2008

Palliative Care Outcomes Collaboration: the challenges of developing a national data set collection

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Publication Details
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Abstract

Background: Palliative Care Outcomes Collaboration (PCOC) is a national voluntary quality initiative established to assist palliative care services across Australia improve practice and meet the National Standards for the Provision of Palliative Care.

Methods: With funding from the Australian Department of Health and Ageing, PCOC is supporting specialist palliative care services to collect an agreed set of data items to measure outcomes for palliative care and to establish national benchmarking activities that will contribute to improving the quality of care for palliative care patients.

Services collect three levels of routine data, patient demographic, episode of care and phase of illness. PCOC training sessions are used to explore how services will incorporate these three levels of data into their everyday practice.

Results: The analysis of the data collected to date has provided palliative care services with information about the clinical state and trajectory of patients. An individual service's data can be compared with other services to demonstrate how patients in one service score on agreed outcomes when compared to other similar services. Data have been provided to services with multiple sites enabling comparison of service provision and work practices that can be used to identify areas for improvement and to drive change.

PCOC is holding national workshops to explain the findings in the reports to services and participants at these gatherings have appreciated the opportunity to consider local issues in a broader forum. Report findings are being used for quality initiatives.

Conclusion: This presentation will explore the many challenges that have confronted PCOC as it works with services to demonstrate how they can use the data for quality improvement processes and forge links with similar services.

Keywords

challenges, set, data, national, palliative, care, outcomes, collection, collaboration, developing

Publication Details


This conference paper is available at Research Online: http://ro.uow.edu.au/ahsri/556
Palliative Care Outcomes Collaboration: the challenges of developing a national data collection

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13th Annual National Health Outcomes Conference 2008: Facilitating Knowledge Exchange and Transfer
For a Dynamic Future

What is PCOC?

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

◆ PCOC aims to:
◆ Support continuous development of palliative care
◆ Introduce a benchmarking service that will improve practice
◆ Demonstrate outcomes (service and patient/caregiver)
◆ Standardise palliative care assessment
◆ Develop a ‘common language’
What is PCOC?

- PCOC is a national network for specialist palliative care services that facilitates the collection of information and the reporting of outcomes.
- Will assist palliative care services meet the *Standards for providing Quality Palliative Care for all Australians* and as a by-product of participation will assist services meet accreditation processes.

What does PCOC do?

- Works with services to incorporate the PCOC data collection into routine practice.
- Three levels of routine data – demographic, episode and phase.
- 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 de-identified aggregated data are reported in the PCOC reports.
PCOC is a collaboration

Funded by the Australian Government Department of Health & Ageing, it is a collaboration of 4 organisations:

- 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 Linda Kristjanson
- Department of Palliative and Supportive Services, Flinders University (PCOC South)
  - Professor David Currow

PCOC Staffing

Team at University of Wollongong:

- Manager
- Training Manager
- Data and IT manager
- Statisticians
- Administrative support

+ Zone coordinators based in Brisbane, Melbourne, Adelaide, Perth and Wollongong
How PCOC aims are being achieved

- Work with services to incorporate the PCOC data collection into routine practice
- Provide ongoing support through training and assistance with IT
- Analyse the data and provide feedback on the results to individual services
- Facilitate benchmarking with other services
- Assist services with practice changes

Overview of Progress (1)

- 78 specialist palliative care services (of about 147 in Australia) have agreed to join PCOC so far, with approximately 50 submitting data for the third PCOC Report
- Majority are large metropolitan services
- These 70 services represent more than 75% 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 currently being conducted for all interested palliative care services
- 42 training sessions conducted in the ACT, NSW, Queensland, South Australia, Victoria and Western Australia for over 370 staff to end 2007
- First benchmarking workshop conducted in August 2007

The Challenges!

The challenge to develop a national data set for specialist palliative care services is due in part to:

- the wide variation in clinical practice,
- the many ways clinicians use assessment instruments, and/or
- the multiplicity of software systems used to collect and/or record data.

These challenges have been both technical and cultural
The IT Challenge

- Large range of data collection methods
- Data collection/reporting requirements vary around the states and territories
- Not always full coverage of all agencies and data often incomplete

The IT Challenge (cont’d)

- Often data at state and territory level is collected to meet system accountability purposes
- Data reported annually and often not in the year the data was collected
- Data therefore not useful to assist in clinical decision making at the patient level
PCOCs Response

- Liaise with State and Territory Health Departments to ensure PCOC data set included in state IT systems
- Developing a list of PCOC compliant software options
- Currently PCOC is undertaking data entry for some services
- Work closely with software developers and IT companies to ensure systems are PCOC compliant
- Provided SnapShot V3.8 free of charge to 35 services around the country

The Challenge for Consultative and Community Services

- Often difficult to measure outcomes
- Service may only see patient once
- Variety of models of care
- What is the threshold to collect data?
PCOCs Response

- Wide consultation with the sector
- Developed a typology of models of care for consultative and community services
- Typology incorporated into a survey together with suggested dataset
- Consultative workshop held to refine typology and dataset

Institutional and Cultural Issues

PCOC commitment = potential change in work practice/culture

- Possible change in the way a service interacts with a patient/family
- Possible changes in the data and the way it is collected or recorded
- Possible lack of administrative support
PCOCs Response

- Zone coordinators = change agents
- Building partnerships with local service providers
- Tailoring the needs of each service
- Education crucial part of culture change
- Employment of a National Training Manager

PCOC Education

- PCOC training programs encourage services to view PCOC data collection as part of routine practice
  - To guide clinical care
- PCOC assessment tools provide trigger points for staff to initiate appropriate treatment in light of assessment results.
  - Helping services to use evidence in their day to day practices.
- Tools also help services use a common language to describe the condition of their patients and to also determine the level and kind of resources needed.
Conclusion

◆ Participation in PCOC is voluntary
  – leading to good commitment and data quality
  – but participation depends on resources (data entry, IT etc)
◆ PCOC collaborates with others to avoid duplication and exploit the potential synergies between the work of different groups
◆ Early days but expectation that PCOC data will describe the palliative care services being provided in Australia