

"This is the peer reviewed version of the following article: [Nephrology (Carlton, Vic.), 2016], which has been published in final form at <http://onlinelibrary.wiley.com/doi/10.1111/nep.12743/abstract;jsessionid=6C6AF079CDD554CD912ED3C54E8FBD8D.f02t04>. This article may be used for non-commercial purposes in accordance with [Wiley Terms and Conditions for Self-Archiving](#)."

Title: Advance care planning in chronic kidney disease: a survey of current practice in Australia

Running title: Advance care planning in CKD

Proposed Authors: Tim Lockett ^{1,2}, Lucy Spencer ³, Rachael L Morton ⁴, Carol A Pollock ^{3,5}, Lawrence Lam ², William Silvester⁶, Marcus Sellars ^{5,6}, Karen M Detering ⁶, Phyllis N Butow ⁷, Allison Tong ⁸, Josephine M Clayton ^{1,5,9}

Institutions:

¹Improving Palliative Care through Clinical Trials (ImPaCCT) New South Wales, Australia; ²Faculty of Health, University of Technology Sydney (UTS), Sydney, Australia; ³Department of Renal Medicine, Royal North Shore Hospital, Sydney, Australia; ⁴NHMRC Clinical Trials Centre, The University of Sydney, ⁵Sydney Medical School, University of Sydney, Australia; ⁶Respecting Patient Choices, Austin Health, Melbourne, Australia; ⁷School of Psychology, The University of Sydney, Australia; ⁸School of Public Health, The University of Sydney, Australia; ⁹HammondCare Palliative & Supportive Care Service, Greenwich Hospital, Sydney, Australia.

Corresponding author: Associate Professor Josephine M Clayton, HammondCare Palliative & Supportive Care Service, Pallister House, Greenwich Hospital, PO Box 5084, Greenwich, Sydney, NSW 2065, Australia.
Email: josephine.clayton@sydney.edu.au Tel. +61 2 8788 3952; Fax +61 2 9903 8384.

ABSTRACT

Aim

Advance care planning (ACP) in nephrology is widely advocated but not always implemented. The aims of this study were to describe current ACP practice, identify barriers/facilitators and perceived need for health professional education and chronic kidney disease (CKD)-specific approaches.

Methods

An anonymous cross-sectional survey was administered online. Nephrology health professionals in Australia and New Zealand were recruited via professional societies, email lists and nephrology conferences. Multiple regression explored the influence of respondents' attributes on extent of involvement in ACP and willingness to engage in future.

Results

375 respondents included nephrologists (23%), nurses (65%), social workers (4%) and others (8%). 54% indicated that ACP at their workplace was performed ad-hoc and 61% poorly. Perceived barriers included patient/family discomfort (84%), difficulty engaging families (83%), lack of clinician expertise (83%) and time (82%), health professional discomfort (72%), cultural/language barriers (65%), lack of private space (61%) and lack of formal policy/procedures (60%). Respondents overwhelmingly endorsed the need for more dialysis-specific ACP programs (96%) and education (95%). Whilst 85% thought ACP would be optimally performed by specially-trained staff, comments emphasized that all clinicians should have a working proficiency. Respondents who were more willing to engage in future ACP tended to be non-physicians (Odds ratio [OR] 4.96, 95% confidence intervals [CI] 1.74-14.07) and reported a greater need for CKD-specific ACP materials (OR 10.88, 95% CI 2.38-49.79).

Conclusion

ACP in nephrology needs support through education and CKD-specific resources. Endorsement by nephrologists is important. A multi-disciplinary approach with a gradient of ACP expertise is also recommended.

KEY WORDS

Chronic kidney disease, advance care planning, conservative care, current practice, health professional views

AUTHOR'S COPY

Introduction

Chronic kidney disease (CKD) is a progressive, life-limiting condition that is associated with cognitive impairment in its advanced stages. Advance care planning (ACP) refers to a process of reflection and discussion by which an individual's values and preferences for future care are clarified and communicated to clinicians and family members so they can make decisions on their behalf should they become unable to make treatment decisions at the time¹. ACP often results in the appointment of a substitute decision maker, and discussion and documentation of a person's wishes. In the context of CKD, ACP also addresses the questions of commencing, withholding, continuing or withdrawing dialysis. When properly implemented, ACP has been found to improve the concordance between patient wishes and end-of-life care received, congruence between patient and surrogate decision-maker wishes and surrogate decision-making confidence as well as improve satisfaction and psychological outcomes in bereaved families^{2,3}.

Clinical practice guidelines recommend ACP for people with CKD⁴. However, a recent systematic review showed that there is limited research on ACP in CKD, especially studies developing and evaluating interventions⁵. One study conducted in Canada found that less than 10% of patients with stage 4 or 5 CKD had discussed end-of-life care in the previous year with healthcare providers⁶. Barriers to ACP include a difficulty in identifying the right timing to undertake ACP⁷, reluctance to raise ACP for fear of upsetting patients, and lack of support from senior staff⁸. In Australia and New Zealand, the Society of Nephrology's *Renal Supportive Care Guidelines* have highlighted that appropriate systems are needed to support ACP in CKD care⁹. Yet no research to date has evaluated national practice patterns or offered a systems perspective of barriers and facilitators to ACP in this setting.

A study was designed that aimed to: 1) describe current ACP practice in Australia and New Zealand nephrology from systems- and clinician-level perspectives, 2) identify barriers and facilitators to ACP, and 3) establish the perceived need for, and desirable content of, health professional education and CKD-specific approaches to ACP. The survey was focused on the perspectives of health professionals because of their influence and insight into likely levels of support for different interventions¹⁰. We were particularly

interested to understand the ACP-related perceptions among motivated clinicians most likely to drive change at their workplace ¹¹.

Methods

This study used a cross-sectional survey design. The survey was administered online via a secure platform, SurveyMonkey® (<https://www.surveymonkey.com/>). Survey data were anonymous to minimize the risk of social desirability bias. The study was approved by the University of Technology (UTS) Human Research Ethics Committee. The survey opened on 30th May 2014 and closed on 21st January 2015. Survey questions were developed by experts in ACP implementation/education, a nephrologist, nephrology nurse, palliative care physician, psychologist and health economist. The draft survey was piloted by 10 renal clinicians from varying disciplines and refined based on their feedback, prior to wider circulation.

