Palliative care, surgery and palliative surgery: three worlds collide
Perioperative Medicine Special Interest Group

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Hull York Medical School, University of Hull, UK
Ten tips for better health (1999)

1. Don’t smoke. If you can, stop. If you can’t, cut down.
2. Follow a balanced diet with plenty of fruit and vegetables.
4. Manage stress by, for example, talking things through and making time to relax.
5. If you drink alcohol, do so in moderation.
6. Cover up in the sun, and protect children from sunburn.
7. Practice safer sex.
8. Take up cancer screening opportunities.
9. Be safe on the roads; follow the Highway Code.
10. Learn the First Aid ABC: **airways**, **breathing**, **circulation**.

Sir Liam Donaldson (1949 - )
Chief Medical Officer for England 1998-2010
London: The Stationery Office
Alternative ten tips for better health

1. Don’t be poor. If you can, stop. If you can’t, try not to be poor for long.
2. Don’t live in a deprived area. If you do, move.
3. Don’t be disabled or have a disabled child.
4. Don’t work in a stressful, low paid, manual job.
5. Don’t live in damp, low quality housing or be homeless.
6. Be able to afford to pay for social activities and annual holidays.
7. Don’t be a lone parent.
8. Claim all benefits to which you are entitled.
9. Be able to afford to own a car.
10. Use education to improve your socio-economic position.

Professor David Gordon
Professor of Social Justice
Director of the Townsend Centre for International Poverty Research
University of Bristol.
Needs-based service provision

Palliative care as a social good
Needs-based service provision

Palliative care as a social good

compared with

Palliative care as a health service that delivers improved health outcomes across the whole community
Palliative care, surgery and palliative surgery

1. What is important to people at the end of life?

2. What are the factors to consider in the event of a need for surgery?

3. Palliative surgery...
1. What is important to people at the end of life?

2. What are the factors to consider in the event of a need for surgery?

3. Palliative surgery...
Measuring what counts in palliative care

Priorities at the end of life

Diagnoses included advanced chronic illnesses
cancers (lung, colon, stomach, oesophagus, pancreas, head and neck, and lymphoid);
end-stage renal disease;
chronic obstructive pulmonary disease; &
congestive heart failure.

Steinhauser et al. JAMA 2000
Measuring what counts in palliative care

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- **Symptom control**

- Prepare for the end of life
- Achieve a sense of completion
- Be consulted about treatment preferences
- Be treated as a ‘whole person’

Measuring what counts in palliative care

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- *Symptom control and personal care*

- Prepare for the end of life
- Achieve a sense of completion
- Be consulted about treatment preferences
- Be treated as a ‘whole person’

Measuring what counts in palliative care

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- Symptom control and personal care as an enabler to ensure people can:
  - Prepare for the end of life
  - Achieve a sense of completion
  - Be consulted about treatment preferences
  - Be treated as a ‘whole person’

Measuring what counts in palliative care

What physical symptoms will people not volunteer (or systematically under-report)?

n=200;

Open questions followed by a 48 question check list;

Median age 65

Median Eastern Cooperative Group performance status 2

Homsi J et al. Support Care Cancer 2006
What physical symptoms will people not volunteer (or systematically under-report)?

Volunteered symptoms
- Median 1 (range 0-6)

Systematically explored symptoms
- Median 10 (range 0-25)

Homsi J et al. Support Care Cancer 2006
What physical symptoms will people not volunteer (or systematically under-report)?

Volunteered symptoms
- Median 1 (range 0-6)
  83% moderate / severe. 91% distressing

Systematically explored symptoms
- Median 10 (range 0-25)

Homs J et al. Support Care Cancer 2006
What physical symptoms will people not volunteer (or systematically under-report)?

Volunteered symptoms
- Median 1 (range 0-6)
  83% moderate / severe. 91% distressing

Systematically explored symptoms
- Median 10 (range 0-25)
  52% moderate / severe. 53% distressing

Homsi J et al. Support Care Cancer 2006
What physical symptoms will people not volunteer (or systematically under-report)? n = 200

69% of severe symptoms were not volunteered (n=522)

79% of distressing symptoms were not volunteered (n=1,393)

Homsi J et al. Support Care Cancer 2006
Measuring what counts in palliative care

Patient-prioritised domains

- Maintaining a sense of humour
- Not being a burden
- Being mentally alert (at the cost of other symptom control potentially)
- NOT being concerned about the place of death

Measuring what counts in palliative care

Patient-prioritised domains

- We do with functional status what we did for pain 30 years ago

- (Many of our colleagues still do the same with breathlessness)
Measuring what counts in palliative care

Patient-prioritised domains

- We do with functional status what we did for pain 30 years ago
  ‘Of course you’re getting weaker and able to do less. You have a progressive life-limiting illness.’

