

## The use of palliative care services amongst end-stage kidney disease patients in an Irish tertiary referral centre

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### Abstract

**Background.** Although patients with end-stage kidney disease (ESKD) have a shortened life expectancy, their end-of-life (EOL) care is suboptimal. The aim of this study was to review the utilization of specialist palliative care (SPC) in patients with ESKD in Dublin, Ireland.

**Methods.** We conducted a retrospective chart review of prevalent patients with ESKD who died between January 2005 and December 2009 at a tertiary referral centre. We recorded SPC referrals, modality of renal replacement therapy, age and place of death.

**Results.** Of 131 included patients, 88 (67.2%) were male, mean age at death was  $63.2 \pm 15.1$  years and 102 (77.9%) were treated with haemodialysis. Forty-eight patients (36.7%) were referred to SPC, who were involved in the patients' management for a median of 12 days (range 0–907) before death. A total 104 patients (79.4%) died in an acute hospital, 19 (14.5%) died at home, 3 (2.3%) died in an inpatient hospice and the place of death was unknown for 5 patients (3.8%). Dialysis was withdrawn prior to death in 50 patients (38.1%), with a median time to death after withdrawal of dialysis of 6 days (0–105 days). A discussion regarding the withdrawal of dialysis was more frequently held with family member(s) rather than the patient.

**Conclusions.** SPC was involved in the antemortem care of  $\sim 1/3$  of the patients with the majority of referrals placed at a late stage. Given the short timeframe until death once dialysis is withdrawn, it is imperative that appropriate EOL care is instituted. This study identifies an underutilization of SPC and improved integration of palliative care and nephrology services may optimize EOL care for patients with ESKD.

**Keywords:** dialysis; end-of-life care; end-stage kidney disease; palliative care; withdrawal of dialysis

### Background

It is well documented that as the glomerular filtration rate declines, patient mortality increases [1]. Studies have consistently shown that patients with end-stage kidney disease (ESKD) have a shortened life expectancy [2]. The illness trajectory of patients with ESKD is not well described. Although some patients have a gradual steady decline, punctuated by periods of acute illness, many exhibit a gradual deterioration in their functional status before a more abrupt decline in the final weeks of life [3]. Murtagh *et al.* demonstrated that the functional status of the ESKD patient managed conservatively is maintained until the last 1–2 months of life, when an abrupt decline is observed [4]. Patients with ESKD appear to have a shorter duration of terminal illness than that described for many other chronic conditions. The major causes of death amongst dialysis patients are cardiovascular disease, infection and withdrawal from dialysis [5]. Cardiovascular death includes sudden cardiac death and cardiac arrest,

and is estimated to account for between 22 and 27% of deaths in dialysis patients [6, 7]. Despite the shortened life expectancy amongst dialysis patients, advance directives are underutilized by this population [8] and many dialysis patients feel they are inadequately educated about their options in terms of withdrawal from dialysis and end-of-life (EOL) care [9]. Dialysis patients have been found to suffer a high burden of symptoms and pain, comparable with cancer sufferers [10, 11]. This burden is often underestimated by physicians. Specialist palliative care (SPC) services can have an integral role in guiding nephrologists in the management of these symptoms as well as in EOL care. There are very few studies looking at the utilization of palliative care services and the implementation of EOL care by nephrologists.

The purpose of this study was to retrospectively investigate the EOL care of dialysis patients in a Dublin teaching hospital. Our aim was to review our utilization of SPC services and assess the degree to which the patient was involved in the decision-making process, particularly looking at the use of advance care planning (ACP).

## Materials and methods

A retrospective chart review of patients undergoing renal replacement therapy (RRT) (haemodialysis and peritoneal dialysis) at a large university teaching hospital was performed. The study location is a tertiary referral centre in Dublin, with a catchment population of ~600 000. It is one of four in-centre haemodialysis units in the region. Using the institution's renal database, patients who underwent dialysis and died between 1 January 2005 and 30 December 2009 were identified. In order to exclude patients with acute kidney injury, who have a higher mortality rate, only patients who had received either form of RRT for a minimum of 90 days were included. Data extraction focused on patient characteristics including age at commencement of dialysis, age at death, cause of ESKD, previous modalities of RRT and the Charlson comorbidity index (CCI). The CCI is a method of predicting mortality in various disease subgroups, based on the weighting of 19 specified comorbid conditions [12, 13]. The CCI used in this study included a point for every decade over 40 years.

To focus on the role of the SPC service, referral patterns were recorded including date of referral and the interval between referral and death. Patient resuscitation status was also reviewed, including the presence of an advance care plan (ACP). We considered an ACP to be a documented discussion about future care between the patient and their care provider. It should include discussions regarding the individual's wishes and their personal goals for care. This definition is based on the NHS National End-of-Life Care Programme Guidelines [14].

