

## Research issues in Elderly patients: gaps in knowledge and suggested directions.

Robert Walker<sup>1</sup>, Robert G Fassett<sup>2</sup> and Rachael L Morton<sup>3</sup>

<sup>1</sup>Professor of Medicine, Department of Medicine, Dunedin School of Medicine, University of Otago, Dunedin, New Zealand <sup>2</sup>Director of Renal Research, Royal Brisbane and Women's Hospital, Herston, QLD

<sup>3</sup>School of Public Health, University of Sydney, NSW

### Concentration of research is recommended in the following areas:

- **Prospective studies of the appropriateness, relevance, timing and sustainability of dialysis in elderly patients**
- **Health related quality of life (HRQoL) in older patients choosing not to dialyse and in those choosing to dialyse with comparison to a matched population without renal disease**
- **Methods of communication of prognosis and factors affecting decision making**
- **Models of care – comparative studies to delineate how best to deliver renal supportive care**
- **Treatment preferences amongst indigenous patients**
- **Symptom control, focussing on those areas specific to the needs of renal patients**

There has been an increase of over 400% in the number of elderly and very elderly patients on dialysis in Australia and New Zealand over the past 2 decades (1). This rapid increase has generated considerable debate resulting in wide variation in attitude towards referral and acceptance of elderly patients for dialysis (2-4). One major reason for this is that there is uncertainty about the outcome from dialysis treatment in this population (5). If conservative management is shown to be an important and valid option with similar outcomes to dialysis, then this can be appropriately discussed with the individual and their family/whanau (Maori - extended family) without this being considered as rationing, or limiting health resources. Current studies suggest poor maintenance of functional capacity and high mortality in nursing home patients accepted for dialysis in the USA (6), and a retrospective study suggests outcomes are much the same on dialysis or with conservative care if aged >75 with greater than two comorbidities(5).

1. Prospective studies are required to address the appropriateness, relevance, timeliness, and the sustainability (both with respect to quality as well as quantity) of dialysis in the elderly. Providing information as to preferred options by this group related to their expectations and perceived quality of life will immediately influence delivery of healthcare. The provision of dialysis, preferably in a home setting or low level self care satellite units closer to the individuals' residences, may allow better integration with primary and community care. Evidence is required to disentangle survival alone versus quality of life with respect to the provision of renal replacement therapy and renal supportive care.

---

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/nep.12084

- Accepted Article
2. Decision-making should, and clearly does, involve the patients and their carers, along with health service providers. However, there is currently a dearth of evidence related to such decision-making among dialysis patients in general, and elderly dialysis patients in particular (7). Studies are required that will make it possible that more informed decision making by future elderly patients and their families can be made, as they contemplate renal replacement therapy.
  3. Results of studies will also allow health professionals to more accurately describe the benefits and harms of dialysis therapy on quality of life and outcomes for patients.

Assumptions are made that dialysis is appropriate for all individuals; however this may not be a valid assumption for everybody. Dialysis by the nature of the intervention has a large potential to influence the quality of life of the individual and immediate family. Dialysis may prolong life, however it also “remains an aggressive tertiary intervention that may challenge the priorities and attitudes of older patients in particular” (8). Dialysis also has hazards, and in some patients it will shorten life. This is a particularly critical issue in the older age group. The patient’s preference and quality of life are central issues. (8) It has also been found that both dialysis patients and their partners are overwhelmed by the impact of dialysis on their lives (4). In a patient survey conducted by Davison and colleagues (9), 60.7% of patients regretted the decision to start dialysis. However, if patients opt for conservative therapy (no dialysis) it is unknown how much life expectancy, as well as the quality of life, is actually altered. It is possible that the intervention of dialysis may actually make the quality of life worse, particularly in the presence of significant co-morbidity. Currently there is a small amount of retrospective data only (5), but no prospective scientific data to support either point of view to help clinicians, their patients and family / whanau to make a decision.

A study from a large London dialysis centre looked at outcomes between two groups of older patients, one group that opted for dialysis therapy and the other that chose maximal conservative care. Those opting for conservative care were older (mean age 82 years versus 76 years). Although the dialysis group survived for a longer period (mean 2 years), the majority in the conservative group survived for over 13 months with substantially lower hospital days (16 days/per patient/year) and the majority in this group died at home (10). The dialysis patients were dialysed in a hospital centre that meant they averaged 173 days per patient/year at the hospital. This study did not record any quality of life assessment, data related to patient satisfaction, cost-effectiveness or the socio-economic impact of the hospital-based treatment (10).