- (Many of our colleagues still do the same with breathlessness)
## Hospice and palliative care

<table>
<thead>
<tr>
<th>Score</th>
<th>Australian-modified Karnofsky Performance Scale (AKPS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) 100</td>
<td>Normal; no complaints; no evidence of disease.</td>
</tr>
<tr>
<td>(A) 90</td>
<td>Able to carry on normal activity; minor signs or symptoms.</td>
</tr>
<tr>
<td>(A) 80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>(B) 70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>(B) 60</td>
<td>Requires occasional assistance but is able to care for most of his needs.</td>
</tr>
<tr>
<td>(B) 50</td>
<td>Requires considerable assistance.</td>
</tr>
<tr>
<td>(C) 40</td>
<td>In bed more than 50% of the time.</td>
</tr>
<tr>
<td>(C) 30</td>
<td>Almost completely bedfast.</td>
</tr>
<tr>
<td>(C) 20</td>
<td>Totally bedfast and requiring extensive nursing care.</td>
</tr>
<tr>
<td>(C) 10</td>
<td>Comatose or barely arousable.</td>
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0 Dead.
Hospice and palliative care

Typical graph of functional decline
Can we increase the time for which a person can be self-caring by better coordinating existing care and better planning for future eventualities?
Hospice and palliative care

Can we increase the time for which a person can be self-caring by better coordinating existing care and better planning for future eventualities?
Hospice and palliative care

Can we increase the time for which a person can be self-caring by better coordinating existing care and better planning for future eventualities?
Palliative services in Australia

Education

National Curriculum development for all Health Sciences
Palliative services in Australia

National Palliative Care Curriculum
4 key areas:
a – individual attributes
- empathy, compassion, self-care
b – clinical skills
- assessment
c – communication skills
- listening, reflection
d – palliative care principles
- philosophy, interdisciplinary care, symptom control principles

Measuring what counts in palliative care

Why routinely measure performance?

What do we say are the ways in which palliative care value adds to the health and wellbeing of our communities?
Measuring what counts in palliative care

Why routinely measure performance?

The value proposition of palliative care:
- Optimising the comfort and function (physical, emotional, spiritual, sexual, social and financial) of people with life-limiting illnesses; and
- Ensuring the wellbeing of caregivers while in the role and subsequently.
Measuring quality in palliative care

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The value proposition of palliative care:

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1. What is important to people at the end of life?

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3. Palliative surgery...
Don’t make me feel helpless; share information

How long have I got? 5 considerations

1. What is the natural history of the person’s life-limiting illness?
2. What are his / her inter-current illnesses?
3. What are the systemic signs of change?
4. What has been the rate of functional change?
5. How does the person see his / her future?
Don’t make me feel helpless; share information

Frequently asked questions

*Patients*
- How long have I got?
- How will I die?
- Why am I so tired?

*Caregivers*
- Why won’t (s)he eat?
- If only you would feed her...
- They just don’t want to live...
Palliative Care – everyone’s responsibility

-Why do people die?

This can help answer frequently asked questions
- How long have I got?
- How will I die?
- Why am I so tired?
- Why won’t (s)he eat?
- If only you would feed her...
- They just don’t want to live...
Palliative Care – everyone’s responsibility

How good are we at prognosticating?

If you are satisfied with broad brush-strokes of time, very accurate

Christakis and Lamont. JAMA 2000
Function in Palliative Care

**AKPS:** $p$ for difference between the levels $< 0.001$

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<th>Median</th>
<th>(IQR)</th>
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<td>(61-283)</td>
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**Survival Distribution Function**

**LOS_all**

**STRATA:**
- akps=50
- Censored akps=50
- akps=60
- Censored akps=60
- akps=70
- Censored akps=70

Abernethy BMC Pall Care 2005
Function in Palliative Care

Abernethy AP et al. BMC Pall Care 2005
Function in Palliative Care

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Abernethy AP et al. BMC Pall Care 2005
Function in Palliative Care