The survey included 43 questions, some of which were divided into sub-questions (see Digital Supplemental Content 1). Respondent characteristics collected included age, gender, country of birth, religious views, clinical role, including discipline, experience in nephrology, and setting and state/territory of primary workplace. Further questions related to experience, skills, comfort and knowledge regarding ACP, workplace policies and procedures concerning ACP, perceived barriers/facilitators to ACP, and perceived need for and desirable content of new CKD-specific ACP programs and materials. Item response options included yes/no, multiple choice, likert scales and comment boxes allowing free text to be entered after most items.

Participants and recruitment

Respondents were eligible if they self-identified as a health professional involved in caring for adults with CKD in Australia or New Zealand. Participants were recruited via email invitations and newsletters sent out by peak professional societies and the authors' networks. Invitations were also extended to delegates at the 2014 annual conferences of the Renal Society of Australasia (RSA) and the Australian and New Zealand Society of Nephrology (ANZSN) via satchel inserts, an oral presentation and display stands. Open online surveys are subject to selection bias because participants self-select, leading to a 'volunteer effect'. In the

current study, an over-representation of respondents with experience of, and interest in ACP was considered supportive of our aims in that a more representative sample would likely have included only a small proportion with ACP experience and insight into problems and solutions.

Analysis

Data were analyzed using SPSS V23.0 statistical software. Descriptive statistics were calculated as frequencies with percentages and means with standard deviation. Inferential statistics used both bivariate and multivariate methods to examine relationships between variables of interest and the extent of involvement in ACP discussions with each of three patient groups (patients with CKD [eGFR<30mls/min/1.73m²] considering treatment options, patients on dialysis, and patients with end stage kidney disease being managed with a supportive care approach), as well as willingness to engage more often in ACP discussion in the future. Variables tested for association included respondent characteristics (age [\leq / \geq 45 years], sex, discipline [physician versus non-physician], years in nephrology [\leq / \geq 10 years], and status as a unit manager), as well as variables hypothesized to influence behavior based on the Theory of Planned Behavior¹². This theory posits that an individual's behavioral intentions and behavior are shaped by his/her attitudes toward the behavior (e.g. perception that ACP falls within one's role), normative beliefs (e.g. knowledge of ACP legislation), and perceived control over the behavior (e.g. perceptions of barriers and facilitators). The Theory of Planned Behavior has been used to design and interpret surveys of health professionals in the past¹³. Bivariate analyses were used to identify unadjusted relationships, with a significance level of $p < 0.10$ used to select variables for inclusion in multivariate analyses of adjusted relationships. Students T-tests and correlation analyses were applied for testing group differences or relationships between continuous variables. Multiple linear or logistic regression analyses were used, with the calculation of 95% Confidence Intervals (CI). These analyses controlled for ACP opportunity, as measured by the number of patients seen each month and proportion of these offered ACP within the unit as a whole. Since this was an exploratory study, no attempts were made to examine the interaction terms between variables included in the multivariate analyses. A Type I error of 5% was adopted for all analyses.

Free text comments were summarized descriptively by a single researcher (TL) and reviewed by another (JC), with any disagreements resolved by discussion.

Results

In total, 417 health professionals responded to the survey, of whom 375 (90%) were deemed to provide sufficient data ($\leq 5\%$ missing on any item) to be included in statistical analyses. Sample characteristics are summarised in Table 1. Data on respondent's occupational postcode suggest that the sample represented at least 157 different renal units – representing 61% of the 259 Australian total¹⁴. The Australian Health Practitioner Regulation Agency's (AHPRA) annual report indicated that there were 388 nephrologists registered nationwide in 2010-2011¹⁵, suggesting that inclusion of 85 nephrologists registered a response rate of 22%. No data were available to estimate response rates for other disciplines.

The main survey results are reported in Tables 2 and 3. Results regarding current practice in ACP with people with CKD are reported in Table 2. Results concerned with ways to improve ACP for people with CKD are presented in Table 3. Other results are described below, including comments made in free text responses.

Of 88% (n=329) of respondents who were not already regularly discussing ACP with their CKD patients, 88% (n=289) said they would be willing to engage more often in ACP and 8% (n=27) were unsure, leaving only 4% (n=13) who were not willing to discuss ACP. Twenty percent (n=69) indicated there were patient groups with whom they perceived it would not be appropriate to discuss ACP, most commonly citing young patients with few comorbidities and a good prognosis, or who might be transplant candidates. Seventy nine percent (n=296) of respondents reported having had no experience of ACP with Aboriginal and/or Torres Strait Islanders, and 51% (n=151) reported no experience of ACP with people from culturally and linguistically diverse backgrounds.

While discouragement from colleagues or managers was considered a barrier by only 19% (n=69) of respondents, the gate-keeping role played by nephrologists was frequently commented upon in free-text responses. Whilst 85% (n=300) thought it would be helpful to make ACP the role of a specially trained

clinician; open-ended responses qualified this by recommending that all clinicians should be sufficiently skilled to discuss ACP should opportunities spontaneously arise. Respondents also highlighted that ACP might be best undertaken by someone with an established relationship to the patient, although it was acknowledged that this might increase emotional difficulty for the clinician involved. Suggestions in free text responses regarding ways to improve ACP included: calls for public health campaigns aimed at helping people understand the limits of modern medicine and the need for ACP; better systems for storage, governance, updating and sharing of advance care directives; and the value of seeking expert advice from specialist palliative care services. There was a concern that ACP for people with CKD should not be considered the sole responsibility of nephrology, with primary and acute care episodes being cited as important opportunities for ACP with this patient group. Respondents commonly suggested for ACP to be integrated as a standard process into routine care to ensure necessary resources (e.g. staff time), enable the development of metrics to drive performance, and elicit more positive perceptions and less stigma from patients and staff. However, a small number of respondents expressed concerns that overly formalising ACP might make the process overly intimidating and lead to a 'tick-box' approach that would not allow for tailoring of timing/content according to the health profile and psychological readiness of individual patients. There were some common suggestions in the free text responses that re-occurred across items. These are summarised in Table 4.

