National survey of the current provision of specialist palliative care services for patients with end-stage renal disease

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Abstract

Background. Patients with end-stage renal disease (ESRD) experience a significant symptom burden and have complex needs. However, involvement of specialist palliative care (SPC) services with these patients has previously been shown to be limited. This study assesses the current provision of and access to SPC services for ESRD patients in the UK and considers how the provision has evolved over recent years.

Methods. A questionnaire was sent to the lead clinician for all UK adult hospital, hospice and community SPC services, identified from the Hospice and Palliative Care Directory 2008. Non-responders were mailed again after 5 weeks. Descriptive statistics and qualitative thematic analysis were performed.

Results. Three hundred and eighteen of 611 (52%) questionnaires were returned. Ninety-six per cent stated that SPC services have a role in caring for patients with ESRD. Two hundred and eighty-one of 318 (88%) accepted referrals, and 185 of 281 (66%) reported that ‘none or few were referred’. Only 7% and 17% of respondents used specific ESRD referral and treatment guidelines, respectively; whereas 79% used the Liverpool Care Pathway for the Dying Patient. Seven per cent undertook joint renal and SPC multi-disciplinary team (MDT) meetings, and 3% held joint out-patient clinics. Forty percent of respondents proposed initiatives to improve palliative care for ESRD patients, with mutual education and collaborative working being key themes for improvement.

Conclusions. The majority of SPC services accept ESRD patients, but limited numbers are referred. Respondents indicated that this barrier could be addressed by closer collaboration and better communication and education between renal and SPC services. Other initiatives to enable delivery of SPC to increased numbers of ESRD patients include the use of specific referral and clinical care guidelines and expansion of joint MDT meetings and out-patient clinics.

Keywords: end-stage renal disease; palliative care

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Introduction

Patients with end-stage renal disease (ESRD) experience a significant symptom and illness burden [1] comparable to that of advanced cancer patients [2]. Specialist palliative care (SPC) has traditionally been provided for those with advanced cancer, but only more recently has this been extended to include those with non-cancer conditions. Recognizing this continuing inequity in provision, the recent End of Life Care Strategy [3] aims to ensure that all adults receive high-quality care at the end of life, regardless of diagnosis. For clarity, in the Department of Health end-of-life strategy publications, end-of-life care (EOLC) is defined as the timeframe of the last year of life for patients, during which their supportive and palliative care needs are identified and met. This definition has been used in this paper.

Several studies have assessed the extent of palliative care provision to ESRD patients from both the perspective of nephrology and SPC. A questionnaire survey conducted in 1995 noted that 13 out of 20 hospices restricted their admissions to patients with malignant disease, and most would not be prepared to consider referral of patients with ESRD [4]. More recently, a survey of renal unit directors examined the availability of SPC services for patients with ESRD [5]. This identified significant variation across the UK. Local hospital palliative care teams and local hospices were ‘usually’ or ‘always’ involved by only 38% and 20% of renal units, respectively.

Since these surveys were undertaken, there have been several policy initiatives aimed at addressing end-of-life care for patients with ESRD. In 2005, Part 2 of the National Service Framework for Renal Services set a quality requirement for end-of-life care in patients with ESRD [6]. In 2005, Part 2 of the National Service Framework for Renal Services set a quality requirement for end-of-life care in patients with ESRD, stating that patients with established renal disease should receive ‘timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences’ [6]. More
recently, the End of Life Care in Advanced Kidney Disease: A Framework for Implementation describes how to achieve high-quality end-of-life care for people with ESRD in practice [7].

These strategic frameworks are underpinned by timely identification of the end-of-life phase of care; by detailed assessment and management of symptoms and psychological, social and spiritual needs; and by agreeing a care plan. A variety of end-of-life tools are recommended to enhance care and advance care planning. These are outlined in Table 1.

These and other initiatives have led to service development across the UK, although provision of high-quality end-of-life care may still be somewhat uneven. In addition, there is greater awareness within SPC of the needs of those with non-malignant conditions, including ESRD.

This study therefore aims to assess the current provision of and access to SPC services for adult patients with ESRD in the UK and to consider how the provision has evolved over recent years. It also seeks to identify factors that facilitate or prevent SPC service involvement with ESRD patients.