Abernethy AP et al. BMC Pall Care 2005
Cancer cachexia

- Affects up to 80% of patients with advanced cancer\(^1\)
- Contributes to 30% of cancer-related deaths\(^2\)
- Ongoing loss of skeletal muscle mass (with or w/o loss of fat mass)\(^3\)

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\(^1\) Kumar N. et al, Current Treatment Options in Oncology 2010;11:107–117
\(^3\) Fearn K. et al., Lancet Oncol. 2011;12:489–95
Evolving Cancer Cachexia Diagnostic Criteria

- **2011: International consensus definition** based on the presence of ≥1 of the following conditions when involuntary weight loss cannot be corrected through nutritional interventions
  - BMI <20 kg/m²
  - Recent history of involuntary loss of body weight (>5%)
  - Sarcopenia

- **2015; BMI and weight scoring system developed:** Patients with stage IIIb/IV mixed tumors (N=8,160; median follow-up, 41.3 mo)
  - Weight loss and BMI are independent prognostic factors for survival
    - 2.1-fold increase in mortality in patients with BMI <20 kg/m²
  - Weight loss adjusted BMI scoring system predicts mortality

Cancer Cachexia Diagnostic Criteria
International Consensus Definition

• At least one of the following:

  – Low BMI < 20 kg/m²

  – Recent weight loss ≥ 5%

  – Low muscle mass

• Fearon K et al., *Lancet Oncology* 2011
### Sarcopenia compared with cachexia

<table>
<thead>
<tr>
<th></th>
<th>Sarcopenia</th>
<th>Cachexia</th>
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</thead>
<tbody>
<tr>
<td>Muscle protein synthesis</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Muscle protein degradation</td>
<td>No change</td>
<td>↑</td>
</tr>
<tr>
<td>Muscle mass, strength, function</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Fat mass</td>
<td>↑</td>
<td>No change or dec.</td>
</tr>
<tr>
<td>Basal metabolic rate / REE</td>
<td>↓</td>
<td>↑</td>
</tr>
<tr>
<td>Inflammation</td>
<td>No change</td>
<td>↑</td>
</tr>
<tr>
<td>Insulin resistance</td>
<td>↑</td>
<td>↑</td>
</tr>
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Clinical Relevance of Low LBM

↓ Physiologic reserve
- Dominant source of protein to react to stressors and support vital organs
- Role especially important in the presence of negative energy balance

↓ Cancer treatment tolerability
- Patients often behave as if overdosed
- More-frequent severe and dose-limiting toxicities
- More frequent unplanned cessation of treatment

↑ All-cause mortality
- Consistent predictor of mortality independent of age, cancer stage, and performance status
- Risk highest in the presence of obesity

↑ Patient symptom burden
- Increased fatigue
- Increased breathlessness
- Higher symptom severity and impact

↓ Exercise capacity and tolerance
- Lower anaerobic threshold
- Reduced exercise performance
- Earlier symptom limitation

↑ Disability and dependency
- Drives sarcopenia and frailty
- Earlier ADL disability (chair rise, stairs) and mobility limitation
- Increased risk of falls, hospitalization, and institutionalization
Significance of Cachexia in NSCLC

- 97 patients with stage IIIB or IV NSCLC participating in routine clinic visits
- Cachexia defined per 2011 criteria
- ≥2 visits required for inclusion in longitudinal analysis
  - n=97 at visit 1
  - n=81 at visit 2
  - n=69 at visit 3
  - n=60 completed all 4 visits

Multimodal approach to treat cancer cachexia

- Nutrition
- Exercise
- Medication
  - Ghrelin (Anamorelin)
  - Androgen Modulator
  - Steroid
  - Myostatin inhibitor
  - Medical Herb
- Psychotherapy
1. What is important to people at the end of life?

2. What are the factors to consider in the event of a need for surgery?

3. Palliative surgery…
Palliative care, surgery and palliative surgery

Palliative surgery...

Intercurrent problems
Iatrogenic problems
Related directly to the life-limiting illness
Palliative care, surgery and palliative surgery

Palliative surgery...

Intercurrent problems

The catabolic insult of surgery should be considered very carefully
Palliative care, surgery and palliative surgery

Palliative surgery...

Iatrogenic problems

Probably changes the threshold for attempted therapy
Palliative care, surgery and palliative surgery

Palliative surgery...

Related directly to the life-limiting illness

Symptom control or heroic attempt to increase life expectancy
Palliative care, surgery and palliative surgery

Palliative surgery...

