A tale of two specialties

United Kingdom

Annual Symposia on Renal-Palliative Care
co-organised by both disciplines

National Service Framework for Renal Services Part 2 (UK) - 2005

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 Intitiative

- 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

Renal Physicians Association of the USA and the American Society of Nephrology. 2000.

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

Moss AH, Holley JJ. Core Curriculum in Nephrology : Palliative Care. *Am J Kid D* 2004;43:172-185.

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 ?

ALBERT

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 ?

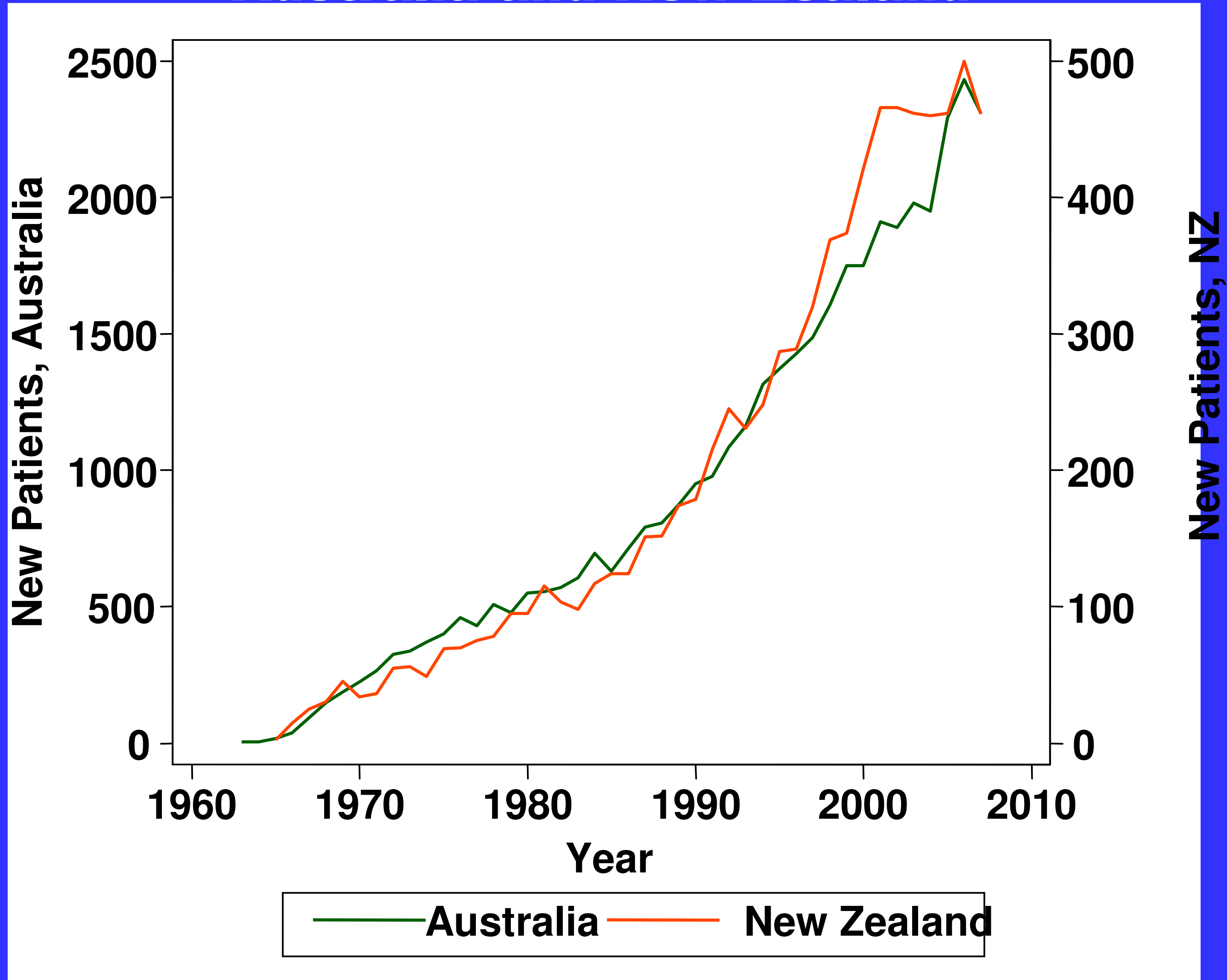
DIALYSIS PATIENTS

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.

Number Starting Renal Replacement Therapy
Dialysis or Transplantation
Australia and New Zealand



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.

ESRD patients

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 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

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.

Murtagh FEM et al. *Neprol Dial Transplant* 2007;22:1955-1962

Dialysis or Not?

