Predicting palliative care needs and mortality in end stage renal disease: use of an at-risk register

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ABSTRACT

Introduction The Gold Standard Frameworks (GSF) Committee devised Prognostic Indicator Guidance in November 2007 to 'aid identification of adult patients with advanced disease, in the last months or year of life, who are in need of supportive or palliative care'.

Methods This research used the GSF `surprise question' to formulate a list of patients predicted to die within 1 year with end stage renal failure and to establish the specificity and sensitivity of this register.

Results 58 patients were added to the list during the follow-up period of which 28 (48.3%) died during the same period giving an annual mortality of 32.2%. In comparison with the patients who died during the follow-up period but were not added to the at-risk register, those on the register had a much higher mortality rate (32.2% vs 7.8%). Identification of patients with chronic kidney disease and reduced life expectancy by this method appears to have a high sensitivity (66.7%) and specificity (77.9%). In particular, the negative predictive value for mortality for those on the at-risk register appears to be very high (88.3%), indicating the very low mortality among those not on the register.

Conclusions Patients with chronic kidney disease and a reduced life expectancy can be accurately identified by a multi-disciplinary team using the surprise trigger question with a relatively high sensitivity and specificity. The accurate identification of patients with reduced life expectancy allows appropriate end of life care planning to begin in keeping with patients' wishes and within published guidelines.

INTRODUCTION

There is increasing recognition of the need for good palliation of symptoms for those patients dying from non-malignant diseases.[1] Palliative medicine is therefore being seen more and more as an integral part of multi-disciplinary team (MDT) care for patients with end stage renal disease (ESRD), with end of life care being one of the quality requirements clearly stated in Part 2 of the National Service Framework for kidney disease.[2] The patients involved often have multiple comorbidities, requiring complex discussions and decisions about the appropriate use of various treatment options. Predicting how long patients may live can be very difficult in those with any disease but non-malignant diseases including end stage renal failure can be particularly challenging especially when complicated by coexisting illness and old age. Patients with end stage cancer tend to follow a more recognised trajectory of dying than those with non-malignant disease[3] and so any tools that may help guide prognosis can allow medical teams to identify patients at risk of dying. Identification of patients with ESRD who are in the last year of life can facilitate the process of advance care planning, the provision of care at the end of life and support for their families, which can mean a higher chance of a good quality death for patients.[4]

Prognostic Indicator Guidance, devised by the Gold Standard Frameworks Committee in November 2007, was created to 'aid identification of adult patients with advanced disease, in the last months or year of life, who are in need of supportive or palliative care'.[5] This work suggested asking whether professionals involved in a patient's care would be surprised if they were to die within a certain time frame and combining this opinion with patient choice and other clinical indicators, would identify the patients thought to be within the last year of life. It is thought that this identification would allow and encourage 'active support' for them during this period.[5] A paper by Moss

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et al[6] in 2008 validated the use of the surprise question by nurse practitioners in assessing the likely prognosis of dialysis patients with ESRD. A further paper by Cohen *et al*[7] evaluated an integrated prognostic tool incorporating both the surprise question and other predictors of survival, for example, age and comorbid conditions. The authors concluded that the tool 'lends itself to the stratification of (haemodialysis) patients' and the work demonstrated that use of the tool produced a higher degree of specificity and sensitivity than any of the individual components. However, to our knowledge no studies have yet been done assessing the use of the surprise question by an MDT of renal and palliative care professionals for patients with ESRD including those not receiving dialysis.

AIM OF STUDY

The aim of this study was to use the surprise question from the Prognostic Indicator Guidance to identify and predict which patients were most likely to die within a year from a single dialysis unit caring for patients on dialysis, those in a clinic looking after patients approaching ESRD and those with failing transplants. The specificity and sensitivity of our prediction tool were quantified.

