

A national audit of information provided to new chronic kidney disease stage 4 & 5 patients: a pilot study

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Abstract

Introduction: Current guidelines recommend the treatment for chronic kidney disease (CKD) incorporates the preference of a fully informed patient. The aims of this pilot study were to assess which treatment options new patients and their carers learnt about via their renal unit, and to test the survey instrument prior to a planned national audit.

Method: Eight Australian renal units were purposively sampled. CKD coordinators completed one questionnaire per patient for their five most recent patients commencing dialysis, having a pre-emptive transplant or commencing supportive non-dialytic care (conservative management). Data were collected about the timing and type of information provided, who it was provided by and whether information was offered specifically for the patient's carer. The study was approved by the University of Sydney human research ethics committee.

Results: New end-stage kidney disease (ESKD) patients (n=41, median age 62, 65% male) commenced centre haemodialysis as their initial therapy in 61% of cases; peritoneal dialysis (15%) and conservative management treatment (10%). 71% received information about treatment options prior to commencing treatment. The mean eGFR for the group at the time of education was 14 ml/min/1.73m² (range 3-33). Renal nurses and nephrologists provided information about treatment options for 91% and 89% of new patients respectively. 56% of patients had a carer present when they received information.

Conclusions: Over two thirds of new ESKD patients received information about treatment options prior to commencing treatment. Education was presented at a low mean eGFR of 14ml/min/1.73m². The pilot study demonstrated that survey data was easy to retrieve for most patients, and that a national audit was feasible.

Key Words

education, dialysis, kidney transplantation, conservative management, carers

Thomson C, 2007) Education for the patients and their family is recommended to occur six months prior to the predicted onset of ESKD or during Stage 4 or Stage 5 CKD when the patient's estimated glomerular filtration rate (eGFR) reaches < 30ml/min/1.73m². (Mactier R, 2007; National Kidney Foundation, 2006).

The rationale for timely education about CKD treatment options is to: (1) allow patients and families time to assimilate the information and consider the treatment alternatives, (2) allow evaluation of recipients and donors for pre-emptive kidney transplantation, (3) allow staff time to arrange training for patients who choose a home dialysis therapy, (4) encourage clear decision making in the context of cognitive impairment associated with progressive chronic kidney disease, and (5) maximize planned treatment initiation using a permanent vascular or peritoneal access for those treated by dialysis. (Levin A et al., 1997; National Kidney Foundation, 2006) In addition, timely education also increases patient satisfaction with care. (Greenfield S, 1985)

Adherence to CKD education guidelines has not been widely reported and there are few published studies that assess the provision and delivery of information about all treatment

Introduction

Therapeutic options for patients with End-Stage Kidney Disease (ESKD) include haemodialysis, peritoneal dialysis, pre-emptive transplantation or supportive non-dialytic care, henceforth known as

conservative management. International guidelines recommend that patients with chronic kidney disease are fully informed about their treatment options. (CARI Guidelines, 2005; Mactier R, 2007; National Kidney Foundation, 2006; Taal M &

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options. One Canadian study reported a third of new patients commencing dialysis did not receive information about their treatment options until after they had commenced dialysis. (Manns BK et al., 2005) Another study of 428 patients in the United States found 66% were not presented with the option of peritoneal dialysis, 88% were not informed about home haemodialysis and 77% were not presented with the option of transplantation. (Mehrotra R et al., 2005) Numerous qualitative studies also report a lack of information about treatment options from both the patient's and carer's perspective. (Ashby M et al., 2005; Landreneau KJ & Ward-Smith P, 2007; Trisolini M et al., 2004)

The aims of this study were to: (1) assess which treatment alternatives had been presented by Australian renal units to incident patients approaching ESKD (Stage 4 and 5 CKD) and their carers; (2) assess the timing of information provision; and (3) pilot the survey instrument prior to a planned national audit.

Methods

A simple one page questionnaire was developed by the authors and distributed to members of the Caring for Australians with Renal Impairment (CARI) vascular access working group, the Kidney Health Australia (KHA) home dialysis advisory group and Sydney Dialysis Centre for review and input. After modifications, the final version addressed three main topics: patient demographics and initial treatment; type and timing of CKD treatment information; and involvement of the patient's friends or family members, herein referred to as 'carers' (See Appendix 1).

