

## Estimating the Total Incidence of Kidney Failure in Australia Including Individuals Who Are Not Treated by Dialysis or Transplantation

Claire Sparke, Grad Dipl Clin Epidemiol,<sup>1</sup> Lynelle Moon, PhD,<sup>1</sup>  
Frances Green, B Human Movement Sci,<sup>1</sup> Tim Mathew, FRACP,<sup>2</sup> Alan Cass, PhD,<sup>3</sup>  
Steve Chadban, PhD,<sup>4</sup> Jeremy Chapman, FRCP,<sup>5</sup> Wendy Hoy, FRACP,<sup>6</sup> and  
Stephen McDonald, PhD<sup>7,8,9</sup>

**Background:** To date, incidence data for kidney failure in Australia have been available for only those who start renal replacement therapy (RRT). Information about the total incidence of kidney failure, including non-RRT-treated cases, is important to help understand the burden of kidney failure in the community and the characteristics of patients who die without receiving treatment.

**Study Design:** Data linkage study of national observational data sets.

**Setting & Participants:** All incident treated cases recorded in the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) probabilistically linked to incident untreated kidney failure cases derived from national death registration data for 2003-2007.

**Predictor:** Age, sex, and year.

**Outcomes:** Kidney failure, a combination of incident RRT or death attributed to kidney failure (without RRT).

**Measurements:** Total incidence of kidney failure (treated and untreated) and treatment rates.

**Results:** There were 21,370 incident cases of kidney failure in 2003-2007. The incidence rate was 20.9/100,000 population (95% CI, 18.3-24.0) and was significantly higher among older people and males (26.1/100,000 population; 95% CI, 22.5-30.0) compared with females (17.0/100,000 population; 95% CI, 14.9-19.2). There were similar number of treated (10,949) and untreated (10,421) cases, but treatment rates were influenced highly by age. More than 90% of cases in all age groups between 5 and 60 years were treated, but this percentage decreased sharply for older people; only 4% of cases in persons 85 years or older were treated (ORs for no treatment of 115 [95% CI, 118-204] for men  $\geq$ 80 years and 400 [95% CI, 301-531] for women  $\geq$ 80 years compared with women who were <50 years).

**Limitations:** Cross-sectional design, reliance on accurate coding of kidney failure in death registration data.

**Conclusions:** Almost all Australians who develop kidney failure at younger than 60 years receive RRT, but treatment rates decrease substantially above that age.

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**INDEX WORDS:** Kidney failure; incidence; treated; untreated.

Chronic kidney disease (CKD), particularly kidney failure, imposes a substantial health burden in the Australian community. It is estimated that 1 in 9 Australian adults older than 25 years have some degree of CKD.<sup>1</sup> CKD contributed to ~10% of all deaths in 2007<sup>2</sup> and 15% of all hospitalizations in 2009-2010,<sup>3</sup> most of which were for maintenance dialysis. Treatment of CKD accounts for almost 2% of allocated direct health care expenditures, and these

costs are increasing in magnitude and as a proportion of total spending.<sup>4</sup>

To date, incidence data for kidney failure in Australia and most other countries have been available for only those who start renal replacement therapy (RRT), referred to here as “treated” kidney failure. Outcomes for all patients receiving RRT for whom kidney function is not anticipated to recover and the intention to treat is long term are captured by the Australia and New

From the <sup>1</sup>Australian Institute of Health and Welfare, Canberra; <sup>2</sup>Kidney Health Australia, Hackney; <sup>3</sup>George Institute for Global Health, University of Sydney; <sup>4</sup>Royal Prince Alfred Hospital, University of Sydney; <sup>5</sup>Centre for Transplant and Renal Research, Westmead Hospital, University of Sydney, Sydney; <sup>6</sup>Centre for Chronic Disease, University of Queensland, Herston; <sup>7</sup>ANZDATA; <sup>8</sup>Central Northern Adelaide Renal and Transplantation Service; and <sup>9</sup>Discipline of Medicine, Faculty of Health Sciences, University of Adelaide, Adelaide, Australia.

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Address correspondence to Claire Sparke, Grad Dipl Clin Epidemiol, Australian Institute of Health and Welfare, AIHW GPO Box 570, Canberra, ACT 2601, Australia. E-mail: [claire.sparke@aihw.gov.au](mailto:claire.sparke@aihw.gov.au)

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Zealand Dialysis and Transplant Registry (ANZDATA).<sup>5</sup> Information about the total incidence of kidney failure, which includes those who die of kidney failure without long-term commencement of RRT (referred to here as untreated kidney failure), is important to help understand the full burden, as well as the characteristics, of patients who die without receiving treatment, whether by choice or lack of access. Such information also might help better understand differences<sup>6</sup> in the incidence of RRT between countries.

