Renal failure and specialist palliative care: an assessment of current referral practice

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Abstract

Aims: This retrospective audit assessed the referral practice for patients with end-stage renal failure from the nephrology service to the specialist palliative care team in a large teaching hospital in the north-west of England.

Methods: Forty-nine referrals with ‘renal’ as a primary diagnosis over a two-year period were identified from referral data. General and palliative care notes were reviewed and a data collection tool was designed.

Results: Most common reasons for referral were for ‘placement’ (38.6%) and ‘dying/distressed’ patients (22.7%), although psychological support was also prevalent (15.9%). Renal teams discussed stopping dialysis in the majority of cases (89%), but documented preferred place of care less frequently (48.3%) and achieved discharge to these locations in less than half of cases (21.4%).

Conclusion: There was well-established referral practice between the renal and the specialist palliative care team at the hospital examined. The renal team appropriately referred for symptom control and support in the dying phase of patients. There are issues surrounding placement and increased implementation of end-of-life care tools, including the Liverpool Care Pathway, Gold Standards Framework and Preferred Place of Care documentation for renal patients, which needs to be an ongoing priority.

End-stage renal failure (ESRF) affects more than one million people worldwide, and diseases of the kidney and genitourinary tract are responsible for more than 10,000 deaths in England and Wales each year (Office for National Statistics, 2005). Gunda et al (2005) suggest that patients with ESRF have unmet palliative care needs, while Neeley (2000) outlines the complexities and specific needs of patients with ESRF moving towards a palliative care setting. Rich et al (2001) report increasing numbers of patients with ESRF being referred to palliative care and the National Service Framework (NSF) for Renal Services (Department of Health (DH), 2005) highlights the importance of involving palliative care teams in the care of patients with ESRF. A holistic care plan assessing and addressing physical, psychological, social and spiritual needs of patients is considered paramount for patients with ESRF. As part of this plan, preferences for place of care of these patients in the dying phase should be ascertained and respected wherever possible (DH, 2005).

The Royal Liverpool University Hospital (RLUH) renal unit is a tertiary referral centre in Merseyside, with renal replacement therapy (RRT) programmes covering a population of some 400 chronic haemodialysis patients and 100 peritoneal dialysis patients. In addition to the RRT regimens, a conservative management programme is in place for patients who decline dialysis; who are unlikely to benefit from RRT; or who are felt too medically unstable for invasive management.

The RLUH specialist palliative care team (SPCT) is a multidisciplinary group with specialist expertise in many aspects of end-of-life care. The SPCT accepts referrals on the basis of need rather than diagnosis and, as such, also sees patients with ESRF. With the development and expansion of non-malignant palliative medicine into areas such as cardiac, respiratory and renal disease, it is of paramount importance that specific issues and barriers to effective care are identified and explored for these diseases. Issues such as referral practice and discharge planning have yet to be addressed in the literature, yet form the beginning and end of good palliative care. This audit aims to examine current referral practice for patients with ESRF to the SPCT. Specifically, it will assess the main reasons for referral, identify frequency and timing of discussion of preferred place of care, as well as examining final place of care as a comparator. It will also identify frequency and timing of discussions surrounding withdrawal of dialysis and examining evidence for communication of prognosis.

Methods

A retrospective audit was carried out to assess current referral practice for patients with ESRF to the Royal Liverpool Palliative Care Team. As part of the routine management of patients, a database is used by the SPCT to record pertinent information for all referrals made from the wards. Data summarising the nature of the
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SPCT’s intervention for each referral are recorded on a palliative care assessment form (PACA) (Ellershaw et al, 1995). The PACA records the referrer’s stated reason for referral in six categories: pain; other symptoms; psychological support; patient dying/distressed; insight; and placement. The form also records the reason for referral, as assessed by the SPCT, and patients are then sub-divided into those requiring general care (i.e. those who could be managed appropriately by the ward team with SPCT support) or those needing specialist palliative care input. All patients with ‘renal’ as a primary diagnosis referred between March 2004 and April 2006 were identified from this database, and where possible, their full case notes were retrieved.

Information from both the PACA database and the full case notes (where available) was recorded onto an audit form created specifically for the purpose. This audit form additionally recorded frequency and timing of discussion surrounding stopping dialysis, as well as subsequent prognosis. It also recorded frequency and timing of preferred place of care, and final place of care. Descriptive statistical analysis of the data was undertaken using the Statistical Package for the Social Sciences (SPSS) version 14.0.