Eight renal units in Queensland, New South Wales and Victoria were invited to participate. These units were selected because their nephrologists or CKD nurses indicated an interest in the area of research and were known to the investigators. CKD coordinators at each unit provided informed consent before completing one questionnaire per patient for their five most recent patients whether commencing dialysis, having a pre-emptive transplant or

commencing conservative management. Data were collected retrospectively from patient's files and the CKD coordinator's records between October 2008 and March 2009 and faxed to the lead investigator (RM).

Patients who needed an interpreter or translated materials when discussing treatment options were categorised as speaking English as a second language. Patients who started their first dialysis session in the home training centre were categorised as home haemodialysis or CAPD/APD.

We collected information about the patient's eGFR and serum creatinine at the time of first discussion about treatment options. The modification of diet in renal disease (MDRD) formula (Levey AS et al., 2007) for calculating eGFR was chosen as it is well-validated, with specific cut off points to categorise the stages of chronic kidney disease, and is used by most biochemical laboratories in Australia. eGFR is the preferred measure of kidney function compared to serum creatinine. (CARI guidelines - Australasian eGFR Working Group, 2005; Marron B et al., 2005)

The pilot study was not powered to find statistically significant differences among groups. Rather, frequencies and proportions were reported for each questionnaire item. Available case analysis was used where there was missing data. (Steyerberg EW, 2009) Implausible or ambiguous data were queried with the CKD coordinators and then corrected if necessary.

With a view to planning a national audit, additional information was sought from each coordinator about the ease of data retrieval, the need for additional data items, and the preference for a web-based or paper-based survey instrument. The pilot study was approved by the University of Sydney human research ethics committee (#10-2008/11261) and endorsed by KHA.

Results

Renal unit characteristics

All eight invited renal units agreed to participate (Table 1). The units were diverse

with respect to geographical location, patient ethnicity, and numbers of new patients per year. They also offered a range of CKD treatment options including satellite and home haemodialysis, peritoneal dialysis, pre-emptive transplantation and conservative management. The role and job title of the nominated coordinator at each unit who completed the questionnaires is shown in Table 1.

Patient characteristics

The total number of patients included in the pilot study was 41. The mean age was 62 years (range 27 – 87 years) and 65% of patients were male. Nine patients (22%) spoke English as a second language and required either an interpreter or translated materials for discussions about treatment options. The initial treatment for CKD patients was: in centre haemodialysis for 25 of 41 (61%); continuous ambulatory peritoneal dialysis (CAPD) for six (15%); conservative management treatment for four (10%); satellite haemodialysis for two (5%); automated peritoneal dialysis (APD) for two (5%); home haemodialysis and pre-emptive transplantation for one patient (2%) respectively. (Table 2)

Options presented

Twenty-nine of 41 patients (71%) received information about CKD treatment options prior to commencing treatment. All 29 of these were educated about haemodialysis, 28 received information about peritoneal dialysis, 21 patients received information about pre-emptive transplant and 21 patients about conservative management treatment. (Figure 1) The one patient who did not receive information about peritoneal dialysis was being worked up for a pre-emptive transplant and the eight patients who did not receive information about conservative management treatment represented a younger group with a mean age of 42 years (range 27-67 years). The eight patients who did not receive information about transplantation were considered not to be 'suitable candidates.'

