Quality and outcomes – Australian experiences

Khon Kaen International Conference in Palliative Care 2018
Modern Medicine

• There has been a real exponential increase in the technology and advancements in Medicine
  – Wealth of information and knowledge, readily available
Modern Medicine

• We had lost the ART of caring
• We needed a paradigm shift
• “Palliative care”: old but new
• Words
  – Compassionate care
  – Patient centred care
  – Holistic care
  – Recognition of Suffering
  – Ethical basis to care
The problem with palliative care is....

- We sometimes are happy to pat ourselves on the back and say we are ‘caring’ people...
Is this good enough?
Why it is important to measure outcomes?

• Outcome measures are widely used in
  – health research to describe patient populations or to assess the effectiveness of interventions

• Standardises treatments, type of care, interventions, program of care

• But they are not always incorporated into routine clinical practice

• Many services develop and don’t look to the standard of care that they provide
  – accountability
Quality outcome and measures

• Need for a quality cycle
• Need to set up outcomes that are measured as routine practice
• They are audited
• Review of the data
• It needs to then impact on your service, patient care or development of the specialty
What our colleagues measure as clinical outcomes

• Surgery
  – Mortality rates
  – Infection rates and other complication rates

• Hospitals
  – Average length of stay
  – Waiting list period
  – Unit of cost of care

• Cardiology / Neurology
  – Thrombolysis – effective versus complications
Outcome Measurement in Palliative Care
The Essentials
Bausewein C, Daveson B, Benalia H, Simon ST, Higginson IJ 2008

• PRISMA

• Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care
PRISMA

• Outcome measurement is a way of measuring changes in a patient’s health
  – which can be attributed to preceding healthcare over time
• It can be used to improve the quality of healthcare services
• Outcome measurement can be used for
  – clinical care
  – audit
  – research purposes
• There is an increasing need for robust outcome measurement in the field of palliative care
• Poses particular challenges and requires special consideration with regard to patients’ situations at the end of life.
Patient Rated Outcome Measures (PROMS)

- It needs to be a valid tool
- It needs to be reliable
- It needs to be acceptable to the patient
  - Easy to use clinically
- It has to be responsive to change
  - Be able to pick up the difference
Examples of outcome measures

• Palliative Care Outcome Scale (POS)
  – 10 point to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training

• Distress thermometer

• Edmonton Symptom Assessment Scale (ESAS)
  – 9 symptoms and 1 ‘other’ problem

• HADS

• EORTC QLQ-C30
Benefits of Audit tools

• Patients
  – Identifying and addressing problems
  – Resource requirements versus their needs
  – Service use and needs

• Staff and departments
  – Monitoring and review of quality of care provided
  – To address problems and challenges
  – Areas for improvement (teasing out the issues)
For organisations

*eg PRISM*

- Providing data to measure the organisation’s performance against palliative care standards.
- Identifying areas for service delivery improvement.
- Bringing together important information for reports to funders.
- Enabling comprehensive and summary reports for those working within the organisation to aid self-monitoring and quality improvement.
Advances in Australia

• Outcome measures and Benchmarking
  – PCOC
• National standards
• Collaborative research
  – Quantitative and qualitative
  – Multidisciplinary
• Government input (funding, peak bodies)
• Education (PEPA, Caresearch)
• Models of Care in many states

CONCORD CENTRE FOR PALLIATIVE CARE
Palliative Care in the form of end of life care now features significantly in the national health standards.

Forms a part of accreditation of hospitals.
National Consensus Statement:
10 Essential Elements for safe and high-quality end of life care.
Figure 2: End-of-life care

Diagnosis/progression of life-limiting illness
- Acknowledgment of uncertainty of prognosis
- Begin advance care planning process in the community, outpatient setting or hospital

Likely to die soon (medium term but timing may be uncertain)
- Goal setting and advance care planning
- Palliative approach for symptom management, and psychosocial and family support (treating team ± specialist team)

Dying (short term but timing may be uncertain)
- Review by senior clinician
- Goal setting and advance care planning
- Clear management planning (including limitations of medical
• Our Vision:

• To ensure that all NSW residents have equitable access to quality care based on assessed need as they approach and reach the end of life
What it is:

• This online resource aims to guide services and Local Health Districts in constructing their own, localised models of care. The website will be dynamic and updated as new resources and evidence develop. It emphasises that everyone can have a role to play in supporting or providing care to people approaching and reaching the end of life.
Core Palliative Care Tools

