

CHRONIC DISEASE AND PALLIATIVE CARE

Dr Peter Allcroft, Kate Swetenham, Aine Greene
Southern Adelaide Palliative Services
Daw Park Repatriation General Hospital

- “To die of age is a rare, singular, and extraordinary death, and so much less than others...” Michel de Montaigne 1533-1592



COPD

- 47 year old male
- Divorced, lives alone
- Type 2 respiratory failure
- Multiple admissions (6 months/year)
- Anxiety+++
- Palliative care involved
 - Team meeting, Respiratory NP, Psych
 - Monthly visits with Pall care NP
 - Marked reduction in admissions

SOUTHERN ADELAIDE PALLIATIVE SERVICES

DAW PARK RGH

- 579 patients on books
 - 72% malignancy (Lung Ca 15%; Breast 5.8%)
 - 28% non-cancer (165 patients)
 - Neurological: 7% (note MND Clinic SA)
 - Cardiac : 7.7 % total patients
 - Respiratory: 5.9% total patients
 - 1,458 new referrals year ending 30/06/2015
 - 60-80 yrs: 47%; 80+ yrs: 40%
 - 889 deaths
 - 548 D/C or case closure (Eg out of area (rural))
 - GP Plus Clinic
 - Initial assessment: NP, SW, Network facilitator, Psycho-social
 - Use PC-NAT; Sig number ESRD pt's initial assessment

DIFFICULTIES

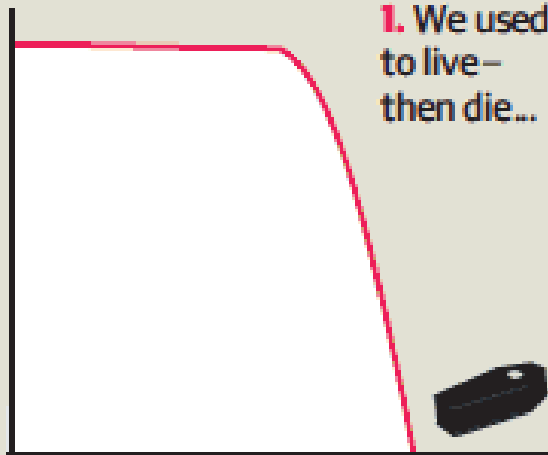
- Prolonged illness trajectory
- ?different palliative care needs
- What is end stage disease?
- Models of care
- Metropolitan Vs Rural and regional
- Funding
 - Staff
 - GP's, Community nurses, Volunteers
 - Equipment
 - Dom Care
 - Inpatient beds

CAREGIVERS OF CHRONICALLY ILL PERSON

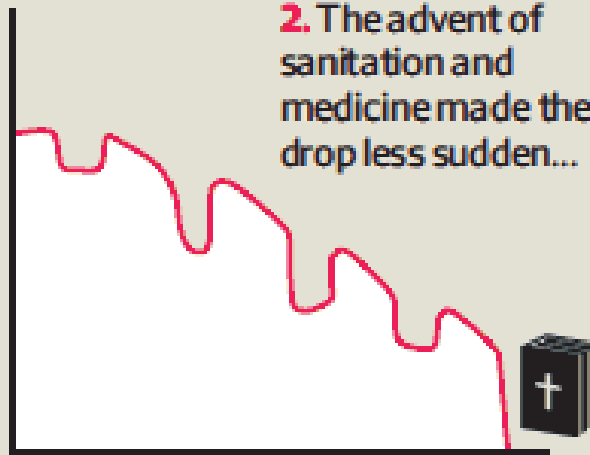
- Demanding role
- Relentless, exhausting
- Increased stress
- Increased depression
- Increased isolation
- Poor sleep
 - “sleep with 1 eye shut”
- SPCS :
 - Muster support around caregiver, social, psychosocial

The long goodbye

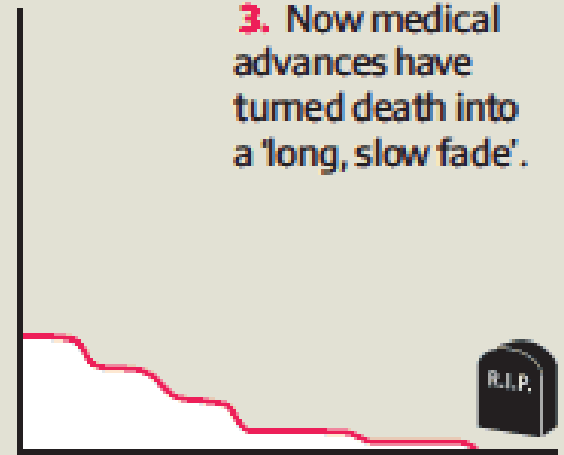
1. We used to live – then die...



2. The advent of sanitation and medicine made the drop less sudden...



3. Now medical advances have turned death into a 'long, slow fade'.



Societal Change

- Medicalisation of death
 - ? Loss of cultural and spiritual significance
- Mode of death has changed
 - Die slowly
 - Loss of supportive community.. To cradle dying
 - Spiritual, cultural: bathe, care, ...attend to them, ..infuse death with meaning and significance
 - Often no-one or only handful of loved ones

DYING WELL

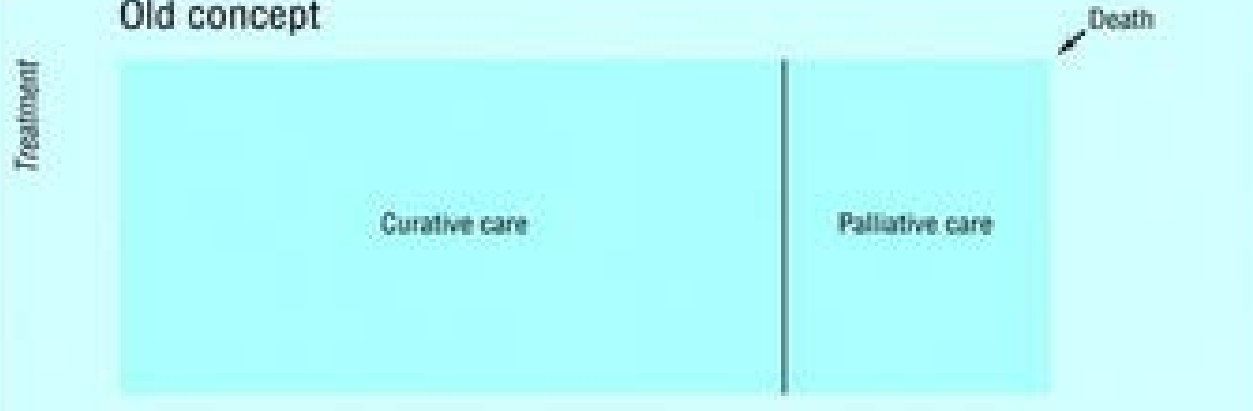
Grattan Institute

- To know when death is coming...what to expect
- Retain control
- Afforded dignity, privacy
- To have choice...home, elsewhere
- To have information
- Spiritual, emotional support..
- Hospice care in any location...
- To issue advance directives