This study expands on results previously published in an Australian government report titled *End-Stage Kidney Disease in Australia: Total Incidence 2003-2007*.<sup>7</sup> It builds on a method used elsewhere to determine kidney failure end points in cohort studies.<sup>8-10</sup> These studies used data linkage to estimate the number of people with kidney failure (or CKD more generally) who did not receive RRT. However, each of these followed up a particular cohort (eg, the National Health and Nutrition Examination Survey [NHANES] in the United States) rather than directly determining the national incidence.

The aim of this study was to estimate the total incidence of kidney failure in Australia for 2003-2007. This was done by linking 2 nationwide data collections—ANZDATA and national mortality data, thereby capturing and allowing analysis of all cases of kidney failure regardless of whether managed with RRT.

## METHODS

### Data Set Sources and Definitions

Kidney failure cases were identified from 2 different data sources. The first was ANZDATA. The second was the Australian Institute of Health and Welfare National Mortality Database, which includes cause of death and demographic information for all deaths registered in Australia starting in 1965. A third data source, the National Death Index, was used in the linkage process to determine the overlap between the 2 main data sources, described later.

An incident case was defined as a case newly registered on ANZDATA in 2003-2007 (treated kidney failure) or a death registered in 2003-2007 with kidney failure recorded as a cause, but which was not recorded in ANZDATA (untreated kidney failure).

Kidney failure in mortality data was defined as chronic renal failure (*International Classification of Diseases, Tenth Revision [ICD-10]* codes N18.0, N18.8, and N18.9), hypertensive renal failure (*ICD-10* codes I12.0, I13.1, and I13.2), or unspecified renal failure (*ICD-10* code N19) as an underlying cause of death, or chronic renal failure, end-stage (*ICD-10* code N18.0), as an associated cause of death. The underlying cause of death refers to the condition that started the course of events leading directly to a person's death. The associated cause of death refers to any other condition thought to have contributed to the death. Mortality data were used to estimate the incidence of untreated cases because by definition, people with kidney failure show signs or symptoms of kidney failure to the extent that they require RRT,<sup>11</sup> and survival for those who do not receive RRT is likely to be short.<sup>12-14</sup> Thus, year of death can be used as a proxy for incidence year.

To avoid double counting, ANZDATA was linked to the National Death Index using probabilistic linkage based on identifying information, including date of birth, name, sex, date of death, and postal code of residence. ANZDATA cases used in the linkage process were all patients receiving treatment in Australia between 2003 and 2007 (regardless of when treatment began), as well as any cases of patients lost to follow-up, to make certain that cases of kidney failure in the mortality data were not mistakenly assigned to the untreated group. These data then were linked to National Mortality Database data (which can be linked to National Death Index data through a unique identifier). If cases were present in both ANZDATA and National Mortality Database data, they were counted only once as treated cases. Approval for the data linkage and analysis was obtained through the Australian Institute of Health and Welfare Ethics Committee.

### Statistical Analysis

Total incidence rates were analyzed using Poisson regression, with year, age (in 5-year groupings), and sex as covariates. Interaction between age group and sex and between age group and year also were tested for significance using type III analysis.<sup>15</sup> Denominator population data came from the Estimated Resident Population series produced by the Australian Bureau of Statistics.<sup>16</sup>

Logistic regression analysis was used to examine treatment rates with RRT. For this, the relationship between year, age group, and sex and the probability of no treatment was assessed. Because of the small number of cases in persons younger than 50 years, age groups were set as those younger than 50 years and then 5-year age groups up to 80 years or older. The interaction between age group and sex also was taken into consideration in the model. Hosmer-Lemeshow test and C statistic were used to assess goodness of fit.

$P < 0.05$  was considered statistically significant for main effects and interactions. All analyses were done using SAS Enterprise Guide, version 4.3 (SAS Institute Inc).

## RESULTS

### Total Incidence

There were 21,370 incident cases of kidney failure in 2003-2007, comprising 10,949 treated cases and 10,421 untreated cases. The overall incidence rate was 20.9/100,000 population (95% confidence interval [CI], 18.3-24.0). The incidence rate increased substantially with age, particularly among those older than 70 years, with 63% of all new cases being individuals 70 years or older. The age-adjusted total incidence was higher for males than females (26.1/100,000 population [95% CI, 22.5-30.0] vs 17.0/100,000 population [95% CI, 14.9-19.2]); however, this sex difference was not apparent at younger than 40 years (Table 1).

### Treatment Rates

Overall, there were similar numbers of treated and untreated cases. However, this varied greatly with age. A very high proportion of cases in younger people were treated: >90% in all age groups between 5 and 60 years. The percentage treated decreased sharply in older people, with only 4% of new cases of persons 85 years or older treated (Figs 1-3).

Logistic regression confirmed that treatment rates were influenced highly by age. The odds of not

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