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- 00834efa/1ed7e5ca0c771faeca2570ec000ace6f!OpenDocument
- 19 World Health Organization. *Rheumatic Fever and Rheumatic Heart Disease: Report of a WHO Expert Consultation Geneva, 29 October–1 November 2001*. Geneva: WHO. 2004 [cited 2013 Dec 2]. Available from URL: http://whqlibdoc.who.int/trs/WHO_TRS_923.pdf
- 20 Carapetis JR, Powers JR, Currie BJ, Sangster JF, Begg A, Fisher DA *et al.* Outcomes of cardiac valve replacement for rheumatic heart disease in Aboriginal Australians. *Asia Pac Heart J* 1999; **8**: 138–47.
- 21 Council of Australian Governments. Project agreement for the rheumatic fever strategy: an agreement between the Commonwealth of Australia and the States and Territories being Queensland, Western Australia and the Northern Territory. 2012. [cited 2013 Dec 10] Available from URL: <http://www.federal>
- 22 Australian Bureau of Statistics. *Appendix 4: Avoidable Mortality. Causes of Death, Australia, 2011*. Cat. no. 3303.0. Canberra: ABS; 2013 [cited 2013 Dec 10] Available from URL: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0Appendix42011>

Kidney disease health literacy among new patients referred to a nephrology outpatient clinic

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Key words

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Abstract

Background: Knowledge about kidney disease among the general population is poor but has not been assessed in the population selected for referral to nephrology care.

Aim: This study aimed to determine patients' understanding of chronic kidney disease (CKD) when first presenting to a nephrology clinic.

Methods: Newly referred patients to a nephrology clinic were surveyed with open-ended questions about their understanding of CKD causes, symptoms and management.

Results: Two hundred and ten patients were surveyed. Median age was 66.5 years (interquartile range 52–77), 50.5% female and mean body mass index 29.7 ± 6.8 kg/m². Prevalence of risk factors for CKD included 31% diabetic, 62% hypertension, 19% family history of CKD and 2% Aboriginal or Torres Strait Islander. CKD stage prevalence was 0 (8%), 1 (24%), 2 (11%), 3 (38.5%), 4 (18%) and 5 (0.5%). Eighty-two per cent were referred by their primary care physician and 29% had seen a nephrologist previously. Kidney Health Australia was mentioned by 2.4%. Sixteen per cent were unsure why they had been referred. CKD causes identified by patients were unsure (40%), alcohol (29%), hypertension (16%) and diabetes (14%). Symptoms identified included asymptomatic (16%), kidney pain (17%) and other (42%). Management suggested by patients was uncertain (51%), dialysis (32%) and anti-hypertensive medication (16%). Eighty-two per cent reported unsatisfactory education from their primary care physician.

Conclusions: New patients referred to a renal outpatient department had poor knowledge about kidney disease. Education of patients should begin in primary care prior to referral. For most patients, education programmes need to be targeted at a simplistic level.

Introduction

Health literacy is a term used to describe the skills required for a person to function effectively in a healthcare environment and to act suitably on health information.^{1,2} Important aspects of health literacy include ability to understand health information, engagement in the healthcare process and the removal of barriers from the medical system that prevent patient understanding and involvement.³

Poor health literacy has been associated with increased emergency medical care, hospitalisations and mortality in the elderly.²

Limited health literacy may affect 23% of people with chronic kidney disease (CKD) and is associated with poorer education, lower income, male gender and non-white race.⁴ Referral for renal transplantation is less likely, although there is no difference in the likelihood of being placed on the waiting list.⁵ Poorer health literacy has also been associated with missed dialysis sessions, emergency department visits, kidney disease-related hospitalisations¹ and mortality.⁴

Improving health literacy through education is necessary to optimise outcomes in people with CKD. Trials aimed at improving patient knowledge have been linked to better clinical outcomes in people with CKD, including higher rates of pre-dialysis nephrologist care, peritoneal dialysis, pre-emptive transplant wait listing, transplantation⁶ and increased time to commencement of renal replacement therapy.⁷

Kidney disease health literacy is poor in the general Australian population.⁸ Health literacy has not previously been studied in non-dialysis patients newly referred to a nephrology clinic. We hypothesised that patients newly referred to a nephrology clinic would have received some education about kidney disease from their primary care physician, and therefore, we performed a single-centre study to assess the understanding of kidney disease in this population.