Inferential analyses

Results of bivariate analyses for unadjusted associations between variables of interest and the involvement in ACP discussions with different patient groups are presented in Table 5, and those for multivariate analysis of adjusted associations in Table 6.

Analysis of variables associated with the intention for future involvement in ACP discussions showed significant relationships with respondents: having a clinical role other than a nephrologist (Odds Ratio [OR] 4.96, 95% confidence interval [CI] 1.74-14.07); being comfortable discussing ACP (OR 1.29, 95% CI 1.12-1.48); and agreeing that more CKD-specific ACP programs/patient education materials might facilitate ACP

(OR 10.88, 95% CI 2.38-49.79). Respondents were significantly less likely to indicate willingness to be involved in future ACP discussions if they were aged ≥ 45 years (OR 0.25, 95% CI 0.08-0.75) or agreed with the statement that ACP did not fall within their role (OR 1.29, 95% CI 1.12-1.48) (see Figure 1).

Discussion

To our knowledge, this is the first nationwide survey of renal clinicians' views about current practice of ACP to be conducted anywhere in the world. Responses to our survey suggest that ACP needs targeted support to improve access and overcome barriers in nephrology. Nearly two-thirds of respondents reported ACP to be done 'poorly' or 'very poorly' at their primary workplace, less than a third reported undertaking ACP with a majority of patients, and a quarter reported having no or almost no knowledge of ACP legislative frameworks. Reports of low initiation by, and involvement of, families in ACP are of particular concern given that family members act as substitute decision-makers when patients lose capacity. Engagement of families in ACP has been shown to improve uptake by patients in other settings¹⁶. Whilst guidelines recommend routinely offering ACP to CKD patients and commencing ACP early in the disease trajectory⁴ and 80% of respondents thought that ACP discussions should occur prior to starting dialysis, only a third of respondents stated that ACP was usually initiated prior to commencement of renal replacement therapies at their workplace. Even patients being managed with a supportive care (non-dialysis) approach were reported to receive ACP all or as a majority by only half of respondents. Given that our sample was likely biased towards clinicians with a greater interest in ACP, these results probably underestimate current gaps and challenges in ACP implementation in Australian CKD settings. However, our results are consistent with research that found nephrology and respiratory specialists to have significantly poorer ACP-related knowledge and comfort than physicians from other specialties¹⁷.

On a more positive note, a large majority of respondents reported willingness to engage more often in ACP in the future and supported approaches for improving ACP, especially education and dialysis-specific ACP program/education materials. Potential for the role of education is highlighted by the finding that respondents consistently rated their level of comfort with discussing ACP higher than their skill. The aspect

of ACP that respondents felt least skilled in was assisting patients to complete advance care directives, suggesting that this could be a specific focus for education and training. Preferred modes of learning included lectures/workshops and online courses rather than role play or observation/feedback, which respondents thought would be intimidating. On the other hand, published studies suggest that experiential learning, with opportunities for constructive feedback and reflection, are the most effective ways to improve clinician's communication skills about sensitive topics¹⁸⁻²⁰. With regard to CKD-specific materials for ACP, Kidney Health Australia provides information sheets and a decision-aid to help people choose amongst treatment options, including supportive care²¹. Similar resources are provided in the USA by the National Kidney Foundation²², and the American Association of Kidney Patients provides an information web-page on advance care directives²³. It may be that an ACP workbook tailored specifically to the needs of CKD patients and their families may be a useful addition to the available online resources.

One fifth of respondents felt that there were some patients for whom ACP may not be appropriate, such as young patients being considered for transplantation. However, at least basic education about ACP and encouraging patients to consider appointing their preferred substitute decision maker in case of an emergency is arguably relevant to all patients with CKD even those with a relatively good prognosis⁹. On the other hand, in view of the significant time barriers noted by respondents, it may be pertinent for renal units who are not already regularly engaging in ACP to initially prioritise more in depth discussions of ACP with pre-dialysis and dialysis patients who are at the greatest risk of dying, such as elderly patients and those with significant comorbidities. Certainly guidelines recommend that ACP is needed for all ESKD patients who are being managed with a supportive care (non-dialysis) approach^{4,9}.

Ideas for improving the quality of ACP volunteered by respondents commonly included the need for time and private space to undertake ACP, as well as systems and processes to ensure storage and access to advance care directives, and closer links with palliative care services. Respondents' call for better systems for accessing patient's advance directives is consistent with previous findings that highlight the need to instil CKD patients with confidence that their wishes can be acted upon⁵. The need for improved access to

advance care directives across sectors has also been acknowledged in Australia by policy²⁴ and the Personally Controlled eHealth System initiative²⁵. In combination, respondents' suggestions represent a call for greater institutional engagement with ACP through acknowledgement of it as core business, development of governance structures around the process, and provision of material support.

Some respondents were ambivalent about allocating responsibility of ACP to expert staff rather than to all clinicians. While a model of having trained and dedicated non-physician ACP facilitators has been shown to be effective in general medical settings², others argue that all clinicians involved in caring for patients with CKD should be comfortable discussing ACP²⁶ and that nephrologists should take responsibility for initiating ACP with their patients²⁷. The reality is that nephrologists often lack time to facilitate ACP conversations, as reflected by our survey results. Perhaps a combination of leadership and endorsement by nephrologists, general education about ACP for all renal clinicians, and allocation of dedicated ACP nurse facilitators to help coordinate the more time consuming parts of the process, may prove most fruitful. An approach of this kind might also strike a balance between embedding ACP as a routine part of care and a 'one size fits all' process that some respondents were concerned would overlook variability between individual patient's needs with regard to timing and content. Further research is needed to evaluate such an approach.