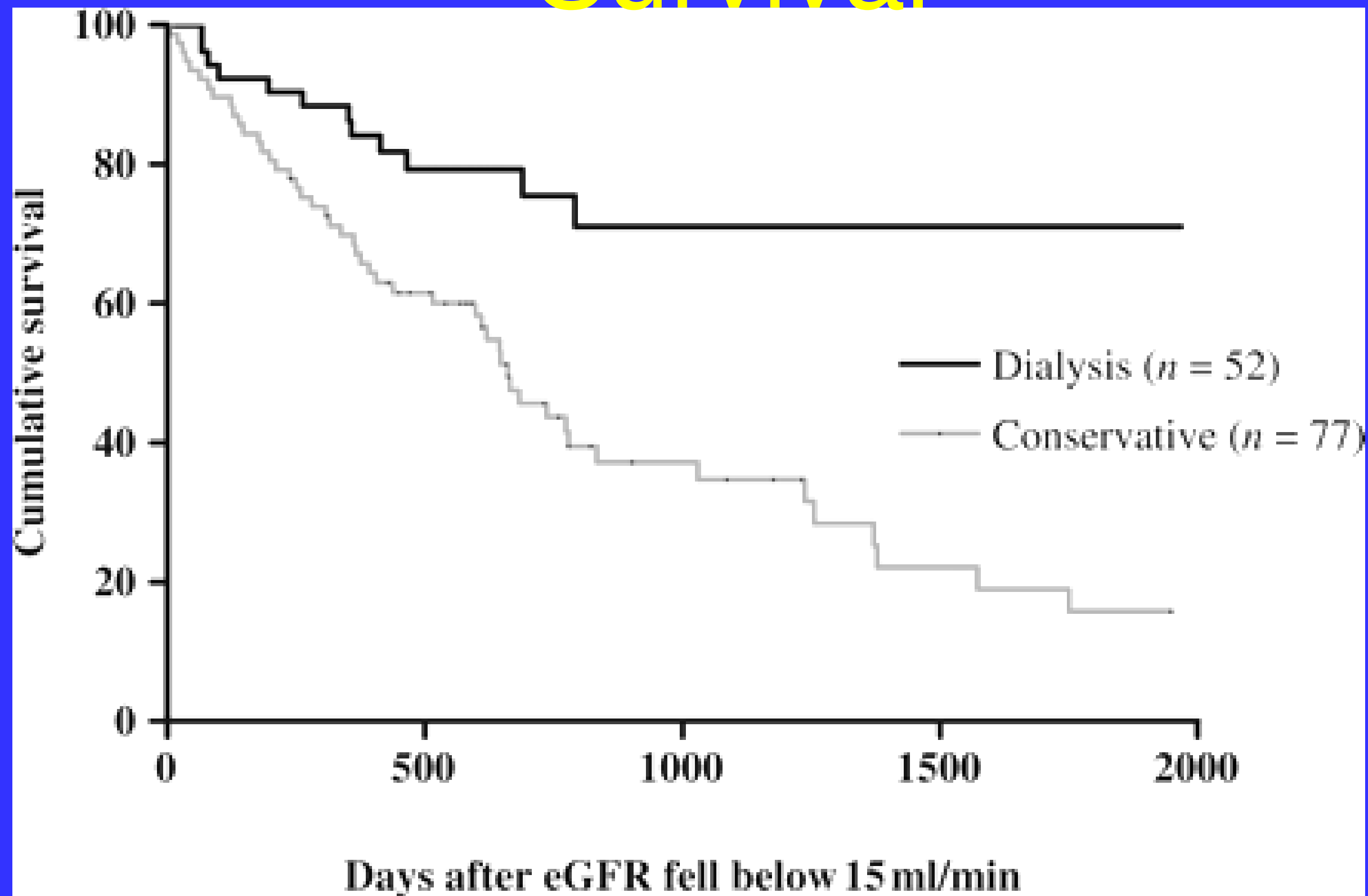
- Age > 75; eGFR <15
- 52 on a dialysis pathway; 77 conservative pathway
- Survival 1 yr – 84 vs 68%

- Survival 2 yrs – 76 vs 47%