METHODS

This study was prospective with data collected from February 2007 to July 2008. The 'at-risk' patients generally fell into four main patient groups at Southend General Hospital:

1. Predialysis patients choosing not to commence dialytic treatment or those who would not be fit enough.
2. Failing renal transplants (diagnosed by rising creatine levels and biopsy).
3. Dialysis patients withdrawing from therapy.
4. Patients who come to the end of their lives while on dialysis.

The main trigger for inclusion in this study was the 'surprise question' from the Prognostic Indicator Guidance. This is an intuitive question integrating comorbidity, social, functional and other factors and asks 'Would you be surprised if this patient were to die in the next 6–12 months?' The question was considered by an MDT consisting of a consultant renal physician, a consultant in palliative medicine and members of the renal nursing staff in relation to any patient in the above groups who were deemed to be suitable for the list. Any patient who was seen over the previous 4 weeks in the low clearance or haemodialysis clinics or on the wards by any member of the MDT could be discussed at the meeting if the member of staff felt that he or she might be appropriate for the at-risk register. The final decision relied on the palliative medicine team's use of their skills of prognostication in combination with the renal team's first hand knowledge of the patients. Very few disagreements ever occurred between members of the

MDT on whether or not to place a patient on the list, and they were always resolved by discussion.A list was then formulated of those deemed to be at high risk of dying within 1 year, the 'At-Risk Register'. A formal renal MDT meeting was regularly held (monthly) to discuss all patients on the list and to discuss those who were being considered for the list.

The at-risk register was created to identify patients with reduced life expectancy with a view to initiating palliative care assessment and intervention. This enabled preparing the patient and family to make informed choices about their later stages of life, with particular emphasis on quality of life, social support and preferred place of care in the event of a life-threatening change in health status. Patients were removed from the list if their perceived life expectancy had improved.

The authors studied patients added to the at-risk register during a follow-up period between 1st February 2007 and 31st July 2008. Patients were characterised by their demographic details, dialysis vintage and modality as well as comorbidities using the Charlson comorbidity index (table 1). Annual mortality rates were calculated and compared with those of patients not added to the register, but were part of the dialysis programme or followed up in the low-clearance clinic. Patients who were on the register and died were also compared with those who died while not on the register in order to determine any systematic differences between the two groups. In order to further characterise the patients on

Table 1 Calculation of the Charlson comorbidity index*

Score for each condition	Condition
1	Myocardial infarct
1	Congestive heart failure
1	Peripheral vascular disease
1	Cerebrovascular disease
1	Dementia
1	Chronic pulmonary disease
1	Connective tissue disease
1	Ulcer disease
1	Mild liver disease
1	Diabetes
2	Hemiplegia
2	Moderate or severe renal disease
2	Diabetes with end organ damage
2	Any tumour
2	Leukaemia
2	Lymphoma
3	Moderate or severe liver disease
6	Metastatic solid tumour
6	AIDS

*Originally designed as a measure of the risk of 1-year mortality attributable to comorbidity in a longitudinal study of general hospitalised patients and validated for the same outcome in a cohort of breast cancer patients.

Table 2 Baseline characteristics of patients on the at-risk register

Age, median	72 years
Sex, n (%)	
M	36 (63.2)
F	21 (36.8)
Ethnicity, n (%)	
Caucasian	36 (63.2)
Non-Caucasian	21 (36.8)
Dialysis, n (%)	
HD	40 (71.4)
PD	4 (7.1)
Predialysis	12 (21.4)
Dialysis vintage, median	2 years
Diabetes, n (%)	12 (31.6)
Charlson comorbidity index, median	4

n=58.
HD, haemodialysis; PD, peritoneal dialysis.

the list who died during follow-up, they were compared with those who were still alive at the end of follow-up, with regard to their demographic details, dialysis vintage, modality and comorbidities. Data were compiled using Microsoft Excel for Windows and STATA 8. All categorical variables were compared using the χ^2 method, while continuous data were compared using non-parametric tests, mainly Wilcoxon Rank-Sum test, where appropriate. p Values were calculated and a level of <0.05 was used as level of significance.

