

Trinity Health, Kidney Centre Tallagh Dublin 2nd Oct 2015 Dr Aine Burns Consultant Nephrologist, Royal Free NHS Foundation Trust Honorary Senior Lecturer, University College London



Royal Free London



Masterly inactivity or benign neglect? Conservative management in CKD

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UCLPartners

Royal Free London MHS

Overview

 Some "evidence" and share a personal experience of trying to set up, oversee and develop holistic services for older people with CKD in a large London teaching hospital setting.

A remarkable journey!





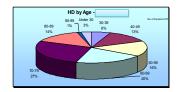


1964:
"the lucky 13!"

2015:
104 and going

strong?







USRDS 2008

Dialysis initiation rates of 1744 per million population for those age ≥ 75





USRDS 2008

Expected remaining lifetime: ESRD on HD Age 75-79 = 2.8 yrs Age 80-84 = 2.3 yrs Age >85 = 1.9 yrs

1/3 to 1/4 of age matched non-dialyzed people

Evidence for harm from dialysis in the elderly, frail and vulnerable!

- 3702 nursing home patients: Kurella NEJM 2009
 - Rapid decline in functional status and high mortality
 - 13% maintained functional status at 12 months
 - 1 year mortality rate was 58%
- Similar study:
- Independently living elderly patients Jassal NEJM 2009



A remarkable journey!



Dialysis withholding in CKD 5!

"Maximum conservative management for elderly patients with renal failure stage 5"

Terminology :~

- Conservative management
- Active supportive care
- · Maximum conservative management
- · Renal supportive care
- · Residual renal support
- · Conservative kidney care
- · The non-dialysis option
- Palliative renal care
- Tablet dialysis!!

Mission :

- · Reverse the reversible
- · Preserve residual renal function
- · Anticipate and Treat inter-currant illnesses
- · Identify and treat symptoms
- Maximize functional status
- Plan end of life care
- · Support family and close persons
- Minimize futile interventions

Not easy :??

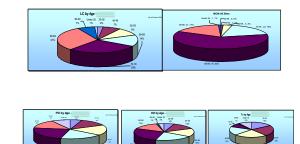
- Frailty
- Dementia
- Cognition
- DepressionLoneliness
- Bereavement
- Mobility
- Functional status
- Advance directives
- Capacity

- Co-morbidity
- Inter-currant illnessFalls
- Difficult conversations
- Ceilings of care
- · Family wishes
- · Absent relatives
- Hospital visits
- Shared careCost

Not easy :??

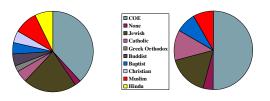




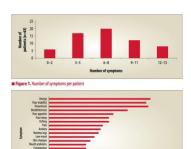


Religious Beliefs

MCM V LCC non MCM patients



- Symptom burden
- · Performance status/trajectories
- · Survival & hospital free days
- · Quality of death
- · Decision making



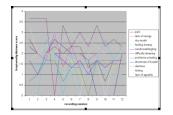
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N= 94 67% response Mean age = 85.9 Median age = 87 Mean eGFR = 17.8 Mean Hb 11.6

Davison &Brown 2013 BJRM:18:2; 26-28

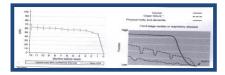
Symptom burden



Dinneen & Burns, British Renal Association Abstract 2011

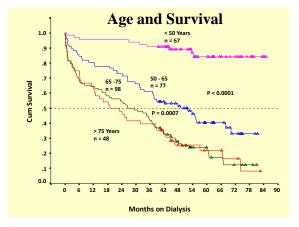
Performance status

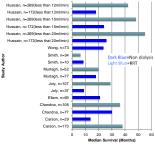
- · Symptom burden
- ✓ Performance status/trajectories
- · Survival & hospital free days
- · Quality of death
- · Decision making



End-Stage Renal Disease: A New Trajectory of Functional Decline in the Last Year of Life Fliss E.M. Murtagh PhD, Julia M. Addington-Hall PhD, Irene J. Higginson PhD. Journal of the American Gerlatrics Society Volume 59, Issue 2, pages 304–308, February 2011

- Symptom burden
- Performance status/trajectories
- ✓ Survival & hospital free days
- · Quality of death
- · Decision making