Methods

All adults (age ≥ 18 years) newly referred by a medical practitioner to a general nephrology outpatient department were invited to participate. Patient recruitment commenced 16 August 2010 and completed 31 October 2011. Exclusion criteria included end-stage kidney disease with a functioning renal transplant or established on dialysis, non-English speaking, cognitive impairment and

patients who had previously been seen at the same nephrology clinic within 12 months. Patients who previously had seen a nephrologist elsewhere were included.

The study was a cross-sectional survey administered in a hospital renal outpatient department at the patient's first visit to the clinic and prior to being seen by a nephrologist. The survey was designed following a review of studies assessing patients' understanding of kidney disease and impressions obtained by staff from clinical experience. A panel of nephrologists and nurses reviewed questions and designed the final study questionnaire. A validated health literacy survey such as Rapid Estimate of Adult Literacy in Medicine⁹ was not used because no surveys specific to CKD literacy were available. The survey collected demographic data including age, gender, indigenous status (whether the participant self-identifies as being of Aboriginal or Torres Strait Islander descent), marital status, education level and occupation. Personal health data included smoking status and family history of kidney disease. Previous self-reported education or treatment for kidney disease was recorded. Open-ended survey questions examined patient perceived reason for referral, and knowledge of symptoms, causes, treatments and outcomes of kidney disease. Medical staff recorded comorbidities (ischaemic heart disease, peripheral vascular disease, cerebrovascular disease, chronic lung disease and diabetes mellitus) as present or absent, reason for referral, proteinuria (and/or albuminuria), serum creatinine and CKD stage from the medical records. Hypertension was defined as being prescribed anti-hypertensive medication or having a systolic blood pressure ≥ 140 mmHg and/or diastolic blood pressure ≥ 90 mmHg. The survey was administered by nursing staff who had been educated about the project and how to administer the survey, strictly adhering to asking open-ended questions (participants were not prompted if they did not have an answer to a question). For all open-ended questions, participants could provide a single or multiple answers.

Creatinine was recorded as the most recent result prior to clinic attendance and was measured by several different laboratories. The use of isotope dilution mass spectrometry in Australian laboratories reduces interlaboratory variation.¹⁰ At the time of the study, estimated glomerular filtration rate (eGFR) was measured and reported using the Modification of Diet in Renal Disease study equation.¹⁰ The eGFR was used to allocate participants a CKD stage based on the National Kidney Foundation criteria.¹¹

A range of methods was used to assess proteinuria in the study population reflecting the heterogeneous approach to the diagnosis of proteinuria at the time. Proteinuria was variably assessed including spot urine

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albumin-to-creatinine ratio (UACR), spot urine protein-to-creatinine ratio (UPCR) and timed (24-h) urine protein collections. Proteinuria or albuminuria was recorded as the most recent result available prior to the clinic visit or at the time of the appointment. Proteinuria was defined as being present if UPCR was more than 50 g/mol, or UACR was more than 25 mg/mmol for men and 35 mg/mmol for women, or timed urine protein collections reported proteinuria >300 mg/day.

Ethical approval to conduct the study was obtained from the Prince Charles Hospital Human Research and Ethics Committee and all participants gave signed informed consent.

Statistical methods

Descriptive statistics were calculated as median and interquartile range (IQR) for continuous variables, or frequency (%) for categorical variables. Results from open-ended questions could include multiple responses from each participant and were therefore presented as graphs of the most frequent responses. Pre-specified analyses of subgroup responses to causes of CKD included diabetic versus non-diabetic patients, age groups by quartiles and those who had seen a nephrologist previously. All analyses were conducted with Stata Version 12 (Stata Corporation, College Station, TX, USA).