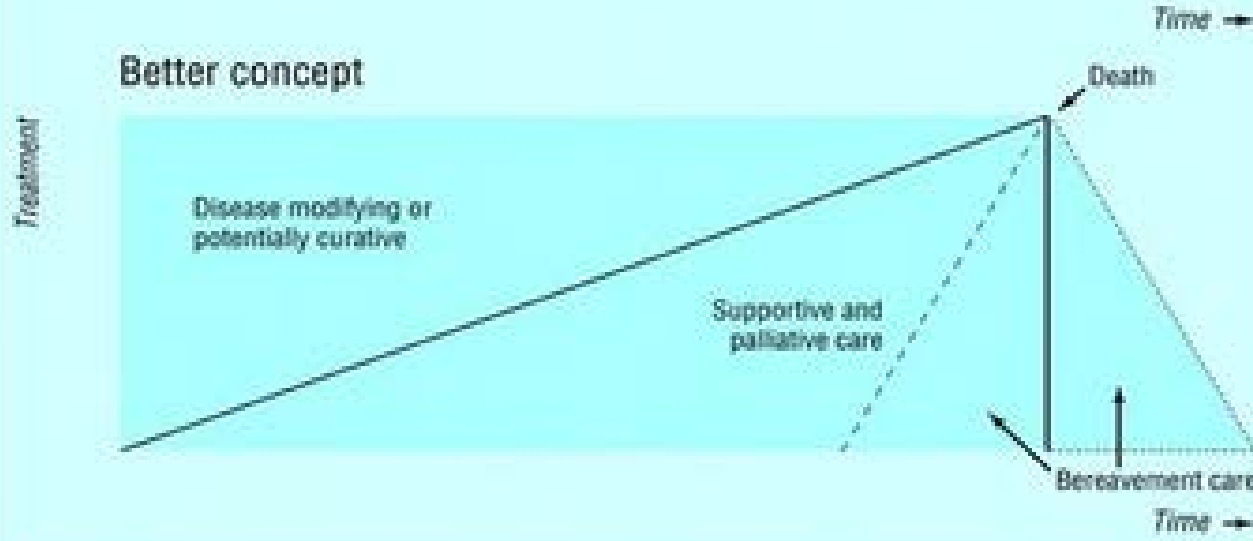
Swerisson & Duckett Sept

2014

Old concept



Better concept



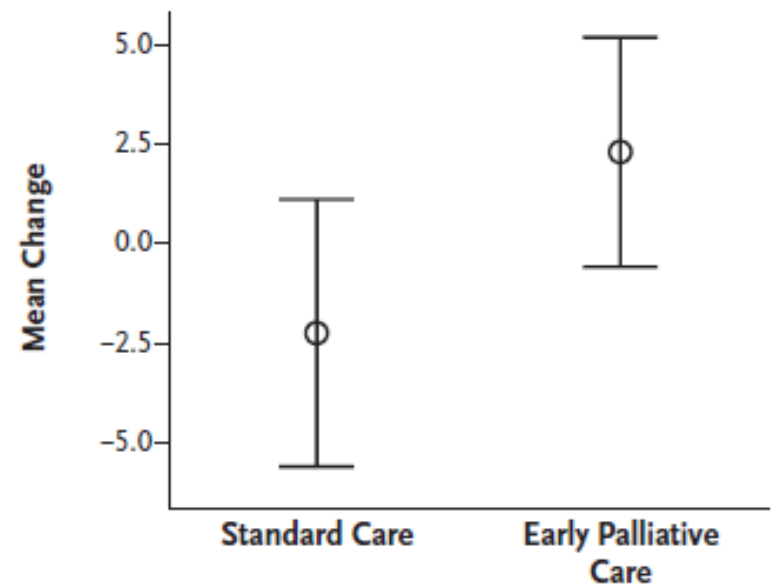
ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,

- Better QoL
- Less depression
- Survived longer
 - Median 12 Vs 9 months

C TOI



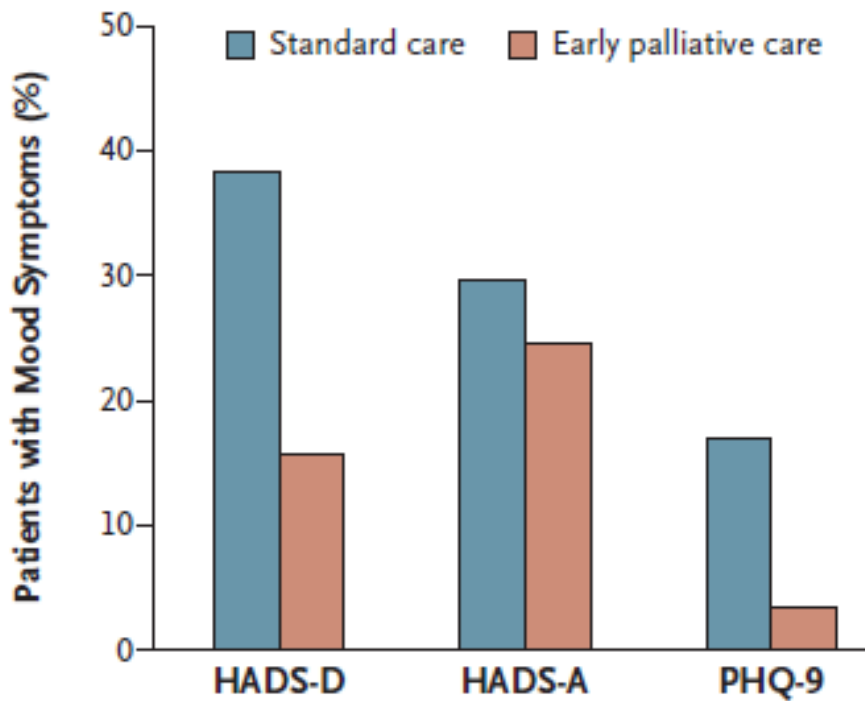


Figure 2. Twelve-Week Outcomes of Assessments of Mood.