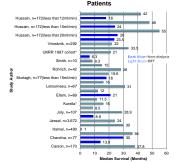


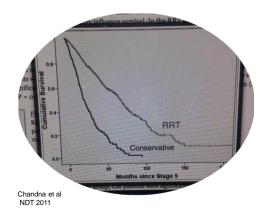


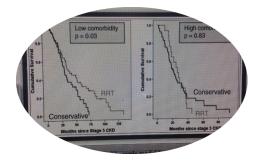
Prognosis with conservative,

nondialytic management of end-stage renal disease

Literature Survey: Survival in Elderly ESRD Patients

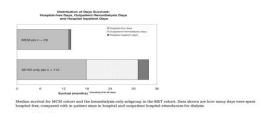






Chandna et al NDT 2011

Survival: Hospital free days



Carson & Burns, CJASN 2008

Clin Interv Aging.2013;8:797-807

Ageism vs the technical imperative, applying the GRADE framework to the evidence on haemodialysis in very elderly patients

GRADE framework:

- Systematic reviews demonstrate median survival benefit of dialysis of at least 6 months (range 6.3-24.3)
- However:
- "The <u>quality of the evidence supporting a</u> <u>modest survival benefit</u> in the elderly is considered to be very low due to methodological limitations of the studies and heterogeneity"

Cause of death: Supportive management in Pts with ESRD Median age = 73, N = 74 *Chan 2010 Hong Kong*

- Advanced uraemia
 28%
- Sepsis
 28%
- Cardiac Event
 23%
- Cerebrovascular 5% accident
- Malignancy
 2%

•

- Sudden death 8%
- Unknown
 5%

Quality of life/death:

- Symptom burden
- Performance status/trajectories
- · Survival & hospital free days
- ✓Quality of life/death
- Decision making

· MCM patients were 4 times more likely to die at home or in a hospice

- · Final illness short 3-7 days
- eGFR circa 4ml/min
- · Pulmonary oedema rarely an issue
- Agitation
- Nausea
- Pain

Carson & Burns, CJASN 2008

Quality of life/death: Da Silva-Gane 2012 Clin J am Soc Nephrol

- · Prospective 3 monthly QOL, HADS, and satisfaction with life scale for up to 3 years
- · CKM patients were older, more dependent, higher comorbidity, higher anxiety levels
- · Mental health, depression and life satisfaction scores were similar in patients choosing CKM and Dialysis
- Life satisfaction (only) decreased significantly after starting dialysis and remained stable in CKM patients
- · Patients choosing CKM maintained QOL

· Survival & hospital free days

Symptom burden

· Quality of life/death

· Performance status/trajectories

✓ Decision making

Decision making

- Shared decision making (pt. autonomy)
- · Why do patients choose MCM?
- · How & when should we have these conversations?
- · Consultant/MDT/palliative care rubber stamping, revisiting decisions,
- · Are decision aids and algorithms helpful?
- · Do many patients change their minds?
- The time factor!!

Decision making

- Dementia
- Mental capacity
- Depression Attention span
- Higher mental function
- · Family pressures (caring for spouse)
- Anxiety
- Dealing with uncertainty
- Maintaining the status guo
- Timing and quality of information given
- Trust in / track record with caregivers
- · Personalities of individual and family
- · In general human nature is to be optimistic "it won't actually happen to me"

Decision making

- Depression
- Family pressures (caring for spouse)
- Anxiet Religious & cultural issues:
- Maintsteine itheratelling and disclosure

- In general human nature is to be optimistic "it won't actually happen to





MCM: A new phase in a remarkable journey

- · Legitimate & positive treatment option chosen by approx 10% of elderly patients which delivers:
 - maintained functional status for many months
 - a short final illness
 - 4 times greater chance of dying at home or in hospice setting
 - Survival & intervention free out of hospital days may not differ much from patients who choose dialysis

Reasons for choice: Supportive management in Pts with ESRD Median age = 73, N = 74 Chan et al 2010 Hong Kong

- Patient felt they were too old (27%) •
- Patient not accepting dialysis therapy (24%)
- Multiple co-morbidity and poor functional state (22%)
- Perceived burden to family (4%)
- Poor social support (28%)
- Other(17%)

Who will likely benefit from conservative care?

- Over 75 or 80 and...
- +++ co-morbidity (IHD, CVA)
- Poor performance status/ frail
- Flat trajectory (little proteinuria)
- *** mental and/or physical problems which make long-term dialysis/ Tx "impossible"

Fantastic team!

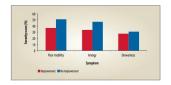




BUT!!

• That's not the whole story!!

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We may have to be honest and realistic about what we can achieve!!

Patient C.L. 83 year old.



Admitted on 26/3/15 from LCC with A93 on CXD secondary to high diuretic use (Furosemide increased to 1g by Cardiologi
 RT discussed with patient who agreed to trialHDx.