RESULTS

A total of 58 patients were added to the list during the follow-up period of which 28 (48.3%) died during the study period giving an annual mortality of 32.2%. The baseline characteristics of these 58 patients are summarised in table 2.

In comparison with the patients who died during the follow-up period but were not added to the at-risk register, those on the register had a much higher mortality rate (32.2% vs 7.8%). Interestingly, these two groups of patients did not have significant difference in their demographic details, dialysis vintage, dialysis modality or comorbidities (table 3). There was however a significantly higher proportion of individuals on the register dying due to discontinuation of dialysis.

All the patients who were on the at-risk register and died during the follow-up period did so within 48 weeks of follow-up, with 53.6% of deaths occurring during the first 12 weeks of follow-up (figure 1). Patients on the register who died during the follow-up and those who did not were compared in order to determine any systematic differences between the two groups with regard to demographic details, dialysis vintage, dialysis modality or comorbidities (table 4).

At the end of the study-period of 18 months, a total of 178 patients were assessed on haemodialysis, peritoneal dialysis, transplant and low-clearance clinics. In all, 58 patients were added to the at-risk register and 120 were not. Of the 58 patients added to the register, 37 died, while only 14 patients not on the list died, giving this approach a sensitivity of 66.7% (table 5). A total of

Table 3 Comparison of patients who died while on the at-risk register to those who were not, but died during the follow-up period

	Patients on the list who died (n=28)	Patients not on the list who died (n=14)	Statistic	p Value
Age (median)	71	71	z=−0.6	0.95
Sex, n (%)			χ^2=0.001	0.97
M	25 (92.6)	12 (92.3)		
F	2 (7.4)	1 (7.7)		
Ethnicity, n (%)			χ^2=1.2035	0.27
Caucasian	16 (59.3)	10 (76.9)		
Non-Caucasian	11 (40.7)	3 (23.1)		
Dialysis, n (%)			χ^2=2.2248	0.33
HD	17 (60.7)	10 (76.9)		
PD	4 (14.3)	0 (0)		
Predialysis	7 (25)	3 (23.1)		
Dialysis vintage, median	2 years	3 years	z=0.756	0.45
Diabetes, n (%)	4 (33.3)	9 (34.6)	χ^2=0.0060	0.94
Charlson comorbidity index, median	4	3	z=−1.525	0.13
Mode of death, n (%)			χ^2=15.0615	0.005
Withdrawal from dialysis	9 (32.1)	3 (23.1)		
Sudden death	1 (3.6)	4 (30.8)		
Cardiovascular	0	0		
Cerebrovascular	5 (17.9)	1 (7.7)		
Sepsis	0 (0)	3 (23.1)		
Unknown	13 (46.4)	2 (15.4)		
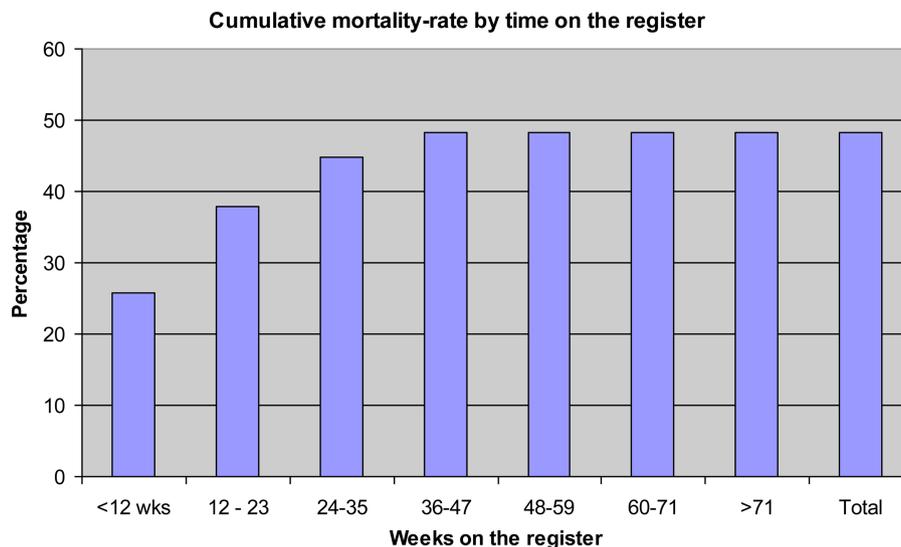
Figure 1 Cumulative mortality-rate by time on the register

