in Cape Town and found that more than half of patients (52.7%) with ESKD were not offered renal replacement therapy in the time period of the study and the reasons in most cases were related to poverty – unsuitable living circumstances, unemployment and lack of education. This study also found that white patients were four times more likely to receive treatment than non-white patients, along with those who were aged between 20 and 40 years, were married, non-diabetic and lived near the dialysis centre. (Moosa & Kidd, 2006 p. 1107). Moosa and Kidd (2006) also found that criteria formalised by the South African Department of Health determined suitability for dialysis by suitability for kidney transplantation. If patients were not acceptable on a transplant list then they were summarily denied dialysis treatment (Sidley, 1997). Moosa and Kidd (2006 p. 1112) concluded from their study that ‘the process of selection for renal replacement treatment, even with the best of intentions, is severely flawed and leads to inequity in service delivery’.

Conclusion

Dialysis represents a paradigm case in rationing of a medical treatment. In its early history in the developed world it was a treatment that was explicitly restricted to certain groups of people with ESKD. Today, the rationing or restriction of treatment appears to be based more on individual patients’ characteristics rather than a more generic set of principles.

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