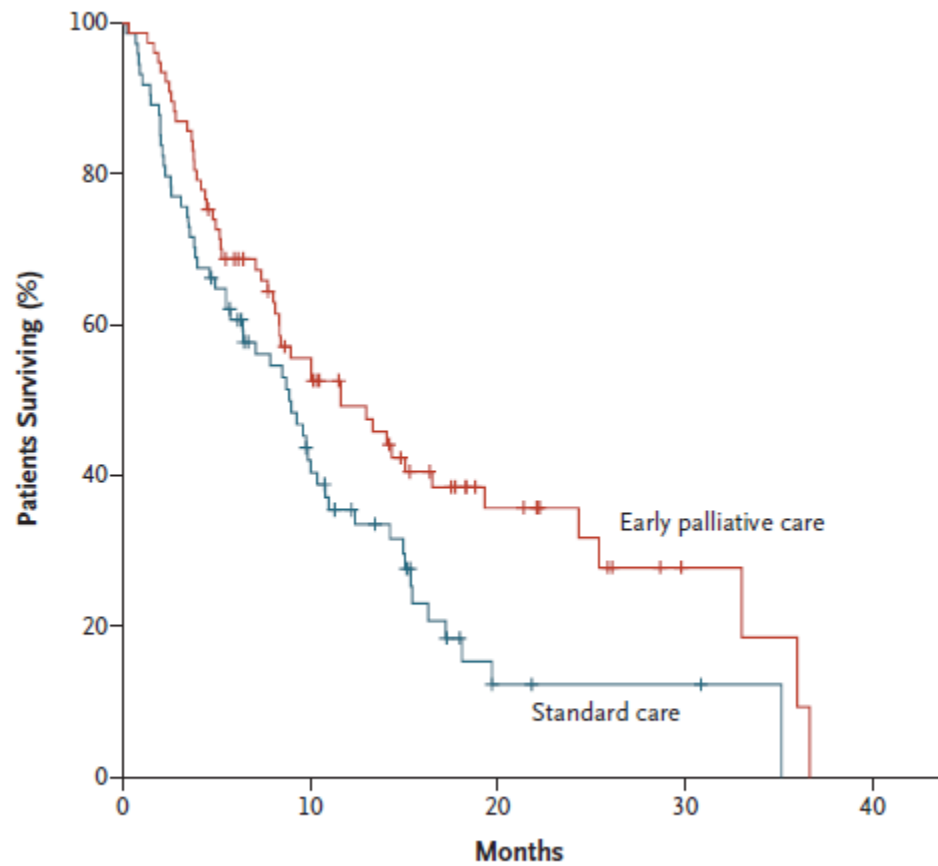


Figure 3. Kaplan–Meier Estimates of Survival According to Study Group.

Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care

Richard Brumley, MD, Susan Enguidanos, PhD, MPH,[†] Paula Jamison, BA,[†] Rae Seitz, MD,[‡] Nora Morgenstern, MD,[§] Sherry Saito, MD,[‡] Jan McIlwane, MSW,[§] Kristine Hillary, RNP,* and Jorge Gonzalez, BA[†]*

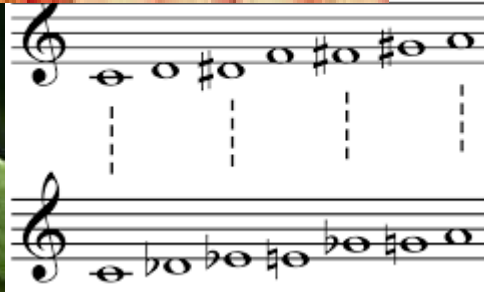
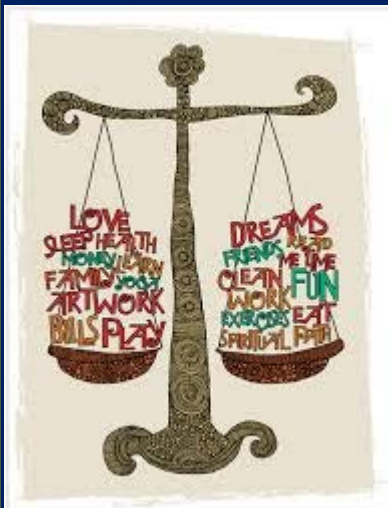
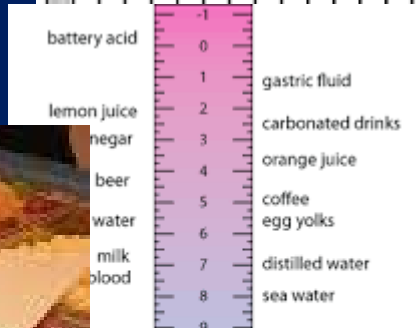
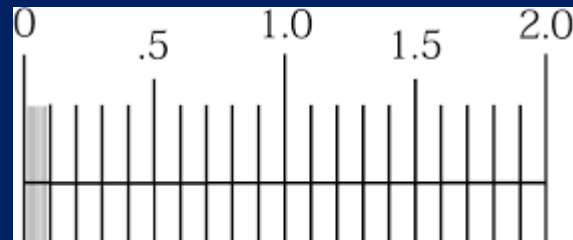
- Randomised trial usual Vs PC
 - 310 patients: Cancer, COPD, CCF
 - Improved satisfaction with PC team care
 - Marked savings with PC team involved:
 - \$95 per day with PC compared with \$212/day usual care
 - Involvement with SPCS:
 - Enables caregivers to move on earlier
 - Reduces the number of unmet needs
- Abernethy et al 2005
- Respecting Patient Choices :
 - Reduces PTSD and HADS in bereaved relatives Detering et al 2010

Thelma

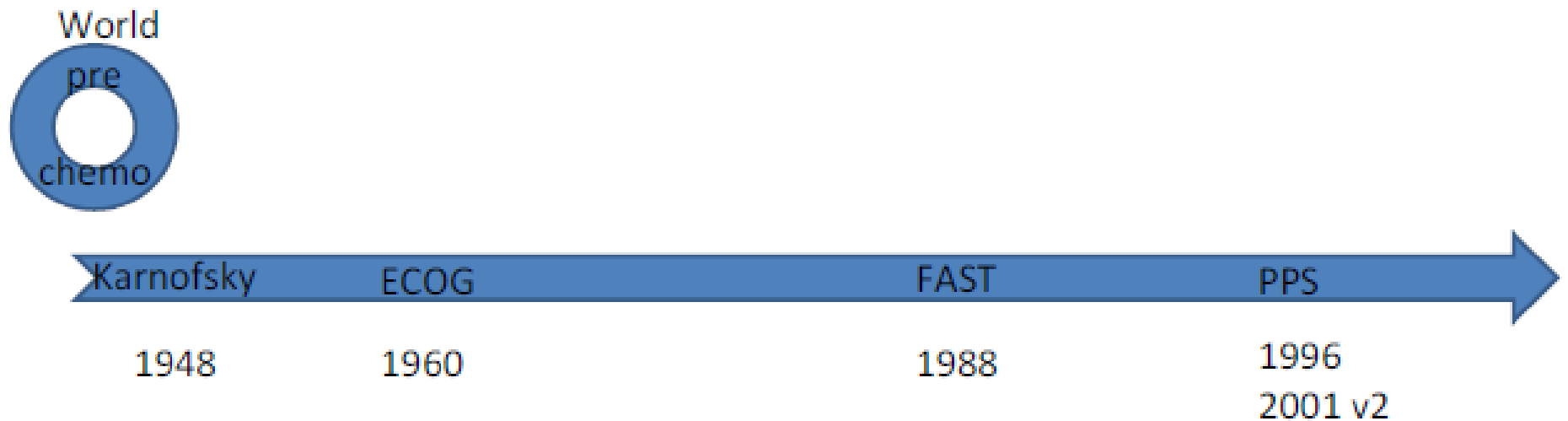
- 72 year old; Lives alone
- COPD: Dom O2
- OSA: CPAP
- IHD, CCF
- Osteoporosis
- Kyphosis
- CRF
- Lower leg ulcers, Skin grafts, cellulitis
- Polypharmacy
- Falls
 - Sub-dural Jan 2014