Reasons given for seven of the 12 remaining patients who did not receive

Appendix 1: Pilot questionnaire

| National survey - Information for patients and carers regarding treatment options for end stage kidney disease (ESKD) | |
|--|---|
| <p>Instructions for completing questionnaire: - One form for each new patient - To be completed at time of commencement of first dialysis; pre-emptive transplantation; or decision made for palliative treatment</p> | <p>Please fax or email to: Rachael Morton Research Fellow – The University of Sydney Fax: +61 2 9351 5049 Email: rachaelm@health.usyd.edu.au</p> |
| 1. BACKGROUND INFORMATION | |
| Renal Unit _____ Data Collector's initials: _____ Date entered: __/__/____ (dd/mm/yyyy) | |
| Patient age in years _____ Patient gender: Male / Female (please circle) | |
| 1.1 Did this patient have English as a second language (ESL)? Y / N (please circle) | |
| 1.2 What type of renal replacement therapy did this patient first commence? (tick one) | |
| Pre-emptive transplant <input type="checkbox"/> Home haemodialysis <input type="checkbox"/> In-centre haemodialysis <input type="checkbox"/> Satellite haemodialysis <input type="checkbox"/> | |
| Peritoneal dialysis (CAPD) <input type="checkbox"/> Peritoneal dialysis (APD) <input type="checkbox"/> Palliative treatment <input type="checkbox"/> | |
| 2. INFORMATION REGARDING TREATMENT OPTIONS | |
| 2.1 Was information about <i>any</i> treatment options (haemodialysis, peritoneal dialysis, transplantation or palliative treatment) provided to the patient prior to renal replacement therapy? (tick one) If No, skip to 27 | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.2 If Yes, what was the patient's eGFR or serum creatinine when information about treatment options was first provided? | |
| eGFR _____ ml/min/1.73m ² or Serum Creatinine: _____ µmol/L | |
| 2.3 If Yes, was information specifically about <i>haemodialysis</i> given to the patient? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.4 If Yes, was information specifically about <i>peritoneal dialysis</i> given to the patient? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.5 If Yes, was information specifically about <i>transplantation</i> given to the patient? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.6 If Yes, was information specifically about <i>palliative treatment</i> given to the patient? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.7 Was the above information about treatment options provided after the patient commenced renal replacement therapy? | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Comments _____ | |
| 2.8 How was information about treatment options provided to the patient? (tick all that apply) | |
| Nephrologist consultation <input type="checkbox"/> Multi-disciplinary seminar <input type="checkbox"/> Multi-disciplinary clinic <input type="checkbox"/> Nurse consultation <input type="checkbox"/> | |
| KHA Health Info Line <input type="checkbox"/> Sent internet links <input type="checkbox"/> Sent printed materials <input type="checkbox"/> No information given <input type="checkbox"/> | |
| Other (please specify): _____ | |
| 3. INFORMATION ABOUT CARERS | |
| 3.1 Did this patient have a carer or family member present when receiving information about treatment options? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/> Comments _____ | |
| 3.2 Did the renal unit provide specific information for this patient's carer or family member? (tick one) | |
| Yes <input type="checkbox"/> No <input type="checkbox"/> Comments _____ | |

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Table 1. Unit and staff characteristics in 8 Australian pilot sites

| Unit location | Number of new dialysis and transplant patients in year 2007 (ANZDATA, 2008) | Coordinator's title/role |
|---------------------------|---|---|
| Regional QLD | 38 | Nurse practitioner CKD |
| Regional NSW | 97 | Renal resource coordinator & Outreach nurse |
| Metropolitan NSW | 56 | Renal CNC |
| Metropolitan/regional NSW | 86 | CKD coordinator |
| Metropolitan NSW | 119 | Pre-dialysis coordinator |
| Metropolitan NSW | 37 | Renal failure coordinator / Renal anaemia coordinator |
| Metropolitan VIC | 158 | Vascular access coordinator |
| Metropolitan/regional VIC | 107 | Dialysis coordinator |