Bridge to more definitive therapy?

Destination therapy?
Palliative care, surgery and palliative surgery

Palliative surgery...

The key question is:

Is surgery the best way to optimise this person’s comfort and function?
1. What is important to people at the end of life?

2. What are the factors to consider in the event of a need for surgery?

3. Palliative surgery...
Measuring what counts in palliative care

AIMS:
Self report (SR) of symptoms compared to systematic questioning (SQ) in palliative care.

METHODS:
A retrospective chart review (n = 50).
An average of 13 symptoms were experienced (Self Report + Systematic questioning) per patient (range, 5-24).
The most common Self Report symptoms were: pain (72%); bowel disturbance (32%); nausea / vomiting (30%); mobility problems (30%); and anorexia (24%).
RESULTS:

On Systematic Questioning (SQ), there was an average of 8 further symptoms per patient detected (range, 1-18).

The most common symptoms detected on SQ were:

- weight loss (66%);
- fatigue (56%);
- anorexia (48%);
- mobility problems (42%);
- oedema/lymphoedema (36%);
- oral symptoms (36%);
- confusion/memory loss (36%);
- sleep problems (36%);
- bowel disturbance (34%);
- drowsiness (32%); and
- low mood (28%).
Measuring what counts in palliative care

1. Why routinely measure palliative care outcomes?

2. What evidence do we have about current performance directly from patients and caregivers?

3. Initiatives in measuring and responding to systems’ performance in palliative care
Measuring what counts in palliative care

Palliative Care Outcomes Collaborative patient and caregiver survey

- Up to 50 consecutive patients per service per year (2008-2011)
- 49 services
- 35% community only, 33% combined community / inpatient
- 1800 respondents

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Palliative Care Outcomes Collaborative patient and caregiver survey

Palliative Outcomes Scale (version 2)
8 items – symptoms, psychological support and information

2 items – practical matters

Measuring what counts in palliative care

Palliative Care Outcomes Collaborative patient and caregiver survey

Pain – 83%

Other symptoms – 80%

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Palliative Care Outcomes Collaborative patient and caregiver survey

Pain – 83%
(25% of respondents had overwhelming pain)

Other symptoms – 80%

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Palliative Care Outcomes Collaborative patient and caregiver survey

Pain – 83%
(25% of respondents had overwhelming pain)

Other symptoms – 80%
(17% had severe or overwhelming symptoms)

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Why do we need to improve the care we offer?

• Caregiver anxiety – 78%

• Family anxiety – 89%

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Why do we need to improve the care we offer?

- Caregiver anxiety – 78% (22% had severe or overwhelming anxiety)
- Family anxiety – 89%

Pidgeon T et al. BMJ Support Palliat Care 2015
Measuring what counts in palliative care

Why do we need to improve the care we offer?

- Caregiver anxiety – 78% (22% had severe or overwhelming anxiety)
- Family anxiety – 89% (45% of respondents had overwhelming anxiety)

Pidgeon T et al. BMJ Support Palliat Care 2015
Dying from cancer: results of a national population-based investigation.

MAIN RESULTS:
At some stage in the last year of life patients:
- 88% were reported to have been in pain (relatively poorly controlled often)
- More than half had loss of appetite, constipation, dry mouth or thirst, vomiting or nausea, breathlessness, low mood, and sleeplessness.

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Symptom burden and performance status in a population-based cohort of ambulatory cancer patients.

RESULTS:
The cohort included 45,118 and 23,802 patients' first ESAS and PPS, respectively.
Fatigue was most prevalent (75%)

More than half of patients reported pain or shortness of breath about half of whom reported moderate to severe scores

On multivariate analysis, worse ESAS outcomes were consistently seen for women, those with comorbidity, and those with shorter survivals from assessment.
Lung cancer patients had the worst burden of symptoms.

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Coming of age

• Choosing Wisely$^R$ – 5 low value things that could stop without compromising clinical care.

• Rather than look at palliative care and its practices, the list looks at:
  – Cardiology
  – Radiation oncology
  – Geriatricians
Palliative Populations

After all, palliative care is a referral-based service with:

- no gold standard in order to initiate a referral;
- multiple entry points in multiple settings across the health system; and
- care provided by a large number of health and social professionals
Measuring what counts in palliative care

Measuring what matters project (MWM):

top-ranked quality indicators for hospice and palliative care from the:

- American Academy of Hospice and Palliative Medicine; and

- Hospice and Palliative Nurses Association.