Thelma

- Increasing frequency admissions
 - COPD Exacerbation
 - LVF
 - Falls
- How to assess:
- Suitable for palliative care?
- How to assess needs, prognosis?
 - Which score/tool?
- Symptom management



Performance Scale timeline



Tools to assist in assessment

- Palliative Performance Score (PPS)*
- Australian Karnofsky Performance Score (AKPS)
- European Cooperative Oncology Group (ECOG)
- PC Needs Assessment Tool (PC-NAT)*
- Prognostic Indicators Group (PIG)*
- Supportive and Palliative Indicators Tool (SPICT)*
- PCOC: RUG-ADL, Phase, SAS, PSS
- Amyotrophic Lateral Sclerosis Functional Rating Score (ALSFRS-R)*
- New York Heart Failure (NYHF) Stage
- BODE Score (in COPD)

Shortlisted Clinical Tools

Table 8 summarises the clinical tools that were shortlisted for evaluation during Phase 4 of the project (as highlighted above).

Domain of Palliative Care	Shortlisted Clinical Tools
Symptoms	Edmonton Symptom Assessment Scale (ESAS) Symptom Assessment Scale (SAS) Memorial Symptom Assessment Scale
Quality of Life	Measuring the Quality of Life of Seriously Ill Patients (QUAL-E) McGill Quality of Life Questionnaire (MQOL) FACIT-Pal
Psych/Emotional Health	General Health Questionnaire (GHQ12) 'Distress Thermometer' Hospital Anxiety and Depression Scale
Multi-domain Assessments / Needs Assessments	Problem Severity Score (PSS) Palliative Outcome Scale (POS) Needs Assessment Tool Progressive Disease – Cancer (NAT PD-C) Needs at the End of Life Screening Tool (NEST13) Distress Management Tool (a.k.a. 'Distress Thermometer')
Family / Caregiver Tools	Carer Support Needs Assessment (CSNAT) Family Inventory of Needs (FIN) Quality of Life During Serious Illness – Family Carers (QOLLI-F)
Performance Status / Function	ECOG Performance Status Palliative Performance Scale (PPS) Edmonton Functional Assessment Tool (EFAT) Australian KPS
Pain	Numerical, Verbal, VA Rating Scale (part of ESAS) Brief Pain Diary Brief Pain Inventory (PBI) Initial Pain Assessment Tool
Prognosis	Palliative Prognostic Score (PaP) Palliative Prognostic Index (PIP)
Spirituality History Tools	FICA Spiritual History Tool Taking a Spiritual History Spiritual Needs Inventory
Care pathway for imminently dying patient	Liverpool Care Pathway (LCP) Palliative Care for Advanced Disease (PCAD) Pathway



PPS = 30, 40, or 50
ECOG = 2, 3, or 4
NYHA = I, II, III, or IV
FAST = 5 7f
KPS 70 . . . 20

PALLIATIVE PERFORMANCE SCALE

- Functional assessment tool
- Rates individuals condition
 - 100% to 0% (death)
- 5 elements:
 - Ambulation
 - Activity and evidence of disease
 - Intake
 - Self care
 - Conscious level

Palliative Performance Scale (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-care	Intake	Conscious level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

PALLIATIVE PERFORMANCE SCALE

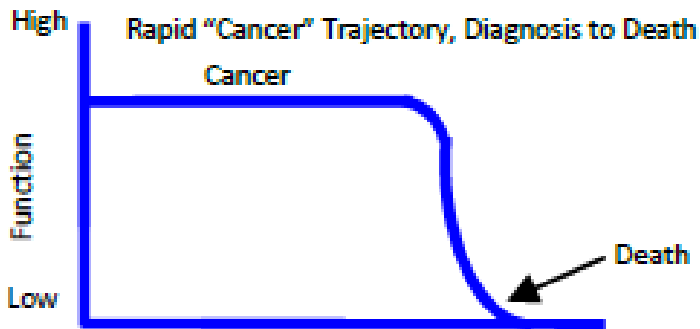
- Enables identification of palliative patient
- Trigger for:
 - Advanced care planning
 - Symptom control
 - End of life care
 - After death review

PROGNOSTIC INDICATORS GROUP GOLD STANDARDS FRAMEWORK (UK)

- Surprise Question:
- “would you be surprised...?”
 - Concern this may enshrine a narrow concept of PC
 - “Continuous palliation” esp older person
 - ? May become surrogate for screening
 - May not suit COPD, CCF
 - Unpredictable illness trajectory

Small et al Pall Med 2010

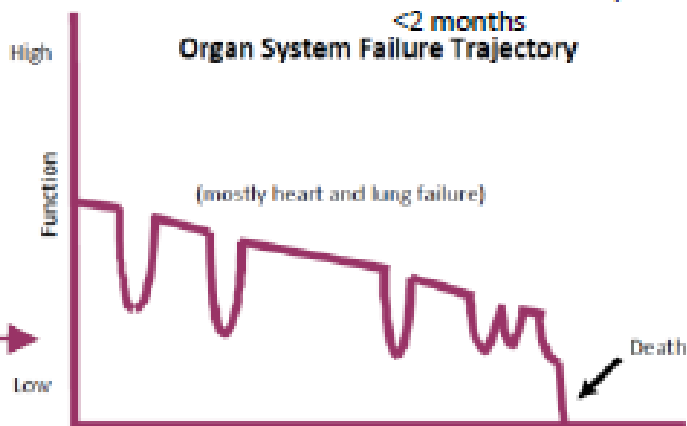
Typical Case Histories



Onset of incurable cancer → Time - Often a few years, but decline usually seems <2 months