Our study informs a better understanding of which clinicians typically carry out ACP in nephrology and who may need more support to do so. In multivariate analyses, only self-rated skills and opportunity according to local practice remained consistently predictive across dialysis, CKD and end-stage patients. To a lesser extent, negative attitudes towards ACP were also associated with ACP practice, albeit inversely. Less expectedly, perceptions of workplace barriers and facilitators did not remain predictive after controlling for respondent characteristics, attitudes and normative beliefs, suggesting that these may not play as major a role in impeding or promoting ACP practice as respondents thought. Self-rated comfort was strongly associated with conducting ACP with all three patient groups in bivariate analysis but lost significance when other factors were controlled for. This was in contrast to the significant role comfort played in predicting willingness to engage in future ACP discussion, suggesting that comfort may be necessary but not sufficient

to carry willingness into practice. Respondents willing to engage in more ACP tended to be younger, from disciplines other than medicine, and report a need for more CKD-specific ACP materials, providing clear direction on ways to target interventions aimed at promoting greater ACP by clinicians most likely to respond.

Finally, it is worth noting that more than three-quarters of respondents had no experience with conducting ACP with patients from Aboriginal and/or Torres Strait Islander backgrounds; targeted strategies may be needed to promote culturally competent ACP in this population given higher incidence of CKD and different rates of dialysis withdrawal compared to other Australians²⁸.

Limitations

As already indicated, the greatest limitation of this study is that the sample is unlikely to be representative of the Australian nephrology workforce more generally. We accepted the likelihood of a volunteer effect on the grounds that we were primarily interested in the views of motivated clinicians likely to drive change. This likelihood is supported by the fact our sample were relatively experienced, had mostly received previous training in ACP and had at least a working knowledge of legal frameworks, and most frequently identified themselves as the person initiating ACP at their workplace. Whilst geographic spread was impressive within Australia, numbers from each discipline were small, particularly for nephrology registrars and social workers. This prevented meaningful comparison between responses from different disciplines beyond physician versus others combined. While more nurses (65%) than physicians (23%) completed the survey, this proportion may somewhat approximate to the composition of the Australian nephrology workforce. The fact that only 4% of respondents worked in New Zealand also mean that our results are mainly focused on Australia. Data from a larger, representative sample would provide useful context within which to consider our findings. The fact that information about systems and processes for ACP collected in this study was clinician-reported represents both a strength and limitation. Clinician perceptions provide important insights into likely levels of support for interventions. However, without data from other sources, it is impossible to ascertain the reliability of these perceptions. For example, the prevalent perception that

patient/family discomfort posed a barrier to ACP may have been based on misguided assumptions or projected clinician discomfort. Qualitative research suggests that at patients on haemodialysis may sometimes want to discuss ACP but feel that opportunities are lacking²⁹.

Conclusion

ACP in patients with CKD needs promotion and support to improve access and quality. Health professionals responding to our survey were highly supportive of more education about ACP for all renal clinicians and development of CKD-specific ACP materials as ways of enhancing ACP. Further leadership and endorsement of ACP by nephrologists may also be needed. The training and appointment of dedicated ACP facilitators to help coordinate the more time consuming aspects of ACP was endorsed by the majority of participants. The latter approach needs further evaluation to examine its effectiveness and cost effectiveness in the CKD setting.

AUTHOR'S COPY

ACKNOWLEDGEMENTS

The study was funded by competitive grant from Kidney Health Australia. We would like to thank all of the respondents who participated in the survey, and the Renal Society of Australasia, the Australian and New Zealand Society of Nephrology and the New South Wales Agency for Clinical Innovation for their help in disseminating the survey.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare. The results presented in this paper have not been published previously in whole or part, except in abstract format

REFERENCES

1. Davison SN, Torgunrud C. The creation of an advance care planning process for patients with ESRD. *Am J Kidney Dis.* 2007 Jan;**49**(1):27-36.
2. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *British Medical Journal.* 2010;**340**:c1345.
3. Song MK, Ward SE, Fine JP, et al. Advance Care Planning and End-of-Life Decision Making in Dialysis: A Randomized Controlled Trial Targeting Patients and Their Surrogates. *Am J Kidney Dis.* 2015 Nov;**66**(5):813-22.
4. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int.* 2015 Apr 29.
5. Lockett T, Sellars M, Tieman J, et al. Advance care planning for adults with chronic kidney disease: A systematic integrative review. *American Journal of Kidney Disease.* 2014;**63**(5):761-70.
6. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol.* 2010 Feb;**5**(2):195-204.

7. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulsy JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *American Journal of Kidney Diseases*. 2012;**59**(4):495-503.
8. Perry E, Swartz R, Smith-Wheelock L, Westbrook J, Buck C. Why is it difficult for staff to discuss advance directives with chronic dialysis patients? *Journal of the American Society of Nephrology*. 1996 Oct;**7**(10):2160-8.
9. Brown MA, Crail SM, Masterson R, et al. ANZSN Renal Supportive Care Guidelines 2013. *Nephrology*. 2013 Jun;**18**(6):401-54.
10. Street A, Ottmann G. State of the Science Review of Advance Care Planning models. Bundoora, Australia: La Trobe University 2006.
11. National Institute for Health and Clinical Excellence. Behaviour Change at Population, Community and Individual Levels. NICE Public Health Guidance. London: NICE 2007.
12. Ajzen I. From intentions to actions: A theory of planned behavior. In: Kuhl J, Beckmann J, editors. Action control: From cognition to behavior. Berlin, Heidelberg, New York: Springer-Verlag; 1985. p. 11-39.
13. Kortteisto T, Kaila M, Komulainen J, Mantyranta T, Rissanen P. Healthcare professionals' intentions to use clinical guidelines: a survey using the theory of planned behaviour. *Implement Sci*. 2010;**5**:51.
14. Kidney Health Australia. Dialysis unit guide. 2015 [cited 2015 6th June]; Available from: <http://www.kidney.org.au/ForPatients/DUGDialysisUnitGuide/tabid/607/Default.aspx>.
15. The Australian Health Practitioner Regulation Agency. Annual report 2010-2011. Brisbane: AHPRA 2012.
16. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Medical Journal of Australia*. 2007;**186**(12):S77- 108.
17. Cartwright CM, White BP, Willmott L, Williams G, Parker MH. Palliative care and other physicians' knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment: Survey results. *Palliat Med*. 2015 May 22.

18. Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of training methods. *Support Care Cancer*. 2005;**13**(6):356-66.
19. Moore PM, Wilkinson SSM, Rivera Mercado S. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev*. 2004;**2**:CD003751.
20. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med*. 2007;**167**(5):453-60.
21. Kidney Health Australia. Kidney disease - what are my treatment options? 2015 [cited 2015 May 8]; Available from: <http://www.kidney.org.au/ForPatients/Treatmentoptions/tabid/604/Default.aspx>.
22. National Kidney Foundation. NKF Brochures. 2015 [cited 2015 August 26]; Available from: https://www.kidney.org/atoz/atozTopic_Brochures.
23. Patients AAOk. Who Needs An Advance Health Care Directive. 2006 [cited 2015 August 26]; Available from: http://www.kidneysupportivecare.org/Files/Articles/WhoNeedsACD_AAKP2006.aspx.
24. Australian Health Ministers' Advisory Council. A national framework for advance care directives. Available online at www.ahmac.gov.au: AHMAC2011 September.
25. nehta. nehta home page. 2015 [cited 2015 May 20]; Available from: <http://www.nehta.gov.au/>.
26. Davison SN, Jhangri GS, Holley JL, Moss AH. Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol*. 2006 Nov;**1**(6):1256-62.
27. Holley JL. Advance care planning in elderly chronic dialysis patients. *Int Urol Nephrol*. 2003;**35**(4):565-8.
28. Australian Institute of Health and Welfare. Chronic kidney disease in Aboriginal and Torres Strait Islander people. Canberra: AIHW2011 Contract No.: PHE 151.
29. Bristowe K, Horsley HL, Shepherd K, et al. Thinking ahead--the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. *Palliat Med*. 2015 May;**29**(5):443-50.
30. Australian Bureau of Statistics. Census of Population and Housing, 2011 Canberra2012.

TABLES

Table 1. Characteristics of participants (N=375)

Characteristics of respondents	n (%)^a
Clinical role	
Nephrologists	85 (23%)
Nephrology nurses	243 (65%)
Nephrology social worker	15 (4%)
Other*	32 (8%)
Age (years)	
Mean (standard deviation)	48.7 (8.8)
≤ 45	116 (31%)
> 45	259 (69%)
Sex	
Male	76 (20%)
Female	299 (80%)
Place of birth	
Australia /New Zealand	263 (70%)
UK	46 (12%)
Asia	39 (10%)
Others	27 (8%)
State and Territories (% Australian population)†	
ACT (1.6)	6 (2%)
NSW (32.3)	139 (37%)
NT (1.0)	3 (1%)
QLD (20.2)	64 (17%)
SA (7.3)	23 (6%)
TAS (2.3)	18 (5%)
VIC (24.9)	81 (22%)
WA (10.4)	26 (7%)
New Zealand	15 (4%)
Religious views self-reported to influence approach to ACP	
None	342 (91%)
Christianity	27 (7%)
Others	6 (2%)
Years of experience in nephrology	
≤10 years	113 (30%)
10 +	262 (70%)
Work setting (multiple responses)	
Dialysis unit	289 (77%)
Outpatient renal clinic	156 (42%)
Inpatient ward	138 (37%)
Private practice	42 (11%)
Others	40 (10%)
In charge of a renal unit	
Yes	106 (28%)
No	269 (72%)
Training in ACP	

Online	89 (24%)
Attend lecture and workshop	250 (67%)
Small group experiential	58 (16%)
Simulated patient	34 (9%)
Role play in a small group	36 (10%)
Mentoring from colleagues	86 (23%)
Feedback from supervisor or mentor	29 (8%)
Others	105 (28%)
Knowledge of state and national legal framework of ACP	
Detailed knowledge of most aspects	23 (6%)
Working knowledge of important features	252 (68%)
No knowledge or almost no knowledge	96 (26%)
Agreement that 'the need to discuss ACP does not arise in my clinical practice'	
Strongly disagree	218 (58%)
Disagree	113 (30%)
Agree	27 (7%)
Strongly agree	15 (4%)
Agreement that 'ACP discussions are not part of my role'	
Strongly disagree	210 (56%)
Disagree	127 (34%)
Agree	27 (7%)
Strongly agree	9 (3%)

^a Frequency may not add to 375 due to missing data and percentages may not add to 100% due to rounding;
[†]Based on demographic data from the Australian Bureau of Statistics ³⁰; * Clinical roles classified as 'other' included educators, nurses from specialties other than nephrology (e.g. palliative care), psychologists, dietitians and managers. ACP = advance care planning; ACT = Australian Capital Territory; NT = Northern Territory; NSW = New South Wales; Qld = Queensland; SA = South Australia; Tas = Tasmania; Vic = Victoria; WA = Western Australia; UK = United Kingdom.

Table 2. Results from survey questions asking about current practice in ACP for patients with CKD (N=375)

Question/response options	N (%)
With what proportion of dialysis patients do you discuss ACP? All or almost all A majority A minority None or almost none N/A (I don't look after this group of patients)	62 (17%) 60 (16%) 145 (39%) 92 (24%) 14 (4%)
With what proportion of end stage kidney disease patients who are being managed with a supportive care approach do you discuss ACP? All or almost all A majority A minority None or almost none N/A (I don't look after this group of patients)	87 (23%) 56 (15%) 54 (15%) 131 (35%) 45 (12%)
With what proportion of CKD patients (GFR<30mls/min/1.73m ²) who are considering their treatment options do you discuss ACP? All or almost all A majority A minority None or almost none N/A (I don't look after this group of patients)	41 (11%) 64 (18%) 102 (27%) 128 (34%) 38 (10%)
Across patient groups, in what proportion of ACP discussions do you involve the patient's family as well as the patient? All or almost all A majority A minority None or almost none N/A (I don't discuss ACP with patients)	94 (25%) 109 (29%) 88 (24%) 44 (12%) 38 (10%)
Agreement that 'I lack access to appropriate ACP materials for CKD patients' Strongly disagree Disagree Agree Strongly agree	97 (26%) 139 (37%) 99 (27%) 38 (10%)
Who mostly initiates ACP with CKD patients in your experience? Myself The patient The family (Another) nephrologist (Another) nurse (Anther) social worker Patient's GP Another health professional from other team It varies too much to say N/A - rarely initiated	105 (28%) 15 (4%) 1 (0.3%) 49 (13%) 45 (12%) 29 (8%) 5 (1%) 10 (3%) 88 (24%) 26 (7%)
Proportion answering 'skilled' or 'very skilled' to the question 'Please indicate how skilled you feel, or would feel, in doing the following with your patients?' Discussing ACP	243 (66%)