Materials and methods

A postal survey of all adult SPC services in the UK was undertaken during 2008, including all categories of service provision (hospital, hospice and community services). SPC services were identified from the Hospice and Palliative Care Directory 2008 and the questionnaire sent to the named lead clinician for each service. Children’s and five ‘cancer only’ services were excluded. Confidentiality was maintained through the use of anonymous questionnaires and numbered return envelopes. The recipients were asked to return the questionnaire within 4 weeks. Non-responders were identified from the absence of a numbered return envelope, and the questionnaire was re-sent to non-responding services after 5 weeks.

The questionnaire (Appendix 1) was derived specifically for this study. It drew on elements of questionnaires assessing the provision of palliative care for patients with other non-malignant diseases [11,12] and was developed further through expert consensus. It was piloted with eight organizations across categories of service provision and refined following feedback from the piloting.

Questionnaire responses were entered into SPSS version 15. Descriptive statistics (numbers and proportions) were used to report the survey findings. Responses to open-ended questions were analysed using thematic analysis.

The Chair of the Salford and Trafford Local Research Ethics Committee and the Secretary to the University of Manchester Ethics Committee confirmed that ethics committee approval was not needed for this study.

Results

Six hundred and eleven SPC organizations were surveyed, and 318 questionnaires were returned (52% response rate). However, 44 of these responses represented a combined response from two or more of the listed organizations. Completed questionnaires were therefore received from 360 of the 611 organizations surveyed (59% response rate). To make the denominator clear, actual numbers used to derive each proportion are provided throughout.

Many organizations listed individually in the directory provide more than one SPC service category, and the overall response rate obscures differential responses from different service categories and countries. In total, the 611 organizations provide 254 hospice, 347 hospital and 346 community services. Table 2 shows the response rate by service category and locality. Sixty-two percent of hospice services, 55% of hospital services and 53% of community services responded.

Almost all of these SPC respondents (306 of 318, 96%) indicated that SPC has a role in providing care for ESRD patients. Most organizations (281 of 318, 88%) accept referrals of these renal patients. Acceptance of referrals was similar across hospice, hospital and community, with 139 of 158 (88%) of hospice, 175 of 192 (91%) of hospital and 165 of 183 (90%) of community services accepting referrals. Of the 281 organizations accepting referrals, 186 of 281 (66%) accepted patients on haemodialysis, 185 of 281 (66%) accepted patients on peritoneal dialysis, 257 of 281 (91%) accepted patients being managed conservatively and 249 of 281 (89%) accepted patients from whom dialysis was being withdrawn.

The number of ESRD patients actually seen by SPC services was low. Across service categories, most services saw five or fewer patients in the year, with only 5 of 113 (4%) of hospice in-patient, 14 of 143 (10%) of community and 5 of 95 (3%) of hospital medical out-patient services seeing six or more patients. In contrast, about a third (52 of 164, 32%) of hospital SPC teams assessed more than six patients per year. See Figure 1.

A number of factors were perceived to limit the numbers of ESRD patients seen (see Figure 2). The most commonly identified barrier was that few or no patients with ESRD were referred (185 of 281, 66% of organizations). The availability of specialist renal support both in hospital (66 of 281,
24%) and community (41 of 281, 15%) and the perception that renal services could provide all necessary care for their patients (41 of 281, 15%) were the next most frequently cited barriers. However, there was a dichotomy of views. Some respondents indicated that the renal service they worked with was well equipped to meet the SPC needs of their patients themselves, and therefore patients were not referred to SPC services. Others reported that there was lack of or little support from their local renal team, and few patients were referred because of the lack of renal service input. Both scenarios resulted in limited numbers of patients being referred to SPC services. Twenty-seven of 281 (10%) respondents perceived that their lack of expertise in caring for patients with ESRD was a barrier to them seeing more referrals.

A minority (31 of 318, 10%) of organizations did not accept patients with ESRD. Further analysis by type of service category showed that 15 of 158 (9%) of hospices, 12 of 192 (6%) of hospital and 15 of 183 (8%) of community services did not accept referrals. The main barriers to referral were only accepting cancer patients (52%), being limited by other referral criteria (19%), implications for staff training (32%), none/few referred (29%) and lack of financial resources (26%).