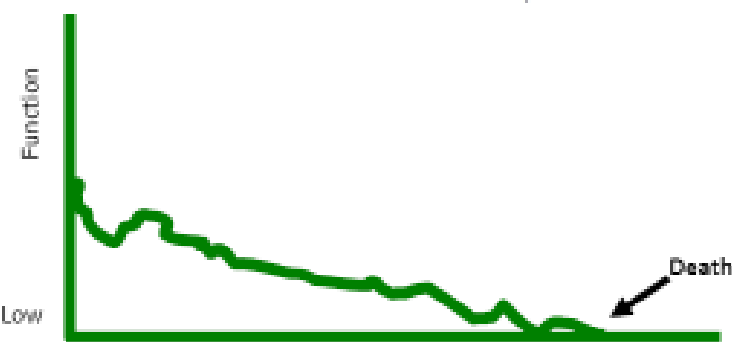


1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline



2) Mr B - An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline

Begin to use hospital often, self-care becomes difficult → Time - 2-5 years, but death usually seems "sudden"



Onset could be deficits in ADL, speech, ambulation → Time - quite variable - up to 6-8 years



3) Mrs C - A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline

PROGNOSTIC INDICATORS GROUP GOLD STANDARDS FRAMEWORK (UK)

- Predicting needs rather than prognosis
- 3 questions:
 - Surprise question...
 - General indicators of decline
 - Specific clinical indicators of specific condition

Step 1

The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2

General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

Chronic Obstructive Pulmonary Disease (COPD)

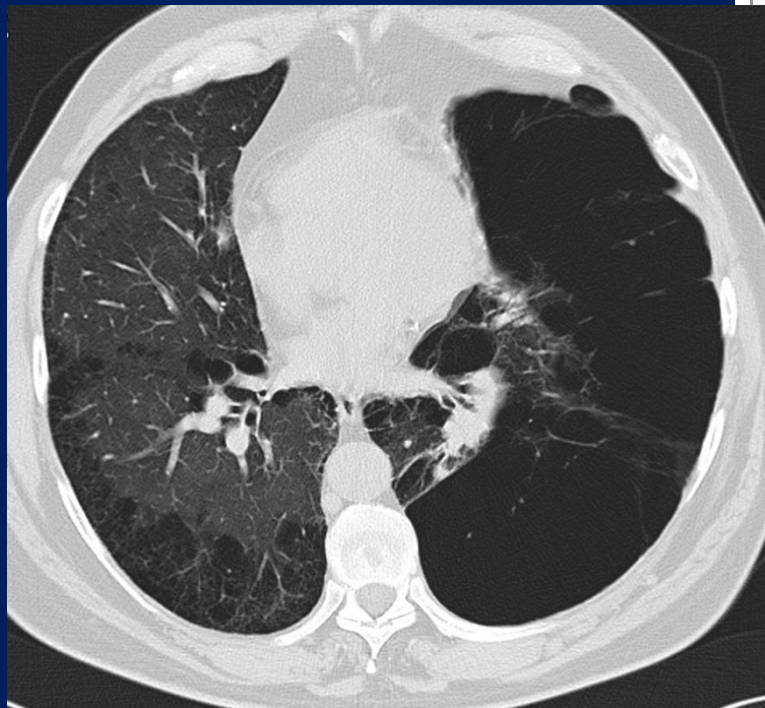
At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level of confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

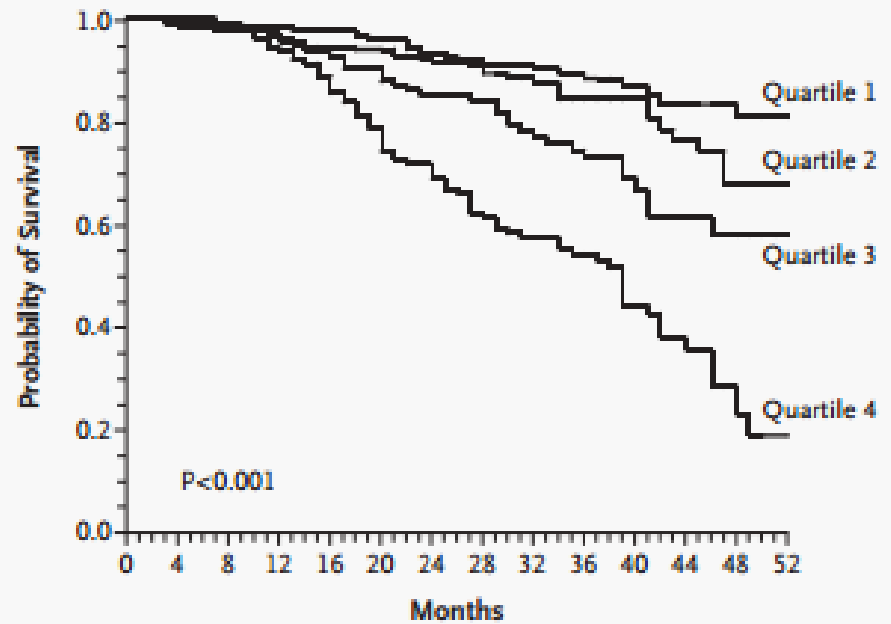
ORIGINAL ARTICLE

The Body-Mass Index, Airflow Obstruction, Dyspnea, and Exercise Capacity Index in Chronic Obstructive Pulmonary Disease