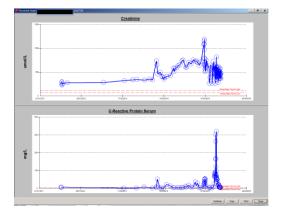
CL

- Frequent and long discussions:
- Alternating plans for CKM/ Assisted PD
- Finally his wife felt she could not cope with PD at home
- Multiple disasters over several years headed off at the pass with intensive monitoring (not helped by colleagues sometimes)
- Finally, admitted AKI on CKD (++inc diuretics from Cardiology, but uraemic Sx ++)
- Family discussion arranged: wife falls on way in to this conversation
- Long discussion in A & E!!
- Patient commenced HD via a tunelled line 30/3/15:
 U= 65, eGFR= 5.7

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CL

- 22 weeks since commencement of HD
- 14 in hospital or rehab
- Each time he sees a nephrologist he initiates a discussion re withdrawal but decides to carry on!
- Hates dialysis, hates transport, life miserable
- 6kg weight loss (flesh)
- Now home again: Carers 4/ day
- Shuffling with zimmer, vision much worse



Three categories of elderly LCC patient decisions given the same information

- A. Certain they do/do not want dialysis under any circumstances and do not deviate
- B. "I want conservative care I don't want dialysis at all, I'd only have it if it really came to it, no I'd prefer not to have it"
- C. Agonizers.... revisit the decision again and again, alternating choices...

• Is this the best outcome we could have achieved for CL?

Three categories of elderly LCC patient decisions

- A. Certain they do/do not want dialysis and do not deviate
- B. "I want conservative care I don't want dialysis at all, I'd only have it if it really came to it, no I'd prefer not to have it"
- C. Agonizers.... revisit the decision again and again, alternating choices...

pressure to have a decision made:

- ?? Flexible/expectant planning in these situations:
- ?? Vascular access and unplanned start targets HARMFUL to these patients

Challenges for the future

Old Woman Dozing Nicolaes Maes (1656). Royal Museums of Fine Arts, Brussels



Old Woman Dozing Nicolaes Maes (1656). Royal Museums of Fine Arts, Brussels



Thank you for your attention!

"GERIATRIC GIANTS"

- FRAILTY
- FALLS (Every year,
 - about one-third of those 65 years old fall
 - over half of those 80 years old fall
 - $-\,$ leading cause of injury and death for old people

DEMENTIA/DELERIUM

- Incontinence
- VERY FAMILIAR TO RENAL COMMUNITY IN PRACTICE BUT little background knowledge of research or training in these areas

Falls prevention

- Old age spells risk for injury from falls that might not cause injury to a younger person
- Every year,
 - about one-third of those 65 years old fall
 - Over half of those 80 years old fall
- Falls are the leading cause of injury and death for old people

Patient centred care

- Renal services focus:
 - holistic symptom control
 - dietary changes
 - psychological impact of renal disease
- Geriatric comprehensive assessment:
 - functional status
 - cognitive impairment
 - polypharmacy
 - maintain or improve QOL
 - prevent hospital admissions

Frailty and multiple co-morbidities

• Frailty "cumulative decline in multiple physiological systems and impairment of homeostasis leading to increased vulnerability to external stressors: *Clegg Lancet 2013*

Mental marks of old age:

- Adaptable "accepting."
- Caution marks old age.
 - antipathy toward "risk-taking" stems from the fact that old people have less to gain and more to lose by taking risks than younger people
- Depressed mood:

 the over-65 population having the highest suicide rate.
- Fear of crime.
- The fear persists in spite of the fact that old people are victims of crime less often than younger people
- Reduced mental and cognitive ability:
 - Memory loss,
 - More time to learn new information.
- Dementia prevalence increases in old age 50% over age 85
 Set in one's ways describes a mind set of old age.
 - A study of over 400 distinguished men and women in old age found a "preference for the routine."

Frailty and multiple co-morbidities

- Rockwood index:
 Continuum
 - unintentional weight loss, self-reported exhaustion, weakness, slow walking speed, low physical activity

Fried frailty phenotype: present or abscent: 3+



Attention to the clinical trajectory is required to calibrate expectations and guide timely decisions, but prognostic uncertainty is inevitable and should be included in discussions with patients and caregivers.

remit

- exploring the geriatric/palliative care interface
- older patients selecting dialysis, avoiding starting dialysis too early, recognising that fluctuations in renal function occur and to avoid knee-jerk starting dialysis with deterioration in GFR

CL

- Same day his wife falls>> 6 weeks hospital
- 3 week admission
- Short period of feeling much better at home
- Since then 4 admissions
- Painful ischaemic ulcer foot
- Hernia repair (as PP: painful haematoma "due to renal failure according to surgeon")
- Fall hip fracture
- Rehab unit>>> back to main hospital
- Home 2 per week HD