Results

Two hundred and ten of 276 eligible patients (76% response rate) were recruited during the study period. Time constraint was the most common reason for not participating in the trial. No participants who commenced the questionnaire withdrew prior to its completion. Patients were referred to the renal outpatient department from primary care physicians (81.9%), specialist physicians (5.2%), other medical specialists (6.7%) or from hospital doctors (6.2%). Overall, 78.5% of people referred to the clinic met the Kidney Check Australia Taskforce guidelines for referral to a nephrologist.¹²

Baseline characteristics are shown in Table 1. The study population was as expected in a general nephrology clinic in this region. Median age was 66.5 years (IQR 52–77), 49.5% male, but only 2% were indigenous. CKD was mild to moderate with median serum creatinine of 115 µmol/L (IQR 82–155). Participant CKD stage was 7.6% (stage 0), 24.3% (stage 1), 11.4% (stage 2), 38.6% (stage 3), 17.6% (stage 4) and 0.5% (stage 5).

One hundred and seventy-two of the 210 patients (81.9%) had an assessment of urinary protein, which was measured by one of three different techniques. Of the 84 participants who had a UACR measured, 54.8% had no albuminuria, 20.2% microalbuminuria and 25%

Table 1 Baseline participant characteristics

Characteristic	
Age (years) – median (IQR)	65.5 (52–77)
Male	49.5%
Level of Education	
Primary school	17.6%
Secondary school	52.9%
Tertiary	23.8%
Other	5.7%
Occupation	
Age pension	44.8%
Self-funded retiree	7.1%
Tradesperson	3.3%
Professional	5.7%
Student	0.5%
Unemployed	5.2%
Invalid/carer pensioner	9.5%
Other	23.9%
Aboriginal or Torres Strait Islander	2.0%
Healthcare worker	4.3%
Married/partner	60%
Diabetes	31.4%
Body mass index (kg/m ²)	
Underweight (<18.5)	4.5%
Normal (18.5–24.9)	20.5%
Overweight (25.0–29.9)	34%
Obese (30+)	41%
Hypertension	62.4%
Ischaemic heart disease	19.6%
Peripheral vascular disease	8.6%
Chronic lung disease	13.4%
Cerebrovascular disease	5.7%
Smoker	15.9% (Current) 30.8% (Former)
Family history of kidney disease	18.6%

IQR, interquartile range.

macroalbuminuria. Of the 52 participants who had a UPCR measured, this was <50 g/mol for 67.3% and >50 g/mol for 32.7%. Thirty-six participants had a 24-h urine protein collection and this was <300 mg/24 h for 52.8% and >300 mg/24 h for 47.2%. Overall, 26% had significant proteinuria or albuminuria.

28.7% of patients had previously seen a nephrologist and 2% had seen a CKD nurse educator. Of those who had previously seen a nephrologist, 7.3% had seen a nephrologist in the past 12 months. 11.1% reported reading paper education material about kidney disease, and 14.8% had conducted an internet search. Only 2.4% of patients were aware of the consumer support group, Kidney Health Australia (or its previous name, the Australian Kidney Foundation).

Figure 1 shows bar graphs of the most common responses provided for the questionnaire. Figure 1A shows responses to the question ‘Did your local doctor or

