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Experience with rationing health care in New Zealand

Colin M Feek, Winston McKean, Loek Hennevel, Graeme Barrow, Wendy Edgar, Ron J Paterson

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Ministry of Health,
PO Box 503,
Wellington,
New Zealand
Colin M Feek,
Chief medical adviser

Clinical Training
Agency, PO Box
588, Christchurch,
New Zealand
Winston McKean,
Project manager

Whangarei Area
Hospital, Northland
Health, PO Box
742, Whangarei,
New Zealand
Loek Hennevel,
Chief medical adviser

Northern Advocate,
New Zealand
PO Box 210
Whangarei, New
Zealand
Graeme Barrow,
Editor

National Health
Committee
Secretariat, Ministry
of Health, PO Box
5013, Wellington
New Zealand
Wendy Edgar,
Programme director

University of
Auckland, Law
School, Private Bag
92019, Auckland,
New Zealand
Ron Paterson,
senior lecturer in law

Correspondence to:
Dr Feek
Colin.Feek@moh.govt.nz

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New Zealand's health reforms were introduced in 1993 and changed the framework for health service delivery; this framework clearly contemplates rationing. We describe the development of guidelines for entry into end stage renal failure programmes in the northern region of New Zealand,¹ how they were used in the clinical decision making process, and how they influenced public opinion. In particular, we describe two cases which put the decision to ration renal dialysis under the public spotlight.

Rationing in New Zealand

The Health and Disability Services Act was introduced in New Zealand in 1993. The purpose of the act was to reform the public funding and provision of health services and disability services in order to secure the best health; the best care or support for those in need of those services; and the greatest independence for people with disabilities that is reasonably achievable within the available funding.

The National Advisory Committee on Core Health and Disability Support Services (core services committee) was appointed under the act to advise the minister on "the kinds, and relative priorities, of public health services, personal health services, and disability services that should, in the committee's opinion, be publicly funded."

The committee was established in March 1992, but by October 1994 its third report to government had rejected the use of a simple list to define the services to which New Zealanders should have free access.² Instead the committee preferred the development of guidelines and clinical priority assessment criteria to help define when a service was of sufficient clinical benefit to warrant public funding.

The development of guidelines to help ration access to end stage renal failure programmes¹ proved to be a flash point. The reasons for this are obvious. People with end stage renal failure will die unless they obtain renal replacement, and there is no privately funded dialysis service in New Zealand, even for those willing to pay. The guidelines constituted an important challenge to those who believe that services should always be provided to avoid death even if the longer term outlook is not necessarily favourable.

Development of guidelines

In November 1992 a national consensus development conference report to the core services committee out-

Summary points

New Zealand's health reforms contemplate rationing of services

Clinical guidelines were preferred to determine access to services rather than a simple list

The development of guidelines for access to end stage renal failure programmes tested the expectations of the public, patients, politicians and clinicians

Public opinion is gradually shifting to accept that rationing of health care is inevitable

lined guidelines for entry into end stage renal failure programmes.³ The report stated that (a) age should not be a sole factor in determining eligibility, but in usual circumstances people over 75 should not be accepted; (b) other serious diseases or disabilities that are likely to affect survival or quality of life (for example, severe complications of diabetes) are reasons for exclusion; and (c) although the need for delivering services within a capped budget was acknowledged, more money needed to be allocated to end stage renal failure even if acceptance rates were not increased.

At the time of the conference there was extensive debate about using the guidelines to ration access to renal dialysis and the levels of funding overall for renal dialysis. Despite agreeing to the consensus statement, some clinicians on the panel felt that the existing level of renal funding forced them to make rationing decisions at a point where there was a high level of clinical discomfort.

Considerable discussion and consultation took place throughout 1993 and 1994, including with renal physicians, patient representatives, and consumer advocacy groups. In late 1995 the ministry agreed to provide additional funding for renal services to maintain current levels of access to dialysis and allowed for a 7% annual increase in funding based on calculation of the number of patients who would meet the criteria from 1995 to 2000. This work enabled the guidelines to be costed and allayed doctors' fears about use of the guidelines to reduce access to services. Doctors agreed not to extend the access criteria for renal replacement and that any consideration to do so would

be made only by the purchaser with respect to other competing claims. The guidelines were finally confirmed in July 1996. The guidelines state that "the aim of the process is to ensure that, so far as possible within the available resources, all patients are offered access to the treatment modality which is most suitable clinically and socially and which offers the greatest opportunity to benefit."

Case of James McKeown

In January 1995, James McKeown, a 76 year old Auckland, was denied access to renal dialysis on the basis of the 1992 consensus conference guidelines. The subsequent media presentation of the case was extremely confused (box). The discussion centred on whether the decision was based on clinical grounds or budgetary restraint. The minister of health argued on television that Mr McKeown was denied dialysis on clinical grounds and said that he also had coronary artery disease and prostate cancer. The head of the dialysis unit said that neither the coronary artery disease nor prostate cancer were pivotal to the decision not to offer dialysis: "Doctors had identified him as someone who may not gain the most benefit from dialysis. Given our resources, he had to fit into a group we said no to." However, he suggested that he might live a further two years if given dialysis.