Murtagh et al. NDT. 2007;22:1955-62

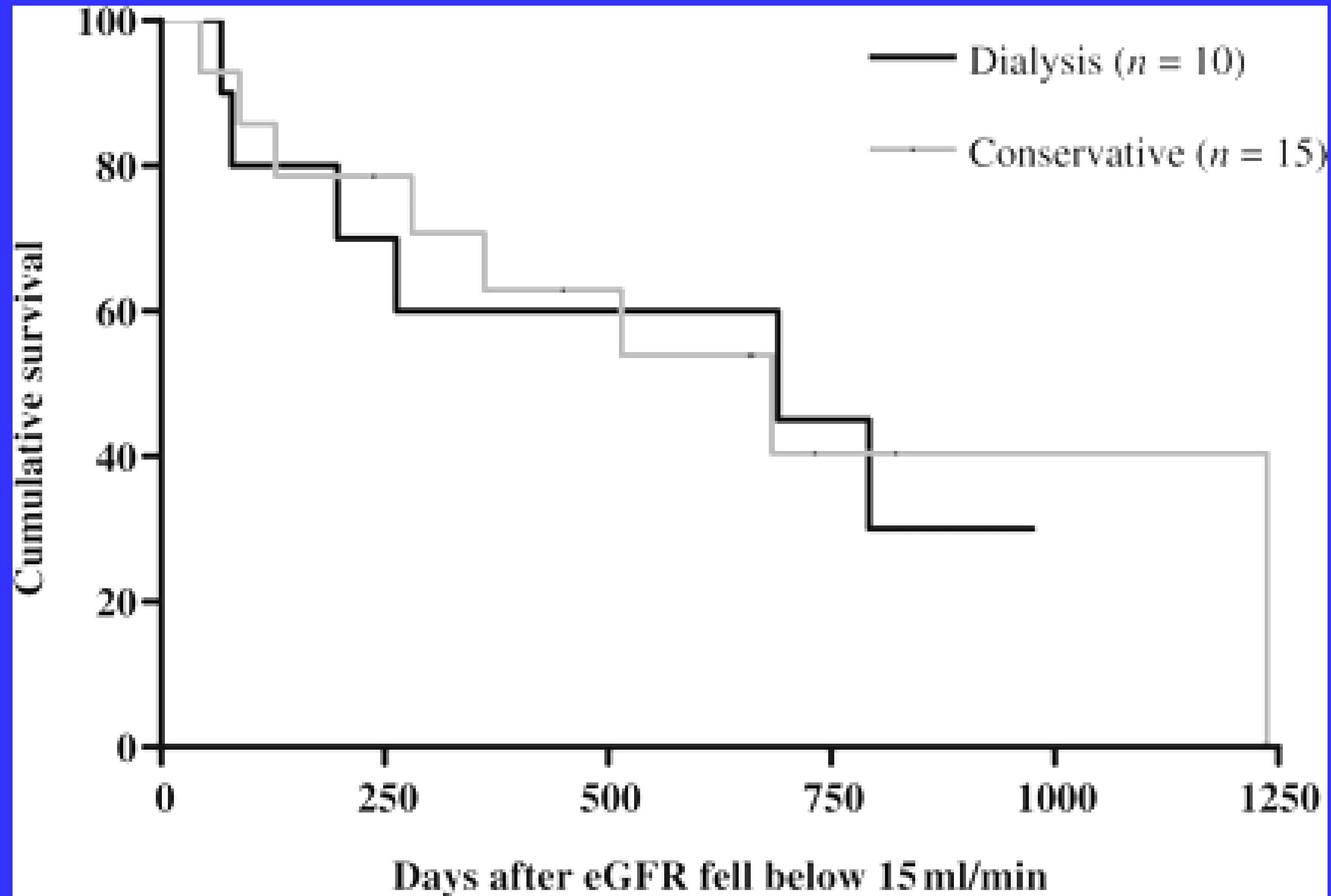
- Survival advantage lost if 2 or more co-morbidities
- Particularly lost if IHD as a co-morbidity