1. In a thematic analysis of the literature Morton and colleagues demonstrated that awareness of factors associated with decision making related to the management of CKD can provide health professionals with evidence on how best to deliver education programmes for patients and their family, as well as enhancing the patient and their family’s capacity to share in that decision making process (11). They identified 4 themes – confronting mortality (life/death, burden on family, state of limbo), lack of choice (options not always discussed), knowledge of options, and weighing the alternatives (11). These are important issues that future research with respect to both active renal replacement therapy and renal supportive care need to address.

- Accepted Article
2. In addition to the impact of dialysis treatment on the individual, there is a significant health-economic implication for Aust & NZ, with the approximate cost of dialysis per individual at about \$65,000 to \$80,000 per year. This equates to around \$56 million per year in New Zealand, and \$370 million per year in Australia for those on dialysis over the age of 65 years (12). This cost does not include the cost of hospitalisation and the impact of any other associated co-morbidity that is frequently present in the elderly and may be exacerbated by ESKD and/or its treatment. Although the crude cost for renal replacement therapy (RRT) can currently be estimated, there is little information about patient-experienced benefits to the individuals beyond survival.
  3. There are gaps in our current knowledge about the cost of a well staffed multidisciplinary renal supportive care programme which also needs to be researched with outcomes measured in quality adjusted life years to match data being acquired for dialysis programmes.

The determinants of successful dialysis in the elderly will be multifactorial including the degree of autonomy or control related to managing dialysis (home care versus satellite or in centre based care), and the many socio-economic factors related to the management of a chronic disease superimposed upon the aging process.

Accepted Article

It is vital for future health care delivery of renal replacement therapy in those aged  $\geq 65$  years in Australia and New Zealand that reliable data are obtained. In New Zealand in 2008, there were 154 new patients over 65 years commencing dialysis. This is a rate of 397 per million compared to the overall rate of new patients at 109 per million (1). Recent estimates from the Australian Institute of Health and Welfare suggest dialysis rates fall from around 90% in the younger population to about 10% in those aged  $\geq 80$  years (13). It is therefore important to have accurate data upon which to base priority decisions regarding health funding and outcomes.

4. Dialysis survival data are collected through the ANZDATA registry (1) but health-related quality of life (HRQoL) information is not collected. The data with respect to outcomes includes only those individuals who have survived the first 90 days on dialysis and does not include data on those who opt out of dialysis. Crucially what remains unknown is: 1) knowledge about HRQoL at the time of commencing dialysis among the elderly, and 2) knowledge about HRQoL and perceptions/experiences across the entire trajectory of dialysis – from the decision to commence dialysis (or not) until death. Withdrawal from therapy now contributes up to 30% of the deaths for individuals on renal replacement therapy (1). Decision-making should, and clearly does, involve the patients and their carers, along with health service providers. However, there is currently a dearth of evidence related to such decision-making in elderly dialysis patients.

Accepted Article

There is virtually no published HRQoL data on the elderly Australian & NZ patient on dialysis. The limited data available from overseas are not relevant to clinical practice in Australia and NZ due to marked differences in how health care is delivered. Dialysis overseas is predominantly privately funded with financial implications having a substantial impact on decision-making (both physician and patient/family). For example, home based dialysis (PD or HD) accounts for less 5% of dialysis in the USA or Europe. This, plus obvious cultural differences makes it

imperative that there is good Australian and NZ data for health care delivery relevant to both countries.

Dialysis buys a period of survival for most with ESKD. HRQoL may be the best measure of the value of this dialysis. There is thus a need to obtain Australian and NZ-specific HRQoL data about this cohort of older patients with CKD, considering renal replacement therapy, including those who elect not to enter the dialysis programme. This needs to be compared to available data addressing HRQoL in the older population of Australia & NZ (not on dialysis) (14, 15). Reliable HRQoL data will be helpful to an older patient and his/her family, whanau contemplating renal replacement therapy and to health care providers to assess the usefulness of dialysis treatment programmes in a comprehensive manner. This type of data can provide a benchmark against which outcomes of future interventions may be measured.