Bartolome R. Celli, M.D., Claudia G. Cote, M.D., Jose M. Marin, M.D.,



A



No. at Risk 625 611 574 521 454 322 273 159 80

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

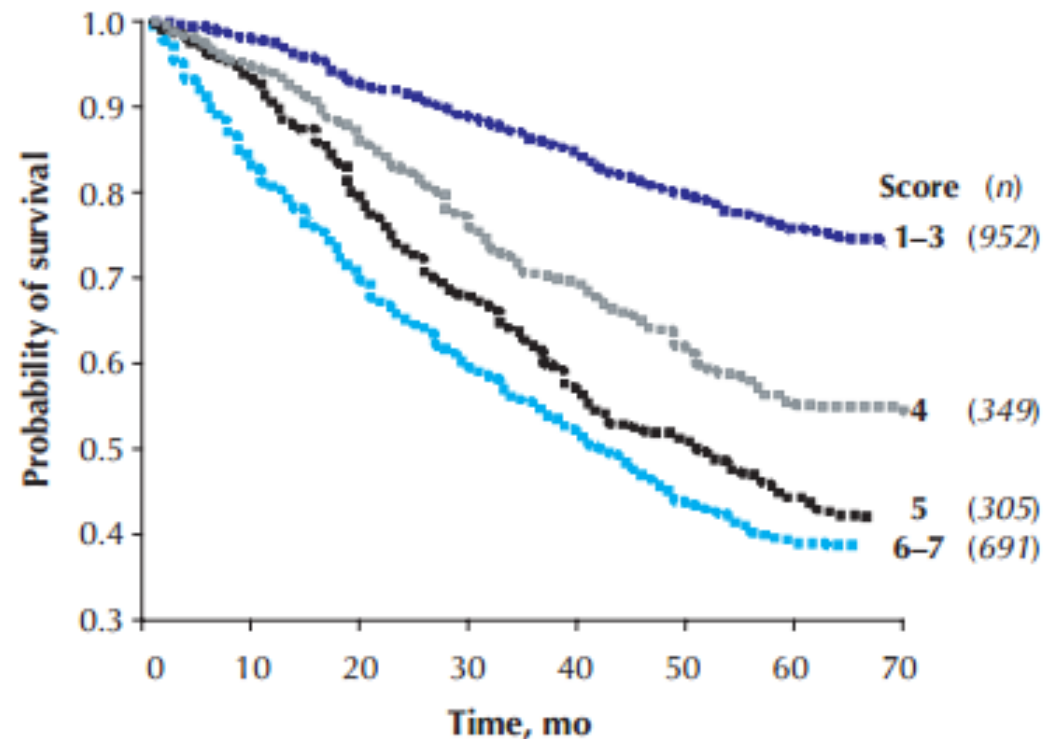
- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
 - weakness
 - slow walking speed
 - significant weight loss
 - exhaustion
 - low physical activity
 - depression.





SPICIT™



Risk of dying

Unmet needs

Goals of care

Supportive care

Care planning

Palliative care

Clinical indicators

Identifying patients

Deteriorating health

Any advanced illnesses

Guide for clinicians



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-8 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

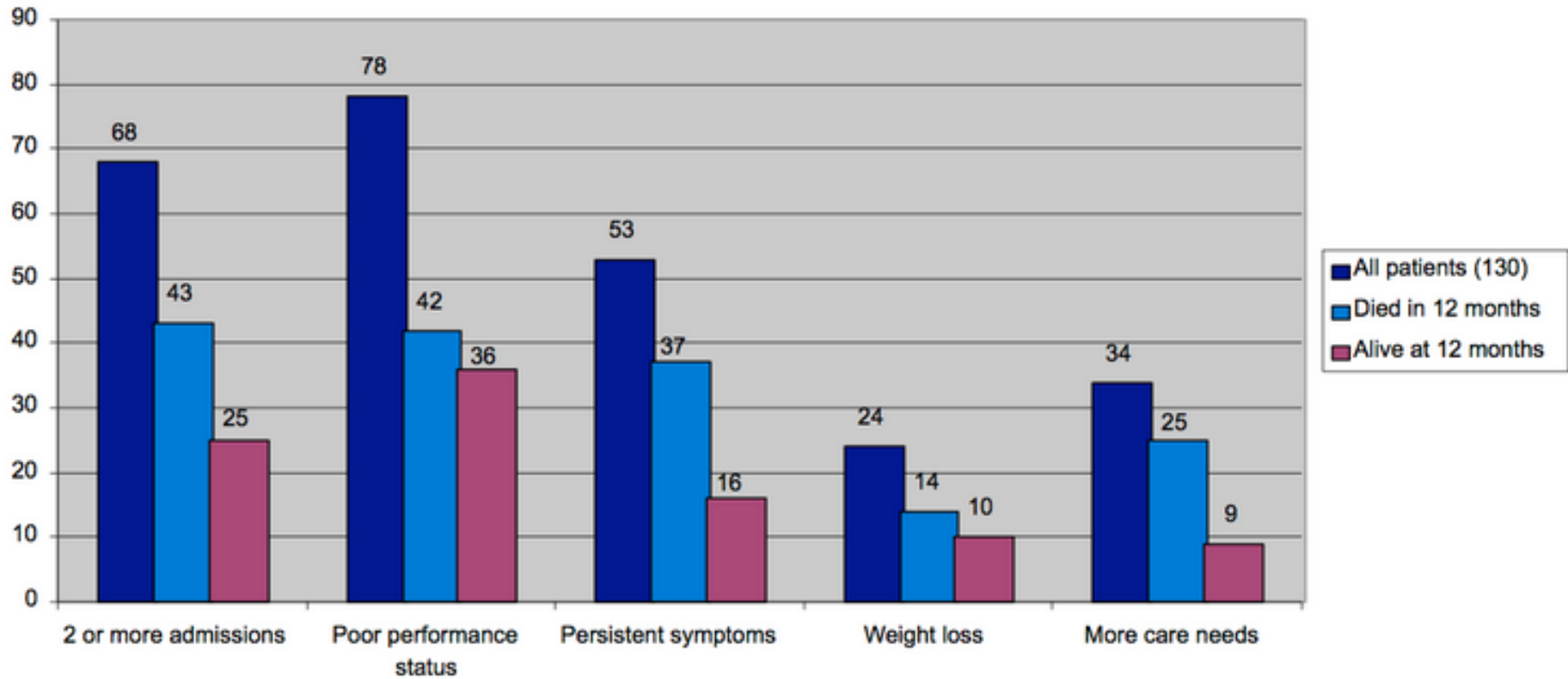
Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

