

Trinity Health, Kidney Centre Tallagh Dublin 2<sup>nd</sup> 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!





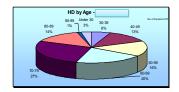


1964:
"the lucky 13!"

2015:
104 and going

strong?







## **USRDS 2008**

Dialysis initiation rates of 1744 per million population for those age  $\geq 75$ 





#### **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 :??

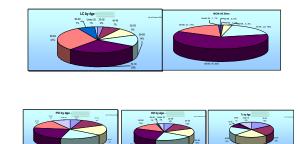
- Frailty
- Dementia
- Cognition
- DepressionLoneliness
- Bereavement
- Mobility
- Functional status
- Advance directives
- Capacity

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

### Not easy :??

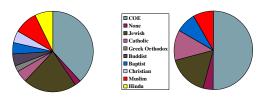




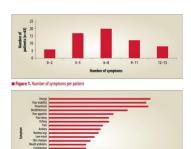


**Religious Beliefs** 

MCM V LCC non MCM patients



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



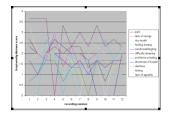
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N= 94 67% response Mean age = 85.9 Median age = 87 Mean eGFR = 17.8 Mean Hb 11.6

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

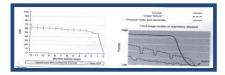
## Symptom burden



Dinneen & Burns, British Renal Association Abstract 2011

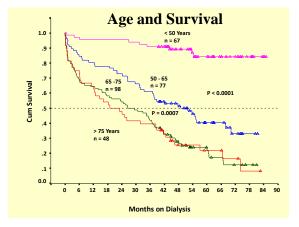
#### Performance status

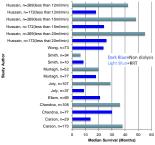
- · Symptom burden
- ✓ Performance status/trajectories
- · Survival & hospital free days
- · Quality of death
- · Decision making



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

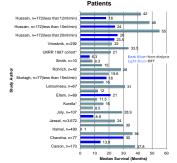


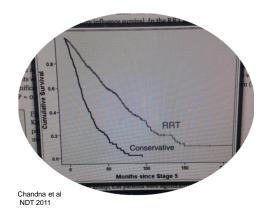


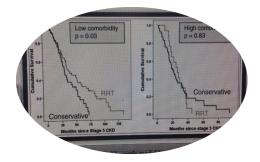
Prognosis with conservative,

nondialytic management of end-stage renal disease

#### Literature Survey: Survival in Elderly ESRD Patients

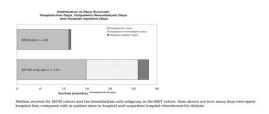






Chandna et al NDT 2011

## 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!

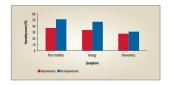




BUT!!

• 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.

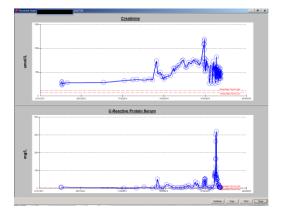
#### CL

- 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