Question/response options	N (%)
Assisting patients to complete an Advance Care directive	170 (46%)
Discussing prognosis	250 (67%)
Discussing death and dying	287 (77%)
Discussing potential future withdrawal or withholding of dialysis	289 (78%)
Discussing whether or not to attempt CPR or intensive care	264 (71%)
Proportion answering 'comfortable' or 'very comfortable' to the question 'Please indicate how comfortable you feel, or would feel, in discussing the following with your patients?'	
ACP	310 (84%)
Prognosis	292 (78%)
Death and dying	307 (83%)
Potential future withdrawal or withholding of dialysis	319 (86%)
Whether or not to attempt CPR or intensive care	292 (78%)
At your primary work place, how routinely is ACP discussed with the patients on dialysis?	
Never and hardly ever	61 (17%)
Some of the time	161 (45%)
Most of the time	68 (19%)
Always or almost always	45 (13%)
Unsure	18 (5%)
N/A (my work place does not look after this group of patients)	8 (2%)
At your primary work place, how routinely is ACP discussed with patients with end stage kidney disease who are being managed with a supportive care approach (i.e. dialysis will not be commenced even if the patients renal function further deteriorates)?	
Never and hardly ever	47 (13%)
Some of the time	82 (23%)
Most of the time	71 (20%)
Always or almost always	95 (26%)
Unsure	25 (7%)
N/A (my work place does not look after this group of patients)	41 (11%)
At your primary work place, how routinely is ACP discussed with CKD patients (with a GFR<30mls/min/1.73 m ²) who are considering their treatment options (e.g. different types of dialysis, transplant or supportive care)?	
Never and hardly ever	57 (16%)
Some of the time	134 (37%)
Most of the time	64 (18%)
Always or almost always	46 (13%)
Unsure	25 (7%)
N/A (my work place does not look after this group of patients)	35 (10%)
Across patient groups, what proportion of patients at your primary work place have a completed advance care directive in their medical file (paper and/or electronic)?	
All or almost all	11 (3%)
A majority	35 (10%)
A minority	220 (61%)
None or almost none	62 (17%)
Unsure	33 (9%)
At your primary work place, at what stage of a patients kidney disease is a	

Question/response options	N (%)
conversation about ACP usually first initiated? ESKD (dialysis, transplantation or conservative care pathway with eGFR<15ml/min/1.73m ²)	63 (17%)
CKD stage 5 (pre-dialysis)	65 (18%)
CKD stage 4	46 (13%)
CKD stage 3 or earlier	10 (3%)
Not initiated	17 (5%)
Unsure	49 (14%)
It varies so much could not say	90 (25%)
Others	21 (6%)
Who most often carries out Advance Care Planning (ACP) at your primary work Place?	
Nephrologists	102 (28%)
Nephrology registrars	12 (3%)
Nurses	54 (15%)
Social workers	39 (11%)
ACP facilitator	31 (9%)
Health professional from another team	5 (1%)
Unsure	22 (6%)
It varies so much could not say	44 (12%)
Not initiated	9 (3%)
Others	43 (12%)
Which of the following most accurately reflects current practice in ACP at your primary work place?	
A formal program of ACP is implemented	81 (22%)
ACP is done on ad hoc basis at the discretion of individual clinicians	201 (54%)
ACP never or hardly occurs	50 (13%)
Unsure	29 (8%)
Which ACP program(s) and/or materials are used at your primary work place? Tick as many as apply.	
CKD-specific program/materials developed	59 (16%)
Kidney Health Australia information	91 (24%)
Generic program developed by health area	93 (25%)
Generic state and national program	97 (26%)
A range of program/materials at the discretion of the user	67 (18%)
Unsure	110 (29%)

ACP = advance care planning; CKD = chronic kidney disease

Table 3. Results from survey questions asking about ways to improve ACP for patients with CKD (N=375)

Question/response options	N (%)
How well do you think ACP is currently undertaken in your primary work place?	
Very poorly	61 (17%)
Poorly	159 (44%)
Well	92 (26%)
Very well	23 (6%)
Unsure	26 (7%)
Answered 'somewhat of a barrier' or 'substantial barrier' to the question 'please rate the degree to which you perceive the following to be barriers to ACP at your work place'.	
Lack of clinician time	290 (82%)
Patient/family discomfort in discussing end-of-life care	298 (84%)
Health professional discomfort in discussing end-of-life care	257 (72%)
Health professional lack of experience in discussing ACP	294 (83%)
Difficulty involving family	293 (83%)
Discouragement from colleagues or manager	69 (19%)
Lack of policy or procedures for ACP	212 (59%)
Environmental problems (e.g. lack of space)	215 (61%)
Cultural or language barriers	232 (65%)
Answered 'somewhat helpful' or 'very helpful' to the question 'please rate the degree to which you think the following might facilitate ACP at your work place'.	
More education about ACP for health professionals in the renal team	335 (95%)
Make ACP the role of a specially trained health professional	300 (85%)
More CKD-specific ACP program/education materials	340 (97%)
What sort of health professional education or training about ACP do you think would be helpful? Tick all that apply	
Online	231 (62%)
Attending a lecture or workshop	270 (72%)
Small group experiential learning	203 (54%)
Practice with a simulated patient or caregiver with feedback from a facilitator	145 (39%)
Practice in role play in a small group with colleagues playing the role of a patient or caregiver	110 (29%)
Mentoring from a colleague	196 (52%)
Feedback from a supervisor or mentor after observing me talking about ACP with a patient and/or family member	110 (29%)
Don't think training is useful	9 (2%)
Others	27 (7%)
Which health professionals should be targeted for ACP training within your renal unit, clinic or ward? Tick all that apply.	
Renal nurses	315 (84%)
Nephrologists	296 (79%)
Renal registrars	247 (66%)
Renal social workers	255 (68%)
No health professionals	9 (2%)
Others	37 (10%)
Answered 'essential' to the question 'To what extent do you think the	