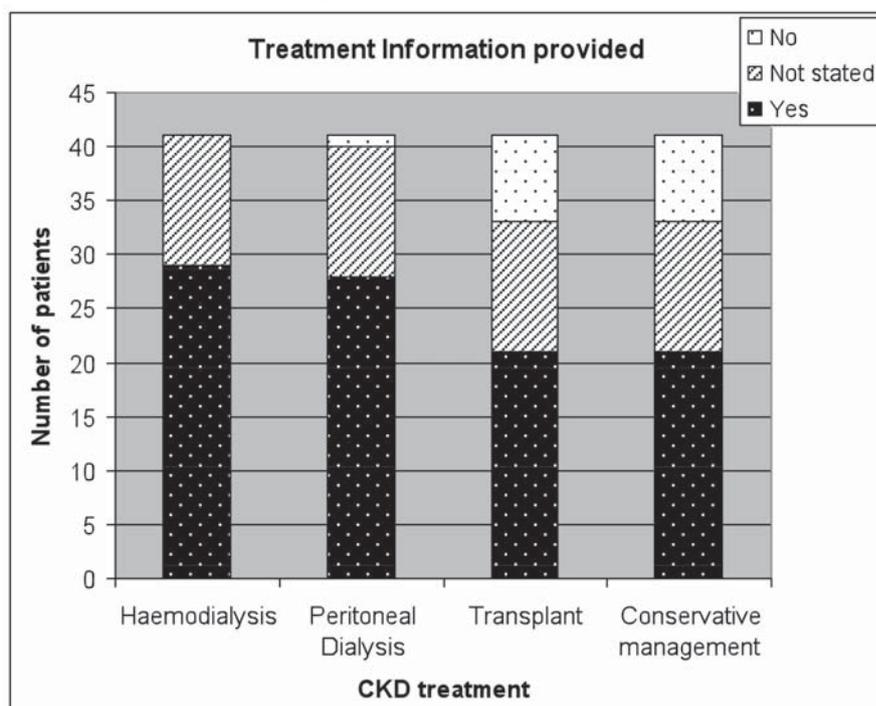
Table 2. Patient characteristics n=41

| Variable | Number | (%) |
|-------------------------------|-------------|------|
| Age | | |
| Median | 62 years | |
| Range | 27-87 years | |
| Gender | | |
| Male | 25 | (65) |
| English second language (ESL) | 9 | (22) |
| Initial treatment | | |
| In-centre HD | 25 | (61) |
| CAPD | 6 | (15) |
| Conservative management | 4 | (10) |
| Satellite HD | 2 | (5) |
| APD | 2 | (5) |
| Home HD | 1 | (2) |
| Pre-emptive transplant | 1 | (2) |

information about options prior to commencing treatment included acute admissions (n=2), late referrals from the community (n=1), no referral for education from the nephrologist (n=3), and one patient with a failed transplant who had prior knowledge of dialysis. Reasons were not given for the other five patients who commenced treatment before receiving information about options.

Seven of the nine patients who spoke English as a second language received information about treatment options prior to starting treatment, however the mean eGFR when options were first discussed was slightly lower in this group (10.5ml/min/1.73m²) compared with 14ml/min/1.73m² for the English speaking group. Five patients who spoke English as a second language commenced in-centre HD, two commenced APD and two commenced conservative management.

Figure 1. Treatment options presented



Timing of information

The eGFR at the time of education was documented in 25 of 41 patients. The mean was 14ml/min/1.73m², (CKD Stage 5) and the range was 3–33 (Figure 2). Serum creatinine was recorded in 27 of 41 patients with the mean level of 462µmol/L (range 182–960µmol/L) at the time when CKD treatment options were first presented. 18 patients had both serum creatinine and eGFR reported.

Provision of information

Information was given to patients in multiple ways using formal and informal methods. Most patients received information about CKD treatment options during a renal nurse or nephrologist consultation. Patients who attended a multi-disciplinary education seminar were also likely to receive printed information and educational DVDs. Two patients received information about treatment options through ‘other’ means which included a social worker consultation and a specific tour of the home dialysis training unit. (Figure 3)

Carer/family member involvement and carer-specific information

Twenty three of 41 patients (56%) had a carer present with them when information regarding treatment options was provided. Fifteen of 41 patients (37%) had no carer or family member present; two patients (5%) stated they had no family or friends and data was incomplete for one patient. (Figure 4)

Details of the provision of carer-specific information was recorded for 29 of 41 patients. For 21 patients, their carers received information specific to their needs including answering their questions on topics such as transportation and carer’s allowance, or providing Carers Australia support group pamphlets. The family and friends of eight patients did not receive carer-specific information regarding CKD treatment options. (Figure 5)

Figure 2. Timing of information with respect to residual renal function (data available for 25 of 41 patients)