Very few organizations (23 of 318, 7%) had specific referral criteria for ESRD. Criteria included were discontinuation of dialysis (87%), decision to be managed conservatively (78%), specific issues concerning symptom control needs (70%), performance status/functional decline (61%), renal function/creatinine clearance/GFR (30%), hyperkalaemia (9%) and other criteria (48%).

Specific treatment guidelines or pathways for patients with ESRD, other than end-of-life care tools, were used by only 53 of 318 (17%) of organizations. Fifty-one percent

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### Table 2. Response rate of SPC services by service category and country

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<thead>
<tr>
<th>Country</th>
<th>Hospice services</th>
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<td>questionnaires</td>
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<td>England</td>
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<td>Scotland</td>
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<td>20 (77%)</td>
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<td>Wales</td>
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<td>10 (42%)</td>
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<td>N. Ireland</td>
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<td>UK Total</td>
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<td>346</td>
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</table>

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Fig. 1. Numbers of referrals accepted in each SPC service category for a 1-year period (1 April 2007 to 31 March 2008).
(27 of 53) of these guidelines related to prescribing for pain and symptom control in renal failure.

The majority of organizations (251 of 318, 79%) used or supported others to use end-of-life care tools for patients with ESRD. Of those using EOLC tools, all (251 of 251, 100%) used the Liverpool Care Pathway for the Dying Patient [8] or equivalent, half (126 of 251, 50%) used the Gold Standards Framework [9], and slightly fewer (106 of 251, 42%) used the Preferred Priorities for Care [10].

When asked concerning specific SPC and ESRD initiatives, about a third (107 of 318, 34%) of respondents were aware of or had developed specific initiatives. A minority (50 of 318, 16%) undertook or participated in teaching sessions for specialist palliative care professionals regarding ESRD, and a similar proportion (47 of 318, 15%) reported that there was an SPC service in their locality with an interest in ESRD. A small number (22 of 318, 7%) took part in a multi-disciplinary team (MDT) meeting attended by both renal and palliative care professionals, and very few (8 of 318, 3%) held a joint clinic involving these services. Under half (176 of 318, 50%) were aware of the National Service Framework for Renal Services: Part 2 [6], and about a fifth of these (39 of 176, 22%) had responded to it with the most commonly cited responses being improving collaborative working by 15 of 39 (38%) and implementing the use of the Liverpool Care Pathway (LCP) for renal patients by 9 of 39 (23%).

Fig. 2. Perceived barriers to referral.

![Figure 2](image)

Fig. 3. SPC organizations’ interests in and involvement with ESRD patients.

![Figure 3](image)
Figure 3 summarizes current involvement of SPC organizations with ESRD patients.

Additional suggestions for improvement in services were proposed by 128 of 318 (40%) respondents. Two hundred and fourteen initiatives were proposed. Increased staffing/financial resources, mutual education, collaborative working and development of guidelines/pathways were the themes of 31%, 23%, 22% and 14% of these initiatives, respectively.

Discussion

This survey demonstrates, in contrast to earlier findings [4,5], that most SPC services are now willing to provide care for patients with ESRD. They recognize the need for improved collaboration with renal services in order to maximize the expertise available to patients and their families, so that the quality and experience of the care that these patients receive is improved.

This is a nationwide survey with a good response rate and therefore represents views from across all service categories of SPC. However the slightly lower response rates from community services in Wales and Northern Ireland, hospital services in Scotland and hospice services in Wales mean that the data may be less representative of these groups. Only one individual per organization was asked to respond, and therefore their reply may not necessarily correspond to the views of the organization as a whole. In addition, some social acceptability bias may have influenced responses, although the anonymous nature of the questionnaire mitigated this. This survey methodology required predominantly closed questions, and therefore there is limitation of the insight that can be gained from the responses. In spite of these limitations, we have been able to demonstrate consistency and clarity in the themes identified.

Estimating the size of the challenge facing SPC and renal services to meet optimally the palliative and EOLC needs of ESRD patients is difficult. The numbers of patients with ESRD are continuing to rise worldwide with a disproportionate increase among those who are elderly, dependent and have multiple comorbidities [13]. However, precise estimates of incidence and prevalence remain elusive because detailed data collected through the national Renal Registries only relate to those who are on dialysis and do not include those never referred to renal services or those who opt not to have dialysis. It is estimated that renal deaths account for 1–2% of all deaths, and this equated to about 5000–10 000 deaths in England and Wales in 2007 [14,15].