To review the EOL care decision process, we investigated if such decisions were made by the medical team alone or if the patient, family member/next of kin (NOK) or both were involved. Only discussions clearly documented in the medical notes could be recorded. We recorded if a decision had been made to withdraw dialysis and whether a documented discussion took place with the patient or a family member/NOK. In cases of withdrawal from dialysis, we recorded the number of days from last dialysis until death. The place of death was categorized as hospital, inpatient hospice, home or elsewhere.

Data were extracted using a proforma created in Microsoft Excel. Continuous variables are reported as mean/median with measures of central tendency and categorical variables are reported as proportions. Comparisons were performed using the  $\chi^2$ , independent samples *t*-test and one-way analysis of variance, where relevant and a two-sided *P*-value of <0.05 was considered statistically significant. Statistical analysis was performed using SPSS for Macintosh, version 20.0.

## Results

We identified 137 patients who were eligible for the study. Of these, six were excluded due to the lack of baseline data. The modality of RRT prior to death was haemodialysis for 102 (77.9%) patients and peritoneal dialysis for 29 (21.9%). Eighty-eight patients were male (67.2%) and 43 were female (32.8%). The mean age at death was  $63.2 \pm 15.1$  years after a median of 27 months of dialysis (range 3–318). The mean CCI was  $7.9 \pm 2.5$ . CCI and age were significantly correlated ( $r=0.564$ ,  $P<0.001$ ). No differences between those referred to SPC and those not referred to SPC were observed (Table 1).

### SPC referrals

A referral to SPC services was placed in 48 (36.7%) cases, with a median duration of involvement of 12 days before death (range 0–907). Two patients were referred to SPC services over 1 year before their death, the first, referred 907 days prior to death, was for control of symptoms associated with chronic liver disease and chronic kidney disease and not in anticipation of an imminent decline. The second, referred 612 days prior to death, was for the management of a complex pain syndrome.

### Place of death

The majority, 104 patients (78.5%), died in an acute hospital, 19 (14.5%) at home and 3 (2.3%) in an inpatient hospice (Table 2). The place of death was unknown for five patients (3.8%). Mean CCI was  $7.9 \pm 2.5$  for those who died in an acute hospital,  $7.6 \pm 2.9$  in those who died at home and  $11.0 \pm 3.5$  in those who died in an inpatient hospice ( $P=0.185$ ). The mean age of those who died in an acute hospital was  $63.4 \pm 15.5$  years,  $60.6 \pm 15.4$  years in those who died at home and  $68.0 \pm 4.6$  years in those who died in an inpatient hospice ( $P=0.788$ ).

### Withdrawal of dialysis

Dialysis was withdrawn in 50 cases, the majority of whom died in an acute hospital setting (79.5%). The median time from the withdrawal of dialysis to death was 6 days (0–105 days). SPC services were involved in the EOL care of 35 of these cases (70%). Dialysis was more likely to be withdrawn in cases where SPC was involved ( $P<0.001$ ) (Table 3).

### Decisions regarding the withdrawal of dialysis

We collected further data on the decision-making process (as documented in the medical records) for the 50 cases of dialysis withdrawal. A discussion with either the patient or a family member/NOK regarding the withdrawal of dialysis was documented in 43 (86.0%) of these cases. According to the medical records, this discussion was held with both the patient and the family in 9 (18.0%) cases. There was a documented discussion with the patient's family but not with the patient in 32 (64.0%) cases. There was a documented discussion regarding the withdrawal of dialysis with the patient but not their family in two (4.0%) cases. Dialysis was withdrawn with no documented evidence of a discussion having taken place with the patient themselves in 39 cases (78.0%). There was documentation of underlying cognitive impairment in the case of nine (23.7%) of these patients. We could find no documented discussion regarding the decision to withdraw dialysis for seven (14.0%) patients. We could not determine whether a discussion was held but not documented, or whether this represented a best interest decision.

### Resuscitation orders

A *Do Not Resuscitate* (DNR) order was documented in the chart of 68 patients (51.9%). This was more likely to be documented in the case of those referred to SPC services (36.1 versus 79.2%,  $P=0.005$ ).