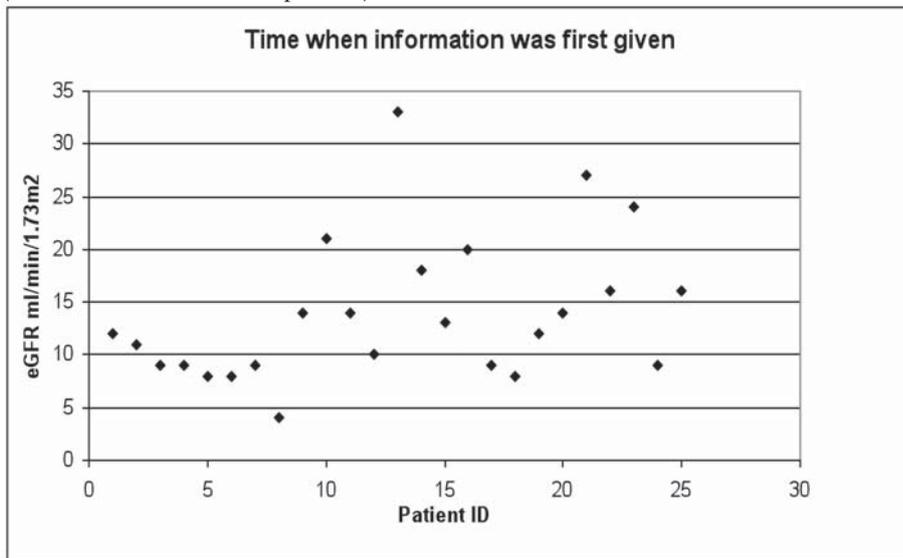
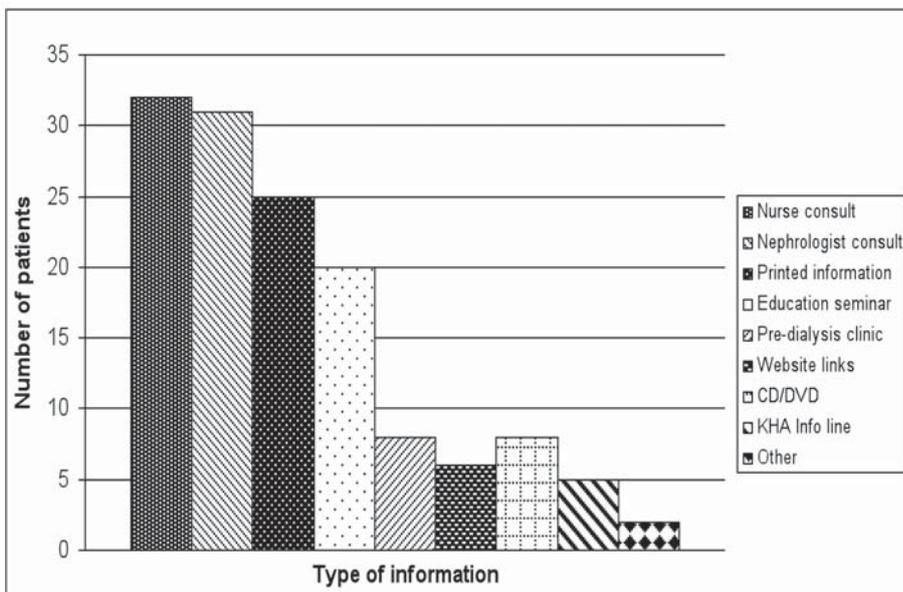


Figure 3. How information about treatment options was provided to patients



Feedback on pilot questionnaire

Overall the questionnaire was well received. Seven of eight staff from the participating renal units found the data required was routinely documented in the CKD coordinator’s database. There was some difficulty determining the exact eGFR at which treatment options were first discussed if the patient was

managed solely by a nephrologist and the consultation specifics were not documented. Three staff highlighted that palliative treatment (as stated on the questionnaire) was usually referred to as ‘conservative management’ in their unit. Staff did not always know this group of patients well, particularly if they were not for dialysis and did not attend dialysis or transplant education. Overall comments

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Dr. Murty Mantha, James Cook
University School of Medicine



on the questionnaire style, language and format indicated that information was usually 'given' (in a face to face format) rather than 'sent' (implying mailed format) and space for additional comments or explanation in some questions was needed.

Discussion

The main findings from the pilot study were, firstly, that nearly one third of ESKD patients commenced renal replacement therapy before being provided with information about treatment options. Second, the mean kidney function at the time patients received education was an eGFR of 14ml/min/1.73m², which is relatively low given that it is generally anticipated that renal replacement therapy will commence once the eGFR reaches around 10ml/min/1.73m². Third, the majority of patients learnt about haemodialysis from their renal units and the majority started haemodialysis as their initial treatment modality. Pre-emptive transplantation and conservative management appeared to be presented as treatment options only for selected patients. Fourth, many patients did not have friends or family members with them when they learnt about their treatment options and many carers did not receive carer-specific information.

Education about treatment options

Seventy-one per cent of our pilot study patients received information about treatment options, almost double the proportion (37%) reported in a retrospective Spanish multicentre study. (Marron B et al., 2005) Our findings were similar to a study of 132 CKD Stage 5 patients in Canada and the US in which 70-80% had knowledge of HD, CAPD or transplantation treatment modalities. (Finkelstein FO et al., 2008) These authors reported patients gained additional knowledge of treatment options as kidney disease progressed from Stage 3 to 5.

