The Value of Data Collection to Palliative Care Program Sustainability and Growth

Kamal, Ritchie, Currow, Bull, Abernethy

Objectives

Objective 1
Understand how data are a pathway to meet the increasing demand for demonstration of value and quality of care.

Objective 2
Review types of data that can be collected, review resources for data collection, demonstrate how data collection procedures can be developed, and review near-term expectations for reporting quality data.

Objective 3
Understand the necessary steps - from idea to implementation - for building a data collection systems for program sustainability and growth.

Collecting Data – A Primer

Story: “In God we Trust. All others must have data.”

Fact: More data is produced annually than all of written history in the preceding years combined

Visual:

Bottom Line: Palliative medicine is science; science depends upon data; data tells the story of who we are, what we do, and how we do it

Collecting Data – The Overarching Imperative

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other symptoms;
- affirms life and regard for patients, families, caregivers, and others;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help families and caregivers face the problems of illness and in their own terms;
- uses a team approach to the care of the patient and their families, including bereavement counseling;
- will enhance quality of life, and may also influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Collecting Data – Why?

- Conduct routine clinical activities (e.g. EHR, billing)
- Demonstrate quality
- Perform research-improve the evidence base
- Exhibit program-specific needs, wants, desires
- Meet payer demands

Disclosures

• Kamal – none
• Ritchie – none
• Currow – none
• Abernethy - Helsinn, Proventys, and GlaxoSmithKline
• Bull – Meda, Pfizer, Archimedes, Wyeth, Salix
Collecting Data – Why?

- Satisfy accreditation standards
- Study workforce shortages
- Address gaps in care across care settings
- Demonstrate clinical value to patients, caregivers, advocates
- Show clinical, financial, and resource utilization value to administrators and hospitals

**Bottom Line:** There is an imperative to collect data routinely

Collecting Data – How?

<table>
<thead>
<tr>
<th>Characteristics of Good Data</th>
<th>Characteristics of Bad Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardized</td>
<td>User-determined</td>
</tr>
<tr>
<td>Efficiently-collected</td>
<td>Burdensome</td>
</tr>
<tr>
<td>Interoperable</td>
<td>Locally-defined</td>
</tr>
<tr>
<td>Communicable</td>
<td>Silied</td>
</tr>
<tr>
<td>Valid</td>
<td>Missing</td>
</tr>
<tr>
<td>Reliable</td>
<td>User-defined</td>
</tr>
<tr>
<td>Usable</td>
<td>For the heck of it</td>
</tr>
</tbody>
</table>

**Bottom Line:** Data collection requires planning

Palliative Care Database Project

- To understand who are palliative care patients and their burden of disease
- To understand impact of palliative care – symptom data, ACP, PQRI factors, hospice referrals
- To improve quality of care to patients with advanced illness by establishing benchmarks and quality initiatives, made possible by a data system that monitors outcomes

Palliative Care Database Project

- To increase access to services through a coordinated statewide approach, made possible by a data system that creates better understanding of patients’ needs and gaps in services
- To align local quality monitoring and reporting with the national Big Picture (legislation, requirements)
R1  Not sure I understand this title
Ritchie, 1/10/2012

R2  Would be good to avoid acronyms
Ritchie, 1/10/2012
Benefits of Community - Academic Collaboration

- Central data repository
- Central data management expertise, statistical analysis, and technical support
- Aggregate data to allow for benchmarking
- Assurance of data interoperability
- Programmers to help develop queries to drill down on data
- Routine data quality assurance practices
- Ability to compare outcomes across populations and settings within the database
- Research expertise
- Publication of results

Approach

- Point of care
- Modular dataset with core
- Site-based collection
- Central analyses

R3 Approach

- Point of care
- Modular dataset with core
- Site-based collection
- Central analyses

Reports

Lessons Learned – Community Perspective

- Organizational buy in
- Clinician buy in
  - User friendly system (Ipad, epens)
  - Real time access
  - Feasible, reliable
  - Allow for increased visit time
  - See impact of data reporting
- Flexible – work with EMR

Lessons Learned

- User friendly reporting system
- Meaningful data analysis
- Feedback loop to front line providers
- Quality assurance initiatives based on data
This looks like benefits of academic collaboration but what about community collaboration? Benefits there would be "real world" "generalizability" "more representative populations"

Ritchie, 1/10/2012

This is a little hard to read--esp if room is long and narrow. How about just including one symptom show instead of two?