**Table 1.** Baseline demographics

Predictor variable	All (n = 31)	Palliative care involvement (n = 48)	No palliative care involvement (n = 83)	P-value
Age at death, years (mean ± SD)	63.2 ± 15.1	64.0 ± 13.9	62.7 ± 15.7	0.625
Male gender	88 (67.2%)	32 (66.7%)	56 (67.5%)	0.925
Female gender	43 (32.8%)	16 (33.3%)	27 (32.5%)	
Haemodialysis	102 (77.9%)	38 (79.2%)	64 (77.1%)	0.785
Peritoneal dialysis	29 (22.1%)	10 (20.8%)	19 (22.9%)	
CCI (mean ± SD)	7.9 ± 2.5	8.4 ± 2.7	7.6 ± 2.4	0.081
Age at dialysis start, years (mean ± SD)	59.9 ± 15.6	60.8 ± 14.0	59.3 ± 16.6	0.506
Dialysis vintage, months (median, range)	27 (3–318)	21 (3–170)	34.5 (3–318)	0.237

**Table 2.** EOL care issues

	All (n = 131)	Palliative care involvement (n = 48)	No palliative care involvement (n = 83)	P-value
Dialysis withdrawn	50 (38.2%)	35	15	<0.001
Duration of palliative involvement in days (median, range)	12 (1–907)	12 (1–907)	–	–
DNR documented	68 (51.9%)	38 (79.2%)	30 (36.1%)	0.005
Place of death				
Home	19 (14.5%)	3 (6.2%)	16 (19.3%)	0.041
Hospital	104 (79.5%)	42 (87.5%)	62 (74.7%)	
Hospice	3 (2.3%)	3 (6.2%)	0	n/a
Elsewhere	5 (3.8%)	0	5 (6.0%)	n/a

**Table 3.** Withdrawal of dialysis

	Palliative care involved (n = 48)	Palliative care not involved (n = 83)	P-value
Dialysis withdrawn	35 (72.9%)	15 (18.1%)	<0.001
Documentation of discussion prior to withdrawal of dialysis	30 (85.7%)	13 (86.7%)	NS

## Discussion

The medical community is becoming increasingly aware of the important role that SPC services play in the management of patients with life-limiting, non-malignant disease, such as ESKD [15]. ESKD and dialysis place a significant burden of physical and psychological symptoms on a patient. This burden often coexists with the symptomatology of comorbid disease and advanced age. Worldwide, there are escalating numbers of elderly and multimorbid patients initiating dialysis [16, 17]. This necessitates a greater focus on EOL care and ACP by nephrologists. This 5-year study is the first to analyse the use of SPC services and EOL care issues amongst dialysis patients in Ireland.

### Referral to SPC services

There are data to suggest that up to 50% of dialysis patients experience chronic pain [18]. Fatigue, sleep disturbance, pruritus, poor appetite and nausea are also frequently reported [9, 19]. Despite the high symptom burden of ESKD, referral rates to SPC services are low [20]. Less than one-third of our study population was referred to SPC services. The majority of these referrals were sent

at a relatively late stage. Dialysis patients have complex and unique palliative care needs and the need for SPC involvement may arise years before death. We have identified an underutilization of SPC services as well as a general trend towards late referral of dialysis patients.

### Place of death

Almost 80% of our study population died in an acute hospital, regardless of the final modality of RRT. A small minority of our study population died in an inpatient hospice and only 14.5% died at home. By comparison, a study of lung cancer patients in Ireland found that ~50% of deaths occurred in an acute hospital, 29% occurred at home and 12% in inpatient hospices [21]. Our population of dialysis patients was more likely to die in hospital and less likely to die at home than patients with a solid organ malignancy. This difference may reflect the fact that dialysis patients have unique medical needs and often require ongoing nephrology care, even at the EOL. Fears and reservations about caring for an ailing dialysis-dependent patient at home can influence the decision to transfer them out of an acute hospital. Patients often opt to remain in the hospital where their renal care has been conducted for comfort reasons as well as for ease of access to ongoing therapies. We were surprised to find that only three patients in our study population died in an inpatient hospice. The duration of time from the withdrawal of dialysis to death is usually a number of days rather than weeks and unfortunately, the waiting period for an inpatient hospice bed often exceeds this timeframe. It is advisable to determine the patient's preferred place of death prior to the withdrawal of dialysis. If their preference is for a hospice death, this should be organized in advance of dialysis withdrawal.

Data on the preferred place of death for those with advanced CKD vary. Results from a UK study suggest that

~50% of patients with advanced chronic kidney disease have a preference to die in hospital [22], but a study by Davison found that this was the preference of approximately a quarter of patients [9]. Owing to the retrospective nature of our study, we cannot comment on preferred place of death for our study population. The high proportion of hospital deaths in our study may reflect patient preference. However, it is more likely that this is a reflection of the high level of comorbid illness of the dialysis population coupled with suboptimal ACP. Further investigation is required to determine why the majority of ESKD patients die in acute hospitals rather than at home.

