

# Planning for end of life care in dialysis

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## Abstract

**Background** With the increasing age and complex comorbidities of dialysis patients globally, there has been increased attention to planning for end of life care (EoLC) and advanced care directives.

**Objectives** We sought to understand the thoughts and experiences of dialysis patients in relation to EoLC planning.

**Methods** An eight-question closed-ended survey at two time points 12 months apart through our Renal Supportive Care Program. All people undergoing dialysis in the service were invited to participate.

**Results** There were good response rates to the survey at both time points (T) (T1 n=224 T2 n=247) and, for the majority, planning for EoLC was considered to be very important (80%). However, only 23% reported having a conversation with their healthcare provider regarding advanced care directives and only 30% had documented their future care goals. At T2 there was an increased awareness of planning in this population which resulted in an improvement in advanced care directives (40%). This study suggests that there is a subgroup of patients who are aware of advanced care directives but do not have any in place.

**Conclusion** There is an ongoing reluctance in dialysis units by patients to have a conversation with their healthcare providers regarding advance care directives despite this population being at heightened risk of deterioration. This is likely impacting on the delivery of complex and possibly unnecessary and unwanted invasive care in the last year/s of life.

## Introduction

Healthcare services continue to strive to improve the safety and quality of healthcare to ensure that we achieve the best possible health outcomes. In dialysis care, this should include addressing the important area of advanced care planning (ACP) and planning for end of life care (EoLC). There is an increase

globally in the incidence and prevalence of end-stage kidney disease (ESKD) and a considerable increase in the number of people with ESKD who are older ( $\geq 65$  years) and have multiple comorbidities (Australian and New Zealand Dialysis and Transplantation Registry, 2017). This means that EoLC planning should be a routine part of clinical practice.

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Quality improvement initiatives to improve EoLC have focused on designing or redesigning care processes to enable patients and their families to experience a “good death” (Lazenby et al., 2017). Guidelines on the delivery of EoLC for people with complex medical conditions inclusive of ESKD have been developed and recommend the timely identification of people who might benefit from supportive and palliative care and coordinated future care planning alongside management of their underlying comorbidities (Lazenby et al., 2017). This is central to improving care for the growing number of people whose health is deteriorating due to one or more advanced illnesses (Haberle, Shinkunas, Erekson, & Kaldjian, 2011; Mullick, Martin, & Sallnow, 2013; Orosz et al., 2014). Ineffective EoLC planning and clinical communication affects the patient, family, clinicians, and the organisation, and has been identified as a leading cause of increased healthcare utilisation in the last year of life (Burgess, Braunack Mayer, Crawford, & Beilby, 2013; Deep, Griffith, & Wilson, 2008; Detering, Hancock, Reade, & Silvester, 2010; Haberle et al., 2011).

In 2013, the advanced care directive (ACD) act came into effect in South Australia which “allows competent adults to write down their instructions, wishes and preferences for future healthcare, residential accommodation and personal matters” (Government of South Australia, 2013). Since 1 July 2014, the ACD document has been the only legal document that people can complete; however, superseded documents completed before 1 July 2014 are still valid and are covered by law under this act. The act also allows “competent adults to appoint one or more Substitute Decision-Makers to make decisions on their behalf” in the event of deteriorating health. The ACD act was introduced to improve the level of satisfaction with EoLC, improve bereavement outcomes, and avoid unwanted and/or inappropriate interventions and/or hospitalisation (Government of South Australia, 2013).

People with ESKD are chronically ill and particularly vulnerable to life-threatening events. This group of renal patients in the last year/s of life often have ongoing declining health, resulting in increasingly complex healthcare needs requiring management by multidisciplinary healthcare teams. This project sought to understand the thoughts and experiences of dialysis patients in relation to EoLC planning. It is well recognised that patient involvement in healthcare decision-making empowers patients and improves outcomes (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014).

## Objectives

The creation of the Renal Supportive Care (RSC) program for deteriorating/frail patients on dialysis was created in our service in 2017. Led by a multidisciplinary group, including a renal supportive care nurse practitioner, the team includes an RSC clinical nurse and link nurses in all country and metropolitan dialysis units. One of the aims of the RSC program is to ensure

all dialysis patients within the service are informed of, or have in place, ACD. This project surveyed a cohort of dialysis patients to determine perceptions of EoLC planning and experiences of conversations with their healthcare professional (HCP) regarding ACD. The implementation of this project enabled HCPs to have an improved understanding of patient's wishes whilst on dialysis and the use of ACD, and heightened consumer awareness of the importance of ACD.