Figure 4. Presence of carers when information was given

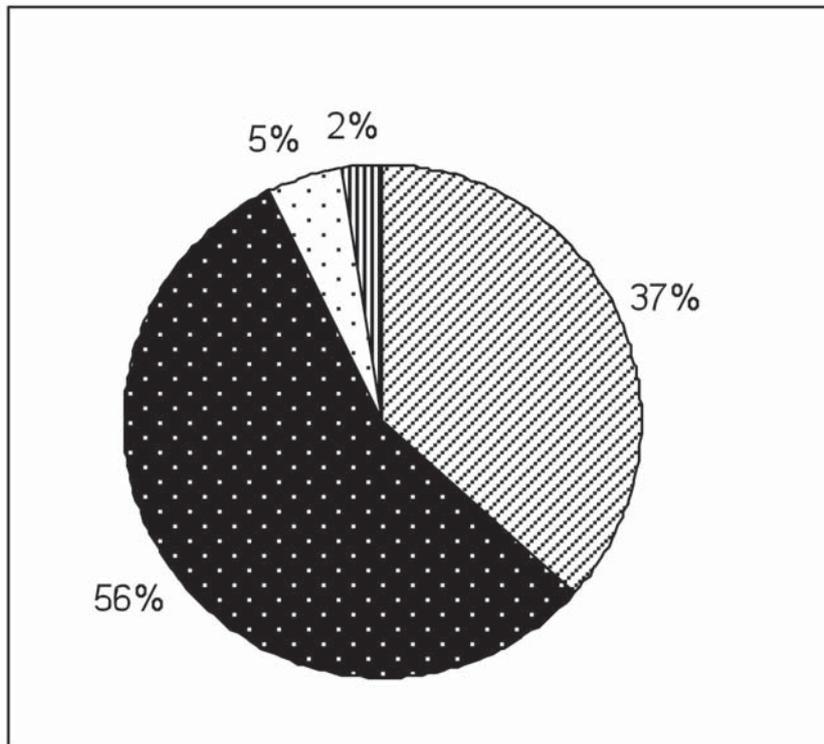
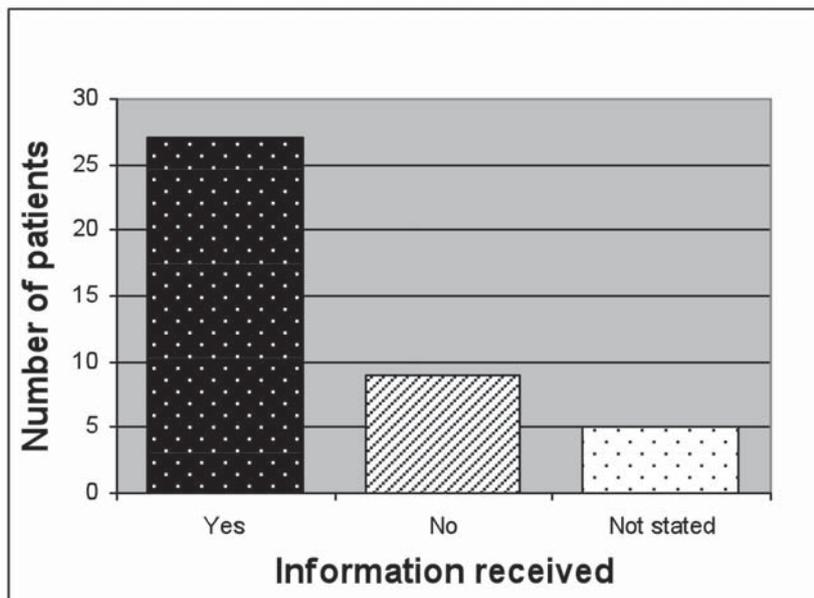


Figure 5. Provision of carer specific information



Timing of information

K/DOQI guidelines emphasise patient education to occur during CKD Stage 4 (eGFR 15–29 mL/min/1.73 m²) and the UK Renal Association recommends 6 months prior to the predicted onset of ESKD. Unlike the K/DOQI or UK Renal Association guidelines, the CARI guidelines do not suggest a specific time or level of kidney function for education about CKD treatment options. (Mactier R, 2007; National Kidney Foundation, 2006; Thomas M, 2007) Professional consensus in the National Service Framework for Renal Services in the UK (Department of Health Renal Team, 2004) is that the optimal time to prepare a patient and their family for renal replacement therapy is around one year. There is however a balance between providing information at a time point that is not too early and not too late. Information presented too early may not be remembered or may be irrelevant if the patient does not progress to ESKD. Education provided too late, when the patient is experiencing symptoms of uraemia, may not be useful because of impaired cognitive processing and decision making. Predictability of decline in CKD differs from person to person, and if rapid may present challenges in information provision.