Survival



Murtagh et al. NDT. 2007;22:1955-62

Survival benefit lost if Co-morbidities include IHD



Murtagh et al. NDT. 2007;22:1955-62

ANZDATA dialysis survival age ≥75

- 1781 patients; 2002-5; retrospective
- Survival 77% 1yr, 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

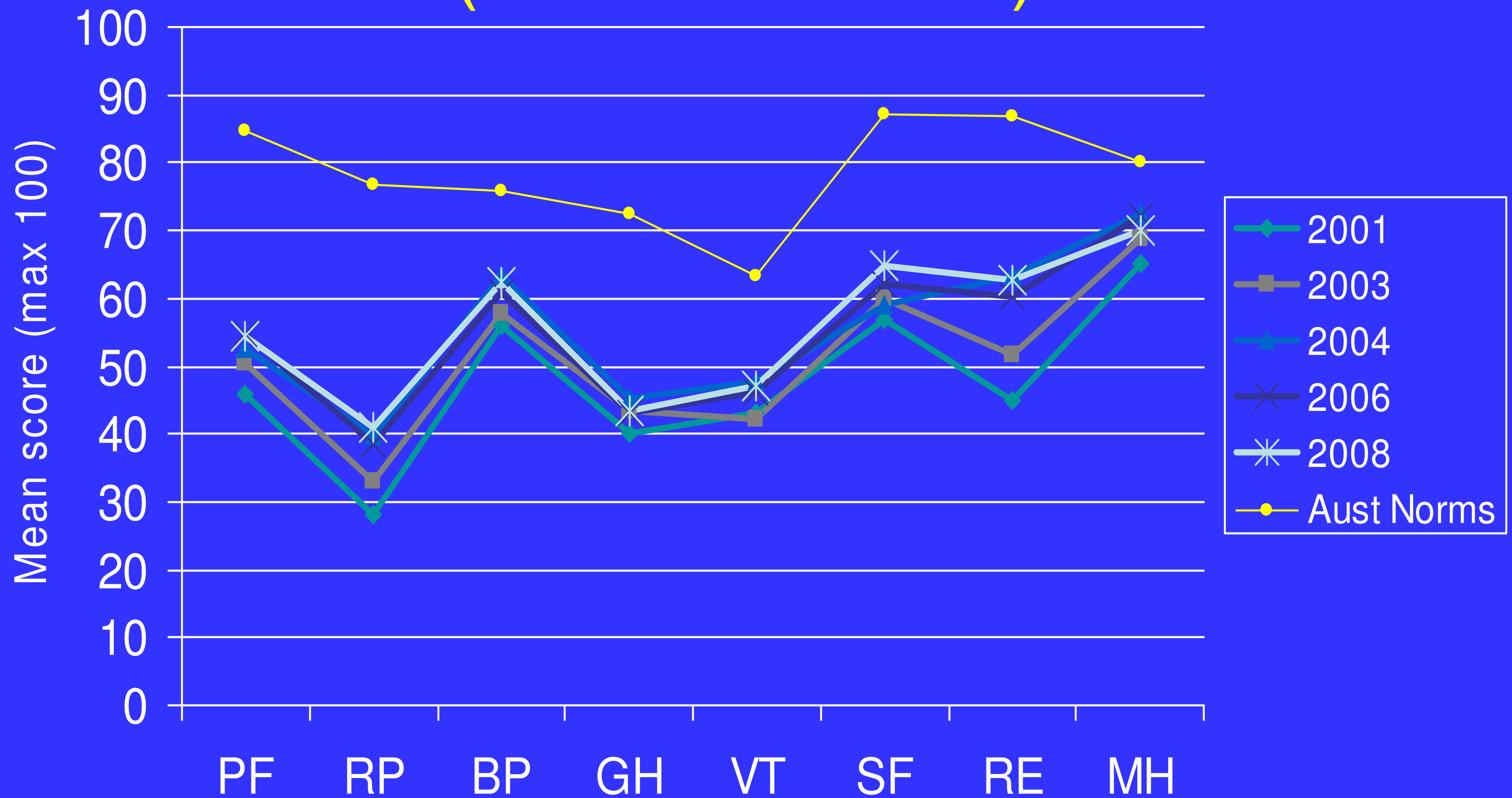
A useful starting point for recommending dialysis is an expectation of survival with a ***quality of life acceptable to the patient***.