## Methods

This project was reviewed by a human research ethics committee (reference number HREC/17/RAH/553). The data survey instrument consisted of eight closed-ended questions on a single page relating to the importance of EoLC planning, the respondent's knowledge relating to ACP, and obtaining information regarding EoLC including ACD. These eight closed-ended questions can be seen in Table 1. The patient information sheet provided with the survey stated:

*Advance Care Planning refers to both legal advance directives and informal advance directives. The documents provide your healthcare team with current information regarding your wishes in the event of something happening to you and you are no longer able to communicate your wishes regarding your future healthcare. Planning for end of life can take place at any time and can be changed as your health changes.*

The inclusion criteria for this study were, adult patients undergoing chronic dialysis and with no current acute illness, able to understand English, and with no cognitive impairment. The survey was distributed to all eligible dialysis patients through the RSC link nurses for time point 1 (T1) in February 2018 and time point 2 (T2) in May 2019. This renal service has a median patient age of 69 years and the survey respondents were primarily haemodialysis. Less than 10% of dialysis patients in the renal service where the survey data was collected are treated with peritoneal dialysis which makes the sample representative. The data were aggregated for each question (1–8) and reported as percentages of Yes/No answers (Table 1).

## Results

The first survey (T1) received good levels of participation, with 42% of all patients in the service (n=224) responding. At T2, there were 247 (39%) respondents, and 99 of these had already completed ACD. The survey for T2 was continued with the 148 respondents who did not already have ACD in place as those with ACD did not need to answer any further questions.

As Table 1 describes, at T1 EoLC planning appeared to be very important, with 80% of the respondents indicating that this was the case. Whilst about half respondents had heard of ACD, only 34% had been given information about completing these and only 23% reported that they have had a conversation

with a HCP regarding ACD. Noting that, at T2, some patients surveyed at T1 had received a renal transplant or had died and new patients had commenced dialysis, so it is important to recognise that the two populations largely overlap but are not exactly the same.

At T2, as previously described, 99 respondents had ACD in place. Of the remaining respondents, there was a consistently demonstrated need for information (49%) and increased awareness of ACD in this group, particularly in the form of increased awareness of access to information in the dialysis unit. However, discussion of ACD with HCP remained static, suggesting that the increased awareness in isolation does not translate to ACD conversations beyond the dialysis unit or in fact to an increase in the rate of completed ACD. At T2, the number of respondents claiming they would like more information was stable at 50%. However, this was reduced by half regarding the willingness to attend an information session; this may be due to the group format of the information session being offered rather than a 1:1 conversation.

Whilst some respondents at both T1 and T2 were able to state there was ACD in place, they were not always able to describe which document had been completed, and some respondents had more than one instruction in place. Whilst ACD was popular, equally favoured was a Medical Power of Attorney and the Enduring Power of Guardianship. There was good uptake of the option to record an electronic medical health record (EMR) resuscitation plan; 27% suggesting that the respondents felt it was important to share this decision with their HCP during a hospital admission.

## Discussion

Our study has demonstrated that, whilst EoLC planning is important to people undergoing dialysis therapy, for a large number ACD is still not occurring. At T1 only 30% of survey respondents had ACD; however, at T2, with heightened awareness, this had increased to 40%.

There are potentially several reasons for low uptake of ACD in dialysis patients. Deciding to complete ACD is a very autonomous decision and qualitative research has found an ongoing reluctance by renal teams to raise the issue with dialysis patients. Some doctors describe ACP as something to avoid, and reasons given for why ACP is rarely carried out included difficulty raising the topic, a lack of training, education and experience, a lack of formal policy, a stronger focus on acute medical issues, and a lack of understanding of the legal implications (Lazenby et al., 2017). Given this, in the dialysis unit, with a focus on maintaining life, EoLC may be neglected or overlooked, yet mortality rates show that about 25% of patients in haemodialysis care are in their last year of life (Axelsson, Randers, Jacobson, & Klang, 2012).