Measuring what matters (MWM) quality in palliative care

The final list of 10 (from 75 initially).

1. Comprehensive assessment
2. Physical aspects
   a) Screening for physical symptoms,
   b) Pain treatment, and
   c) breathlessness screening and management.
3. Psychological and psychiatric aspects (emotional or psychological needs)
4. Spiritual, existential or religious concerns
5. Ethical and legal aspects
   a) Documentation of surrogate decision maker;
   b) Treatment preferences; and
   c) Care consistency with documented care preferences.

(The list also recommends a global indicator of patient/family perceptions of care, but does not endorse a specific instrument)

Measuring what counts in palliative care

Advancing the science of hospice care: Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE)

The Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE). CHOICE is a national network of hospices that use compatible electronic health record-based data collection procedures to answer key questions relevant to clinical care and policy.

Measuring what counts in palliative care

QDACT

37 questions within five domains:
- Demographics;
- Symptom management;
- Advanced care planning;
- Prognosis; and
- Transition / discharge
Measuring what counts in palliative care

QDACT (Quality data collection tool v1.0)

OUTCOMES:
May 2008 through March 2011, data on 5959 patients in 19,734 visits have been collected.
Outcomes include:
- steady quarterly growth in data collection;
- positive clinician feedback; and
- successful mapping of data to quality metrics.

Information gathered characterised practice variations and suggested quality improvement initiatives.

The Australian Palliative Care Outcomes Collaborative (PCOC)

A national program funded by the Department of Health & Ageing to improve systematically the quality of palliative care service provision.

PCOC:

• Supports continuous *outcome improvements* in palliative care
• Uses benchmarking nationally that will improve practice
• Is improving the use of standardised palliative care clinical assessments
• creates a “common language” for clinicians including primary care
The aims of PCOC

• Work with services to incorporate the PCOC data collection into routine practice
  \textit{in order to}
• Analyse the data and provide timely feedback on the results to individual services - reports every 6 months
  \textit{in order to}
• Facilitate benchmarking with other services
  \textit{in order to}
• Improve systematically the outcomes delivered by specialised palliative care services
Key questions

• How do we compare with other similar services? (baseline)
• What can we learn from each other about what needs to be improved?
• What can we learn from the literature about what needs to be improved?
• What is best practice (ie, the benchmark) and how do we work towards systematically achieving this?
PROGRESS TO DATE

• PCOC represents >85% of all palliative care patients referred to specialist services in Australia

• Incorporates
  – Direct inpatient care
  – Community care
  – Consultative care
PCOC cycle

Point-of-care data collection

Structured feedback

Routine reporting

Benchmarking

Every six months
Data architecture

• **Patient/Demographic items – once only**
  – eg, age, sex, postcode

• **Episode – recorded with change of place of care**
  – eg, referral source, time between referral and first assessment, episode type, accommodation at start and end, level of support at start and end, place of death

• **Phase – recorded with change in clinical condition**
  – eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start and end, symptoms at start and end, model of care, number of days seen
Point-of-care data collection

- Assessments
- Setting of care (Episode)
- Demographics
Five assessment tools

- Palliative Care Phase (Phase) - Eagar et al, 2004
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) - Fries et al, 1994
- Australia-Modified Karnofsky Performance Status (AKPS) - Abernethy et al, 2005
- Palliative Care Problem Severity Score (PCPSS) - Eagar et al, 2004
- Symptom Assessment Scale (SAS) - Aoun et al, 2004
Routine PCOC data

Symptom Measurement tools

Symptom Assessment Scale (patient reported)
- 7 domains: pain, fatigue, appetite, nausea, bowels, breathing and sleep
- 0-10 numerical rating scale

Palliative Care Problem Severity Scale (clinician reported)
- 4 domains (pain, other symptoms, psychological / spiritual and family / caregiver)
- 4 levels of (categorical) reporting

PCOC Data

1. Routine voluntary point-of-care data collection
   (data owned by the participating service: captured at 3 levels
   (patient, episode, phase))

2. Periodic (Snapshot) data collections
   (e.g. patient and carer experiences)

3. Developmental/experimental or one off collections
   (testing items for future versions of the data set)
PCOC PROGRESS TO DATE

• 22 six monthly report has been circulated to participating services

• Three annual Patient and Caregiver experience surveys conducted

• Analysis against improvement in national benchmarks, compared to the July – December 2008 data
Understanding causes for variation