CARI guidelines – Ethical Considerations

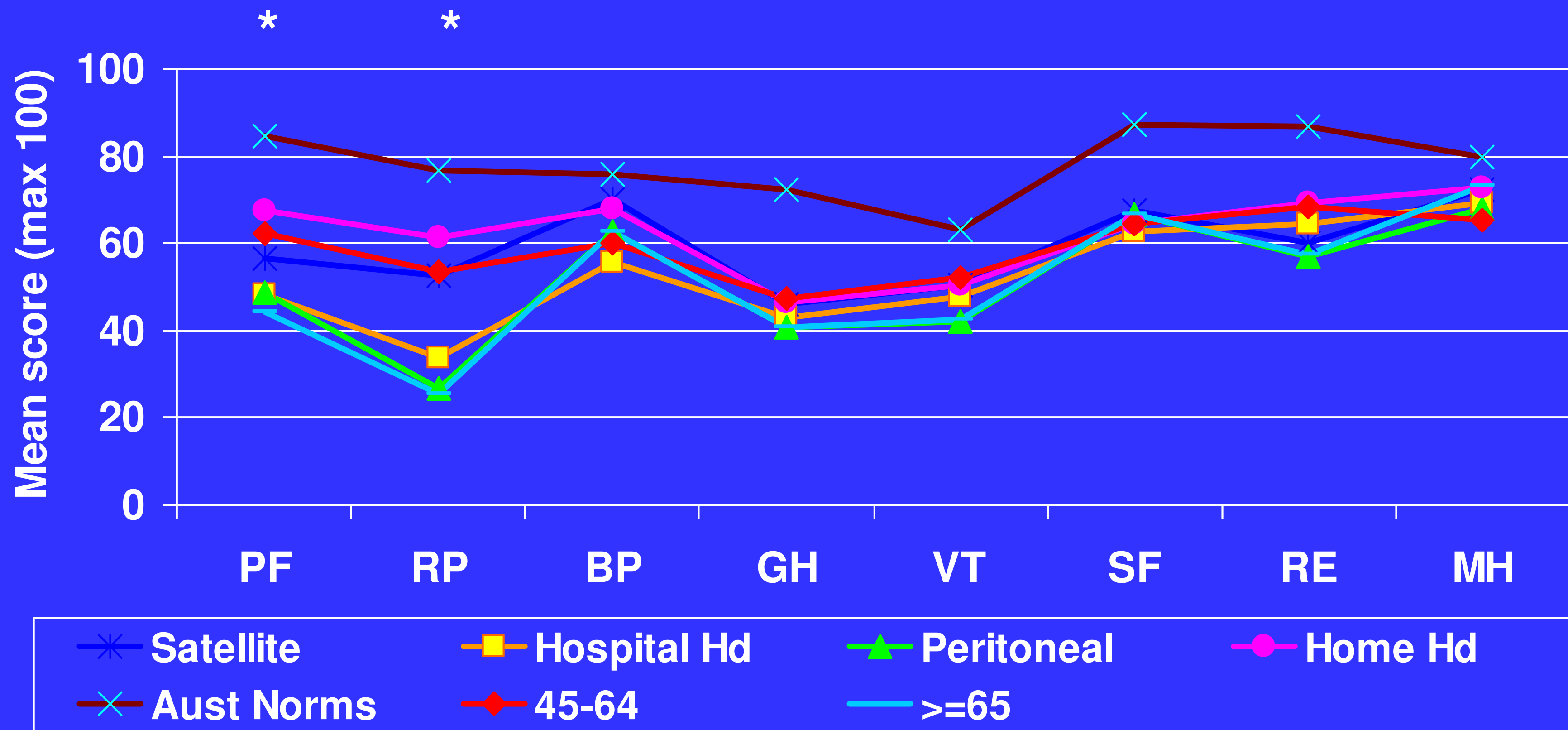
Quality of Life (QoL) in the St George Dialysis Population

Elizabeth Josland
Prof Mark Brown
St George Hospital

QOL - St George dialysis (SF-36 Scores)



SF-36 scores for modality and >= 45 years in the 2008 survey



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.

The NEW ENGLAND JOURNAL of MEDICINE

Volume 361:1597-1598 October 15, 2009

Next

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

Tamura MK, et al. Functional status of elderly adults before and after initiation of dialysis. NEJM, 2009; 361: 1539-47.