Precise figures relating to place of death of patients with ESRD are also difficult to obtain because of poor concordance of death certification in renal failure [16,17]. Death is often from sepsis, cardiac events or other comorbidity rather than ESRD per se. However, Office for National Statistics data for deaths from all diseases of the genitourinary system (which includes deaths with a primary cause of ESRD) indicate that 11% died at home or in a care home and 88% died in hospital [18]. This is in contrast to clear evidence that 60–70% of people have a home death preference [19].

The smaller size of the ESRD population as compared with other conditions seen by SPC services, such as cancer, heart failure and chronic obstructive pulmonary disease, adds to the current challenge in delivering high-quality SPC to ESRD patients as it is more difficult for professionals to develop and maintain the expertise needed to deliver optimal care to this patient group [11,15]. Patients with ESRD do have a considerable symptom burden, with pain and lack of energy, for instance, being reported by 53% and 76%, respectively, among conservatively managed patients with stage 5 chronic kidney disease [20]. ESRD patients on dialysis also experience multiple symptoms, with pain, fatigue, pruritus and constipation in more than one in two patients [1]. Dialysis may be a means of maintaining or improving a patient’s quality of life, but studies have also shown that the physical quality of life of patients on dialysis is substantially impaired compared with the general population [21,22]. For patients approaching ESRD who are older, have multiple comorbidities and who are more functionally impaired, there may be little survival benefit over those treated conservatively [23]. Therefore, patients with ESRD have considerable palliative and end-of-life care needs. This raises questions about why the referral rate is still so low.

There is little published evidence on the preferences or views of ESRD patients about their own palliative or end-of-life care. A recent systematic review by Morton et al. describes the common experience for renal patients of ‘living in limbo’ and sometimes perceiving little choice around their treatment options [24]. A proportion do choose conservative (non-dialytic) management, despite the possibility of an earlier death [20,24,25]. The sense of not wanting to be a burden to others and to have good symptom control is well described in this population, and this echoes the same concerns in the wider advanced disease population [24,26,27]. The lack of more detailed knowledge about renal patient preferences with regard to end-of-life care makes it difficult to draw more concrete conclusions, but certainly the availability of high-quality holistic care (as delivered by specialized palliative care teams for other conditions) is likely to be important for improving the quality of life of renal patients and their families.

The previous survey of renal units undertaken by Gunda et al. showed that SPC services were only involved in the minority of ESRD patients’ care, and Andrews’ survey of hospices showed that the majority of hospices did not accept patients with a diagnosis of ESRD [4,5]. Since this time, more emphasis has been placed on the palliative care needs of patients with non-malignant diseases, and the data from our survey would support this change in attitude. Of the few (31 of 318) respondents not accepting referrals, just under half were still limited to taking only patients with cancer diagnoses, with a further fifth being limited by other referral criteria. However, several of these units were undertaking review of referral criteria or putting forward bids for additional funding in order to broaden their criteria to cover non-malignant disease, and so the numbers of organizations able to take ESRD patients could rise further in the future.

Gunda et al. concluded that ‘existing palliative care services need to be made available to non-cancer patients if
we are to provide an adequate service to ESRD patients [5]. This survey shows that the first barrier to this has been overcome; services are now accepting referrals. The second step (increasing the level of referrals) has yet to be taken; the numbers of ESRD patients being referred is still low, and this is now perceived as the main barrier to SPC services being involved with these patients.

This raises a further question: what is the best model of care for these patients? It could be proposed that renal teams are increasingly able to meet the palliative care needs of their patients without needing to refer them to SPC services. Supporting information sent by a small number of organizations would support this view. They describe a model of care where SPC teams have worked closely with renal services and focused on education and developing the skills of renal nurses to provide good quality supportive and palliative care to ESRD patients, with the SPC team only needing to be involved in more complex cases. With this model, the numbers of ESRD patients referred to SPC services are low because close working links and education of the teams on both sides have enabled appropriate care to be delivered to the patients by the renal team. The SPC team is therefore more involved in skills development rather than direct patient care.