Indicators of deteriorating health in SPICt identified patients



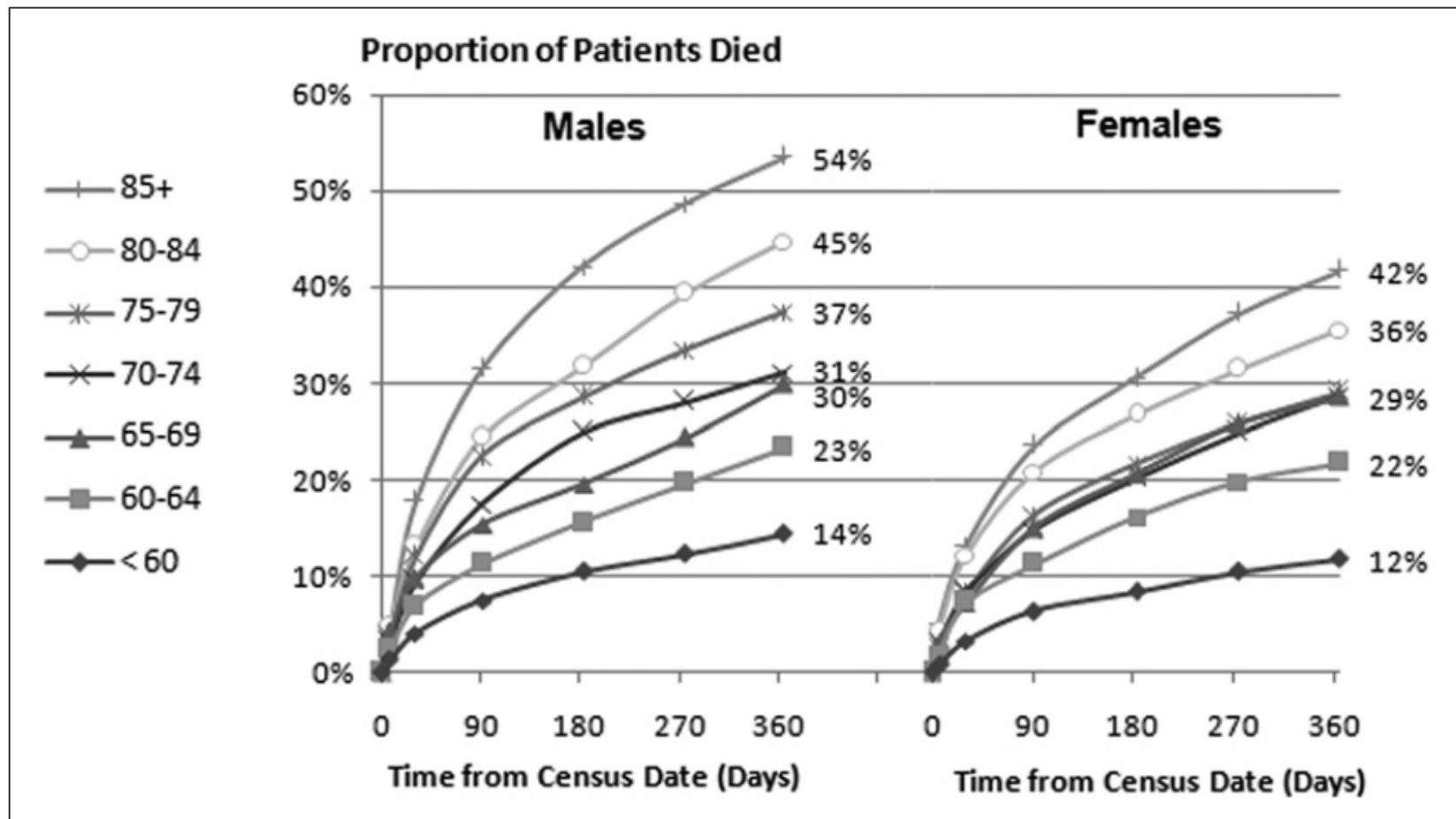


Figure 1. Mortality over time for all patients in teaching and general hospitals in Scotland on 31 March 2010.

PREDICTING LAST YEAR OF LIFE

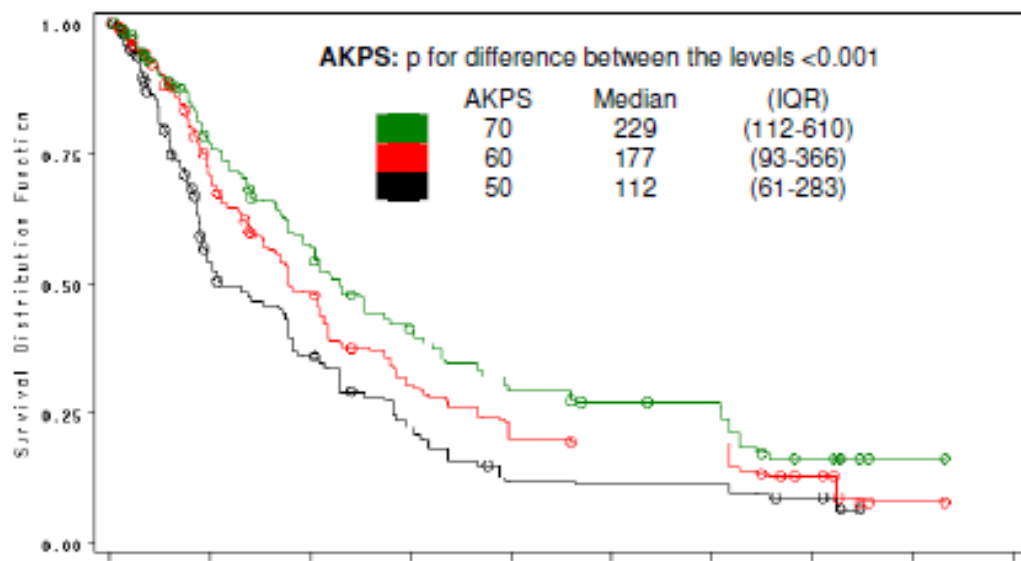
- Prospective study acute care hospital patients
- Utilised GSF Prognostic Indicator Guidance
- Snapshot of 22 wards
 - 501 patients
 - 99 met 1 or more of GSF-PIG triggers
 - Av age 70 (most >83 years)
 - Cancer 46%
 - Cardiac 11%
 - Many with 3 co-morbid conditions

