2008

Palliative Care Outcomes Collaboration - establishing measures of palliative care patient outcomes

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Publication Details
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Abstract
PCOC is: - A national initiative - Funded by the Department of Health and Ageing to introduce routine assessment of palliative care outcomes across Australia.

Keywords
measures, patient, collaboration, care, establishing, outcomes, palliative

Publication Details

This conference paper is available at Research Online: http://ro.uow.edu.au/ahsri/340
PCOC – establishing measures of palliative care patient outcomes

Department of Health & Ageing Casemix Conference

Prue Watters and Maree Banfield
November 2008

PCOC is:

- A national initiative
- Funded by the Department of Health and Ageing to introduce routine assessment of palliative care outcomes across Australia.
PCOC aims to:

- Support continuous improvement and development of palliative care practice
- Introduce a benchmarking service that will improve practice
- Demonstrate outcomes (service and patient/caregiver)
- Standardise palliative care assessments
- Develop a “common language”

PCOC:

- Works with services to collect agreed data set
- Assists with incorporating data collection into routine practice
- Provides ongoing support through training and assistance with IT
- Analyses the data and provides feedback on the results to individual services
- Assists services with practice changes
PCOC assists services to:

- facilitate the collection of information and the reporting of outcomes.
- meet the Standards for providing Quality Palliative Care for all Australians
- comply with ACHS accreditation standards as a by-product of participation

PCOC is a collaboration

- Centre for Health Service Development, UOW (PCOC Central)
  - Professor Kathy Eagar
- Institute of Health & Biomedical Innovation Queensland University of Technology (PCOC North)
  - Professor Patsy Yates
- Western Australian Centre for Cancer and Palliative Care, Curtin University of Technology and Edith Cowan University (PCOC West)
  - Professor Samar Acun
- Department of Palliative and Supportive Services, Flinders University (PCOC South)
  - Professor David Currow
PCOC Governance

Management Advisory Board – strategic and executive management

Scientific & Clinical Advisory Committee (SCAC) – advises Board on development priorities, data and reporting policy, education and training issues and research and benchmarking priorities

Overview of Progress (1)

- 70 specialist palliative care (of about 147 in Australia) have agreed to join PCOC so far, with 51 submitting data for the fourth PCOC Report
- Majority are large metropolitan services
- Estimate is that these 70 services represent more than 70% of specialist palliative care episodes
- All other specialist PC services across Australia are at various stages of follow up, with most expected to join
Overview of Progress (2)

- Version 2 of the PCOC data set released and software adapted
- Patient and carer surveys conducted for interested palliative care services between October 2007 and June 2008
- 56 training sessions conducted for over 430 staff to June 2008
- Benchmarking workshops conducted in August 2007 and July 2008

PCOC Reports

- Four to date covering period April 2006 to March 2008

<table>
<thead>
<tr>
<th>Measure</th>
<th>1st report (Apr06-Sep06)</th>
<th>2nd report (Oct06-Mar07)</th>
<th>3rd report (Apr07-Sep07)</th>
<th>4th report (Oct07-Mar08)</th>
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<tbody>
<tr>
<td>Number of services</td>
<td>8</td>
<td>28</td>
<td>31</td>
<td>51</td>
</tr>
<tr>
<td>Number of patients</td>
<td>2230</td>
<td>4310</td>
<td>4207</td>
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<td>Number of episodes</td>
<td>3093</td>
<td>5367</td>
<td>5066</td>
<td>7330</td>
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<tr>
<td>Number of phases</td>
<td>2565</td>
<td>7149</td>
<td>11499</td>
<td>16570</td>
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</table>
Data ownership and access

- Data collected by services are owned by them
  - services need to give written approval for PCOC to release their data to anyone else
- PCOC is the owner of aggregate data and a data custodian of individual site data
- Nationally aggregated data are reported in the PCOC reports
- Will be possible in time to provide de-identified reports at state level
  - problem with doing this for small states and territories as individual services will be potentially identifiable

PCOC Data

- 1. Routine Data Collection
- 2. Snapshot Quality Activities
- 3. Developmental/Experimental
Development of PCOC Data Set

Decision processes for selecting data items

Australian National Sub-Acute and Non-Acute Patient casemix classification

(AN-SNAP)
Version 1 AN-SNAP

- Developed in 1996
- An information tool and funding tool
- Inpatient palliative care
  - 11 classes
- Ambulatory palliative care
  - 32 classes
- Based on a study of 30,057 episodes (4,530 palliative care) episodes in 104 services in Australia and New Zealand

