Digging deep when stretched thin:
Setting up a supportive care service with limited resources

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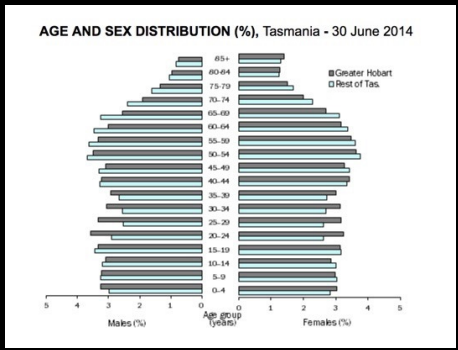
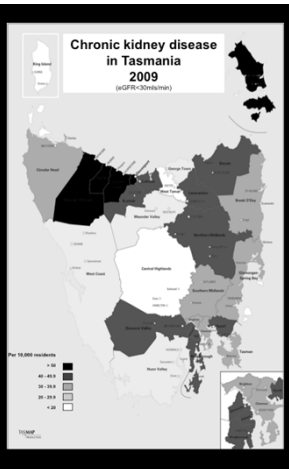
45% populace >45 yrs
18% over 65, highest among the states

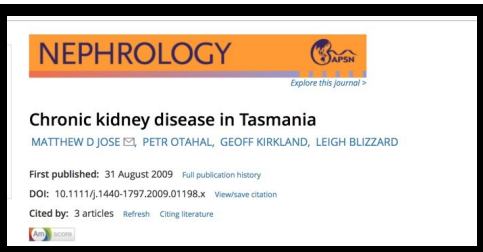




Launceston General Hospital

- 2.5 FTE nephrologists
- 6 acute HD beds; about 40 outpatient dialysis beds in 2 satellite sites; 2 'home' sites in smaller hospitals
- About 100 HD, 40 PD, 15 Home HD
- About 100 public outpatients seen every week (all of northern Tasmania)

a few important publications


NEPHROLOGY

Chronic kidney disease in Tasmania

MATTHEW D JOSE, PETR OTAHAL, GEOFF KIRKLAND, LEIGH BLIZZARD

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DOI: 10.1111/j.1440-1797.2009.01198.x View/save citation

Cited by: 3 articles Refresh Citing literature

"There is a broad gap between the number of people with eGFR of less than 15 mL/min per 1.73 m2 (stage V CKD) and those receiving dialysis treatment."

Dialysis numbers accounted for only ~60% of eGFR<15

CLINICAL EPIDEMIOLOGY www.jasn.org

Age Affects Outcomes in Chronic Kidney Disease

Ann M. O'Hare,* Andy I. Choi,† Daniel Bertenthal,‡ Peter Bacchetti,§ Amit X. Garg,‖ James S. Kaufman,¶ Louise C. Walter,† Kala M. Mehta,† Michael A. Steinman,† Michael Allon,** William M. McClellan,†† and C. Seth Landefeld†

- with CKD 3 -5
- Followed for av. 3.2 years
- 47% were over 75
- At same eGFR, older more likely to die than develop ESRD compared to younger
- If > 85, any EGFR:- risk

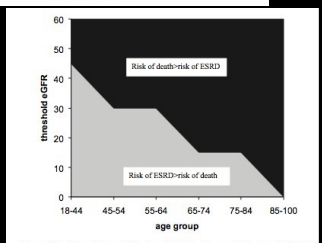


Figure 2. Baseline eGFR threshold below which risk for ESRD exceeded risk for death for each age group.

Nephrol Dial Transplant (2007) 22: 1955–1962
doi:10.1093/ndt/gfm153
Advance Access publication 4 April 2007

NDT Nephrology Dialysis Transplantation

Original Article

Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5

Fliss E. M. Murtagh[1], James E. Marsh[2], Paul Donohoe[3], Nasirul J. Ekbal[4], Neil S. Sheerin[5] and Fiona E. Harris[2]

Dialysis and non-dialysis pathways were compared
Patients > 75, with eGFR <15, 2003 to 2004
Followed till June 2005
Study of variables associated with survival

Where were the untreated patients with advanced CKD?

- Usual practice - discharge back to GP
- Hospitalised for EOL care; palliative care involved late
- Not receiving most elements of 'maximal conservative care'

Traditional avenues of palliative care

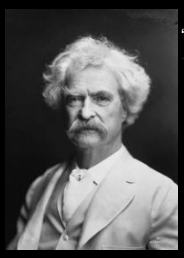
- Palliative care departments and services
- Need for continued 'renal' management
- Patient / family needs : continuing a pattern of care they were used to for many years

Facilities in Launceston

- Two palliative care specialists - one hospital-based; another based in local hospice
- Local hospice - run within a private hospital
- Community palliative care - nurse-led services
- Renal patients : difficulties

Nephrology *or* Palliative Care?