Question/response options	N (%)
<p>following contents should be included in patient and family CKD-specific ACP education materials and/or discussions, over and above those in general resources (e.g. information about CPR/ventilation and surrogate decision-making)?</p> <p>Information about disease trajectory in CKD</p> <p>Information about prognosis on dialysis</p> <p>Information on the option to withdraw from dialysis</p> <p>Practicalities of dialysis withdrawal</p> <p>Information about conservative care including symptom management</p> <p>First-person accounts from other CKD patients /family</p>	<p>285 (81%)</p> <p>323 (92%)</p> <p>333 (95%)</p> <p>303 (87%)</p> <p>332 (95%)</p> <p>170 (49%)</p>
<p>When do you think is the best time to begin to discuss ACP with patients with CKD who are receiving or being considered for dialysis? Please tick only one option.</p> <p>With all patients when considering treatment options (e.g different types of dialysis or supportive care)</p> <p>With all patients before starting dialysis as part of pre-dialysis education</p> <p>With all patients after starting dialysis</p> <p>Only when the patient has poor prognostic factors (e.g. elderly, significant co-morbidities, if you wouldn't be surprised if they were to die within 12 months) or patients choosing a supportive care pathway to care</p> <p>Optimal timing varies between patients</p>	<p>208 (59%)</p> <p>68 (19%)</p> <p>8 (2%)</p> <p>20 (6%)</p> <p>46 (13%)</p>
<p>How often should ACP ideally be discussed with patients who are receiving dialysis? Tick all that apply.</p> <p>Annually</p> <p>When there is a change of clinical status</p> <p>Whenever the patient requests it</p> <p>Other</p>	<p>174 (46%)</p> <p>260 (69%)</p> <p>196 (52%)</p> <p>39 (10%)</p>

ACP = advance care planning; CKD = chronic kidney disease

Table 4. Descriptive summary of free text comments related to improving advance care planning for people with chronic kidney disease

Suggestions	Illustrative verbatim comments
<u>Societal</u>	
Address community myths	<p>“Unrealistic expectations of the community in general” (barrier)</p> <p>“Stigma that 'palliative care' = death imminent still persists in some people’s minds” (barrier)</p>
<u>Health System</u>	
Health professionals across settings share responsibility for ACP	<p>“GP's and practice nurses play an important role with this group of patients”</p> <p>“Often the life-limiting condition is non-renal. Therefore I wonder if we should be taking up the discussion for the cardiologists”</p>
Develop better systems for sharing ACDs	<p>“Once a ACP is in place it is not always adhered to because there seems to be a lack of being able to communicate this across other services” (barrier)</p> <p>“Integrated eMR tools that allow documentation to a source of truth than can be shared across the health system, including to the PCEHR” (facilitator)</p>
Involve palliative care	<p>“More involvement with palliative care” (suggestion for improving ACP)</p> <p>“I use palliative care doctors to help me”</p>
<u>Health Service</u>	
Acknowledge ACP importance through dedicated time, space and resources	<p>“Due to the number of patients under the care of the renal unit it is hard to allocate sufficient time to dedicate an appropriate degree of time to discuss in depth ACP”</p> <p>“Current clinic demands mean there is no space available to have dedicated ACP clinics”</p> <p>“Previously our renal unit had a staff member who was working for the ACP unit specifically to see the renal patients but funding was not continued and therefore the percentage of our patients completing the ACP has decreased”</p>
Integrate ACP into routine care	<p>“Stop making it a special deal, make it routine, link to Medicare card”</p> <p>“Should be a formal step in the CKD pathway”</p>
<u>Clinician</u>	
Provide more education and training	<p>“More education will increase acceptance”</p> <p>“Educate staff to become skilled in ACP discussions”</p>
Foster support among colleagues (especially nephrologists)	<p>“Old school physicians who don't have inclination and/or the skills to undertake ACP but won't allow others to facilitate the process” (barrier)</p> <p>“Often feel that we are restricted by what the nephrologist wants for the patient”</p>
<u>Patient / Family</u>	
Overcome reluctance to discuss ACP	<p>“People will often join in a discussion about ACP but are reluctant to go to the next step”</p> <p>“Patients unwilling to discuss ACP”</p>
Ensure patients are informed	<p>“Poor health literacy - patients not understanding the concepts well” (barrier)</p> <p>“Patient and family unrealistic expectations despite being fully informed” (barrier)</p>
Engage families	<p>“We do not see a lot of some families so this is a challenge”</p> <p>“Families disagree with the patients wishes and convince them to change their decisions” (barrier)</p>
<u>Materials / Resources</u>	

Cater for variability

“The problem with general information and particularly content about trajectory is that patients differ”

“Culturally appropriate material, material available in several languages”

ACD = advance care directive; ACP = advance care planning; eMR = electronic medical record; PCEHR = Personally Controlled Electronic Health Record (now rebadged as ‘My Health Record’)

AUTHOR'S COPY

Table 5. Results of unadjusted bivariate associations between variables of interest and the extent of involvement in ACP discussions with dialysis, end stage, and chronic kidney disease patients