Results

Patient sample

Forty-nine referrals were made to the SPCT for patients with ‘renal failure’ as a primary diagnosis over the two-year period examined. This represents between 16–17% of all non-cancer referrals to the SPCT and 3% of total referrals for this time frame. The SPCT received a 20% total non-malignant referral rate during this time, and there were a total of 319 deaths recorded with ‘renal’ diagnosis. Of these referrals, four were referred twice during the audit period, but only the last episode for these four patients was analysed. On reviewing the case notes, one patient had no renal problems and it was presumed this case was mislabelled. For the remaining 44 referrals, only 29 sets of notes could be retrieved. Of these 29 patients, 19 (65.5%) were on RRT, and four (13.8%) were in a ‘conservative management programme’. The remaining patients had either acute renal failure (ARF) or pre-dialysis chronic renal failure (CRF). The mean age of the 44 patients in the sample group was 67 (range 33–91), with a slight male:female bias (54% vs 46%). The entire population was white/white British.

<table>
<thead>
<tr>
<th>Ward referral reason</th>
<th>PCT referral reason</th>
</tr>
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<tbody>
<tr>
<td>Placement</td>
<td>17 (36.6%)</td>
</tr>
<tr>
<td>Dying/distressed</td>
<td>10 (22.7%)</td>
</tr>
<tr>
<td>Psychological support</td>
<td>7 (15.9%)</td>
</tr>
<tr>
<td>Pain</td>
<td>5 (11.4%)</td>
</tr>
<tr>
<td>Other symptoms</td>
<td>5 (11.4%)</td>
</tr>
</tbody>
</table>

Table 1. Reason for referral from renal to specialist palliative care team

Reason for referral to the SPCT

The main reason for referral as assessed by both referrers and SPCT was for support with ‘placement’ issues (36.8 and 43.2% respectively), with ‘dying/distressed’ the next most common reason (22.7% and 27.3% respectively). Of all the referrals, just under half (43.2%) were felt to be problems that could be managed by the referring team with SPCT support, with the remainder (56.8%) thought to be suitably complex to require more specialist palliative care input (Table 1).

Summary of SPCT intervention

Fifteen (31.8%) of 44 referrals received telephone advice only. Twenty-nine (60.2%) had face-to-face contact, with the majority (55.2%) of patients being seen on more than one occasion (average 3.7 contacts). The number of days from referral to SPCT and discharge from SPCT ranged from 0–87, with the median being four days.

Median time from referral to death or discharge was four days (range 0–87 days). The Liverpool Care Pathway for the Dying Patient (LCP) was used in 22 (50%) of the patients referred, and the Liverpool Care Pathway for the Rapid Discharge Home of the Dying Patient was used for two patients (4.5%). In the same period there were a total of 52 deaths on the LCP with ‘renal’ as a diagnosis for the whole of RLUH.

Discussion regarding stopping dialysis and prognosis

Of the 29 patients whose notes were available, 19 (65.5%) were on regular dialysis before SPCT input. In 17 of these 19 cases (89.5%), discussions around prognosis and the decision to stop dialysis took place with either the patient or the family before any contact with the palliative teams occurred. For one patient, the decision to stop dialysis was discussed with the SPCT, and the remaining patient had no docu-
mented discussion at all. Irrespective of underlying diagnosis or treatment, there was documented discussion regarding prognosis in 23 of the 29 (79%) referrals, 21 of these before SPCT input.

**Preferred Place of Care**

A discussion about the patient’s preferred place of care was documented in 14 (48.3%) of the 29 case notes. Eight (57%) of these 14 discussions occurred pre-SPCT, five (35.7%) with the SPCT and one (7%) post-SPCT intervention. Seven (50%) of those 14 patients who did have the preferred place of care documented chose home, four (28.6%) chose a hospice setting, and two (14%) chose hospital, one (7%) choosing a nursing home. However, on examination of actual place of discharge/death of these 14, 11 (78.6%) died in hospital, the remaining three (21.4%) going home. For the 29 patients whose notes were available, 19 (65.5%) died in hospital, five (17.2%) died at home and three (10.3%) in a hospice (Figure 1).

**Discussion**

This project was a retrospective audit, with the aim of assessing current referral practice for patients with ESRF from a large nephrology unit to the specialist palliative care team within a university hospital in the north-west of England. Issues examined included reason for referral, timing of discussion regarding withdrawal of dialysis, prognosis, discussion of preferred place of care and comparison of preferred versus final discharge location.

Need and benefit from referral of terminally ill renal patients to specialist palliative care services have been well recognised in both the palliative and nephrology literature (Holley, 2005; Chater et al, 2006). It has been shown that physicians in general will consider referring patients with non-malignant disease to the specialist palliative care teams (Dharmasena and Forbes, 2001). The renal team at RLUH appeared comfortable with referring patients for symptom management and seemed to refer patients appropriately when they needed support in the dying phase. In contrast, the renal team felt that ‘psychological support’ was a more common reason for referral than the SPCT. This may highlight a slight lack of confidence by the renal team in dealing with some of the issues and circumstances of patients dying from a terminal illness, although small numbers and rapidly changing patient states make it difficult to draw firm conclusions.