• Amber Care Bundle
• The Australia-modified Karnofsky Performance Score
• [FACIT-Pal: Functional Assessment of Chronic Illness Therapy - Palliative Care](https://www.facial-pal.com)
• [Supportive and Palliative Care Indicators Tool (SPICT)](https://www.spicthome.org)
• The Surprise Question
<table>
<thead>
<tr>
<th>Essential Component</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Informing community expectations and perceptions on death and dying</td>
</tr>
<tr>
<td>2</td>
<td>Discussions about palliative and end of life care and planning for future goals and needs</td>
</tr>
<tr>
<td>3</td>
<td>Access to care providers across all settings who are skilled and competent in caring for people requiring palliative and end of life</td>
</tr>
<tr>
<td>4</td>
<td>There is early recognition that a person may be approaching or reaching the end of life</td>
</tr>
<tr>
<td>5</td>
<td>Care is based on the assessed needs of the patient, carer and family</td>
</tr>
<tr>
<td>6</td>
<td>Seamless transitions across all care settings</td>
</tr>
<tr>
<td>7</td>
<td>Access to specialist palliative care when needs are complex</td>
</tr>
<tr>
<td>8</td>
<td>Quality care during the last days of life</td>
</tr>
<tr>
<td>9</td>
<td>Supporting people through loss and grief</td>
</tr>
<tr>
<td>10</td>
<td>Quality care is supported through access to reliable, timely clinical information and data</td>
</tr>
</tbody>
</table>
Palliative Care Outcomes Collaboration

• PCOC worked with participating services in 2009 to develop our first set of national outcome measures. These were the subject of extensive consultation at three workshops held in Brisbane, Sydney and Adelaide in May and June 2009 to which all participating services were invited.

• In December 2009, national benchmarks (standards of performance that all services are measured against) were formally adopted for each measure.
Symptom Assessment Scale (SAS)

• Patient-rated tool that clinicians use to measure the amount of distress caused by seven of the most common symptoms in palliative care

• A clinician asks the patient to rate their distress relating to each of the seven symptoms on a scale from 0 to 10, – 0 being absent and 10 being severe.
**Symptom Assessment Scale**

Please use this form to tell us about the symptoms that bother, worry or distress you. This information will help us to meet your needs.

**Abnormality**

<table>
<thead>
<tr>
<th>Absent</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8</td>
<td>9</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

1. Write the day or date in the first row.
2. Use the scale above to choose a number between 0 and 10 that shows how bothered, worried or distressed you are.
3. You can add other symptoms in the blank space at the bottom of the list.

<table>
<thead>
<tr>
<th>Day or date</th>
<th>Difficulty sleeping</th>
<th>Appetite problems</th>
<th>Nausea</th>
<th>Bowel problems</th>
<th>Breathing problems</th>
<th>Fatigue</th>
<th>Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Palliative Care Phase

• Phase is used to describe the distinct stage in the patient’s journey
• Phases are classified according to the clinical need of the patient and their family and carers
• Phases may not be sequential and a patient may move back and forth between phases
Palliative Care Problem Severity Score (PCPSS)

• The PCPSS is a clinician rated score of palliative care problems that provides a summary measure of problems in four domains: pain, other symptoms, psychological/spiritual and family/carer.

• The four scores of PCPSS are
  – Absent – 0
  – Mild – 1
  – Moderate – 2
  – Severe – 3
Functional Assessment in Palliative Care (RUG-ADL & AKPS)

• The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) is a 4-item scale measuring motor function with activities of daily living: bed mobility, toileting, transfer and eating

• The assessment is based on what the person does, not what they are capable of doing

• It informs us about the patient’s functional status, the assistance they require to carry out these activities and the resources needed for the patient’s care
The Australia-modified Karnofsky Performance Status (AKPS) Scale

- A measure of the patient’s performance across the dimensions of activity, work and self-care at phase start
- It is a single score between 10 and 100 assigned by a clinician based on observations of a patient’s ability to perform common tasks relating to activity, work and self-care
<table>
<thead>
<tr>
<th>AKPS ASSESSMENT CRITERIA</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal; no complaints; no evidence of disease</td>
<td>100</td>
</tr>
<tr>
<td>Able to carry on normal activity; minor sign of symptoms of disease</td>
<td>90</td>
</tr>
<tr>
<td>Normal activity with effort; some signs or symptoms of disease</td>
<td>80</td>
</tr>
<tr>
<td>Cares for self; unable to carry on normal activity or to do active work</td>
<td>70</td>
</tr>
<tr>
<td>Able to care for most needs; but requires occasional assistance</td>
<td>60</td>
</tr>
<tr>
<td>Considerable assistance and frequent medical care required</td>
<td>50</td>
</tr>
<tr>
<td>In bed more than 50% of the time</td>
<td>40</td>
</tr>
<tr>
<td>Almost completely bedfast</td>
<td>30</td>
</tr>
<tr>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
<td>20</td>
</tr>
<tr>
<td>Comatose or barely rousable</td>
<td>10</td>
</tr>
<tr>
<td>Dead</td>
<td>0</td>
</tr>
</tbody>
</table>
The Concord Centre for Palliative Care

Patient outcome dashboard
July to December 2017, Inpatient setting

Patient outcomes

Date ready for care to episode start
Day of/day after 100.0%

Time in unstable phase
Three days or less 98.2%

Symptoms & problems
Start absent/mild, end absent/mild
Pain PCPSS 91.6%
Pain SAG 87.9%
Fatigue 94.9%
Breathing problems 95.1%
Family/carer 96.4%
Start mod/severe, end absent/mild
Pain PCPSS 78.7%
Pain SAG 63.3%
Fatigue 70.2%
Breathing problems 65.1%
Family/carer 47.2%