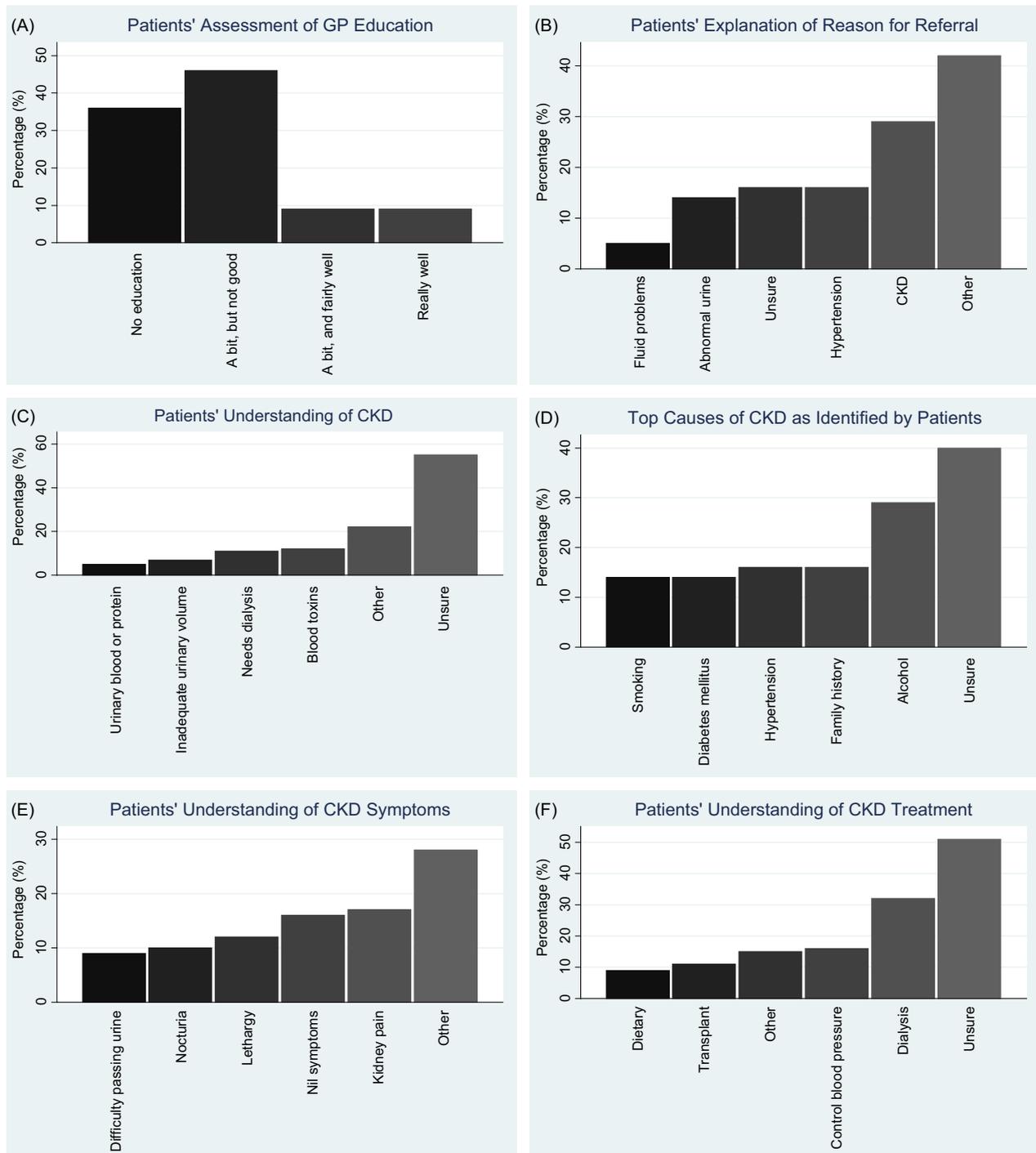


Figure 1 Patient responses to open-ended questions about prior education, referral reason and CKD causes, symptoms and treatment.

general practitioner (GP) explain your kidney problem before sending you to this clinic?' 35.8% reported no education and 46.2% a little, but not adequate. However, 18% found education prior to referral to be good. Figure 1B shows that 16% of participants responded as unsure when asked 'What do you understand to be the

reason you have been referred to this clinic?' and 29% responded kidney disease. Less common responses were specific to renal disease and included hypertension, abnormal urine and fluid problems. Figure 1C shows most were unsure when asked 'What does it mean if you have chronic kidney disease?' Unsure and alcohol were

the most common responses to the question 'What sort of things do you think may lead to a person developing kidney disease?' (Fig. 1D). When age was divided into quartiles, younger people were more likely to identify alcohol as a risk factor for CKD ($P \leq 0.001$). Differences in patients' age were not associated with recognising diabetes mellitus as a cause for CKD ($P = 0.47$). Those patients who had previously been reviewed by a nephrologist were not more likely to consider alcohol ($P = 0.29$) or diabetes mellitus ($P = 0.52$) as risk factor for CKD. Perhaps not surprisingly diabetic patients were more likely to report diabetes mellitus as a cause for CKD ($P < 0.001$). Patients reporting alcohol ($P = 0.054$) or diabetes mellitus ($P = 0.19$) as a risk factor for CKD were not dependent on stage of CKD (stages 0–3 vs 4–5). Figure 1E shows responses to 'What symptoms might you have if you had chronic kidney disease?' The response 'other' included shortness of breath, kidney stones, itch and taste disturbance. Lastly, Figure 1F shows responses to the question 'How do we treat chronic kidney disease?' Most patients were unsure or identified renal replacement therapy (dialysis or transplantation).