The fact that psychological support was seen as less of a problem by the SPCT may indicate that the renal team was, in fact, doing much better than they thought they were in managing psychological issues. Overall, however, there were a high proportion of ‘telephone advice contacts’ by the SPCT only, and the team felt that 43.2% of referrals could have been managed by the renal teams with support from the SPCT. This may suggest that further education in symptom management and information regarding the role of the SPCT may be helpful, enhancing confidence of specialist renal teams to...
manage dying patients.

An interesting addition to the literature was that most patients with or without RRT, and their next of kin, in this audit had end-of-life care issues, such as stopping dialysis and prognosis discussed with them and these discussions were documented in accordance with NSF and literature guidance (Galla, 2000; DH, 2005). However, most of these discussions were had without involvement of the SPCT. This may suggest that nephrology teams are recognising the need for these discussions and their role in the patient’s ongoing palliative care at an early stage. However, the involvement of the SPCT at an earlier stage of discussion, as suggested in NSF guidance, may further strengthen co-ordination and communication with patients and relatives, and help to address issues such as placement and preferred place of care.

Fewer than half of the referred patients had a documented discussion regarding preferred place of care in their notes and, in cases where there was a documented discussion, this tended to take place after involvement of the SPCT. Despite this, the commonest ‘reason for referral’ by the renal team to the SPCT was placement. Exploring issues of preferred place of care seem vital, and the apparent lack of discussion of such issues is concerning. Documentation is a great limitation on retrospective review, but the researchers feel that this issue is rarely broached with patients due to general discomfort about discussing end-of-life care.

The preferred place of care was home for most patients, which compares to patients with malignant disease (Tang, 2003). However, this goal was met infrequently and the majority of the audit population died in hospital, irrespective of their wishes. The reasons for these difficulties in achieving preferred place of care and appropriate placement are likely to be multi-factorial; ties between renal teams and specialist palliative care support systems are not yet as established as they are for cancer patients. Those who continue dialysis commonly require ongoing specialist inpatient nephrology support, and fear difficult symptom complexes, including fluid overload, that are actually not confirmed as any more severe than in patients dying from cancer (Saini et al, 2006).

It has been identified previously that preferred place of care should be discussed and the decision supported (Galla, 2000); in fact, it has been shown for patients with a malignant diagnosis that if discussion regarding preferred place of care has taken place at an early stage, this can be achieved (Tieran et al, 2002; Beccaro et al, 2006). These discussions are probably even more important in patients with ESRF where discharge, particularly to home, seems more complex. Closer links between renal teams and specialist palliative care services, both in hospital and the community, as well as flexible discharge planning and good links with district nurse services, appear vital here to achieve a higher rate of home deaths. In addition, all three nationally supported end-of-life care frameworks, i.e. the Liverpool Care of the Dying Pathway (LCP), the Preferred Place of Care document (PPC) and the Gold Standards Framework (GSF) may be helpful in supporting patients dying from renal disease in a place of their choice (DH, 2004). This issue may perhaps benefit from further qualitative investigation to try to better understand the barriers to discharge that arise in this specialised patient group.

In our sample, the LCP was used in only 50% of the dying patients during the audit period. However, the LCP was introduced to the renal unit during the second half of the audited period. It is, therefore, expected that uptake of the LCP will be significantly higher now that more regular use has been established.

There were several restrictions and limitations to this audit. It was retrospective and the initial sample group was derived from all patients with ‘renal’ as a primary diagnosis. There is the possibility that not all patients with ESRF were included in the sample group. The percentage of non-malignant disease referred to the SPCT is higher than in other regional and national centres, reflecting good local relationships and may reduce generalisability. However, the authors would argue these good relations make the issues identified more important to regions with less established links.

Not all of the most recent case notes were available, reducing the sample size to 66% of referrals. This was due renal failure patients often having multiple sets of notes and several storage areas in RLH. There is no reason to suggest that the missing referral notes were disproportionately representative, although it is recognised that larger prospective studies are required in this area.

Conclusion

There was an established referral practice between the renal and the SPCT at the hospital examined. The renal team referred appropriately for symptom control and support in the dying phase of patients. There may be less confidence in managing psychological issues. There was an indication that further education into managing
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terminally ill patients may empower renal teams more to deal with dying patients. There seem to be issues surrounding discussion of preferred place of care, and barriers to successful discharge to these locations when identified. Discussions surrounding stopping dialysis and prognosis were had in the majority of patients, but involving the SPCT more commonly in these discussions may strengthen care and help to achieve preferred place of care for more patients. Increased implementation of end-of-life care tools, such as the LCP, GSF and PPC for renal patients needs to be an ongoing priority.

Key words
- Palliative care
- Terminal care
- Dialysis
- Kidney failure
- Referral and consultation
- Patient discharge