Our results suggest that patients from a non-English speaking background may receive information about treatment options at a later stage than English speaking patients. This may be due to a later presentation to the renal unit which in turn could be reflective of a broader impediment to accessing health care. One study suggests that renal services are often underutilised by patients of non-English speaking backgrounds because of transport difficulties, fear of deportation or the inability to find health care providers who speak their language. (Duffy MM & Alexander A, 1999)

Two international trials of pre-dialysis education programmes targeted the intervention at a mean eGFR of 20.4 mL/min/1.73m² (95% CI 18.7–22.0) (Manns BK et al., 2005), and between

20–25 mL/min/1.73m². (Goovaerts T et al., 2005) The authors concluded that education in Stage 4 (i.e. eGFR < 30 mL/min but > 15 mL/min) was necessary to facilitate group discussion and planning, particularly for home based therapies. An audit of pre-dialysis clinical pathways at one centre in Melbourne reported an eGFR of 13–22 mL/min/1.73m² for patients notified to the renal unit which then triggered education and planning for vascular access. (Owen J et al., 2006)

Current guidelines also suggest the options of pre-emptive transplantation or conservative management are presented at the same time as information about dialysis. Limited published data relating to the timing of education about pre-emptive transplantation or conservative management is available. From a renal social worker's perspective 'considerable' time was required in the transplant work up period to allow for an assessment of pre-morbid psychiatric disorders, psychological or social pressures, as well as an assessment of the motivation for pre-emptive transplantation in both the recipient and donor (Fisher M, 2006). Others stated that consistent with the palliative care paradigm, the appropriate time to discuss end-of-life care was when ESKD was expected within the next 12 months. (Davison SN & Simpson C, 2006)

Carer-specific information

The information needs of CKD carers have been identified in several published qualitative studies. Commonly cited topics include: food preparation and cooking, hygiene, transport availability, managing appointments, work leave certificates, carer's allowance, medication management (both ordering and dispensing), fluid balance, checking vascular access, pain control, emotional support, carer respite and carer support groups (Courts NE, 2000; Luk WSC, 2002; Trisolini M et al., 2004) The carer-specific information provided by units in the pilot study included pamphlets from Carers Australia – a national support group for carers; Carer Assist – support for mental health carers;

Home and Community Care (HACC); and local hospital services such as patient accommodation or carer's programmes.

Strengths and Limitations

The pilot study was limited to data on a small number of patients from purposively selected renal units on the east coast of Australia, and therefore may not be generalisable to the wider population. However, ANZDATA figures for new patients commencing renal replacement therapy in 2007 have similar proportions for patient sex (62% male), median age (62.6 years) and centre based haemodialysis (69%) to the pilot sample in our study. Our study did not aim to elucidate information about treatment options that patients or their carers received from external sources, neither did it seek to evaluate the quality of the information provided. A strength of this pilot study was the attempt to systematically capture data on the provision of information about conservative management as an CKD management option and to include the patients who chose not to start dialysis.

Based on the positive feedback from the participating units in the pilot study, a national audit is planned to take place between July and September 2009. This audit called Patient Information about Options for Treatment or 'PINOT' will capture data on all new or incident dialysis, pre-emptive transplant or conservatively managed patients known to renal units across Australia. It is designed to examine the relationships between the information provided and the treatment commenced and patient sociodemographics such as age, sex, health insurance status, whether English is spoken as a second language and CKD stage. The value of this study will be in determining the stage of disease when education about treatment options occurs and mapping the subsequent treatment patterns. The results of the PINOT audit may initiate the development of clinical practice guidelines for the timing of education. Further details about the PINOT audit can be obtained by contacting the corresponding author.

Conclusion

One third of new ESKD patients received information about treatment options after commencing treatment. For the majority, information was provided at a mean eGFR of 14ml/min/1.73m². All patients learnt about haemodialysis as a treatment option, and the majority of patients commenced haemodialysis as their initial treatment modality. Education about pre-emptive transplantation and conservative management was given to selected groups of patients and many patients did not have friends or family members with them when receiving education. The pilot study demonstrated that survey data was easy to retrieve for most patients and that a planned national audit of information about treatment options (PINOT) is feasible.

Further information about the audit is available from the lead author.

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