Co-morbidities

Coexisting condition (%)	
Diabetes	68
Congestive heart failure	66
Coronary artery disease	44
Peripheral vascular disease	37
Cerebrovascular disease	39
Chronic obstructive pulmonary disease	24
Cancer	12
Dementia	22
Depression	35
Hemodialysis (vs. peritoneal dialysis) (%)	95
Hospitalized at initiation of dialysis (%)	69

Functional status

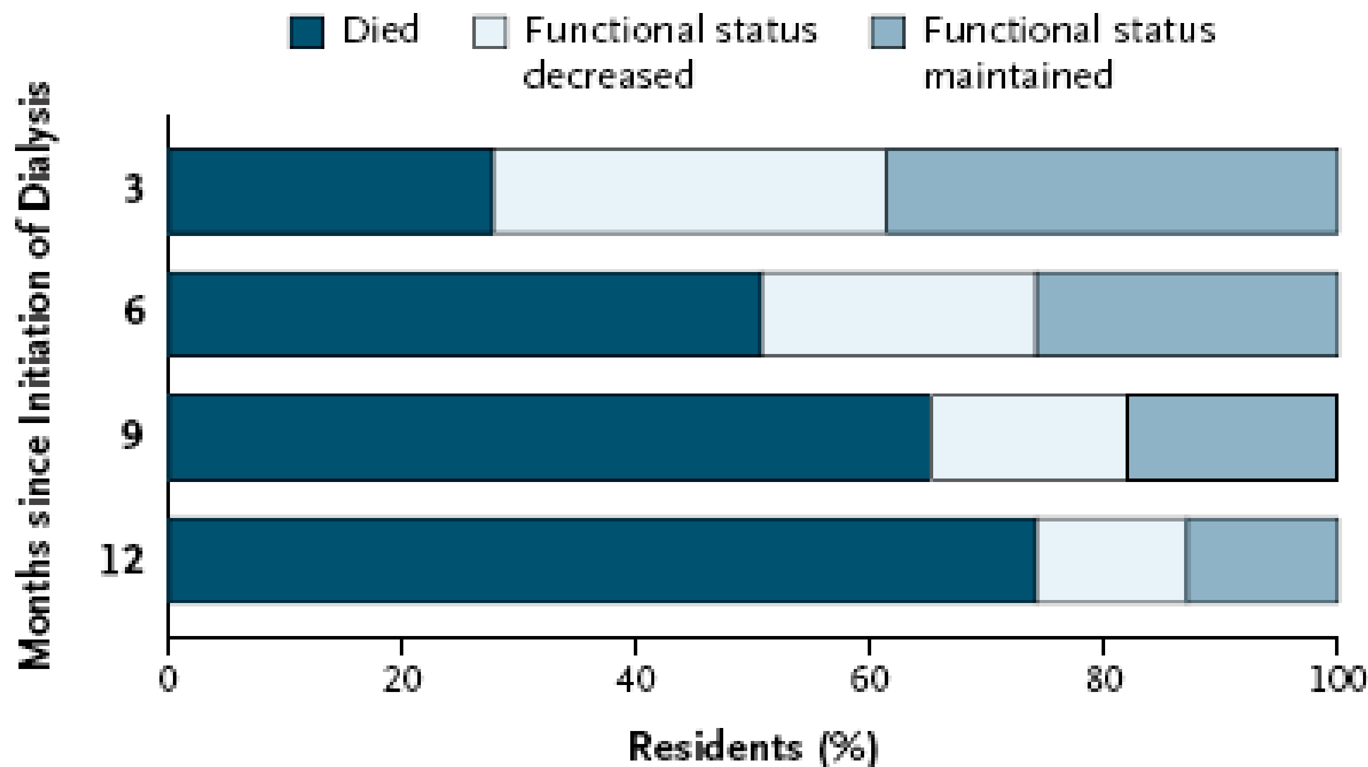
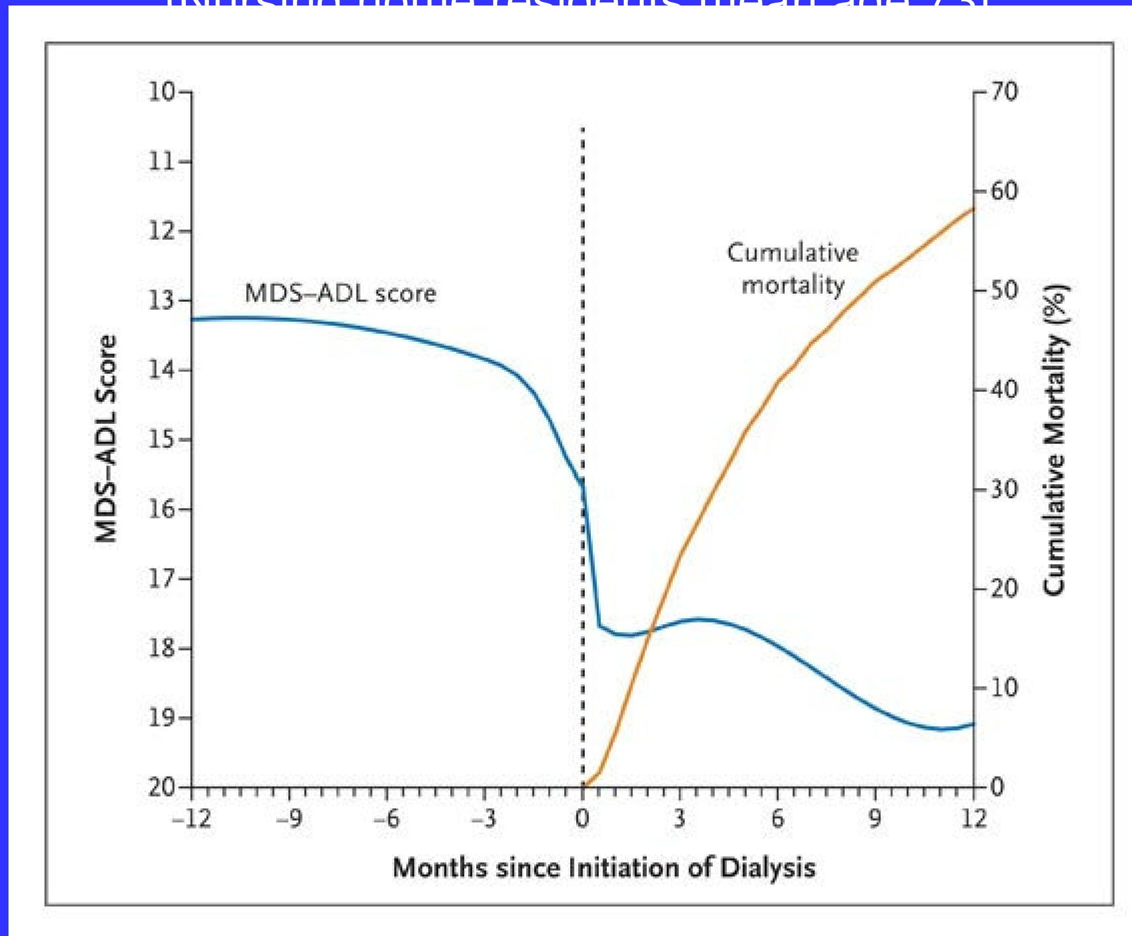