- Long periods in the patient journey where support is required, before they need end-of-life care, usually provided by the palliative care team
- Patient issues specific to dialysis, to renal failure
- Large body of renal-specific literature to deal with - guidelines, targets



" The secret to getting ahead is getting started."

Mark Twain

Starting

- Buy -in from departmental colleagues
- 'Negotiations' with outpatient clinic managers
- Including multidisciplinary team members - nurse, social worker

Starting

- CKD education nurse (rather than a palliative care nurse)
- Renal social worker
- Support from Palliative Care - at initiation, we chose a day the palliative care physician was definitely in hospital

Starting

- Two clinics - one for the doctor, the other for the social worker & CKD nurse
- Repetitive, tiring for patients
- Single paper-based record had to be passed room to room
- Now truly multidisciplinary

Referrals

- From other nephrologists
- From the CKD education process

Usual process

- First visit: Exploration of patient understanding of disease process, decisions, role of the supportive care clinic
- Detailed symptom review with the POS-Renal
- Early discussions regarding advance care directives, health care proxies

Subsequent visits

- Symptom review
- Blood tests
- Active renal management - anemia, BMD
- Contacting GPs

Revising referrals / expanding services

- Most patients in this clinic had eGFR 20 - 25 : low burden of symptoms
- Need to address issues of dialysis patients

Renal Provider Recognition of Symptoms in Patients on Maintenance Hemodialysis

Steven D. Weisbord,*†‡ Linda F. Fried,*†‡ Maria K. Mor,*§ Abby L. Resnick,* Mark L. Unruh,‖ Paul M. Palevsky,†¶ David J. Levenson,** Stephen H. Cooksey,** Michael J. Fine,*‡ Paul L. Kimmel,¶ and Robert M. Arnold‡

Including dialysis patients

- 4 years ago - the surprise question, for all hemodialysis patients, to all dialysis nurses
- In 24 out of 91 patients : majority answered “no, I wouldn’t be surprised”
- 26% of patients !

The 20 minute renal appointment!

Call in, meet & greet, seat, carer settles	2 to 3 minutes
Initial enquiries and replies	2 to 3 minutes
Review dialysis progress, blood pressures, weight gains, targets	3 to 5 minutes
Check biochemistry, match dialysis orders K, Ca, HCO3	3 to 5 minutes
Fluid assessment, auscultate lungs, check fistula	2 to 3 minutes
Talk to patient - phosphate binders, weight gain,	3 to 5 minutes

Nephrologists’ concerns at clinic visits

- Volume status? Weight gains?
- Adequacies? Dialyser sizes? PET ?
- Good flow? Good AVF? Good catheter?
- Chemistries - Hb,Ca, PO4 challenges
- Compliance - meds, fluid, diet, appointments

Some things never get done

- A detailed enquiry into symptoms
- Discussion of trajectory
- Advance care planning
- ‘Seeing the patient as a whole’
- Carer concerns

Changes to referral process

- Every dialysis patient is offered an annual visit to the supportive care clinic
- Symptom review and documentation, discussions of prognosis / advance care planning / nomination of healthcare proxies
- Aim: (KPI) most dialysis patients should have had an advance care discussion

Patients seen at the clinic

- Choosing conservative management
- Undecided about choice of therapy
- Those on dialysis with severe symptoms
- Those considering withdrawal from dialysis

Referrals to the clinic

- CKD education nurse
- Nephrologists in outpatient clinics
- Dialysis patients - one visit every year
- Dialysis nurses in discussion with treating nephrologist

Supportive Care Clinic

- Established 2011
- About 500 consultations over last 5 years
- Conservative care - 52 patients
- Patients on dialysis - 49 (HD 32, PD 17)

Table 1: Capability and Resource Matrix

Level	Capability	Typical resource profile
Primary care	Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care. Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.
Specialist palliative care level 1	Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. Has quality and audit program.	Multi – disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/ consultant, allied health staff, pastoral care and volunteers. A designated staff member If available coordinates a volunteer service.
Specialist palliative care level 2	As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community. Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.	Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.
Specialist palliative care level 3	Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has comprehensive research and teaching role. Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.	Interdisciplinary team including a medical director and clinical nurse consultant/ nurse practitioner and allied health staff with specialist qualifications in palliative care.

