Renal Supportive Care –
An Introduction

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Renal Supportive Care Master Class
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Overview

1. What possible role does Palliative Care have in Nephrology?

The interface of the two disciplines.
2. Decision making around dialysis including the possible withholding and withdrawing from dialysis.

3. The conservative, non–dialytic management of ESKD.
4. The international perspective
    including the New South Wales experience.
1. What possible role does Palliative Care have in Nephrology?

What is Palliative Care?
WHO definition

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.
A. Epidemiology
In developed nations the mean age of patients commencing RRT is 60 - 65 years.

In the UK – 63.7 years.

In developed nations the age cohort that has the greatest prevalence on dialysis is the 65-84 year old group.


The other aspect of the change in epidemiology globally is the rise of Diabetes Mellitus.
The percentage of incident patients with ESKD that have diabetic nephropathy is:

> 50 % in Singapore, Malaysia, New Zealand

40 -50 % in Hong Kong, Taiwan, Republic of Korea, Japan and the USA.

UK – 29 % (2017)  UK Renal Registry Report 2019
Does everyone who has ESKD start dialysis?

In Australia, for every one patient with ESKD receiving Renal Replacement Therapy (RRT) there is another who does not receive RRT

Australian Institute of Health and Welfare Research, 2011
Globally

Nation A

May have resources that are universally available and allow elderly, frail, co-morbid patients onto dialysis programs.
Nation B

• Limited resources

• Dialysis reserved for younger, fitter patients, or simply reserved for those that can afford dialysis

Nation C

• Poor resources

• Dialysis is not available
Throughout the world, therefore, many patients with ESKD embark on a conservative, non-dialysis pathway not by choice...

but simply because dialysis/transplant is not available or affordable.

This raises the question of the level of care of those on dialysis and the many who never receive dialysis.
B. Mortality

ESRD patients

Overall patients with ESKD with or without RRT have a reduced life expectancy compared to age-matched controls.
DIALYSIS

For patients on dialysis 13.3 % die each year (ANZDATA 2016 Report)

For those aged 75 years and older that figure is 25 %.
Annual mortality UK – for 75-84 y.o. – 23 %
- for 85 years plus – 35 %

UK Renal Registry Report 2019

C. Symptomatology
“Patients with CKD, particularly those with ESRD are among the most symptomatic of any chronic disease group.”


D. Quality of life
E. The “quality” of dying
The circumstances in which patients with ESRD die varies considerably.

If it is an expected death (e.g. after the cessation of dialysis or if on a non-dialysis pathway) the management of the dying phase is crucial

and the manner of that dying will be remembered forever by the family.
The interface of Nephrology and Palliative Care

1. Epidemiology
2. Mortality
3. Morbidity
4. QOL
5. “Quality of dying”
Decision making around dialysis
Once ESRD is diagnosed it is important examine the various options.

| RRT | Conservative |
One could start with the assumption that for all patients, in all circumstances, dialysis is the preferred option.

Is there a cohort of patients with ESKD where it may be more appropriate to recommend a conservative, non-dialysis pathway over dialysis?
Factors to consider:

1. Survivorship
2. QOL
3. Hospitalisations
4. Effect on carers

Factors to consider:

1. **Survivorship**
2. QOL
3. Hospitalisations
4. Effect on carers
Dialysis or not? A comparative study of survival of patients over 75 years with CKD Stage 5.


**Survival**

![Survival Curve](image)

Survival benefit lost if Co-morbidities include IHD

<table>
<thead>
<tr>
<th></th>
<th>Dialysis ($n = 10$)</th>
<th>Conservative ($n = 15$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days after eGFR fell below 15ml/min</td>
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</tbody>
</table>


RRT v Conservative
Chandra et al NDT Nov 2010

Low comorbidity $p = 0.03$
High comorbidity $p = 0.83$
Carson et al CJASN 2009 went one step further...

For the dialysis cohort how did they spend their extra time?

Approximately 80% of the extra days survived were spent on dialysis or being hospitalised for complications of dialysis.

Carson et al CJASN 2009
Dialysis in Frail Elders — A Role for Palliative Care

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

Change in Functional Status after Initiation of Dialysis

3702 Nursing home residents mean age 73

Mean eGFR 10
Female 60%
Diabetes 68%
CHF 66%
CHD 44%
Cerebrovascular dis. 39%
Depression 35%
Dementia 22%

Kurella Tamura et al. 361 (16): 1539, October 15, 2009
Smoothed Trajectory of Functional Status before and after the Initiation of Dialysis and Cumulative Mortality Rate

[Nursing home residents mean age 73]

CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life

Mark A. Brown, Gemma K. Collett, Elizabeth A. Josland, Celine Foote, Qiang Li, and Frank P. Brennan

CIASN 2015; 10 (2) : 260-268
In patients over 75 years with 2 or more co-morbidities (one of which was IHD or CCF) there was no survival advantage with dialysis compared to those who did not commence dialysis.
Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis


The Netherlands. CJASN. April. 2016

Survival advantage lost if > 80 years old.
Hospitalisations

In elderly patients on dialysis the rates of hospitalisation - 20-35 days per year.