106 patients not added to the list were alive, while only 21 patients on the list were alive among those added to the list, giving the register a 77.9% specificity. The study also demonstrated an impressively high negative predictive value of 88.3%.

DISCUSSION

Patients with ESRD are well recognised to have a significant morbidity[6] and burden of symptoms.[1] The End of Life Care Initiative developed by the Department of Health in 2004 aimed to extend the boundaries of Palliative Care services to cover patients with non-malignant disease at the end of life, by using the Gold Standard Frameworks, Liverpool Care Pathway and the Preferred Priorities of Care documents.[8] There is an increasing awareness of the benefits of joint working between renal and palliative care teams in order to provide ongoing care for patients with respect to their renal needs as well as addressing physical, social, psychological and spiritual needs. Joint working also allows excellent educational opportunities for those in each team to learn from one another in order to enhance patient care.

The median age of haemodialysis patients in Southend during the study period was 67.1 years, similar to that of the UK average at the time (65.2 years).[9] There were many more Caucasian patients than non-Caucasian patients on the register but this reflects the population of the local area.

Table 4 shows a significant difference between the survival of patients from ethnic minority groups and Caucasian patients with those from ethnic minority groups being more likely to survive. This is in keeping with other studies demonstrating that patients from black and ethnic minority groups often do better in survival studies on dialysis.[10 11] It is possible that there may

Table 4 Comparison of patients on the at-risk register who died during follow-up to those who did not

	Patients on the list who died (n=28)	Patients on the list who are alive (n=30)	Statistic	p Value
Age (median)	71 years	73 years	z=−0.141	0.89
Sex, n (%)			χ^2=0.3351	0.56
M	16 (59.3)	20 (66.7)		
F	11 (40.7)	10 (33.3)		
Ethnicity, n (%)			χ^2=17.2575	<0.0001
Caucasian	25 (92.6)	12 (40)		
Non-Caucasian	2 (7.4)	18 (60)		
Dialysis, n (%)			χ^2=2.1647	0.339
HD	17 (63.)	23 (79.3)		
PD	3 (11.1)	1 (3.5)		
Predialysis	7 (25.9)	5 (17.2)		
Dialysis vintage, median	2 years	1.5 years	z=0.123	0.7122
Diabetes, %	34.6	25	χ^2=0.3513	0.553
Charlson comorbidity index, median	4	5	z=0.6485	0.735

Table 5 Sensitivity and specificity of the at-risk register in predicting mortality among patients with chronic kidney disease

Sensitivity	66.7%
Specificity	77.9%
Positive predictive value	48.3%
Negative predictive value	88.3%

Numbers used to calculate sensitivity and specificity.
No. of patients on the register who died during the study period=37.
No. of patients who died during the study period who were not on the register=14.
No. of patients on the register who were alive at the end of the study period=21.
No. of patients not on the register who were alive at the end of the study period=106.

have been a degree of selection bias with patients on dialysis from ethnic minority groups being less unwell than the Caucasian patients and therefore fewer of these patients dying.

Identification of patients with chronic kidney disease and reduced life expectancy by this method appears to have a high sensitivity (66.7%) and specificity (77.9%) in the population studied. In particular, the negative predictive value for mortality for those on the at-risk register appears to be very high (88.3%), indicating the very low mortality among those not on the register (table 5).

