A tale of two specialties
United Kingdom
Annual Symposia on Renal-Palliative Care co-organised by both disciplines
Concentrated on the care of Dialysis patients nearing the end of life
Royal College of Physicians (UK)

The Changing Face of Renal Medicine in the United Kingdom

2007
Recommended:

Joint working between the Renal multiprofessional team, primary care and other services such as Palliative Care promoting integrated care for patients with CKD.
National End of Life Care Strategy

UK Department of Health, 2008
Excellent end of life care should not be confined to patients cared for by Palliative Care services but all patients in all settings and with all conditions including ESRD
National Framework for the Implementation of End of Life Care in Advanced Kidney Disease

2009
USA
In 1998 -

The Baystate Renal-Palliative Care Initiative
• Treatment protocols
• Annual Renal Memorial Service
• Bereavement support
• Increasing collaboration between Renal and Palliative Medicine
Clinical Practice Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis


www.renalmd.org
In 2002 –

*RPA/ASN Position Paper on Quality Care at the End of Life*
Robert Woods Johnson Foundation
Formation of an ESRD Working Group

“…to make recommendations to promote excellence and improved QOL of ESRD patients and their families through supportive care.”
In 2003 –

Robert Woods Johnson Foundation

*National End-Stage Renal Disease Working Group on Renal-Palliative Care*

- *Recommendations to the Field*
In 2004 –

Renal-Palliative Care Curriculum for Nephrology Trainees

In 2010 –

*Clinical Practice Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*

Renal Physicians Association of the USA 2010.
Australia
Northern Territory
Palliative Care for Renal Clients Living in a Remote Setting
Victoria
Victorian Renal Health Clinical Network

CKD Work Group
St Vincent’s Hospital, Melbourne

CKD Clinic –
with Palliative Care Consultant/Registrar
Ballarat
Victorian Department of Health
Renal Conservative Care Project Officer
Renal Conservative Care Conference
Royal Melbourne Hospital
March 2010
NSW
St George Hospital, Sydney

Collaboration between the Renal Medicine and Palliative Medicine Departments.
Formation of a Renal Medicine – Palliative Care Working Group
Formation of a Renal Palliative Care Clinic

March 2009
Renal Palliative Care Symposium

Orange, NSW

December 2009
ANZSPM Fora 2010

Brisbane, Sydney
A/Professor Mark Boughey

“Renal Palliative Care”
NSW Department of Health funding of two new positions 2010
• Renal-Palliative Care Physician

• Renal-Palliative Care Nurse
Textbooks
Chambers EJ, Germain M, Brown E (eds)  
*Supportive Care for the Renal Patient*  
2nd edition, 2010  
Oxford University Press
Brown E, Chambers EJ, Eggeling C.

*End of Life Care in Nephrology -from Advanced Disease to Bereavement*

2007

Oxford Specialist Handbooks
Conclusion

The histories of the two disciplines are intersecting
The last decade has seen considerable levels of advocacy, attitudinal shift, research, publications and collaboration
RENAL FAILURE AND PALLIATIVE CARE - Challenges and structure

Frank Brennan
Palliative Care Consultant
St George Hospital
Sydney
What is Palliative Care?
What possible role does Palliative Care play in End Stage Renal Failure?
WHO definition (2002)

Palliative Care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Modern view of Palliative Medicine

A. That Palliative Care is involved in all patients with life-limiting illnesses – not just cancer patients.
Modern view of Palliative Medicine

B. Early involvement: “There is wide recognition that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness.”
C. The concept of concurrent care: that active care and palliative care can and should occur concurrently.
D. That the “death–bed consultation” is a set of missed opportunities.
Benefits of early involvement—

- reinforcement of idea of comfort.
- that symptom control is impeccable throughout.

- establishing a rapport/trust
- demystifying analgesia (opioids)
- introducing idea of Community Palliative Care

- helps avoid sense of abandonment
Why is Palliative care/ a palliative approach relevant to patients with ESRD?
Characteristics of patients on dialysis have changed over the years.

Essentially more elderly patients with co-morbidities.