Carson et al CJASN 2009
Rohrich et al NDT 1998

In elderly patients on a conservative pathway the rates of hospitalisation - 10 - 16 days per year.

Carson et al CJASN 2009
Wong et al Renal Failure 2007
Impact on carers

Median 56-70 hours of care per week.

Belasco et al AJKD 2006
All aspects of QOL affected.

Increasing carer burden with increasing patient age and co-morbidities and worsening functional status and QOL.

Belasco et al. AJKD 2006
Alvarez et al. J Nephrology 2004
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. It is reasonable to consider forgoing dialysis in those patients aged >75 with stage 5 CKD who meet 2 or more of the following statistically significant very poor prognosis criteria:

1. Clinician’s response of “no, I would not be surprised” to the surprise question (“Would I be surprised if this patient died in the next year?”)

2. High co-morbidity score

3. Significantly impaired functional status

4. Severe malnutrition
The conservative, non–dialytic management of ESKD.

1. This may be decided in consultation with a Nephrologist.
2. The patient cannot access or afford dialysis.

3. The patient is not referred to a Nephrologist in the first place.
What level of care occurs for this group?

Nephrologist A

“I am sorry...
• I cannot offer dialysis to you. or
• That you cannot afford dialysis.

So I cannot help you....”
Nephrologist B

“Even though you are not starting dialysis, you still have kidney disease.

As a Nephrologist, I still have much to offer you.
Keep coming to see me.”

Even though the patient may not be commencing or continuing dialysis, the Nephrologist has a great deal to offer.
Renal medicine

• Preserving residual renal function
• Blood pressure control
• Calcium/phosphate control
• Anaemia
• Fluid balance

So what does the conservative, non-dialysis care of a patient with ESKD look like?
The care should be the best of the two disciplines

**Renal Medicine**
- Preserving residual renal function
- Blood Pressure
- Calcium/Phosphate
- Anaemia
- Fluid balance

**Palliative approach**
- Symptom management
- Advance Care Planning
- Psychosocial support
- Care of the dying

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**CKD conservative management**

Not abandonment
CKD conservative management

Not simply transfer to Palliative Care

Challenge is to ensure that this pathway of management is thorough, systematic and evidenced-based.
What do we know about the conservatively managed group of patients?

A. Survivorship.

B. Symptoms

C. Needs
Survivorship

“How long do you think I will live if I do not start dialysis?”
CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life

Mark A. Brown, Gemma K. Collett, Elizabeth A. Jonsland, Coline Foote, Qiang Li, and Frank P. Brennan

CIASN 2015; 10 (2) : 260-268

One-third of non-dialysis patients lived more than 12 months after eGFR fell below 10ml/min.
B. Symptoms

A Cross-sectional Survey of Symptom Prevalence in Stage 5 CKD managed without Dialysis = NFD 1

Murtagh FEM et al. J Pall Med 2007; 10(6) :1266-1276

The symptoms of patients with CKD stage 5 managed without dialysis. = NFD 2

## SYMPTOM PREVALENCE

<table>
<thead>
<tr>
<th>Symptom</th>
<th>NFD1</th>
<th>NFD2</th>
</tr>
</thead>
<tbody>
<tr>
<td>FATIGUE/TIREDNESS</td>
<td>75%</td>
<td>88%</td>
</tr>
<tr>
<td>PRURITUS</td>
<td>74%</td>
<td>69%</td>
</tr>
<tr>
<td>CONSTIPATION</td>
<td></td>
<td>43%</td>
</tr>
<tr>
<td>ANOREXIA</td>
<td>47%</td>
<td>62%</td>
</tr>
<tr>
<td>PAIN</td>
<td>53%</td>
<td>45%</td>
</tr>
<tr>
<td>SLEEP DISTURBANCE</td>
<td>42%</td>
<td>57%</td>
</tr>
<tr>
<td>ANXIETY</td>
<td></td>
<td>43%</td>
</tr>
<tr>
<td>DYSPNEA</td>
<td>61%</td>
<td>60%</td>
</tr>
<tr>
<td>NAUSEA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RESTLESS LEGS</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>DEPRESSION</td>
<td></td>
<td>52%</td>
</tr>
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### C. Needs
Over time, what happens to patients on a conservative, non-dialysis pathway?