Ritchie, 1/10/2012
2012 AAHPM & HPNA Annual Assembly

Consortium
- 4 Organizations
- Over 22,000 visits entered
- Benchmarking
- Usability and feasibility testing across sites
- QDACT v2 iteration

Benefits to Data Collection
- Continued hospital funding
- Funding for programs that decrease hospital readmissions of COPD and CHF patients
  - Increase in DNR
  - Increase referral to hospice programs
  - Improvement in pain/symptom management
- Use of data for continued grant funding
- Contribution to palliative care clinical science and publications

Data Reporting

Quality
- Increased knowledge of impact of palliative care in ACP, symptom management, and hospice referrals
- Increased knowledge of symptom burden per disease care setting, and demographics
- Increased revenue from 2011 PQRI reporting
- Improved understanding of impact of functional status and specific symptoms on QOL
- Differences seen among care settings – opportunities for improvement

Palliative Care Outcomes Collaboration (PCOC)
David Currow
Flinders University, Adelaide

Funded by the Department of Health & Ageing

The aim of PCOC
- Work with services to incorporate the PCOC data collection into routine practice
  in order to
- Analyse the data and provide feedback on the results to individual services - reports every 6 months
  in order to
- Facilitate benchmarking with other services
  in order to
- Systematically improve the quality of care offered by specialised palliative care services

PROGRESS TO DATE
- 123 of estimated 160 services agreed to join PCOC representing approximately 80% of palliative care episodes
  - Incorporates
    - Direct inpatient care
    - Community care
    - Consultative care only
Not sure why "quality" is the heading here since the content seems to encompass more
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)

Routine, voluntary point-of-care
PCOC data collection

- Patient/Demographic items – once only
  – e.g. age, sex, postcode
- Episode – recorded with change of place of care
  – e.g. 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
  – e.g. Phase (stable, unstable, deteriorating, terminal, bereaved), function
    at start and end, symptoms at start and end, model of care, number of
    days seen

Wide variation in outcomes nationally

<table>
<thead>
<tr>
<th>Measure</th>
<th>Heal</th>
<th>Mid</th>
<th>Low</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average length of stay</td>
<td>14.4</td>
<td>8.2</td>
<td>13.8</td>
<td>3.3</td>
</tr>
<tr>
<td>Discharge to community</td>
<td>27.1%</td>
<td>12.1%</td>
<td>54.2%</td>
<td>15.4%</td>
</tr>
<tr>
<td>Stable after unstable</td>
<td>20.9%</td>
<td>4.2%</td>
<td>41.6%</td>
<td>18.7%</td>
</tr>
<tr>
<td>Function better</td>
<td>3.8%</td>
<td>3.6%</td>
<td>10.7%</td>
<td>3.6%</td>
</tr>
<tr>
<td>Symptoms improve</td>
<td>23.4%</td>
<td>3.8%</td>
<td>40.6%</td>
<td>12.2%</td>
</tr>
</tbody>
</table>

Routine PCOC data

Symptom Measurement tools (both ideally self-report
although often done by proxy health care providers)
- Symptom Assessment Scale
  – 7 domains: pain, fatigue, appetite, nausea, bowels,
    breathing and sleep
  – 0-10 numerical rating scale
- Palliative Care Problem Severity Scale
  – 4 domains (pain, other symptoms, psychological / spiritual
    and family / caregiver)
  – 4 levels (categorical) reporting

PCOC Data
1. Routine Voluntary point-of-care Data Collection
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   (patient, episode, phase))
2. Periodic (Snapshot) Data Collections
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Patient Survey Results
"Over the past 3 days have you been affected by pain?"
2008
37% percent of patients complained of moderate pain, and
28% had severe or overwhelming pain
2009
42% percent of patients complained of moderate pain and
23% severe or overwhelming pain
Data Collection Pearls

- It takes a “team” (front line clinical staff, database developers, data analysts and interpreters)
- It takes “buy-in” from those paying for the database development and those collecting the data
- It takes continuous monitoring of data quality and outcomes
Summary

• High quality clinical databases in palliative care contribute to:
  – Excellence in the field
    • Identification of gaps in clinical care
    • Recognition of variability in quality
    • Continuous quality improvement
  – Better understanding of patient experiences, clinical care delivery and effectiveness of interventions
  – Demonstration of “value added”