Discussion

This study has shown that among newly referred patients to a general nephrology outpatient clinic, most receive limited or no education from their primary care physician. Many people are uncertain of the reason for referral and most do not know what CKD is, what causes it or how it is managed. Misunderstanding and misconceptions about CKD are common.

The finding of poor education by primary care providers prior to first nephrology clinic attendance is unsurprising. CKD is common,⁸ but its recognition and management in primary care, where multiple competing health issues exist, could be improved. An Italian study examining people with hypertension managed in primary care found that 23% had CKD but this was only diagnosed by the primary care physician in 3.9% of cases.¹³ In Australia, CKD in general practice has been shown to be under-recognised and under-treated.^{14,15} Furthermore, discussions with patients about CKD in the primary care setting are rare and if they do occur, the GP may use technical terms that hamper education. These discussions occur more frequently with more educated patients, longer consultations or when diabetes is discussed.¹⁶ With the large burden of CKD in the community, it is not possible (or necessary) for all patients to attend a nephrology clinic and it is therefore essential that education about CKD occurs in the primary care setting. Efforts such as the Kidney Check Australia Taskforce¹² and Kidney Health Australia's

guidelines for CKD management in general practice¹⁷ will hopefully increase GP awareness and knowledge about CKD. This should translate into improved patient outcomes and knowledge. For example, when a GP diagnoses CKD in a patient with hypertension, the doctor manages the blood pressure better than if CKD is not diagnosed.¹³

The poor kidney disease literacy noted in our study is unlikely to be solely due to inadequate education by the primary care physician. Knowledge among the Australian Diabetes, Obesity and Lifestyle study population,⁸ a sample of adults across Australia both with and without CKD, found poor levels of knowledge about CKD in the general community. This poor kidney disease health literacy is not unique to Australia. In America, awareness of CKD among people with an eGFR <60 mL/min per 1.73 m² was only 10% for people with two to four markers of CKD and 16% for people with ≥ 5 markers.¹⁸ Another American study reported only 9% of those with albuminuria or eGFR <60 mL/min per 1.73 m² were aware they had kidney disease.¹⁹

Patient-reported awareness in our study of the peak consumer group, Kidney Health Australia, was poor. This may reflect the low profile of kidney disease in the Australian health system. Kidney disease is not one of the nine national health priority areas of Australian Governments,²⁰ but does constitute one of the elements of the National Service Improvement Framework for heart, stroke and vascular disease.²¹

While our study is the first to examine knowledge among patients newly referred to a nephrology clinic, the problem of poor kidney disease health literacy extends to those already known to renal units. Observational data from North America has shown that only half of patients with CKD stage 3–5 and seen at least four times in the previous year by a nephrologist knew of haemodialysis, peritoneal dialysis or renal transplantation.²² Furthermore, one third reported limited or no understanding of CKD. Even among patients established on dialysis, knowledge of phosphate and phosphate binder use is poor.²³ In our study, despite 28% of participants having seen a nephrologist previously, overall knowledge was generally poor.

There are reports of interventions to improve health literacy successfully among patients with kidney disease. A systematic review has shown efforts to improve diet and fluid concordance among dialysis patients with multicomponent interventions can be successful.²⁴ In Canada, one-on-one pre-dialysis education, provision of a booklet and regular telephone follow up was associated with increased time until commencement of renal replacement therapy.⁷ Follow up of this group showed

overall longer survival and longer survival after commencement of dialysis.²⁵ Participation in the National Kidney Foundation Kidney Early Evaluation Program (KEEP) resulted in higher rates of pre-dialysis nephrologist care, peritoneal dialysis, pre-emptive transplant wait listing and transplantation but not permanent vascular access. Recently, a physician-delivered education tool has made patients more aware they have CKD, their stage of CKD and awareness of kidney function.¹ Knowledge may be further assisted by novel approaches such as a Medicare education benefit in the United States for patients with CKD stage 4.²⁶