In addition, further research could focus on other gaps in our knowledge such as:

1. How to best communicate prognosis (for example using graphs, quantitative risk charts, or comparison with cancers)
2. How to best deliver renal supportive care – i.e. comparison of models of care
3. The exploration of carer experiences of a family member treated within a renal supportive care programme
4. The treatment preferences of indigenous patients and their family
5. Better studies on therapies for symptom control specific to the needs of renal patients.

### Current Research

Dialysis and supportive care for the elderly is an area that is attracting interest with a number of studies already initiated. These include:

1. PINOT - **P**atient **I**nformation about **O**ptions for **T**reatment, (national follow-up study): CIs R Morton, N Gray, P Kerr, P Snelling, A Webster, K Howard, K Mc Geechan. Trial register number: NCT01298115
2. End -of-Life Care in End Stage Renal Disease: Integration of an advance care planning process. CI S Davison (Canada) & Cochrane Renal Group. Trial register number: ACTRN12610000782033
3. Dialysis outcomes in those aged 65 years or over. CI R Walker, S Derritt, J Campbell, M Marshall (NZ). Trial register number: ACTRN12611000024943
4. A Representational Intervention to Promote Preparation for End-of-life Decision Making (SPIRIT). CI Mi-Kyung Song (Chapel Hill, US). Trial register number: NCT01259011

### Unregistered studies

1. CONSIDER - **C**onsiderations of **N**ephrologists when **S**uggesting **D**ialysis in **E**lderly patients with **R**enal Failure. CIs C Foote, R Morton, M Jardine, M Kimman, K Howard, A Cass. A discrete choice analysis survey assessing nephrologist preferences for dialysis recommendation in elderly patients with varying co-morbid conditions.
2. Pre-Dialysis Options Discussion, Prognosis and Conservative Care: A Pilot Project. CI M Germain (Springfield, US). A multi-attribute survey study in pre-dialysis patients 75 years and older with CKD stage 4 or 5.

## References

- (1). ANZDATA. Australia and New Zealand Dialysis and Transplant Registry. (30<sup>th</sup> Annual report. Appendix III New Zealand). Disney A, MacDonald S, editors. 2008. Adelaide, South Australia.
- (2). Schena FP. Epidemiology of end-stage renal disease: International comparisons of renal replacement therapy. *Kidney International* 2000; 57(s74):39-45.
- (3). U.S. Renal Data System, USRDS 2003 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. 2004. Bethesda, MD, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.
- (4). Madhan K. The epidemic of elderly patients with dialysis-requiring end-stage renal disease in New Zealand. *N Z Med J* 2004; 117(1195):U912.
- (5) Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol. Dial. Transplant.* 2007; 22: 1955–62.
- (6). Kurella Tamura M, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, et al. Functional Status of Elderly Adults before and after Initiation of Dialysis. *New England Journal of Medicine* 2009; 361: 1539-1547.
- (7). Tattersall J. Dialysis in the over-80s. *Age and Ageing*; 2005; 34:100-101
- (8). Jager KJ, van Dijk PC, Dekker FW, Stengel B, Simpson K, Briggs JD. The epidemic of aging in renal replacement therapy: an update on elderly patients and their outcomes. *Clin Nephrol* 2003; 60(5):352-360.
- (9). Davison SN. End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease. *Clin J Am Soc Nephrol.* 2010; 5(2): 195–204.
- (10). Carson RC, Juszczek M, Davenport A, Burns A. Is maximum conservative management an equivalent treatment option to dialysis for elderly patients with significant comorbid disease. *Clin J Am Soc Nephrol* 2009; 4: 1610 – 19.
- (11). Morton R, Tong A, Howard K, Snelling P, Webster AC. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; 340: c112
- (12). ANZDATA. Australia and New Zealand Dialysis and Transplant Registry. (34<sup>th</sup> Annual report. Chapter 4. Method and location of dialysis). Briggs N, Hurst K, McDonald S. 2011. Adelaide, South Australia.
- (13). AIHW 2011. End-stage kidney disease in Australia: total incidence, 2003-2007. Cat. no. PHE 143. Canberra: AIHW.
- (14). A Portrait of Health: Key Results of the 2002/2003 New Zealand Health Survey. 2004. Wellington, Ministry of Health, New Zealand Government.

Accepted Article

(15). Living Standards of Older New Zealanders. A Summary 2001. 2004. Wellington, Ministry of Social Development, New Zealand Government.