There has been no previous Australian research describing the perspectives of people receiving dialysis and ACD which is surprising given that we are one of the few regions in the world in which ACD is not only legalised but also recognised as a healthcare priority. There have, however, been previous studies of dialysis patients and ACD in Ireland, Italy and North America. Collins & Lehane (2013) conducted a small study (n=50) in the Irish haemodialysis population and described that 78% of respondents were comfortable talking about death but that

Table 1. Survey responses by T1 and T2

Question number	Survey T1 (n=224)		Survey T2 (n=247; of whom n=148 without ACP are outlined here)	
	Yes	No	Yes	No
1. Is planning for EoL care important for you?	180 (80%)	37	106 (72%)	41
2. Have you heard of Advanced Care Directives?	95 (42%)	129	82 (55%)	66
3. Have you ever been given information on Advance Care Directives?	77 (34%)	145	63 (42%)	85
4. Have you had a discussion with a health professional regarding Advanced Care Directives?	52 (23%)	170	34 (23%)	114
5. Have you completed any of the following forms regarding your health*?	68 (30%)	150	99 (40%)	147
6. Are you aware that you can get information from your dialysis unit?	80 (36%)	143	70 (47%)	78
7. Would you like to receive more information on Advanced Care Directives?	144 (64%)	80	73 (49%)	74
8. Would you attend an information session on Advanced Care Directives?	109 (49%)	114	36 (24%)	112

\* If yes, please circle which one/s: Advanced Care Directive, The Good Palliative Care Plan, 7 Step Pathway, EPAS Resuscitation Plan, The Statement of Choices, Anticipatory Direction, Medical Power of Attorney, Enduring Power of Guardianship, Unsure.

more than half of respondents, if they were dying, would “want medical interventions to keep them alive as long as possible” (Collins & Lehane, 2013). In a similar study conducted in Hawaii (n=50), people receiving haemodialysis were comfortable talking about death; however, only 40% of respondents had completed an ACD (Kataoka-Yahiro, Conde, Wong, Page, & Peller, 2010). Panocchia et al. (2017) reported that a significant number of their Italian survey respondents did not want to be involved in EoLC decisions and that frail elderly patients want to continue dialysis despite having a poor quality of life or a poor prognosis (Panocchia et al., 2017). This is mirrored in qualitative work in an American population that focused on haemodialysis patients' perspectives on ACP (n=20) and described the participants' desire to focus on living rather than dying (Calvin, 2004).

Our study concurs that, globally, there appears to be a consensus that, whilst comfortable talking about death, many dialysis patients remain reluctant to formally plan for death. Kidney Health Australia provides resources for consumers and HCPs to access support conversations regarding ACP (Kidney Health Australia, 2017). Yet both the patient-perceived and clinician-perceived barriers that impede the process of shared decision-making in relation to ACP have not yet been fully elucidated. This study has, however, identified good uptake of a documented resuscitation plan in this population (27%) which is much higher than reported previously in a large Australian study of hospital admissions (7.5%) (Smith et al., 2017).

### Study strengths and limitations

The survey instrument used has not been previously validated; however, its strength is its simplicity in capturing central concepts in EoLC. A limitation of the data collected is that the reason for patients stating ‘No’ for ACD does not explore the reasons why. A further limitation is that no clinical data about the survey responders were collected as we surveyed the patients across the service irrespective of age or comorbid conditions. An additional strength of the study, however, is that this survey has included a much larger sample size than the previously reported research on this topic.

### Implications for clinical practice

Ideally, planning for EoLC and ACD before clinical deterioration with ongoing review of the decision-making represents the best clinical practice and, by doing so, health services can reduce the complexity and the burden of treatment goals in the last year/s of life.

### Conclusion

Dialysis patients send ‘mixed messages’ to their HCP regarding planning for EoLC and preparing with ACD. Whilst indicating the value and importance of planning for EoLC, many dialysis patients still fail to undertake planning by way of ACD and there is an ongoing reluctance by clinicians and patients alike to

raise the issue before an unequivocal deterioration in condition becomes evident.

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### Author contribution

LL conceived and conducted the research and contributed to the manuscript, KB assisted with survey distribution and contributed to the manuscript, SC contributed to the manuscript, and KH analysed the data and drafted the manuscript.

### Conflict of interest

The authors declare no conflicts of interest.

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