There are several limitations to our study that impact the generalisability of the results. Our data are from a single-centre and health literacy and primary care physician education practices along with awareness of renal disease support organisations reported in this study may not reflect those in other regions. The study relied on patient recall of previous nephrologist consultation or CKD education. Our population included few indigenous patients. Poor CKD health literacy has been shown among the Australian Indigenous population²⁷ and hence areas with larger indigenous populations may face a greater challenge with kidney disease health literacy. Non-English speakers were excluded and our population did not have many non-white participants, groups that have been found to have poorer health literacy in other studies.^{28–31} Lastly, we did not use a validated scoring

system for CKD health literacy but did focus on patient identification of alcohol and diabetes mellitus as risk factors for CKD because of a previous study in a survey of kidney disease knowledge in an Australian population.³² There are also strengths in our study, including the high response rate and use of open-ended questions without prompting.

Conclusion

The present study has shown that despite the known benefits of improved health literacy, CKD knowledge is poor among patients newly referred to a nephrology clinic and an opportunity to educate patients in the primary care setting is being missed. Ongoing efforts to improve primary care providers' recognition and knowledge of CKD will hopefully translate into improved efforts to educate patients about their illness and better outcomes. Nephrologists need to be aware that newly referred patients are likely to have a poor understanding of kidney disease and should tailor their consultation appropriately.

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References

- Green JA, Mor MK, Shields AM, Sevcik MA, Arnold RM, Palevsky PM *et al.* Associations of health literacy with dialysis adherence and health resource utilization in patients receiving maintenance hemodialysis. *Am J Kidney Dis* 2013; **62**: 73–80.
- Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011; **155**: 97–107.
- Raynor DK. Health literacy. *BMJ* 2012; **344**: e2188.
- Fraser SD, Roderick PJ, Casey M, Taal MW, Yuen HM, Nutbeam D. Prevalence and associations of limited health literacy in chronic kidney disease: a systematic review. *Nephrol Dial Transplant* 2013; **28**: 129–37.
- Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. *Clin J Am Soc Nephrol* 2009; **4**: 195–200.
- Kurella Tamura M, Li S, Chen SC, Cavanaugh KL, Whaley-Connell AT, McCullough PA *et al.* Educational programs improve the preparation for dialysis and survival of patients with chronic kidney disease. *Kidney Int* 2014; **85**: 686–92.
- Devins GM, Mendelssohn DC, Barre PE, Binik YM. Predialysis psychoeducational intervention and coping styles influence time to dialysis in chronic kidney disease. *Am J Kidney Dis* 2003; **42**: 693–703.
- Chadban SJ, Briganti EM, Kerr PG, Dunstan DW, Welborn TA, Zimmet PZ *et al.* Prevalence of kidney damage in Australian adults: the AusDiab kidney study. *J Am Soc Nephrol* 2003; **14**: S131–8.
- Davis TC, Long SW, Jackson RH, Mayeaux EJ, George RB, Murphy PW *et al.* Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med* 1993; **25**: 391–5.
- Mathew TH, Johnson DW, Jones GR, Australasian Creatinine Consensus Working Group. Chronic kidney disease and automatic reporting of estimated glomerular filtration rate: revised recommendations. *Med J Aust* 2007; **187**: 459–63.
- National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis* 2002; **39**: S1–266.
- Gallagher MP, Kelly PJ, Jardine M, Perkovic V, Cass A, Craig JC *et al.* Long-term cancer risk of immunosuppressive regimens after kidney transplantation. *J Am Soc Nephrol* 2010; **21**: 852–8.
- Ravera M, Noverasco G, Weiss U, Re M, Gallina AM, Filippi A *et al.* CKD awareness and blood pressure control in the primary care hypertensive population. *Am J Kidney Dis* 2011; **57**: 71–7.
- Razavian M, Heeley EL, Perkovic V, Zoungas S, Weekes A, Patel AA *et al.* Cardiovascular risk management in chronic kidney disease in general