A second model of care was described where the hospital SPC team was very involved with providing care to ESRD patients and saw a large number of patients. This occurred where the service was led by a key individual within the SPC team with an interest in ESRD, usually a consultant, and tended to be at a renal centre. Joint MDT meetings and clinics were held, and through these mechanisms and through effective communication between services, patients with supportive care needs were identified and referred to appropriate local SPC services.

Currently, it is not known what model of care is most effective or acceptable, both to patients and health care professionals. However, the underpinning theme with both the models of care identified by this survey is that close working links between SPC and renal services enable delivery of high-quality palliative care either by developing the skills of the renal services to deliver this or by identifying appropriate patients to be referred on to SPC.

Respondents cited the limited numbers of referrals made to them as the major barrier preventing SPC service involvement with ESRD patients, and so it is worthy to note that only 23 organizations (7%) had specific referral criteria for patients with ESRD. Mutual education and collaborative working were suggested as initiatives which would enhance the care of ESRD patients, and yet only 7% of organizations took part in joint MDT meetings and only 3% undertook joint clinics. In conclusion, we propose that (i) the development and use of specific referral criteria would aid identification of patients that may need SPC input and improve the pathway to referral, (ii) the development of joint MDT meetings and clinics may enable the exchange of expertise and aid collaborative working and (iii) research now needs to provide the evidence as to which models of care are most effective (and cost-effective) in meeting the needs of these patients and their families. Such research needs to address the complex nature of the different models of care proposed, identify and evaluate the role of professional education in providing these models of care and understand how services need to transcend traditional boundaries to deliver patient-centred care.

Supplementary data

Supplementary data is available online at http://ndt.oxfordjournals.org.

Acknowledgements. We would like to thank Lucy Sutton and Adrian Jones from the National Council for Palliative Care for their support and assistance with data analysis and acknowledge the support given by Salford Royal NHS Foundation Trust. We confirm that the results presented in this paper have not been published previously in whole or part, except in abstract form. We have had no involvements that might raise the question of bias in the work reported or in the conclusions, implications or opinions stated.

Conflict of interest statement. None declared.

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Dialysate sodium and sodium gradient in maintenance hemodialysis: a neglected sodium restriction approach?

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Abstract

Background. A higher sodium gradient (dialysate sodium minus pre-dialysis plasma sodium) during hemodialysis (HD) has been associated with sodium loading; however, its role is not well studied. We hypothesized that a sodium dialysate prescription resulting in a higher sodium gradient is associated with increases in interdialytic weight gain (IDWG), blood pressure (BP) and thirst.

Methods. We conducted a cross-sectional study on 1084 clinically stable patients on HD. A descriptive analysis of the sodium prescription was performed and clinical associations with sodium gradient were analyzed.

Results. The dialysate sodium prescription varied widely across dialysis facilities, ranging from 136 to 149 mEq/L, with a median of 140 mEq/L. The mean pre-HD plasma sodium was 136.7 ± 2.9 mEq/L, resulting in the majority of subjects (n = 904, 83%) being dialyzed against a positive sodium gradient, while the mean sodium gradient was 4.6 ± 4.4 mEq/L. After HD, the plasma sodium increased in nearly all patients (91%), reaching a mean post-HD plasma sodium of 141.3 ± 2.5 mEq/L. We found a direct correlation between IDWG and sodium gradient (r = 0.21, P < 0.0001). After adjustment for confounders and clustering by facilities, the sodium gradient was independently associated with IDWG (70 g/mEq/L, P < 0.0001). There were no significant associations among sodium gradient and BP, whether measured as pre-HD systolic (r = −0.02), diastolic (r = −0.06) or mean arterial pressure (r = −0.04). Post-HD thirst was directly correlated with sodium gradient (r = 0.11, P = 0.02).

Conclusion. Sodium gradient is associated with statistically significant and clinically meaningful differences in IDWG in stable patients on HD.

Keywords: dialysate sodium; hemodialysis; hypertension; interdialytic weight gain; sodium gradient

Introduction

Patients with end-stage renal disease (ESRD) on hemodialysis (HD) experience exceptionally high rates of cardiovascular mortality and morbidity [1]. Important risk factors include hypertension (HTN) [2, 3] and fluid retention,