4 fold increase in the number of patients over 75 years in western countries.
In Australia – the mean age of commencement on Renal Replacement therapy is 60.4 years (ANZDATA Registry 2009 Report)

Increasing number of patients returning to dialysis after transplant failure.
The age cohort that has the greatest prevalence is the 65-84 year old group.
Overall patients with ESRD with or without RRT have a reduced life expectancy compared to age-matched controls.
DIALYSIS

For patients on dialysis 15.4 % die each year (ANZDATA Registry 2008 Report)
For those aged 75 years and older that figure is 25 %
The circumstances in which patients with ESRD die varies considerably
If it is an expected death (eg. after the cessation of dialysis) the management of the dying phase is crucial

and the manner of that dying will be remembered forever by the family
Patients with ESRD have a significant symptom burden related to both the disease itself and other co-morbidities.
Overall QoL is very resistant to significant change
Throughout the course of the illness there are times when difficult conversations may need to occur
Palliative Care/ a palliative approach can play an important role throughout the course of ESRD
Timing of involvement

- Purely Conservative Management
- Pre-Dialysis
- Dialysis
- Withdrawal from Dialysis
- Terminal phase
Realistically, given issues of manpower, it may not be possible for a Palliative Care health professional to be present in every Renal Unit.
How could you incorporate a “Palliative approach” to your patients?

Indeed the Renal team are almost certainly doing that at present.
What are the core competencies in a “Palliative approach” to patients with ESRD?
4 Pillars of a Palliative approach

- Communication
- Symptom management
- Psychosocial support
- Care of the dying patient
Communication
Discussions at critical times –

- Pre-Dialysis
- Dialysis
- Withdrawal from Dialysis
• Advance Care Planning
• End of Life preparation
• Care of the dying patient
Pre-Dialysis
Once ESRD is diagnosed it is important to examine the various options.
RRT

Conservative
Should all patients who are candidates for dialysis commence dialysis?
Necessarily this decision must involve medical, logistical and ethical considerations.
CARI guidelines

Caring for Australasians with Renal Impairment

Council of the Australian and New Zealand Society of Nephrology and the Board of Kidney Health Australia
Ethical Considerations

...the decision concerning acceptance onto a dialysis program should be made on the basis of the patient’s need.

CARI guidelines – Ethical Considerations
Decision to recommend or not recommend dialysis should not be influenced by either availability of resources or potential litigation.

CARI guidelines – Ethical Considerations
The cardinal factor for acceptance onto dialysis or continuation of dialysis is whether dialysis is likely to be of benefit.

CARI guidelines – Ethical Considerations
A useful starting point for recommending dialysis is an expectation of survival with a quality of life acceptable to the patient.

CARI guidelines – Ethical Considerations
Conservative management is a recognised option for patients with end stage renal disease.

CARI guidelines – Ethical Considerations
A useful starting point for recommending dialysis is *an expectation of survival* with a quality of life acceptable to the patient.

CARI guidelines – Ethical Considerations
Dialysis or not? A comparative study of survival of patients over 75 years with CKD Stage 5.

Dialysis or Not?

• Age > 75; eGFR < 15

• 52 on a dialysis pathway; 77 conservative pathway

• Survival 1 yr – 84 vs 68%

• Survival 2 yrs – 76 vs 47%

– Survival advantage lost if 2 or more co-morbidities

– Particularly lost if IHD as a co-morbidity
Survival

Survival benefit lost if Co-morbidities include IHD

ANZDATA dialysis survival age ≥75

- 1781 patients; 2002-5; retrospective
- Survival 77% 1 yr, 59% 2 yrs
- Predictors of death:
  - Age
  - Underweight
  - Late referrals
  - Lack permanent access at start
Chance of dying worse by co-morbidities
- 36% for 1
- 54% for 2
- 85% for 3

Phounpadith et al. ASN 2009
[SA-PO2475] Mortality in Elderly Dialysis Patients: The Association with Demographic, Patient and Practice Variables
A useful starting point for recommending dialysis is an expectation of survival with a quality of life acceptable to the patient.
Quality of Life (QoL) in the St George Dialysis Population