Mr McKeown's family laid a complaint of age discrimination with the Human Rights Commission. They alleged that in applying a guideline that people over 75 are not normally accepted on to a dialysis programme the hospital had breached the Human Rights Act 1993. This act prohibits age discrimination in the provision of services to the public, although age can be considered as a criterion in clinical decision making if it can be shown that age affects outcome. The chief executive of the hospital ordered a clinical review of the case on the grounds that use of age as an exclusive criterion for renal dialysis may not be legal. Although age was not a sole factor, the chief executive chose to focus only on this aspect when he required doctors to review the case. As a result of the review, renal dialysis was started. Mr McKeown subsequently died, as predicted, of his other conditions about 18 months later.

Case of Mr Williams

In September 1997 Mr Rau Williams, a 63 year old man with renal failure, diabetes, and dementia, was denied access to renal dialysis by Northland Health. The clinical decision was based on his response to interim dialysis to assess his suitability and the northern region's guidelines.

Interim dialysis was stopped on 17 September, and on 19 September a relative instituted judicial review proceedings in the High Court for the hospital to continue treatment. In his judgment the next day Salmon J concluded:

"It is inappropriate for me to make an order in this case. There is no evidence that the respondent's medical staff are acting in bad faith. That being the case, they must be allowed to act in accordance with their clinical judgment. It is totally inappropriate for the Court to attempt to direct a doctor as to what

Media discussion of dialysis rationing in McKeown case

"The medical profession will always have difficult decisions to make on the quality of a patient's life; such moral dilemmas cannot be made any easier knowing officialdom is only interested in budgets"—*Daily Telegraph*, 19 January 1995

"Dr Martin Searle said that Mr McKeown was refused treatment largely because of lack of funds rather than on clinical grounds. . . . It's essentially a resource issue. It's quite unfair to say that we turned him down solely on clinical grounds"—*New Zealand Herald*, 27 January 1995

"The hospital was told to operate within its fixed dialysis budget and apply the draconian Core Services criteria. (These exclude anyone over 75)"—*Sunday Star-Times*, 29 January 1995

"The tactic appears to be to present one side of the story, then rely on the privacy laws to prevent the public from gaining a rounded view"—*Dominion*, 31 January 1995

"Dr Levy's decision is completely at odds with the conclusions of the panel charged with developing honest, consistent, national criteria for making the best use of limited resources. Can Dr Levy honestly say that age is not considered when medical specialists assess a patient for a treatment they know to be costly and in high demand? . . . age is degenerative and therefore of inevitable clinical concern"—*New Zealand Herald*, 2 February 1995

"It is both legitimate and necessary to insist that public health dollars flow primarily to those who will get the greatest benefit physically, mentally, emotionally and in quality of life"—*Dominion*, 7 February 1995

treatment should be given to a patient. It must be remembered that the respondent is not refusing to treat this patient. Rather it is exercising through its medical staff as to the appropriate treatment to adopt."

The relative then made a complaint to the Human Rights Commission. After mediation involving the human rights commissioner, clinicians, and the family the complaint was withdrawn.

Despite agreement on the guidelines and the funding for dialysis services, discussion of the case in the media by some doctors continued to raise clinical and resource issues without acknowledging that they are inseparable (box). The public debate, understandably, remained confused between clinical decisions and resource allocation. The doctor who had treated Mr McKeown said that "the James McKeown case two years ago—in which a decision to deny dialysis was overturned because it was found to be discriminating on the grounds of age—had contributed to a softening in health authorities' attitudes to growth in dialysis demand. Previously, they had demanded the numbers on dialysis be kept static, but had (subsequently) allowed for 7% annual growth."

The High Court heard a further application by a relative on 9 October. The judge was satisfied that the decision not to accept Mr Williams on the programme was a clinical one without significant administrative component and that the hospital staff had approached the decision thoroughly and conscientiously. The judge was also satisfied that resources, if they played any part in the decision, were a minor component and that the guidelines were principally clinically based.