Research


NEPHROLOGY

Original Article

Symptoms and their recognition in adult haemodialysis patients: interactions with quality of life

Rajesh Raj[1,*], Kiran D. K. Ahuja[2], Mai Frandsen[2] and Matthew Jose[1]

DOI: 10.1111/nep.12754

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Issue

Nephrology

Accepted Article (Accepted, unedited articles published online and citable. The final

Survey of Symptoms (*article in press)*

- 35 patients; mean age 79, mean eGFR 19
- At least 4 symptoms rated as more than trivial per patient (POS-Renal survey)
- Weakness, poor mobility, drowsiness and dyspnoea were commonest symptoms

Lessons learnt

- Resources and needs will never reconcile - for new services, just START!
- With some planning, existing staff services can be re-routed for this essential part of renal care
- Every cause needs a champion or two! A core team, and 'buy-in' by the others is important
- Close links with palliative care are central

In practice : Problems

Patient Concerns: those on dialysis

- One more clinic!!
- Discussions are confrontational
- So is there something wrong with me?
- Desire for continuity

Nurses' issues

- 'Standard approach' to palliative care - any clinical team member can request referral?
- Lack of clarity - what happens in the clinic?
- Palliative care = death clinic; flip side of the 'surprise question'

Nephrologists' issues

- Continuity of care
- Can't we do this ourselves?
- Issue of 'permissions' - patients 'belong' to doctors
- Confusion regarding 'goals' - especially with regard to statin use, ESAs, BMDs,restrictions

Other hospitalists

- SIADH - anti-death hormone (!!) - or, how dialysis patients are indestructible
- The fine line between supportive and curative intent; problems with mixing the paradigms
- Speciality admissions Vs general medicine admissions

General Practitioners

- “What can you do that I don’t already do?”
- Unfamiliarity with supportive care for chronic illness (as opposed to cancer)
- Who manages symptoms? How do you manage without dialysis?
- Continuity of care; ‘my patient’ syndrome

Administrative issues

- Palliative care Vs Nephrology
- Rooms / space / support staff
- Typical hospital: one department, two kinds of clinics, and the confusions that follow
- Appointments - general clinic vs supportive

Some lessons in retrospect

- Documentation is central - for the patient journey, for standards setting, for KPIs and for business cases
- “Normalisation” - is a worthy goal, where supportive care visits are the norm, not exception
- Concentrate on expanding your team early

What is ‘insufficient’

- Actively discouraging dialysis when you think outcomes are going to be poor
- Deliver prognostic information ‘frankly’; the over-rated importance of “telling it like it is”, or “straight-shooting”
- Easing restrictions on diet / BP control / scaling down prescriptions

Future plans: growing the clinic

- Marketing !!!
- The default option?
- Many hoops to pass through before a supportive pathway is chosen
- Accept GP referrals - they do know their patients better

Unanswered questions

- How do we achieve tighter links to palliative care services?
- How do we train doctors, nurses, trainees specifically in palliative care while they continue in Nephrology?
- How do we build business cases?
- Where do we put resources - primary prevention?CKD? More dialysis? More home therapies? More supportive care? Is there an order of priorities?


The Renal Palliative Care Initiative.

J Palliat Med 2003 Apr;6(2):321-6

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Predicting Six-Month Mortality for Patients Who Are on Maintenance Hemodialysis

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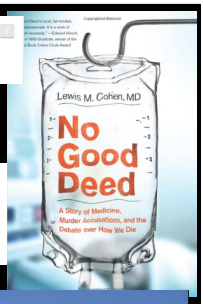

Baystate Med Center
Tufts University
Springfield, MA

The development and piloting of the REnal specific Advanced Communication Training (REACT) programme to improve Advance Care Planning for renal patients

Katherine Bristowe

King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, London, UK

Kate Shepherd

Department of Palliative Care, King's College Hospital NHS Foundation Trust, London, UK

Kings College Hospital, London

- Clinical Nurse Practitioner / Lead Nurse for supportive care (renal and palliative care training)
- Works through low clearance clinics
- Sees patients monthly; home visits
- Presents at Palliative Care MDMs, refers patients there if needed

Royal Free Hospital, London

- Conservatively managed patients seen in the low clearance clinic
- Palliative care nurse with renal interest follows up outpatients and inpatients needing support

Why we need to keep doing what we do

- Dialysis is not curative
- Our patients lead fractured lives, frequently bereft of choice or autonomy