Variables	Patients on dialysis	Patients with end stage kidney disease being managed with a supportive care approach	Patients with CKD (with a eGFR<30mls/min/1.73m²) who are considering treatment options
<u>Characteristics</u>			
Clinical role non-physician	P<0.001	P<0.01	P<0.001
Sex		P<0.001	P<0.001
Age group (above/below 45 yrs)		P<0.01	P<0.05
In charge of unit		P<0.01	P<0.01
<u>Attitudes</u>			
The need to discuss ACP does not arise in my clinical practice	P<0.001	P<0.001	P<0.001
ACP discussions are not part of my role	P<0.001	P<0.001	P<0.001
<u>Skills, confidence and knowledge</u>			
ACP training	P<0.001	P<0.01	P<0.05
Skills discussing ACP	P<0.001	P<0.001	P<0.001
Comfort discussing ACP	P<0.001	P<0.001	P<0.001
Knowledge about ACP legislature	P<0.001	P<0.001	P<0.001
<u>Perception of barriers and facilitators</u>			
Discouragement from colleagues or manager	P<0.01		
Lack of policy or procedures for ACP	P<0.001	P<0.05	
Agrees they lack access to appropriate ACP materials for CKD patients	P<0.001	P<0.001	P<0.001
Agrees more education about ACP would be helpful	P<0.05	P<0.001	P<0.05
Agrees that making ACP the role of a specially trained health professional would be helpful	P<0.01	P<0.01	P<0.001
<u>Other</u>			
Patients in this group seen each month		P<0.001	P<0.001
Unit's ACP practice with this group	P<0.001	P<0.001	P<0.001

Table 6. Results from the multiple linear regression analysis for the extent of involvement in ACP discussions with three groups of patients: those on dialysis, those with end stage kidney disease on supportive care and those with chronic kidney disease considering their treatment options

Variables*	Patients on dialysis		Patients with end stage kidney disease being managed with a supportive care approach		Patients with CKD (with a GFR<30mls/min/1.73m ²) who are considering treatment options	
	β (s.e.)	Significance	β (s.e.)	Significance	β (s.e.)	Significance
<u>Characteristics</u>						
Clinical role non-physician			-0.81 (0.12)	P<0.001		
In charge of unit			0.38 (0.11)	P<0.001	0.40 (0.10)	P<0.001
<u>Attitudes</u>						
The need to discuss ACP does not arise in my clinical practice	-0.31 (0.15)	P<0.05	-0.59 (0.16)	P<0.001		
ACP discussions are not part of my role	-0.45 (0.17)	P<0.01			-0.72 (0.17)	P<0.001
<u>Skills, confidence and knowledge</u>						
Skills discussing ACP	0.05 (0.01)	P<0.001	0.07 (0.02)	P<0.001	0.05 (0.02)	P<0.01
Knowledge about ACP legislature	0.19 (0.08)	P<0.05				
<u>Perception of barriers and facilitators</u>						
Agrees that making ACP the role of a specially trained health professional would be helpful					-0.16 (0.06)	P<0.01
<u>Other</u>						
Patients in this group seen each month			0.22 (0.08)	P<0.01	0.23 (0.05)	P<0.001
Unit's ACP practice with this group	0.60 (0.05)	P<0.001	0.47 (0.05)	P<0.001	0.38 (0.05)	P<0.001

* Only variables that maintained a significant relationship (p<0.05) after controlling for other variables are listed

DRAFT COPY

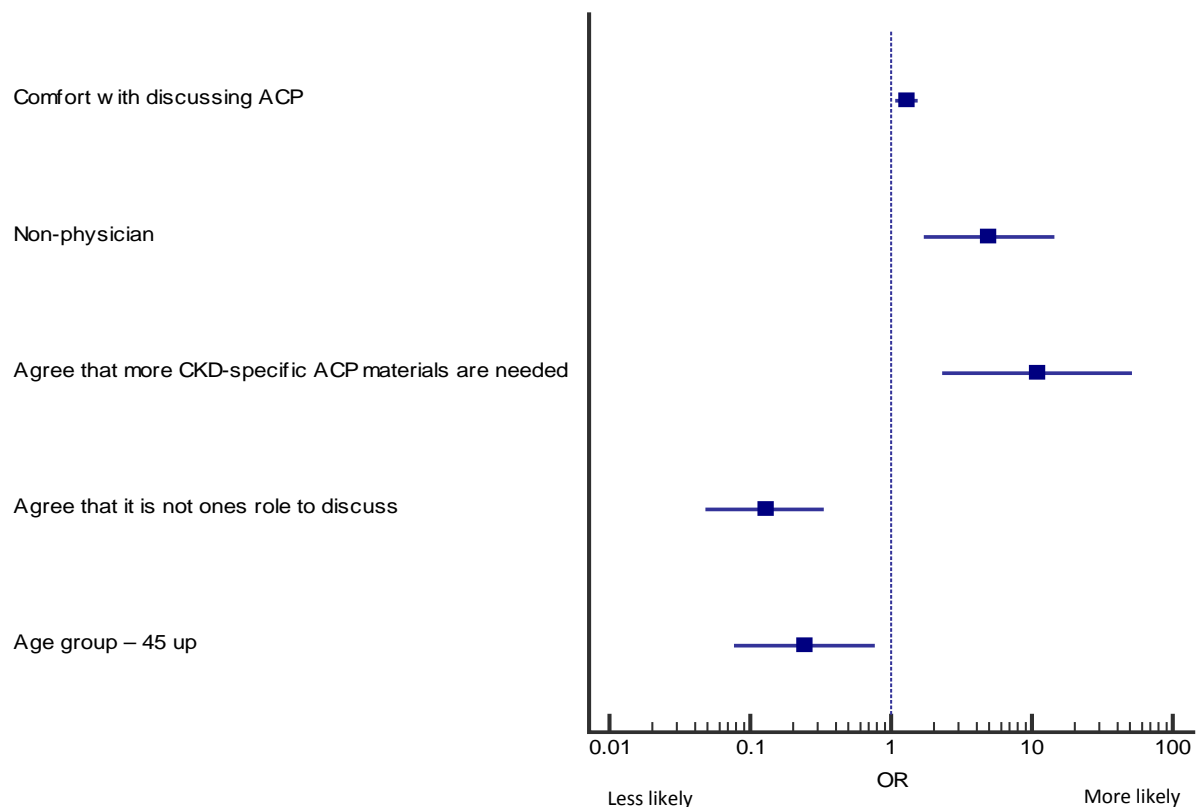


Figure 1. Forest plot of the Odds Ratios and 95% Confidence Intervals of variables associated with the intention to engage more often in ACP discussion in the future