The overnight classes

- All overnight PC
  - Stable
    - 3 classes split by RUG-ADL
  - Unstable
    - 2 classes split by RUG-ADL
  - Deteriorating
    - 3 classes split by RUG-ADL and age
  - Terminal
    - 2 classes split by RUG-ADL
  - Dercaved
    - 1 class
The Ambulatory classes

<table>
<thead>
<tr>
<th>Ambulatory classes</th>
<th>Version 1</th>
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</thead>
<tbody>
<tr>
<td>151 Medical only</td>
<td></td>
</tr>
<tr>
<td>152 Therapies only</td>
<td></td>
</tr>
<tr>
<td>153 Stable, Multidisciplinary</td>
<td></td>
</tr>
<tr>
<td>154 Stable, Nursing only, severity &lt;10, RUG 4, age 65+</td>
<td></td>
</tr>
<tr>
<td>155 Stable, Nursing only, severity &lt;10, RUG 4, age &lt;=65</td>
<td></td>
</tr>
<tr>
<td>156 Stable, Nursing only, severity &lt;10, RUG 5-18</td>
<td></td>
</tr>
<tr>
<td>157 Stable, Nursing only, severity 11+</td>
<td></td>
</tr>
<tr>
<td>158 Unstable, Multidisciplinary, RUG 4, severity &lt;=11</td>
<td></td>
</tr>
<tr>
<td>159 Unstable, Multidisciplinary, RUG 4, severity 12+</td>
<td></td>
</tr>
<tr>
<td>160 Unstable, Multidisciplinary, RUG 5-18</td>
<td></td>
</tr>
<tr>
<td>161 Unstable, Nursing only, RUG &lt;=14, age 60+</td>
<td></td>
</tr>
<tr>
<td>162 Unstable, Nursing only, RUG &lt;=14, age &lt;=59</td>
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</tr>
<tr>
<td>163 Unstable, Nursing only, RUG 15+</td>
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<tr>
<td>164 Deteriorating, Multidisciplinary, severity &lt;10</td>
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<tr>
<td>165 Deteriorating, Multidisciplinary, severity 11+, RUG &lt;=10</td>
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<tr>
<td>166 Deteriorating, Multidisciplinary, severity 11+, RUG 11+</td>
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<tr>
<td>167 Deteriorating, Nursing only, RUG 4</td>
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<td>168 Deteriorating, Nursing only, RUG 5-18</td>
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<tr>
<td>169 Terminal, Multidisciplinary</td>
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<tr>
<td>170 Terminal, Nursing only</td>
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</tr>
<tr>
<td>171 Bereavement, age &gt;45</td>
<td></td>
</tr>
<tr>
<td>172 Bereavement, age &lt;44</td>
<td></td>
</tr>
</tbody>
</table>
Control for casemix?

- AN-SNAP is a casemix classification
  - a method of grouping episodes of care based on consumer attributes that best explain the cost of care (and predict the outcomes of that care)
  - iso-resource - consumers in the same class receive similar amounts of treatment and care

Controlling for differences between patients

- Assign episodes to a 'casemix class’.
  - Similar consumers in the same class
  - Different consumers in different classes

- When outcomes results are standardised to take account of the mix of consumers, any remaining differences can be attributed to differences between providers.
  - Similar to standardising for age and sex in calculating standardised mortality rates
The program logic for PCOC data

Information being collected at 3 levels-
1. Patient (Person) – Demographic
2. Episode (Location) – How
3. Phase (Clinical) - Assessments
Summary of measures in the PCOC routine data collection

Also snapshot patient and carer surveys
Data being collected by PCOC

- **Level 1 Patient/Demographic items**
  - eg, age, sex, postcode

- **Level 2 Episode**
  - 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

- **Level 3 Phase**
  - eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start and end, symptoms at start and end, model of care, number of days seen

Casemix adjusters (AN-SNAP classes)

- **Phase**
- **Function (RUG-ADL)**
- **Age**
- **Problem severity (ambulatory only)**
- **Provider type (ambulatory only)**
Quality and outcome measures - Version 2 data set (1)

- Phase movements
- Change in function
  - RUG-ADL and Karnofsky
- Change in problem severity
  - PC problem severity scale and SAS
- Mode of start/end
- ALOS (days seen) x phase
- Place of death x Level of support

Quality and outcome measures - Version 2 data set (2)

- Access measures
  - Postcode
  - ATSI
    - Language / country of birth
- Time between referral and assessment
- Diagnostic group
- Model of care planned / provided
- (Consultative services)
What is benchmarking?

- 'Finding and implementing best practice' (Bulivant (1994)).
- 'The ongoing, systematic process to search for and introduce international best practice into an organisation'.
  - Australian Manufacturing Council (1994).
- So:
  - benchmarking is the process of establishing 'best practice' and
  - a benchmark is a standard of performance derived from that process.