Elizabeth Josland
Prof Mark Brown
St George Hospital
SF-36 scores for modality and >= 45 years in the 2008 survey

Mean Scores by Modality 2008

Kruskal-Wallis Test p<0.05 for difference in modality
>=65 years overall show a poor QoL

That deteriorates when analysed by dialysis mode - Hospital HD fairs worse physically, while PD still has a poor physical score and the worst emotional score.
Diabetics have a worse QoL particularly in physical and general health parameters.
Dialysis in Frail Elders — A Role for Palliative Care

Robert M. Arnold, M.D., and Mark L. Zeidel, M.D.

Volume 361:1597-1598

October 15, 2009
Survival vs QOL : Nursing home dialysis

- 3702 NH residents with ESKD
  - 95% HD; started 1998-2000
  - 62% Vascaths
  - Registry analysis of survival & ADL
- Mortality 1st year after starting HD
  - >70y 35%
  - >80y 50%
- Functional status deteriorated within 3 months

## Co-morbidities

<table>
<thead>
<tr>
<th>Coexisting condition (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>68</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>66</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>44</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td>37</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>39</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>24</td>
</tr>
<tr>
<td>Cancer</td>
<td>12</td>
</tr>
<tr>
<td>Dementia</td>
<td>22</td>
</tr>
<tr>
<td>Depression</td>
<td>35</td>
</tr>
<tr>
<td>Hemodialysis (vs. peritoneal dialysis) (%)</td>
<td>95</td>
</tr>
<tr>
<td>Hospitalized at initiation of dialysis (%)</td>
<td>69</td>
</tr>
</tbody>
</table>
Figure 2. Change in Functional Status after Initiation of Dialysis.
Data were missing for 549 nursing home residents at 3 months, 696 residents at 6 months, 823 residents at 9 months, and 787 residents at 12 months from the full analytic cohort of 3702 residents.
Smoothed Trajectory of Functional Status before and after the Initiation of Dialysis and Cumulative Mortality Rate

[Nursing home residents mean age 73]
Clinical Practice Guidelines on Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Renal Physicians Association of the USA 2010.
Recommendation No. 6

It is reasonable to consider forgoing dialysis for ... ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely.
1. Those whose medical condition precludes the technical process of dialysis because the patient:

(a) is unable to co-operate (eg. Advanced Dementia)
(b) unstable medically (eg. Significant hypotension)
2. Another life-limiting illness – although this may be negotiated
3. Over 75 years with 2 or more of the following statistically significant criteria predictive of very poor prognosis:

(a) Surprise question.
(b) High Co-morbidity Score
(c) Significantly impaired Functional status such as Karnofsky < 40,
(d) Severe chronic malnutrition (s. Albumin < 25.)
Conservative management of ESRD
If this is being raised as an option:

What does a Conservative pathway mean?

What is its content?

Can we make predictions about their course?
Challenge is to ensure that this pathway of management is not seen as “second best” or inadequate but is thorough, systematic and evidenced-based.
Renal Medicine
- Calcium/Phosphate
- Anaemia
- Fluid balance

Palliative approach
- Symptom management
- Psychosocial support
- Care of the dying
There is a modest, but growing body of literature of research on this cohort of patients.
Longitudinal study of conservative stage 5 CKD

• Included patients with Stage 5 Chronic Kidney Disease with definite decision for conservative (non dialysis) management, and with capacity for consent
• 73 participants (response rate 62%)
• 49 (66%) died during follow-up
  • mean age 81 years, range 58-95 yrs
  • 24 (49%) men
  • median follow-up 8 months (range 1-23 months)
• Outcomes measured monthly until death or study end
  • Symptoms (MSAS-SF)
  • Palliative needs (POS)
  • Functional status (KPS)
Trajectory of functional status:

<table>
<thead>
<tr>
<th>Time before death (months)</th>
<th>KPS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>80</td>
</tr>
<tr>
<td>1</td>
<td>70</td>
</tr>
<tr>
<td>2</td>
<td>60</td>
</tr>
<tr>
<td>3</td>
<td>50</td>
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<td>4</td>
<td>40</td>
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<td>30</td>
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<td>6</td>
<td>20</td>
</tr>
<tr>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>8</td>
<td>n=10</td>
</tr>
<tr>
<td>9</td>
<td>n=43</td>
</tr>
</tbody>
</table>

www.kcl.ac.uk/palliative
Trajectory of symptom distress:

MSAS-Global Distress Index
(0-100 scale)

Time before death (months)

www.kcl.ac.uk/palliative
Trajectory of palliative needs:

Palliative outcome scale
(0-100 scale)

Time before death (months)

mean POS score
95% confidence intervals

www.kcl.ac.uk/palliative
Course of symptoms

Individual variation

Implications for patients

Implications for care
  - Symptom burden
  - Assessment of symptoms
  - Advance planning

www.kcl.ac.uk/palliative
If the decision is made to commence Dialysis
Clear statement that Dialysis does not guarantee a normal life span
How are you going with the dialysis?

In what circumstances would Dialysis become too much for you?
Advance Care planning
Challenges

• Should these discussions be initiated?

• Who should initiate these discussions?

• What should their content be?

• ACD and ACP
Discussions about ceasing Dialysis
These discussions may become very pertinent when other conditions are causing significant morbidity
These are difficult discussions
How would I die if I were to cease Dialysis?
Symptom control
“Patients with CKD, particularly those with ESRD are among the most symptomatic of any chronic disease group.”

What are the common symptoms associated with ESRF?
The Prevalence of Symptoms in End-stage Renal Disease: A systematic Review

Murtagh FE et al. Advances in Chronic Kidney Disease
Vol 14, No 1 (January) 2007; pp 82-99
A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis

<table>
<thead>
<tr>
<th>Condition</th>
<th>Dialysis</th>
<th>Conservative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>75</td>
<td>71</td>
</tr>
<tr>
<td>Pruritus</td>
<td>55</td>
<td>74</td>
</tr>
<tr>
<td>Anorexia</td>
<td>49</td>
<td>47</td>
</tr>
<tr>
<td>Pain</td>
<td>47</td>
<td>53</td>
</tr>
<tr>
<td>Insomnia</td>
<td>44</td>
<td>42</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>35</td>
<td>61</td>
</tr>
<tr>
<td>Restless Legs</td>
<td>30</td>
<td>48</td>
</tr>
</tbody>
</table>
Challenges

- Under-detection
- Under-treatment
- Medications
Death in dialysis patients
DIALYSIS

For all patients on dialysis 15.4% die each year (ANZDATA Registry 2008 Report)

For those aged 75 years and older that figure is 25%
<table>
<thead>
<tr>
<th>Cause</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac</td>
<td>36%</td>
</tr>
<tr>
<td>Infection</td>
<td>10%</td>
</tr>
<tr>
<td>Vascular</td>
<td>10%</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>8%</td>
</tr>
<tr>
<td>Social</td>
<td>36%</td>
</tr>
</tbody>
</table>
‘Social’ causes of death in dialysis patients 2007

Withdrawal from dialysis

<table>
<thead>
<tr>
<th>Cause</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial</td>
<td>13% of all dialysis patients</td>
</tr>
<tr>
<td>Access, CVA etc</td>
<td>22%</td>
</tr>
<tr>
<td>Accident</td>
<td>0.8%</td>
</tr>
<tr>
<td>Suicide</td>
<td>1 / 1452 patients</td>
</tr>
</tbody>
</table>

ANZDATA 2008 report
Care in the Terminal phase
• Preparation of patient and family
• Anticipation of symptoms
• Symptom management
• Support for the family
• Bereavement
End of Life Care guidelines specific to patients with ESRD
Conclusion

A mutual acknowledgement of need-

The role of Palliative Care in ESRD
The core competencies in a “Palliative approach” to patients with ESRD
4 Pillars of a Palliative approach

- Communication
- Symptom management
- Psychosocial support
- Care of the dying patient
Applies to patients who are being managed with either with RRT or conservatively