Once included on the register, patient care (eg, dialysis or medication) did not routinely change, but it is possible that clinical staff could have considered the need for interventional procedures more carefully in those patients on the list and that they may have been deemed inappropriate more often in this group. The positive predictive value (48.3%) suggests that there were a number of patients on the register who survived for longer than predicted. It could be argued that in these cases resources are being misused, for example, when the care of these patients is being discussed at meetings. However, if these patients are symptomatic, have palliative care needs or are benefitting from input, then resources are not being wasted. It also helps to reinforce the fact that palliative care services should be available to patients with a life limiting condition before they are considered to be at the very end of life.

There are many factors that need to be addressed in this group of patients including prognosis, quality of life issues (with and without treatment), treatment burden (if dialysis is undertaken) and patient preferences.[12] These topics often make up part of 'advance care planning' which is a very familiar process to professionals from palliative medicine teams, but one that many nephrologists do not feel as comfortable or confident taking part in.[4] Galla[13] stressed the importance of shared decision making between the patient and the physicians and this is another key aspect of advance care planning. It can be challenging to decide when to broach the subject of advance care planning with patients as there is a fine balance between attempting to make plans too soon, when patients may not see the need to discuss the issues, and leaving it too late. Asking the surprise question can focus an MDT's attention on a particular patient by making them consider their prognosis in a formal way. This means that there is an opportunity to involve the wider MDT (including palliative care services) in this patient's care where appropriate and also it can act as a prompt to teams to start considering advance care planning with the patient and their families.

Symptom control issues can also be challenging in this group of patients, as their limited renal function and significant multiple comorbidities have to be considered when implementing drug regimes. The most common physical symptoms experienced by patients after stopping treatment are confusion or agitation, coma and dyspnoea,[1] all of which can usually be well controlled with adequate medication. However, patients may experience spiritual and emotional difficulties that often require management using a holistic approach. It is vital that patients are supported if they do not receive treatment for their ESRD but also in making the decision to withdraw from treatment once dialysis has started. The withdrawal of renal replacement therapy in a patient with ESRD will almost inevitably lead to their death but the period of time between treatment being discontinued and death is variable. Previous studies have suggested the mean survival of 10 days, after treatment had stopped, with a range of 1–48 days.[1]

Being able to predict when patients with ESRD are within their last year of life would allow services to be focused on these patients to ensure that they have adequate time to make decisions regarding treatment and end-of-life decisions. This may mean that more patients are able to die in the place of their choosing, which is an important aim of the UK Government's End of Life Care Initiative.[8] Previous research has suggested that earlier discussion of wishes around treatment withdrawal and death will lend itself ultimately to better dying.[1 4]

Various different methods of identifying at-risk groups of renal patients exist including the United States Renal Data System. This allows a realistic expectation of survival and projected life span to be made taking into account age, diabetes and other major coexisting illnesses.[2] Similar data are becoming available from the Renal Association UK Renal Registry[3] encompassing a scoring system developed in the UK to identify and provide survival data for high, medium and low risk patients.

In one study[3] of high risk patients who started dialysis in a large District general Hospital over a 4-year period and who were identified by functional status, severity of coexisting conditions and age, the majority survived for <1 year. Functional capacity has been shown in several studies to be an accurate

predictor of morbidity of patients receiving haemodialysis and a useful tool to use when assessing whether patients should receive renal replacement therapy or not.[14][15]

Since this study commenced the Prognostic Indicator Guidance has been updated.[16] The surprise question in the 2011 version uses a less rigid time frame, asking 'Would you be surprised if this patient were to die in the next few months, weeks, days?' Physicians may be concerned about being perceived to have 'got it wrong' when predicting survival and so may feel more comfortable using a question that applies a less specific time frame to a patient's survival. The disease specific indicators for renal disease in the 2011 version also include difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy as well as the presence of symptomatic renal failure. All these factors are likely to influence a patient's choices about treatment modalities and thereby affect their prognosis.