Figure 2. Change in Functional Status after Initiation of Dialysis.

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]



Kurella Tamura et al. 361 (16): 1539. October 15, 2009

The NEW ENGLAND JOURNAL of MEDICINE

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

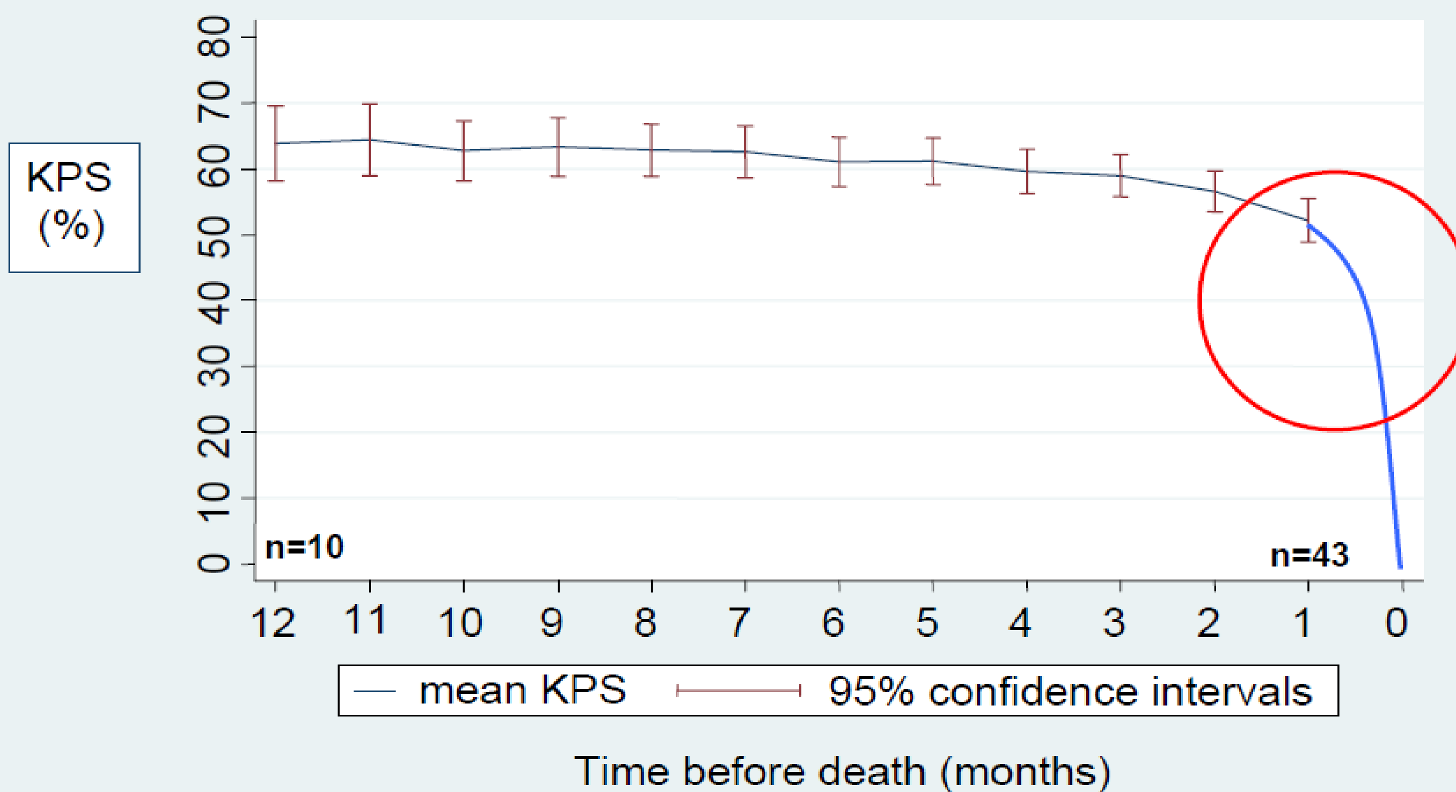
Care of the dying

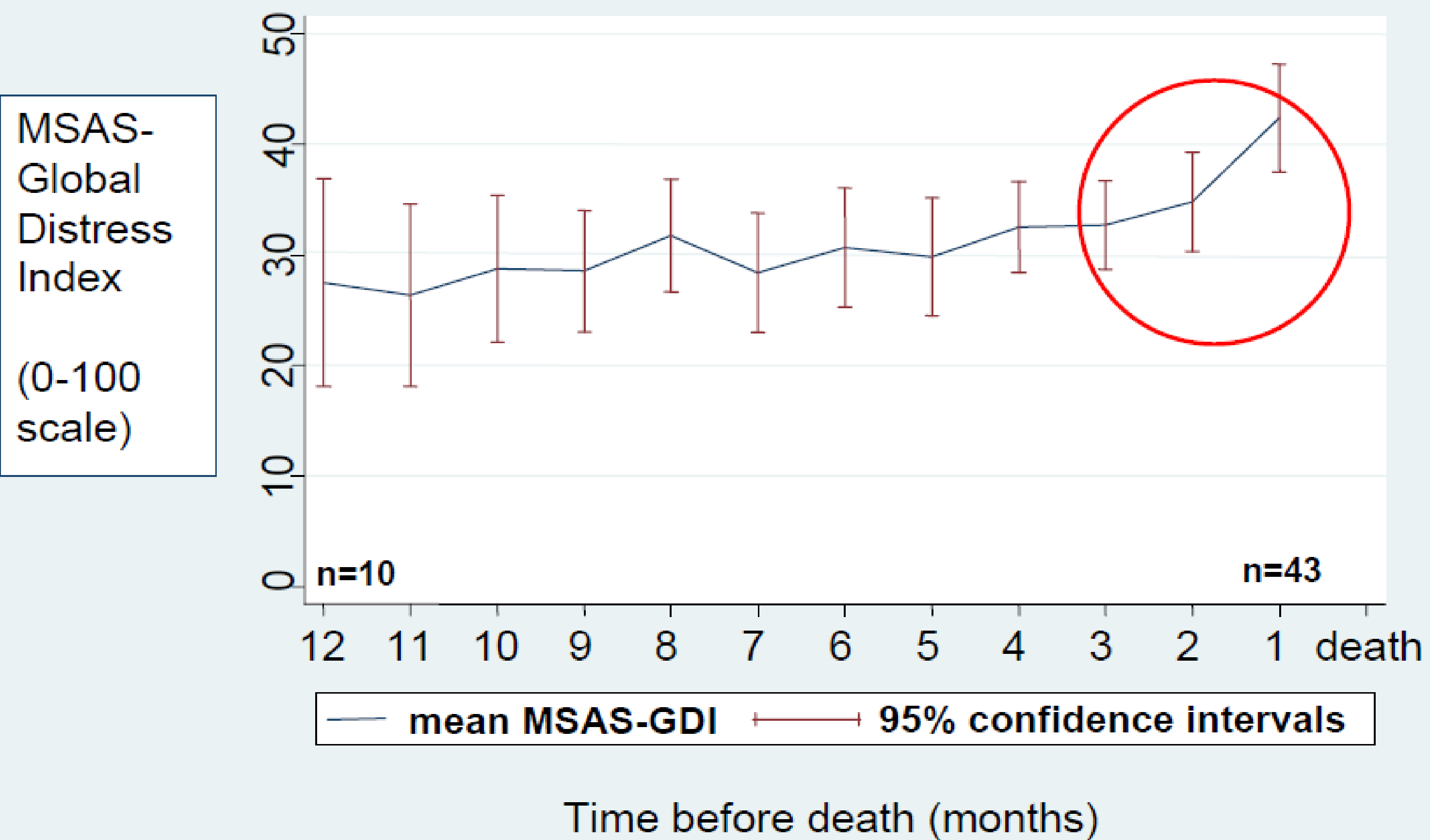
There is a modest, but growing body of literature of research on this cohort of patients.