Trajectories of Illness in Stage 5 CKD: A Longitudinal Study of patient symptoms and concerns in the last year of life.

*CJASN* 2011; 6(7): 1580-1590.

Murtagh FE et al.
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 symptom distress:

MSAS-Global Distress Index (0-100 scale)

Trajectory of palliative needs:

Palliative outcome scale (0-100 scale)
What is happening internationally in Renal Supportive Care?
Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

Sara N. Davison¹, Adeera Levin², Alvin H. Moss³, Vivekanand Jha⁴, Edwina A. Brown⁵, Frank Brennan⁶, Fliss E.M. Murtagh⁶, Saraladevi Naicker⁷, Michael J. Germain⁸, Donal J. O'Donoghue⁹, Rachael L. Morton¹²,¹³ and Gregorio T. Obrador¹⁴

In 2018
The International Society of Nephrology hosted a summit on integrated kidney care

This endorsed the role of Renal Supportive Care.

Harris D et al. Kidney Int 2019; 95; S1-S33.
There are several national statements.

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

Renal Physicians Association of the USA 2010.
National RSC Position Statements
have been published or are in preparation in:

- India
- Czech Republic
- Thailand
- South Africa
Annual Renal Supportive Care Symposia

London
St George and Nepean Hospitals, Sydney
Royal Brisbane Hospital

Master Classes/ workshops on
Renal Supportive Care
• Sri Lanka (2015)
• Ireland (2016)
• Malaysia (2017)
• Thailand (2017, 2018, 2019)
• India (2018) – Zoom lecture series
• India (2019)
• South Africa (2019)
• Australia (2015, 2019)
• United Kingdom – Oxford (2019)

The New South Wales experience
Commenced in the Renal Department
St George Hospital, Sydney.

It started with a conversation
It started with a conversation about the needs of patients.

Much of that conversation consisted of a series of meetings between Palliative Care team and the Renal Nurses.

There was a clear recognition that it was the Renal/dialysis nurses who were witnessing the struggles of dialysis patients on a daily basis.
There was also an early recognition that:

with so few Palliative Care health professionals, already engaged with other diseases,

it was vital to enhance the skills of Nephrologists, Renal trainees, Renal Nurses and Allied Health in this area.

At the beginning there was no funding.
“Start will good will.”

Professor Mark Brown, Nephrologist, St George Hospital, Sydney.

A Renal Supportive Care Service
within the Department of Nephrology
RSC Clinic weekly:

65% conservative patients
35% dialysis patients

RSC Clinic weekly:

65% conservative patients
35% dialysis patients – symptomatic, struggling
Lines of referral

Open

Triaged by Renal Supportive Care Nurse

Symptom census of all dialysis patients every 6 months.
Symptom census of all dialysis patients every 6 months.

If report any moderate to overwhelming symptoms – automatic referral the RSC Clinic.

Each patient, at each presentation, completes the IPOS-Renal in the waiting room.
Personnel:

Palliative Care Physician
Nephrology Trainee
Renal Supportive Care Nurse
Renal Social Worker
Renal Dietician
In other clinics in Australia
the Nephrologist has led the clinic

The crucial role of a Renal Supportive Care Nurse
To co-ordinate the Service and the other members of the team.

To ensure that patients needs are being addressed and followed up.

From the beginning the attendance of the Nephrology Trainee at the RSC Clinic has been crucial.
The model in Christchurch, New Zealand

Clinic (non-funded)
Clinic – non-funded

Data collection

Taking that data to the Dept of Health – seed funding to St GH
Clinic – non-funded

Data collection

Taking that to the Dept of Health – seed funding to St GH

Permanent funding to St GH

Annual Symposia, publications, lectures, National Guidelines, JMO/Registrar/Nursing teaching. Observerships by national and overseas visitors.
Clinic – non-funded

Data collection

Taking that to the Dept of Health – seed funding to St GH

Permanent funding to St GH

State wide funding

In addition to the Clinic
the RSC Service includes...
• In-patient referrals

• Community visits

• Education and research

6 x tutorials on RSC for junior doctors working in Renal Medicine.

Department of Nephrology, St George Hospital, Sydney.
Annual Renal Memorial Service

Conclusion

The role of Palliative Care/Supportive Care in ESKD

A mutual acknowledgement of need.
Conclusion

Over the past decade there has been an emerging interest, research and engagement at this interface of the disciplines.

Much work needs to be done at all levels.