Casemix adjusted outcomes
Pain PCPSS 0.20
Other symptoms 0.36
Family/carer 0.21
Psychological/spiritual 0.44
Pain SAG 0.30
Nausea 0.26
Breathing problems 0.30
Bowel problems 0.51

Diagnosis
malignant non-malignant
0 20 40 60 80 100 %

Age at episode start
Mean: 74.4
Median: 76.0

Symptoms & problems proportion of moderate/severe scores
Family/carer
Psychological/spiritual
Other symptoms
Clinician rated Pain
Patient rated Pain
Fatigue
Breathing problems
Bowel problems
Nausea
Appetite problems
Difficulty sleeping

Episode end
Death
Discharge

Phase
% and mean length in days
Stable
Unstable
Deteriorating
Terminal

Phases per episode
3.3

Volume of data
Patients: 237
Episodes: 275
Phases: 909

Episode length in days
Mean: 10.9
Median: 8.0

Concord Centre for Palliative Care

Evidence to improve patient outcomes
www.pcoc.org.au
Benchmarking with other centres. Looking at State and National data.
So what do we do with the data?

• Time in the unstable phase
• Time in the unstable phase is calculated as the difference between the phase start date and the phase end date.

• Benchmark 2: 90% of patients are in the unstable phase for 3 days or less.
Pain (PCPSS & SAS)

• Change in pain is calculated by the difference in pain score from the beginning of a phase to the end of phase and is calculated using the pain measures in the Palliative Care Problem Severity Score (PCPSS) and Symptom Assessment Scale (SAS).
Pain (PCPSS & SAS)

• Benchmark 3.1: At least 90% of patients with absent or mild PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.

• Benchmark 3.2: At least 60% of patients with moderate or severe PCPSS pain at the beginning of their phase of palliative care have absent or mild PCPSS pain at the end of the phase.

• Benchmark 3.3: At least 90% of patients with absent or mild SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.

• Benchmark 3.4: At least 60% of patients with moderate or severe SAS pain at the beginning of their phase of palliative care have absent or mild SAS pain at the end of the phase.
Family/carer problems (PCPSS)

• Benchmark 3.9: At least 90% of patients with absent or mild family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.

• Benchmark 3.10: At least 60% of patients with moderate or severe family / carer problems at the beginning of their phase of palliative care have absent or mild family / carer problems at the end of the phase.
How does evidence medicine help in palliative care?

• Basis of ethical practice
  – Benefits versus risks/harms

• Quality of life indicators
  – Not just about survival
  – Quality: benefits versus harm

• Justice and resource implications

• To standardise practice

• To improve care as new and emerging information comes to light
The Success?

- The Success has been the integration of the science of medicine and the art of caring

- "We, physicians, have to understand that our humanity is the crux of our art."

  *Dr. Sherwin B. Nuland, professor and surgeon at Yale University*
How do we measure the science and the art of caring?
What you need: is this the case in Thailand?

- Resources
- Tools
- Government buy in and funding
- Ownership by all organisations and staff
- Data collection in a uniform way
- Work towards National Standards
- Process must be a cycle
- Benchmark capability
Culture of Change
How do we improve our teams?

• Reflective practice
• Cultural change in how we see change and improvement
• Review of cases as a team (MDT)
• Interaction with interdisciplinary teams
  – Not just isolated in palliative care
  – Run the risk of narrow minded views
  – Not understanding new treatments that our patients and families hear about
What should we do?

• Audit and benchmarking are important in identifying
  – standards of outcome measurement practice
  – areas of good measurement practice
  – and areas to improve

• Every service that you have should have a process of quality/audit processes and

• You should be now starting to benchmark against other services
Training and Specialist recognition

• Strong measure of success or failure:
• Should be the quality of clinicians working in the discipline
• Medical / nursing
• The curriculum
  – Benchmarked against the world
  – Core competencies of training (mini CEX/ case reports/ case discussions/ supervisors reports as compulsory tools)
• The pathway of training
  – Should not be altered and minimum requirements should be met
• The numbers trained to meet the needs of the country/community
Success is about ensuring Ethical Conduct

- Understand ethical principles
  - Autonomy
  - Beneficence
  - Non-maleficence
  - Justice
- Futility (withholding and withdrawing Rx)
- Medical Restraint: pause before acting
- Understanding medical terminology
  - Euthanasia
  - Sedation at the end of life
  - Not for resuscitation
Conclusion

• We need to uphold our ideals and goals
• Medical ethics need to guide our practice
• Evidence based medicine needs to underpin our practice which we need to assess/discriminate and use wisely
• We need to demonstrate ‘Success’, not just claim what we do is successful
• We need standards in clinical practice
• We need to measure outcomes (patient related and service related)
• We need to benchmark between services
• We need to continually monitor this