In this unit, input from the palliative care team began at the point of inclusion on the at-risk register. The patients were discussed at a monthly renal-palliative care MDT meeting where any issues that require palliative care involvement were addressed, for example, symptom control and advance care planning. Whenever appropriate a member of the renal team or the palliative care team would discuss the Preferred Priorities of Care document with the patient allowing patients to express their wishes regarding treatment and their future care. Although not part of this study, it is hoped that this early involvement of planning with the patient and palliative care may prevent unnecessary and inappropriate out of hours admissions and avoid inappropriate treatment being given to these patients including cardiopulmonary resuscitation. It was hoped that this input may lead to a higher number of patients being given the opportunity to identify their preferred place of care and death and a higher number dying in the place of their choosing. It has previously been shown that stating end of life preferences clearly can help facilitate a death at home in cancer patients[17] and it could be suggested that this may be similar in renal patients. It was also felt that the educational aspects of this type of MDT approach were very valuable as this is an area that is very complex and training for professionals has sometimes been lacking. This need for better education and training in this area was highlighted in a recent work done by the pan-Thames renal audit group measuring the quality of end of life management of patients with advanced kidney disease.[18]

The palliative care team were also able to meet with patients and their carers when considering withdrawal from dialysis to discuss the physical, emotional and spiritual issues surrounding these difficult decisions. Once a mutual decision had been taken to withdraw from dialysis either at the patient's request or on medical grounds, the palliative care team would try to ensure that the patient could be cared for in which ever setting they chose, whether that was the renal ward in the hospital, home or the local hospice. Community support was arranged with district nurses, Community Macmillan nurses and the local Hospice at Home team who were able to give ongoing symptom management and provide emotional support for the patients and their carers. The hospital palliative care team were well placed to support staff on the renal unit and those on the renal ward at Southend hospital when dealing with patients with difficult symptom control and those approaching death. They were also able to provide help with difficult conversations especially when there were complex psychosocial, emotional or spiritual elements both for patients and their carers.

Overall, the creation of the at-risk register provided a useful tool for prognostication in patients with renal disease. The focus on MDT working allowed close working relationships to develop between members of the renal and palliative care teams which provided better patient-centred care, better support for carers and improved advanced planning, as well as allowing the different teams to learn from one another.

LIMITATIONS

There were several limitations to this study. First, the numbers of patients involved were small and so results may not be fully generalisable. As members of the MDT brought the names of the patients they felt were appropriate to the meetings to be considered for the register there could be a degree of selection bias. However, within the resource and time constraints of a 'real life' clinical setting, it would not have been possible to consider every renal patient for inclusion in the list. Also, the lack of disagreements between MDT members about which patients to include suggests that correct patients were being considered for inclusion. It is possible that this methodology meant that some patients who should have been included on the register were not identified. Documentation of preferred place of care was not considered as part of this study due to time and resource constraints but could have demonstrated whether patients were being offered the opportunity to discuss their wishes in advance and whether their wishes were being met.

FUTURE WORK

Analysing the impact of the use of the prognostic indicator guidance on quality of life and symptom management was beyond the scope of this paper but could provide an interesting insight into the effect of earlier involvement of palliative care with this group of patients. Future work could also include exploration of the effect of better prognostication on choice of, and eventual place of, death.

CONCLUSIONS

This study demonstrates that the surprise question allows patients with chronic kidney disease and a reduced life expectancy to be identified by the MDT with a relatively high sensitivity and specificity, independent of traditional risk factors like demographic variables, dialysis vintage or comorbidities. Although this work included only a small number of patients and predominantly those receiving haemodialysis, we believe that it contributes towards the validation of the use of the prognostic indicator guidance in this group of patients within an MDT setting.

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Corrections

Feyi K, Klinger S, Pharro G *et al*. Predicting palliative care needs and mortality in end stage renal disease: use of an at-risk register. *BMJ Support Palliat Care* 2015;5:19-25. The corresponding author's email address has been updated to s.klinger@nhs.net