Longitudinal study of conservative stage 5 CKD

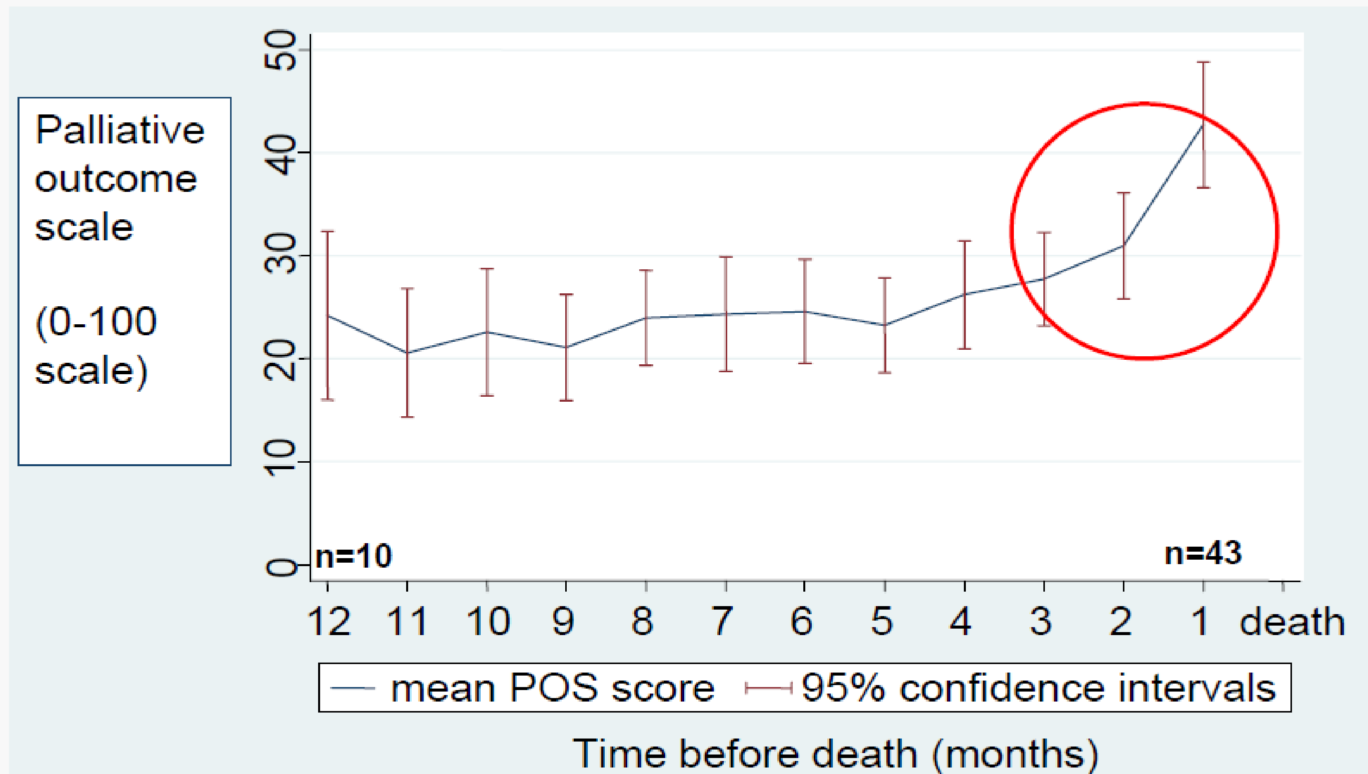
- Included patients with Stage 5 Chronic Kidney Disease with definite decision for conservative (non dialysis) management, and with capacity for consent
- 73 participants (response rate 62%)
- 49 (66%) died during follow-up
  - mean age 81 years, range 58-95 yrs
  - 24 (49%) men
  - median follow-up 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:




Trajectory of symptom distress:
MSAS-Global Distress Index
(0-100 scale)
0
10
20
30
40
50
n=10
n=43
12
11
10
9
8
7
6
5
4
3
2
1
death
mean MSAS-GDI
95% confidence intervals
Time before death (months)
www.kcl.ac.uk/palliative

Trajectory of palliative needs:



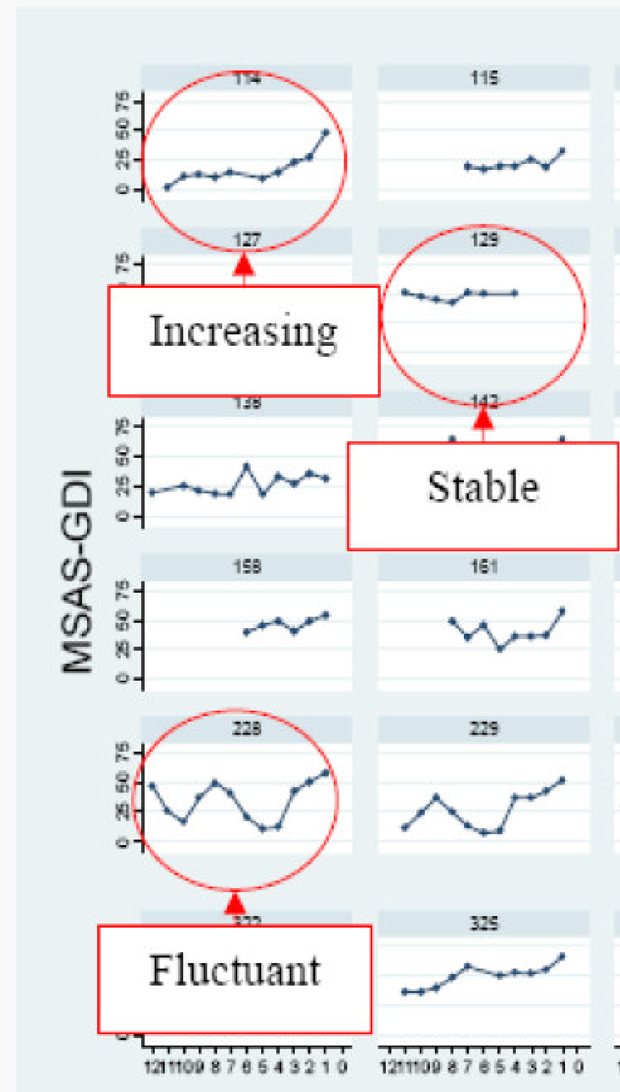
Course of symptoms

Individual variation

Implications for patients

Implications for care

- Symptom burden
- Assessment of symptoms
- Advance planning



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."

Murtagh F, Weisbord S. Symptoms in renal disease. In Chambers EJ et al (eds) *Supportive Care for the Renal Patient* 2010, 2nd ed, OUP.

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

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

	Dialysis	Conservative
Fatigue	75	71
Pruritus	55	74
Anorexia	49	47
Pain	47	53
Insomnia	44	42
Dyspnea	35	61
Restless Legs	30	48

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 %

Causes of death (ANZDATA) in dialysis patients 2007

Cause	%
Cardiac	36%
Infection	10%
Vascular	10%
Miscellaneous	8%
Social	**36%**

‘Social’ causes of death in dialysis patients 2007

Withdrawal from dialysis

Psychosocial	**13% of all dialysis patients**
Access, CVA etc	22%
Accident	0.8%
Suicide	1 / 1452 patients

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