#### *Withdrawal of dialysis*

Withdrawal of dialysis was found to be an important cause of death in our study population. There was a documented decision to withdraw dialysis in over one-third of patients. The proportion of deaths occurring in the setting of the withdrawal of dialysis is higher in our study than reported in other countries [23–28]. We have not differentiated between the withdrawal of dialysis as a cause of death and withdrawal of dialysis before death. Neither have we differentiated between cases in whom dialysis was withdrawn despite it being technically feasible and those in whom it was withdrawn due to factors which limited the ability to perform dialysis (e.g. hypotension and access difficulties). The median time to death after the withdrawal of dialysis was 6 days, with no statistically significant difference between haemodialysis and peritoneal dialysis patients. Once dialysis is discontinued, the time available to ensure optimal EOL care is short, highlighting the importance of ACP and ideally, referral to SPC services prior to making the decision to withdraw dialysis.

#### *Advance care planning*

In concordance with previous Irish data, only a minority of the study population had an advance care plan in place [29, 30]. There is currently no legislation in Ireland to recognize or enforce advance care directives. Irish people are not familiar with certain terminology used in relation to EOL care, with one survey reporting that 71% of respondents had never heard the term ‘advance directive’ before [29]. Evidently, efforts to improve public awareness are required but it is also imperative that physicians are mindful of the fact that patients and their families may not understand the terminology being used during ACP or EOL discussions.

#### *Discussions regarding EOL care*

In the majority of cases, patients did not appear to be involved in discussions regarding EOL care. In contrast to this was the finding that family members/NOK were frequently involved in the decision-making process. For example, there was a documented discussion with the family/NOK regarding the decision to withdraw dialysis in over 80% of cases. By comparison, documentation of the same discussion taking place with the patient themselves was found in only 24.5% of cases. Undoubtedly, family members play an important role in decision-making at the EOL; however, the patient is the major stakeholder in their own EOL decisions and their views must be respected. We cannot explain why EOL discussions were preferentially

held with family members, rather than the patient. One possible explanation is that physicians have concerns regarding the ability of a patient to understand or accept the decision being discussed with them. Irish people (particularly older people) place a great amount of trust in doctors when decisions regarding their medical care are required [29] and this finding may represent a feature of Irish healthcare. Timely ACP provides the patient with a forum to clearly document their wishes well in advance of a decline in their health. Our findings emphasize the importance of ACP in the ESKD population.

This study has a number of limitations. The main limitations are its retrospective design and reliance on documentation in the medical record. These effects were minimized by adoption of a systematic approach to patient identification and data extraction. There is likely to be regional variation in the availability of SPC and our results may not be truly representative of the overall Irish practice patterns. As we were unable to determine patient preference regarding the place of death, we cannot determine if our results mirror patients’ wishes. We have not differentiated between a ‘sudden’ death and an ‘expected’ death. A certain proportion of the home deaths may have been sudden in nature and therefore not reflective of a patient who is in a phase of anticipated decline in health. We encountered difficulties accessing all data in some cases, particularly those patients who died outside of the acute hospital setting. Despite its limitations, this study is the largest of its kind to analyse EOL care issues and the use of SPC services in an Irish ESKD population and provides an important insight into current EOL care practices.

## **Conclusion**

This study examines a population of established ESKD (predominantly haemodialysis) patients with a broad spectrum of baseline renal pathologies. The majority of patients died in an acute hospital without involvement from SPC services and dialysis was withdrawn in over one-third of patients. NOK or family members played an important role in the decision-making process in relation to EOL care, highlighting an important cultural trend in Ireland. It appears that the patient was less likely to be involved in decision-making, however, this may be attributable to poor documentation of discussions held by physicians.

We have identified an underutilization of SPC services amongst dialysis patients in our unit. This study highlights the need to structure EOL care planning on an individual patient basis. The cornerstone of such a strategy is the recognition of those patients who are at a high risk of death within the next 6–12 months and the identification of patients with a high burden of symptoms. Tools are available for both prognostication and symptom assessment in dialysis patients [31–34]. Universal screening of dialysis patients to determine their symptom burden and palliative care needs would be a helpful strategy to guide both nephrology and palliative care teams. Such a screening tool would alert dialysis staff to involve SPC services. At-risk patients require early referral to SPC services, who can provide valuable guidance in the management of many of the problematic symptoms associated with ESKD, even before the patient reached a terminal phase. We suggest that nephrologists hold a discussion with each patient regarding prognosis, goals of care and ACP. Important issues

to address include patient preferences regarding future hospitalizations (including the specific circumstances under which a patient would wish to be hospitalized), place of death, the withdrawal of dialysis and resuscitation. Ideally, this discussion should take place before dialysis initiation. Coordinated input from both nephrology and SPC teams will ultimately result in improved EOL care for ESKD patients.

*Conflict of interest statement.* None declared.

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