The benchmarking cycle

- Comparison of performance between services
- Investigation to identify practices and processes that result in superior performance
- Implementation of best practices and
- Evaluation in order to make improvements.
The benchmarking cycle

- **Outcome studies**
- **Routine outcome measures**
- **Routine outcome systems** (training, data collection protocols & processes)
- **Culture Change**
- **Evaluate & refine** (measures & systems)
- **Benchmark** (use the data to identify best practices and then implement them)
- **Feedback**
- **Performance measurement**

**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)?
Benchmarking and specialist palliative care in Australia

- Prior to the introduction of PCOC no systematic collection of palliative care outcomes data nationally
- No benchmark measures
- No baseline

Benchmark measures under consideration

- Time between referral and 1st contact
- Change in pain scores from beginning to end of phase
- Time in the unstable phase
- First phase after the unstable phase
Questions about proposed benchmarks

- Why are there differences between services?
- What is best practice (ie, the benchmark)?
- Should the benchmark be the same for different types of services?
  - Inpatient, community, consultative?
  - Rural, urban?
  - Large and small services, public and private?
- If not, what peer-groups and what benchmarks?
- What implications for practice and/or data collection?

Benchmark Measure 1 - Time between referral and first contact

- Data set captures:
  - Referral date
  - Date of first assessment
    - First assessment (telephone or face to face) by palliative care service following receipt of referral
  - Episode start date
- Data are either 1st assessment or episode start date, whatever came 1st
Time from referral to first contact - community services

Reasons for variations

- Service type
- Source of referral
- Urgency of referral
- Date used as referral date
- Lack of clarity in definitions of referral and first contact
Next steps

- Retain time between referral and first contact as a developmental item.
- Analyse measure controlling for phase and function (RUG-ADL or Karnofsky).
- Analysis may only be possible yearly because of small sample size.

Benchmark Measure 2 - Change in pain from beginning to end of a phase

- Pain management core business for palliative care services.
- Significant variability in PCOC data irrespective of pain tool used.
- Pain alone is not a good indicator; need to control for phase and function.
- What is a clinically significant change in pain score?
Change in pain from beginning to end of a phase

![Pain change as measured by SAS](image)

Change in pain from beginning to end of a phase

![Pain change as measured by PCPSS](image)
Reasons for variations

- Service type
- Length of phase
- Change in pain may be different depending on phase of patient
- Changes in pain score may differ if pain was not an issue compared to being reason for admission
- Lack of control for phase and function

Next steps

- Retain change in pain from the beginning to the end of a phase as a benchmark measure
- Include four adjustments:
  - Change in phase taking into account the pain score at the start and end of the phase
  - Proportion of patients with high levels of pain
  - Length of phase
  - Setting of care
Benchmark Measure 3 - Time in the unstable phase

- Time in the unstable phase considered to be an important measure of quality
- Following table summarises results from services with more than 10 unstable phases

Time in the unstable phase
Reasons for variations

- Service type
- Different interpretations of the unstable phase:

**Definition of the unstable phase**
The person experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which require an **urgent change in management** or emergency treatment or the family/carers experience a sudden change in their situation requiring **urgent intervention** by members of the multidisciplinary team. In both cases, the problems were unexpected.

Next steps

- Retain time in the unstable phase as a benchmark measure
- Re-validate phase definitions
- Include three adjustments:
  - Setting of care
  - Time in the unstable phase for patients whose first phase is unstable
  - Time in the unstable phase for all other patients
Benchmark Measure 4 - First phase after the unstable phase

- Indicator captures phase a patient classified to immediately after the unstable phase – stable, deteriorating, terminal or bereaved
- Perception that getting a percentage of patients back to stable is an indicator of quality

First phase after the unstable phase

![Bar chart](chart.png)
First phase after Unstable

- What phase are patients classified to after the Unstable Phase?
  - Stable
  - Deteriorating
  - Terminal
  - Bereaved

Reasons for variations

- Service type
- Length of phase
- Diagnosis
- Lack of control for phase and function
Unstable phase

- The person experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which require an **urgent change in management or emergency treatment**.
- The family/carers experience a sudden change in their situation requiring **urgent intervention** by members of the multidisciplinary team.
- In both cases, the problems were unexpected.

Next steps

- Retain first phase after the unstable phase as a developmental item.
- Include four adjustments:
  - Prior phase
  - Functional status using RUG-ADL or Karnofsky
  - Duration of unstable phase
  - Setting of care
Conclusion

- In 3 years, PCOC has over 70 specialist palliative care services collecting and submitting data
- Benchmark measures under consideration will be casemix adjusted
- Outcomes of palliative care service delivery can be measured and reported