The next day the case went to the Court of Appeal, which carefully scrutinised the guidelines because it was claimed that the decision was not purely clinical but involved resource allocation. The Court of Appeal concluded that there was no resource element in Mr Williams's case, noting affidavit evidence that a decision to place Mr Williams on the end stage renal programme would have no detrimental effect on

Media debate on Williams's case

"Two top kidney doctors say the refusal to give Rau Williams renal dialysis is a rationing decision ... Mr McKeown's renal physician is also reported as saying: Northland's explanation that Mr Williams was denied treatment on purely clinical grounds ... is only 80% of the story"—*Sunday Star-Times*, 5 October, 1997

"While it may sound hard-hearted in the case of Mr Williams, the reality is that his case was not a priority. First concerns have to be for patients who are not terminally ill, who do not have other complications and who have a better chance of rehabilitation"—*Nelson Mail*, 13 October 1997

"The Rau Williams case was not about resources but about appropriate medical care; the two issues became thoroughly muddled in the public mind. And the hard facts are that money, for any area of public expenditure, including health care, is limited ... There will always be greater calls on the public purse than that purse can, or should, dispense"—*Evening Post*, 13 October 1997

"In deciding Rau Williams' mild dementia was a hindrance to continuing treatment, the hospitals (and courts) handed out a death sentence ... while it is possible to see merit in some of the discussion in support of the move (denial), there has so far been nothing which has the strength to override a person's right to life—no matter what that quality of life"—*New Zealand Truth*, 17 October 1997

Northland Health's budget. If long term dialysis was withheld from Mr Williams because it was not a clinically viable, the issue was one of medical futility. Mr Williams died on 10 October 1997, 24 days after dialysis was stopped. A complaint to the United Nations Human Rights Committee was subsequently withdrawn.

Lessons to be learnt

Health resources in New Zealand are, and have always been, finite. This means that judgments must be made about who will receive publicly funded services and, conversely, who to exclude. Those judgments are based on the benefit people will gain from services. Despite some public disquiet, increased by media coverage of the cases of individual patients, people in New Zealand are becoming increasingly aware that not everything can be afforded for all who might need health services. This applies not only to renal dialysis but to every other treatment.

Explicit rationing will work only when clinicians accept the link between clinical decision making and resource allocation. This was not so in Mr McKeown's case. There was concern that the level of funding for end stage renal failure at the time would not meet the threshold at which clinicians were prepared to ration. The clinicians felt unsupported by government in making their rationing decisions. In contrast, at the time of Mr Williams's case there was national clinical agreement on the guidelines,⁴ the threshold for rationing, the level of funding, and support from government.

The clinical circumstances of the two men were different, but the expected degree of benefit was similar. The difference between the decisions seems to arise from the processes used to reach agreement on

the guidelines. If doctors agree with access criteria and funding, they may be prepared to defend rationing decisions even when subjected to the bright spotlight of the media and the courts. It remains to be seen whether New Zealand doctors would be willing to support reduced access to renal dialysis if funding was cut.

The link between clinical decision making and resource allocation needs to be accepted not just by clinicians but also by politicians in order to avoid a sterile public debate about clinical or resource allocation decisions. Politicians and clinicians can engage in public discussion only if they are united over the issue of language and resources. The debate cannot be won unless politicians support the rationing process.

The process of rationing is important. The guidelines for end stage renal failure met administrative standards and were fair, reasonable, and within the law. The processes of development and dissemination of the guidelines, and openness of the assessment, indicated procedural fairness; the guidelines accorded with renal physicians' practice throughout New Zealand, and there was an overwhelming consensus that Mr Williams was unsuitable for long term dialysis, so no hint of unreasonableness arose. In addition, the guidelines were not slavishly applied in this case but used to inform clinical judgment, thus avoiding any suggestion that Northland Health had unlawfully fettered its discretion. The guidelines were administered within the resources allocated.

The development of clinical guidelines can be considered as a framework for discussing rationing decisions. Guidelines can be used as a tool to communicate with the public how much of a beneficial procedure can be provided for a certain amount of money.

We are not claiming that New Zealand has all the answers to rationing of healthcare services but politicians, clinicians, and the public are beginning to debate this serious issue. Our presentation of this paper at the conference in London last year did not go uncriticised in the New Zealand media. Clearly, not everyone in New Zealand agrees with rationing. However, the media have a vital role in public discussion and informed commentary on the realities of resource constraints and the trade offs which follow.

The cases discussed are only two of the myriad clinical decisions made daily. The development of clinical guidelines is one way to ration healthcare services. Guidelines are an open, consistent, and clinically defensible decision making tool. The availability of a review process—through judicial and human rights mechanisms in New Zealand—allows patients and their families to have their case re-evaluated. New Zealanders fundamentally believe in fairness. Rationing may not always be palatable, but it can be made understandable and fair.

- 1 Northern Regional Health Authority. *Guidelines for entry into northern regions end stage renal failure programme*. Auckland: Northern Regional Health Authority, 1996.
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- 3 National Advisory Committee on Core Health and Disability Support Services. *A consensus development conference report to the National Advisory Committee on Core Health and Disability Support Services. The management of end stage renal failure (ESRF)*. Wellington: NACCHDSS, 1992.
- 4 Collins JF. Who should receive dialysis? *New Ethical Journal* 1998;August:13-9.