- practice (the AusHEART study). *Nephrol Dial Transplant* 2012; **27**: 1396–402.
- 15 Pilotto LS, Ball PA, Smithard JM, Kennedy DR. Electronic records suggest suboptimal management of chronic kidney disease in general practice. *Aust J Rural Health* 2012; **20**: 195–9.
 - 16 Greer RC, Cooper LA, Crews DC, Powe NR, Boulware LE. Quality of patient-physician discussions about CKD in primary care: a cross-sectional study. *Am J Kidney Dis* 2011; **57**: 583–91.
 - 17 Kidney Health Australia. *Chronic Kidney Disease (CKD) Management in General Practice*, 2nd edn. Melbourne: Kidney Health Australia; 2012.
 - 18 Tuot DS, Plantinga LC, Hsu CY, Jordan R, Burrows NR, Hedgeman E *et al*. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. *Clin J Am Soc Nephrol* 2011; **6**: 1838–44.
 - 19 Whaley-Connell A, Shlipak MG, Inker LA, Kurella Tamura M, Bombardieri AS, Saab G *et al*. Awareness of kidney disease and relationship to end-stage renal disease and mortality. *Am J Med* 2012; **125**: 661–9.
 - 20 Lippens S, Denecker G, Ovaere P, Vandenaebroeck P, Declercq W. Death penalty for keratinocytes: apoptosis versus cornification. *Cell Death Differ* 2005; **12**(Suppl 2): 1497–508.
 - 21 National Health Priority Action Council (NHPAC). *National Service Improvement Framework for Heart, Stroke, and Vascular Disease*. Canberra: Australian Government Department of Health and Ageing; 2006.
 - 22 Finkelstein FO, Story K, Firaneck C, Barre P, Takano T, Soroka S *et al*. Perceived knowledge among patients cared for by nephrologists about chronic kidney disease and end-stage renal disease therapies. *Kidney Int* 2008; **74**: 1178–84.
 - 23 Toussaint ND, Pedagogos E, Beavis J, Becker GJ, Polkinghorne KR, Kerr PG. Improving CKD-MBD management in haemodialysis patients: barrier analysis for implementing better practice. *Nephrol Dial Transplant* 2011; **26**: 1319–26.
 - 24 Mason J, Khunti K, Stone M, Farooqi A, Carr S. Educational interventions in kidney disease care: a systematic review of randomized trials. *Am J Kidney Dis* 2008; **51**: 933–51.
 - 25 Devins GM, Mendelssohn DC, Barre PE, Taub K, Binik YM. Predialysis psychoeducational intervention extends survival in CKD: a 20-year follow-up. *Am J Kidney Dis* 2005; **46**: 1088–98.
 - 26 Young HN, Chan MR, Yevzlin AS, Becker BN. The rationale, implementation, and effect of the Medicare CKD education benefit. *Am J Kidney Dis* 2011; **57**: 381–6.
 - 27 Anderson K, Devitt J, Cunningham J, Preece C, Cass A. 'All they said was my kidneys were dead': indigenous Australian patients' understanding of their chronic kidney disease. *Med J Aust* 2008; **189**: 499–503.
 - 28 Cavanaugh KL, Wingard RL, Hakim RM, Eden S, Shintani A, Wallston KA *et al*. Low health literacy associates with increased mortality in ESRD. *J Am Soc Nephrol* 2010; **21**: 1979–85.
 - 29 Cavanaugh KL, Wingard RL, Hakim RM, Elasy TA, Ikizler TA. Patient dialysis knowledge is associated with permanent arteriovenous access use in chronic hemodialysis. *Clin J Am Soc Nephrol* 2009; **4**: 950–6.
 - 30 Bostock S, Steptoe A. Association between low functional health literacy and mortality in older adults: longitudinal cohort study. *BMJ* 2012; **344**: e1602.
 - 31 Green JA, Mor MK, Shields AM, Sevick MA, Palevsky PM, Fine MJ *et al*. Prevalence and demographic and clinical associations of health literacy in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2011; **6**: 1354–60.
 - 32 White SL, Polkinghorne KR, Cass A, Shaw J, Atkins RC, Chadban SJ. Limited knowledge of kidney disease in a survey of AusDiab study participants. *Med J Aust* 2008; **188**: 204–8.