Improving palliative care through point-of-care data collection, structured feedback and benchmarking

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Measuring quality 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?
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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’

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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’

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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
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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

Homsj J et al. Support Care Cancer 2006
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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
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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.
Nausea was least prevalent (25%).
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.

Cultural issues

• Palliative care has traditionally focused on measuring processes
• Has often been really happy with a draw full of thank you letters
• Always feel there are too few resources so care cannot improve

• All services sincerely believe that they are doing a great job (but some are doing a greater job than others)
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Measuring and understanding patient outcomes at a systems level

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 electronic health record-based data collection procedures to answer key questions relevant to clinical care and policy.

Measuring quality in palliative care

Measuring and understanding patient outcomes at a systems level

QDACT

37 questions within five domains:
- Demographics;
- Symptom management;
- Advanced care planning;
- Prognosis; and
- Transition / discharge

Measuring quality in palliative care

Measuring and understanding patient outcomes at a systems level
Quality improvement in cancer symptom assessment and control: the Provincial Palliative Care Integration Project (PPCIP).

OBJECTIVES:
The project involved:
1) implementation of the Edmonton Symptom Assessment System (ESAS) for symptom screening;
2) use of "rapid-cycle change" quality improvement processes to improve screening and symptom management; and
3) improvements in integration and access to palliative care services.

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

  *in order to*

• Analyse the data and provide timely feedback on the results to individual services - reports every 6 months

  *in order to*

• Facilitate benchmarking with other services

  *in order to*

• Improve systematically the outcomes delivered by specialised palliative care services
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
DO I HAVE PERMISSION TO FAKE THE TEST DATA?

I DIDN'T EVEN KNOW DATA CAN BE REAL.
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)
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

The situation of Mount Lofty was found from hence and from some other cross bearings, to be 34¡ 59' south and 138¡ 42' east. No land was visible so far to the north as where the trees appeared above the horizon, which showed the coast to be very low, and our soundings were fast decreasing.

From noon to six o'clock we ran thirty miles to the northward, skirting a sandy shore at the distance of five, and thence to eight miles; the depth was then 5 fathoms, and we dropped the anchor upon a bottom of sand, mixed with pieces of dead coral.
Point-of-care data collection

Assessments

Setting of care (Episode)

Demographics
# Five assessment tools

<table>
<thead>
<tr>
<th>Tool</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Phase (Phase)</td>
<td>Eagar et al, 2004</td>
</tr>
<tr>
<td>Australia-Modified Karnofsky Performance Status (AKPS)</td>
<td>Abernethy et al, 2005</td>
</tr>
<tr>
<td>Palliative Care Problem Severity Score (PCPSS)</td>
<td>Eagar et al, 2004</td>
</tr>
<tr>
<td>Symptom Assessment Scale (SAS)</td>
<td>Aoun et al, 2004</td>
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</tbody>
</table>
Seven symptoms / problems

SAS - Patient rated
- Pain
- Nausea
- Bowel problems
- Breathing problems

PCPSS - Clinician rated
- Pain
- Psychological/Spiritual
- Family/carer
- Other symptoms

In both
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

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
PCOC framework for improvement

Continues to support the embedding of routine clinical assessments and point-of-care data collection to drive improvement through:

• providing a feedback loop to individual services

• identifying individual improvement opportunity

• service to service benchmarking.
Research question

Can patient outcomes be improved if outcomes are routinely measured at point-of-care?
Initial method

• Analysis of 30 services participating in the PCOC cycle consistently between January 2009 and December 2011

• Assessing patient outcomes using both SAS and PCPSS
Initial results: 2009 - 2011

- 19,747 patients and 65,463 phases
- 46% female
- 85% malignant diagnosis
- Average age 70.9 years
- Statistically significant improvements in all domains with the exception of pain
% patient outcomes better than baseline (casemix adjusted)

- Individual service results
- Modelled average

Six-month reporting period:
- Jan - Jun 2009
- Jul - Dec 2009
- Jan - Jun 2010
- Jul - Dec 2010
- Jan - Jun 2011
- Jul - Dec 2011

Nausea
% patient outcomes better than baseline (casemix adjusted)

Nausea

Six-month reporting period

% patient outcomes better than baseline (casemix adjusted)

Breathing

Six-month reporting period


Individual service results

Modelled average
% patient outcomes better than baseline (casemix adjusted)

Breathing

Six-month reporting period

Jan - Jun 2009
Jul - Dec 2009
Jan - Jun 2010
Jul - Dec 2010
Jan - Jun 2011
Jul - Dec 2011
% patient outcomes better than baseline (casemix adjusted)
% patient outcomes better than baseline (casemix adjusted)

Pain (PCPSS)

% patient outcomes better than baseline (casemix adjusted)

- **Family/carer**

- **Six-month reporting period**
  - Jan - Jun 2009
  - Jul - Dec 2009
  - Jan - Jun 2010
  - Jul - Dec 2010
  - Jan - Jun 2011
  - Jul - Dec 2011

- **Individual service results**
- **Modelled average**
% patient outcomes better than baseline (case mix adjusted)

Other symptoms

Six-month reporting period


Individual service results
Modelled average

PCOC
Palliative care outcomes collaboration
% patient outcomes better than baseline (casemix adjusted)

Other symptoms

Six-month reporting period

PCOC
palliative care outcomes collaboration
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)

- Individual service results
- Modelled average

Six-month reporting period

Pain (SAS)
% patient outcomes better than baseline (case mix adjusted)

Graph: % patient outcomes better than baseline (case mix adjusted)
- **Nausea**
- **Six-month reporting period**
- **Individual service results**
- **Modelled average**

PCOC
palliative care outcomes collaboration
% patient outcomes better than baseline (casemix adjusted)

Nausea

Six-month reporting period

% patient outcomes better than baseline (casemix adjusted)

Breathing

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
% patient outcomes better than baseline (casemix adjusted)

Breathing

Six-month reporting period

Individual service results

Modelled average
% 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

Bowels
% patient outcomes better than baseline (casemix adjusted)

Bowels

Six-month reporting period
% patient outcomes better than baseline (casemix adjusted)

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
% patient outcomes better than baseline (casemix adjusted)

- Individual service results
- Modelled average

Family/carer

Six-month reporting period

% patient outcomes better than baseline (casemix adjusted)

Family/carer

Individual service results

Modelled average

Six-month reporting period
% patient outcomes better than baseline (casemix adjusted)

Family/carer

Six-month reporting period

% patient outcomes better than baseline (casemix adjusted)

Psychological/spiritual

Six-month reporting period

Individual service results
Modelled average

% patient outcomes better than baseline (casemix adjusted)

Other symptoms

Six-month reporting period


Individual service results

Modelled average

PCOC (palliative care outcomes collaboration)
% patient outcomes better than baseline (casemix adjusted)
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
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 quality in palliative care

- Evidence that highly relevant data collection can be feasibly built into routine care
  
  *in order to*

- Compare and contrast current patient-centred outcomes
  
  *in order to*

- To learn from each other in service provision and resourcing
  
  *in order to*

- Continue to drive the best possible outcomes for patients and their caregivers
Acknowledgements

Services that participate in PCOC and the 45 services included in this study

PCOC is a national palliative care project funded by the Australian Government Department of Health