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Palliative Care Outcomes Collaboration – The Challenges of Developing a National Data Collection

PCOC background

Governments across the developed world are increasingly grappling with how best to provide palliative care for people with life limiting illnesses (Lynn 2005) and how best to measure the quality and outcomes of that care (Higginson and Carr 2001).

In Australia, palliative care evolved as a specialty area in the 1980s when it became apparent that more support and care was needed for dying patients and their families. Whilst still a relatively new field, palliative care is now an essential part of Australia's health care.

In October 2000, the Australian Government released the National Palliative Care Strategy: A National Framework for Palliative Care Service Development (2000). Funding to support the Strategy was provided through the Australian Health Care Agreements 2003-2008. State-wide Ministerial agreement was reached to improve the provision of palliative care services and to report national minimum data to the Department of Health and Ageing and to develop and report on performance indicators.

As part of its Strategy it was proposed that a Palliative Care Service Development Centre be established with the aim of collecting and reporting on data nationally that would assist in service quality improvement.

The idea of a Development Centre led to the establishment of the Palliative Care Outcome Collaboration (PCOC). PCOC is a voluntary, quality initiative specifically designed to support continuous improvement in palliative care through the collection of a suite of data items. It provides an opportunity for participating palliative care service providers to collect routine clinical outcome measures.

This process provides many potential benefits for palliative care service providers in that it promotes consistency in the collection of data and facilitates a 'common language' between clinicians. The data can also assist with quality and standards reporting as well as providing the potential to benchmark palliative care services.

How PCOC aims are being achieved?

The overall coordination of PCOC is provided from a central base in Wollongong where the PCOC Manager, Zone Coordinator, Training Manager and Data Manager oversee a central training and information unit. Zone Coordinators are located in Adelaide, Brisbane, Melbourne and Perth and have responsibility for service recruitment and training.

Participation in PCOC is voluntary and open to specialist palliative care services across Australia. When a service agrees to join PCOC, Zone Coordinators meet with senior administrative and clinical staff. Discussions with services include an assessment of current data collection methods and how data extraction and mapping issues can be resolved. PCOC encourages services to use the data collected to inform clinical practice rather than collecting and reporting a minimum data set.

PCOC also recommends that services apply the data items in everyday language for communicating with other health care professionals, including staff handovers for patient care, discharge planning

and discharge and transfer of patients. The goal is to have a common language for recording and analysing palliative care services nationally across inpatient, outpatient and community care, reflecting the functional continuum of a person's care across the health care system.

This process is supported by workforce training and education and as part of this four modular education packages are delivered by the PCOC Training Manager as required by services.

PCOC progress to date

PCOC has identified 143 palliative care services that are within scope for the PCOC quality improvement initiative. To date, over 50% of these services have been recruited with estimates that this represents more than 75% of palliative care episodes. This process has been supported by training to over 40 palliative care services for over 370 staff.

The production of the first PCOC report on de-identified data submitted by the eight lead services for the period April to September 2006 in February 2007 was a major milestone. Despite the small sample size, services were able for the first time to compare levels of activity, demographic information and clinical assessment data. Each service received a report analysing their data and comparing them to all other services. PCOC is currently collating data for the fourth round of PCOC reports for the period October 2007 to March 2008. It is expected that over 50 services will submit data for this round.

Another major achievement was holding the first national benchmarking workshop in Sydney in August 2007. Representatives from 26 palliative care services attended the workshop, reviewed their Report and discussed how to control for variations in the mix of patients seen by each service. The workshop also included a presentation on supplementary data analysis to assess the information that services might find useful in future reports.

The Challenge

It has proved to be a significant challenge to develop a national data set for specialist palliative care services. This is in part due to the wide variation in clinical practice, the many ways clinicians use assessment instruments and the multiplicity of software systems used to collect and/or record data. These challenges have been both technical and cultural.

The information technology challenge

In November 2004 the Australian Institute of Health and Welfare (2004) published a report summarising data collection practices, data flows and reporting requirements in the area of community-based palliative care provision.

The report identified a large range of data collection methods and systems used by agencies involved in the provision of community-based palliative care. These ranged from crude paper-based systems to spreadsheets to more sophisticated client information systems.

This is further complicated by the fact that palliative care data collection and reporting requirements vary around Australia. In some states and territories data collections do not have full coverage of all funded agencies, and when data is collected is not always complete. In most cases, at state and territory level, palliative care data are collected to meet system accountability purposes. These are reported annually and often not in the year in which the data was collected. Clearly this data is not collected to assist in clinical decision making at the patient level.

However, the PCOC system is completely different. It is based on a clinically relevant data set that collects data as part of a clinical assessment of patients. Data also provides services with contextual information that helps describe their patient population. The results are aggregated and fed back to services on a 6 monthly basis to help improve the quality of care. The results are also used in a

service benchmarking process that allows services to compare results with each other and discuss ways to improve care provided.

Whilst the AIHW report focuses on community based palliative care its findings are equally as relevant to other modes of service delivery such as admitted patient care and consultancy services. In the hospital setting information on admitted patient palliative care has now been reported for a number of years through various state and commonwealth data collections. However, the data collected together with the IT systems used to collect this data also vary widely.

