Outcomes measurement in palliative care (Invited keynote paper)

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Outcomes measurement in palliative care (Invited keynote paper)

Abstract
The ultimate measure of the quality of health care is the outcomes that patients and carers achieve.

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Outcomes Measurement in Palliative Care

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The ultimate measure of the quality of health care is the outcomes that patients and carers achieve.
The Palliative Care Outcomes Collaboration (PCOC)

A national initiative funded by the Department of Health & Ageing to introduce routine assessment of palliative care quality and outcomes across Australia.

PCOC:
- Supports continuous quality improvement of palliative care
- Benchmarks service to improve practice
- Measures outcomes (service and patient/carer)
- Standardises palliative care assessment
- Develops a “common language” for clinicians including primary care
How PCOC works

- Work with services to incorporate the PCOC patient outcome measures into routine practice
- Provide ongoing support through training and assistance with IT
- Analyse the data and provide feedback on the results to individual services - reports every 6 months
- Facilitate benchmarking with other services
- Assist services with practice quality changes
Overview of Progress (1)

- 111 palliative care services (of about 160 in Australia) have agreed to join PCOC so far, with 85 submitting data for last PCOC Report.
- Majority are large metropolitan services.
- Estimate is that these services represent more than 80% 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)

- Seven national reports
  - Report #7 covers 1 Jan to 31 Jul 2009
- Annual national patient and carer surveys
- Over 2,500 clinicians trained
- Three national benchmarking workshops in 2009
- Early stage planning for V3 dataset of the patient outcomes data set has started
PCOC benchmarking
The PCOC benchmarking cycle

Outcome studies

Routine outcome measures

Routine outcome systems (training, data collection protocols & processes)

Evaluate & refine (measures & systems)

Benchmark (use the data to identify best practices and then implement them)

Feedback

Performance measurement

Culture Change
PCOC information architecture

- **Level 1 Patient**
  - eg, age, sex, diagnosis, postcode

- **Level 2 Episode of palliative care**
  - eg, referral source, time between referral & 1st assessment, episode type, accommodation at start & end, level of support at start & end, place of death

- **Level 3 Phase**
  - eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start & end, symptoms at start & end, reason for phase end
3 initial benchmark measures

- Time between referral and 1st contact
- Change in pain from beginning to end of phase
- Time in unstable phase
- Next step is to introduce 3-4 additional measures. Under consideration are:
  - psychological/spiritual problems - PCPSS (Palliative Care Problem Severity Score)
  - carer problems - PCPSS
  - nausea – SAS (symptom assessment score)
  - fatigue - SAS
  - dyspnoea - SAS
A constant theme - unexplained variation

No matter what the measure, we find significant variations between services that we are working to understand and reduce

Some examples…
## Variability among inpatient units

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mean</th>
<th>Min</th>
<th>Max</th>
<th>SD</th>
<th>Difference (Xfold)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average length of stay</td>
<td>14.0</td>
<td>6.2</td>
<td>18.6</td>
<td>3.3</td>
<td>3</td>
</tr>
<tr>
<td>Discharge to community</td>
<td>25.1%</td>
<td>12.1%</td>
<td>64.2%</td>
<td>15.4</td>
<td>5</td>
</tr>
<tr>
<td>Stable after unstable</td>
<td>25.9%</td>
<td>4.2%</td>
<td>51.5%</td>
<td>16.2</td>
<td>12</td>
</tr>
<tr>
<td>Function better</td>
<td>9.8%</td>
<td>3.6%</td>
<td>15.7%</td>
<td>3.6</td>
<td>4</td>
</tr>
<tr>
<td>Symptoms improve</td>
<td>22.4%</td>
<td>5.8%</td>
<td>40.6%</td>
<td>11.2</td>
<td>7</td>
</tr>
</tbody>
</table>

The picture is no different for community and consultative services.
Pain at phase end for patients with moderate or severe pain at start (SAS)
Pain at phase end for patients with no or mild pain at start (SAS)
Patients self-reported pain in last 3 days (POS-2)
Patients self-reported other symptoms in last 3 days (POS-2)
Patients self-reported depression in last 3 days (POS-2)
Carers - Have you had someone to help you with practical tasks?

Yes, I've had all the help I need  Yes, but not enough  No
Carers - Information on Carer Payment or Allowance?

- Yes, all information given
- Mentioned, no detail
- No
An increasingly sophisticated evidence-based sector

- Early days - ‘We don’t need to measure outcomes, our patients and carers are really satisfied with the care we provide’
- Then - ‘The data must be wrong’
- Now - ‘We now have information we’ve never had before. What does this mean for the way we provide care? How can we improve the way we organise our service?’
Conclusion

**PCOC goal** is to work with services to optimise the quality of care and to minimise variations in practice that compromise patient and carer outcomes.

The demonstrated variability justifies investment in routine data collection and benchmarking between services.

Significant progress so far but a long way to go!