• Variations due to the mix of patients (the casemix)
• Variations due to differences in practices (administrative and clinical factors including resources and models of care)

in order to understand

Variations in patient-centred clinical outcomes
Improving outcomes

• All data anchored in 2008
• The relative performance of services is then mapped against that baseline to ascertain improvements
• From >20000 phases of care for the first six months to more than >40000 for the most recent six months
Baseline anchor

• All data categorised by phase (stable, unstable, deteriorating and terminal)
• Within each phase, each level of symptom assessment reported separately
• Aggregated into overall symptom performance nationally

• ...performing above the national overall performance when compared to baseline...’ OR ‘...we are controlling this symptom better...’
This score was calculated by averaging the change for each patient in the same phase (stable, unstable, deteriorating, terminal) with the symptom score at the start of the phase in order to create the baseline expected change score. This forms the anchor point against which changes in services’ performances (improving or worsening) were assessed longitudinally, ensuring that patient-level data compared similar patients.
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Currow DC et al. Supp Care Cancer 2015
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Updated study: 2011 - 2014

• January 2011 – December 2014
• 45 specialist palliative care services of which 20 were also included in initial study
• Changes in study population caused by:
  – Improving data quality
  – IT system changes
  – Service restructuring
Updated method

• Analysis of 45 services participating in the PCOC cycle consistently between January 2011 and December 2014

• Assessing patient outcomes using both SAS and PCPSS
Updated results: 2011 - 2014

- 60,816 patients and 196,152 phases
- 47% female
- 79% malignant diagnosis
- Average age 72.7 years (SD 14.3)
- Statistically significant improvements in all domains
% patient outcomes better than baseline (casemix adjusted)

Pain (SAS)

Individual service results

Modelled average

Six-month reporting period

% patient outcomes better than baseline (casemix adjusted)

- **Individual service results**
- **Modelled average**

Six-month reporting period:
- Jan-Jun 2011
- Jul-Dec 2011
- Jan-Jun 2012
- Jul-Dec 2012
- Jan-Jun 2013
- Jul-Dec 2013
- Jan-Jun 2014
- Jul-Dec 2014

Breathing
% patient outcomes better than baseline (case mix adjusted)

- **Modelled average**
- **Individual service results**

**Pain (PCPSS)**

Six-month reporting period:
- Jan-Jun 2011
- Jul-Dec 2011
- Jan-Jun 2012
- Jul-Dec 2012
- Jan-Jun 2013
- Jul-Dec 2013
- Jan-Jun 2014
- Jul-Dec 2014

PCOC: palliative care outcomes collaboration

UTS: UNIVERSITY OF TECHNOLOGY SYDNEY
% patient outcomes better than baseline (casemix adjusted)

- Individual service results
- Modelled average

Six-month reporting period

Family/carer

PCOC
palliative care outcomes collaboration

UTS
UNIVERSITY OF TECHNOLOGY SYDNEY
Summary of results

• Statistically significant improvements in all seven symptoms and problems
  – Now including pain, the last symptom to significantly improve

• Less variation in service level outcomes
  – More equity of patient outcomes across Australia
Summary

PCOC outcome measures show consistent improvement in palliative care over time

A broad range of quality improvement activities have resulted from PCOC reporting

A culture of quality improvement is firmly embedded in services participating in PCOC
Measuring what counts in palliative care

• Variations seen are not simply because of resources.

• Some well resourced services are doing quite poorly and some poorly resourced services are delivering great patient outcomes.
Measuring what counts in palliative care

• Evidence that highly relevant data collection can be feasibly built into routine care  
  \textit{in order to}

• Compare and contrast current patient-centred outcomes  
  \textit{in order to}

• To learn from each other in service provision and resourcing  
  \textit{in order to}

• Continue to drive the best possible outcomes for patients and their caregivers
Measuring what counts in palliative care

1. Why routinely measure palliative care outcomes?

2. What evidence do we have about current performance directly from patients and caregivers?

3. Initiatives in measuring and responding to systems’ performance in palliative care
Measuring what counts in palliative care

I cannot pretend I am without fear.
But my predominant feeling is one of gratitude.
I have loved and been loved;
I have been given much and I have given something in return;
I have read and travelled and thought and written.
I have had an intercourse with the world, the special intercourse of writers and readers.

Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure.

Oliver Sachs (2015) – on learning that he had cancer which was going to lead to his death imminently.