O'Callaghan et al 2014 Pall Med

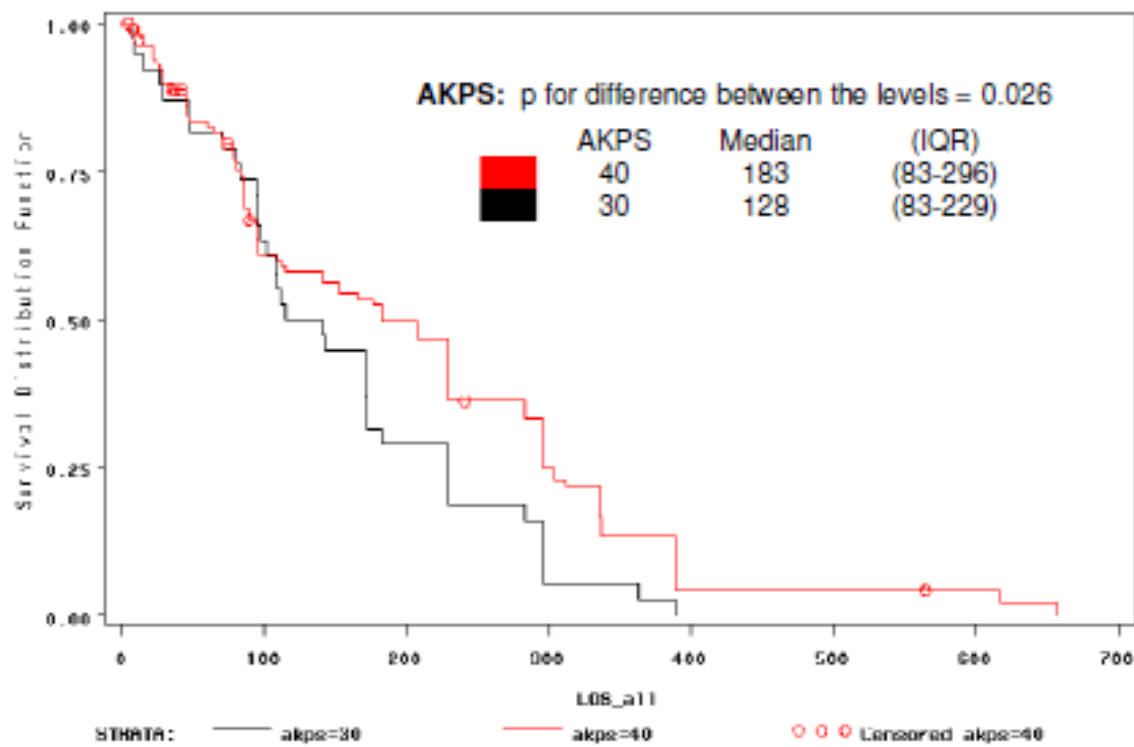
PREDICTING LAST YEAR OF LIFE

- “Identified group” (19.8% of inpatients)
 - 56/99 (57%) died 6 months
 - 67/99 (67%) died 12 months
 - 40/402 (10%) of “non-identified” died 12 months
 - Odds ratio dying in “identified” group:
 - 23.63 at 6 months
 - 18.94 at 12 months
 - GSF-PIG highly specific and moderately sensitive

O’Callaghan et al 2014 Pall Med



STRATA: — akps=50 ○ ○ ○ Censored akps=50
 ○ ○ ○ Censored akps=60 — akps=70



STRATA: — akps=30 — akps=40 ○ ○ ○ Censored akps=40

Rate of disease progression: a prognostic biomarker in ALS

Julie Labra,¹ Parvathi Menon,² Karen Byth,^{3,4} Shea Morrison,¹ Steve Vucic²

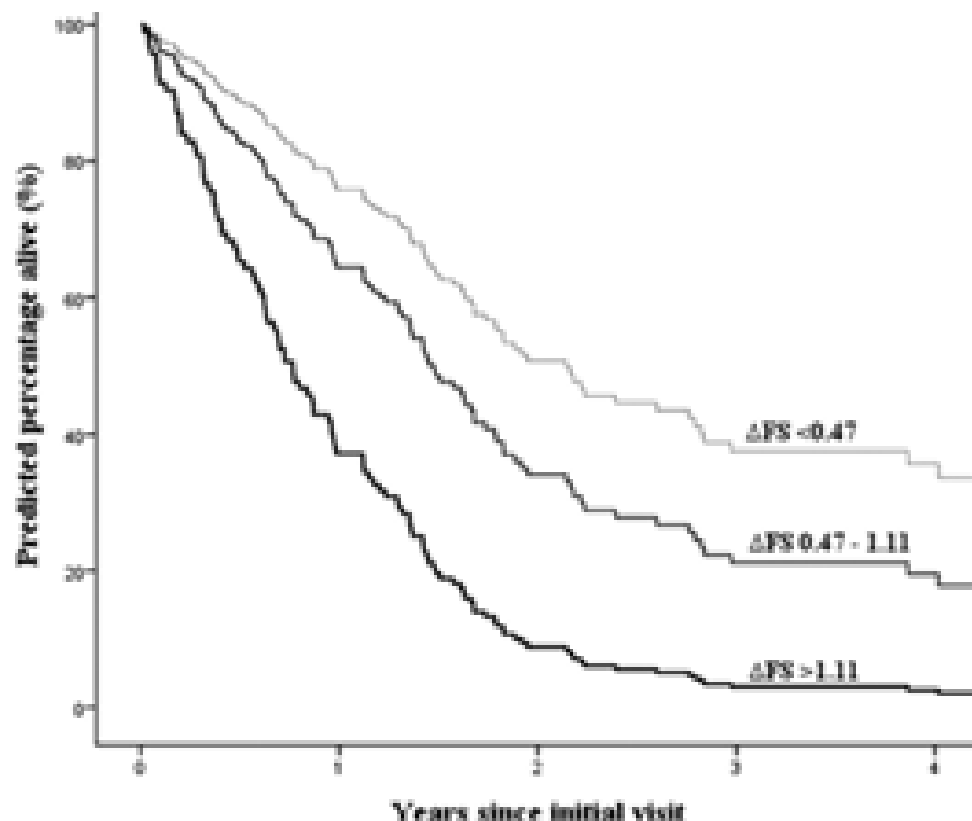


Figure 1 Kaplan-Meier survival curves indicating that a rate of disease progression (ΔFS) < 1.11 at initial assessment was associated with poorest survival.



Adelaide Institute for Sleep Health

The human face of MND and Bi-level

- Mr T.; Divorced
- 64 years age,
- diagnosed with MND 2004,

2006, commenced Bi-level

- Lower limb weakness, bilateral dexterity loss, slurred speech, occasional choking, headaches on waking,
- **PCO₂ 51, PaO₂ 72**
- Supportive carer but also deaf



ISSUES WITH VENTILATION

- Deterioration
 - Disease continues to progress
 - Reduced ability for communication
 - “Locked in”
- Family concerns
 - Massive impact, particularly when NIV 24/7
- Discussion regarding withdrawal NIV
 - Should commence at initiation
- Staff concerns

POSSIBLE APPROACH TO PATIENT WITH CHRONIC DISEASE

- Assess and review patient, family/caregiver
- If positive trigger:
 - AKPS/PPS/PCOC: RUG-ADL
 - ? Score of 60
- Case Conference with General Practitioner, Specialist RN, SPCS
 - ?PC-NAT
 - ? Palli-aged
 - New app for GP
 - Respecting patient choice/Advanced Care Plan/

CHRONIC NON MALIGNANT ILLNESS AND PALLIATIVE CARE

- SUMMARY

- Increasing need to provide care
 - Frail, older persons, heterogeneous with unique differences
 - Unpredictable and prolonged trajectories
 - Increased dependence on others; often RACF
- Palliative approach:
 - can reduce futile investigations and treatment
 - Can improve patient's QoL
 - Enables caregivers/bereaved to move on, less PTSD
 - Variety of tools/scales to help identify suitable patients
 - PPS; GSF-PIG; SPICT; PCOC (RUG-ADL); AKPS
- Further prospective studies of early PC intervention indicated