This national variation in IT systems and data collection protocols has to some degree hampered the recruitment of PCOC services in some states and territories.

What has been PCOCs response?

PCOC is doing a significant amount of work to try and address IT issues. At the jurisdictional level PCOC is liaising with various State and Territory Health Departments. For example in New South Wales, South Australia and Victoria work is currently under way to include the PCOC Version 2 data into their state-wide data collection systems.

From a software perspective PCOC is developing a list of PCOC compliant software products that currently meet the Version 2 specifications. The PCOC team has also been working closely with programmers and IT companies to try and ensure that their systems are PCOC compliant. As a result of these negotiations a new version of SNAPshot, V3.8 was released in 2007 which incorporates Version 2 of the PCOC data set. This has been provided free of charge to 35 services around the country. Assistance with installation and training is also being provided to staff of these services. The Version 2 data set has also been included in the latest versions of the Palliative Care System (PCS) and PalCIS.

PCOC will continue to negotiate with states and commercial software suppliers to incorporate the PCOC data set into the different systems used by services, thereby ensuring that service staff are not burdened with double data entry.

The challenge for consultative and community services

Initially PCOC focussed on collecting the PCOC V2 dataset in dedicated inpatient palliative care units as these services, for the most part, were already collecting some data and had the administrative personnel to support this. However, collecting PCOC data from a consultative service or in the community setting has been more of a challenge.

For consultative services it can be difficult to measure patient outcomes, as the link between their type of services and patient outcomes is less direct than that for inpatient palliative care units. A palliative care consultation may take place in a variety of settings and the service may only see the patient once.

This is further complicated by the varying models of care that consultative services engage in. In some consultations a patient may not be even seen by the service. The palliative care consultant may simply provide informal advice to another clinical team over the phone or in the corridor. At the other end of the scale the consultative service could have ongoing involvement with a patient and/or their treating clinicians.

With this variation in patient contact it can be difficult to define the threshold that a consultative service should collect data. Once this threshold has been reached PCOC is then faced with the problem of what data should be collected?

For community services the problems are similar. A palliative care community service may provide direct care to a patient where they assume full clinical responsibility or they may share the patient

care with another service provider. They also may provide consultative care in a similar way to a dedicated consultative service.

What has been PCOCs response?

To gain a better understanding regarding the varying models of service delivery in consultative services the sector has been widely consulted. Consultative services have also been surveyed and a typology of four possible models of care has been developed. This typology was further refined at a workshop consisting of more than 70 representatives from hospital-based consultative services held in Sydney in March 2008. There will be considerable follow up work to agree on final definitions and data to be collected by consultative services.

In a similar way PCOC will hold a workshop in Melbourne in May 2008 for community palliative care services. One of the key issues for this workshop will be defining the different models of care and characteristics of palliative care patients in the community.

Institutional and cultural issues

When a service commits to becoming a member of PCOC they are also committing to a change in work practice. This can prove to be a major challenge. With many service staff holding to the view that 'this is the way we do things around here', convincing staff of the efficacy of proposed changes in the workplace has been a challenge for PCOC. These changes may be in the way services work with their patients and families and/or changes in the way they collect and record data. Either way this generally involves a change in work culture.

Often it is easier to gain the commitment of a palliative care service that has not had any experience in data collection to successfully engage with PCOC. Conversely a service that has been collecting data for many years and 'wedded' to their in-house assessment tools may be more reluctant to change practice.

Another issue for services is a perceived lack of administrative support to enter the PCOC data into a database.

What has been PCOCs response?

Zone Coordinators have been instrumental as change agents in the successful implementation of PCOC at a local service provider level. This role has evolved from building partnerships with local service providers to supporting them at all phases of introducing PCOC into their workplace. As models of care, staffing and assessment and documentation practices vary, an approach tailored to the needs of each service is necessary.

PCOC has established that education is paramount when addressing cultural change or change in practice issues. This is critical, not only to ensure more robust, consistent data but also to demonstrate that the data can be used on a daily basis as part of clinical practice and to manage and improve services.

As a result of this PCOC embarked on a substantial training program following receipt of Australian Government approval for a variation to the Standard Funding Agreement. PCOC has consequently been able to employ a national training manager who after wide consultation with the sector has developed an extensive training program for staff in all PCOC services. The program is modular-based and the complete program can be conducted over a day or selected modules can be delivered as required.

The education session include case studies that give participants a chance to understand the process of using the various assessment tools in their clinical practice. The value of using these tools as a measure of service quality is also explored. Another focus of the training sessions is to ensure that strategies are in place to incorporate PCOC into everyday practice so that staff do not regard PCOC simply as a data collection exercise. This may necessitate changes in work practice and

organisational structure. For example, participants learn how the data can be used in case conferencing and interdisciplinary team meetings and at staff handovers for patient care, discharge planning and discharge and transfer of patients.

Post education and further training sessions are provided by Zone Coordinators who also assist with the development of appropriate forms tailored to the needs of each service in an effort to reduce unnecessary duplication of data elements.

Conclusion

PCOC is a significant national development in understanding palliative care service delivery. In combination with other national developments, PC Standards, Knowledge Network etc, it demonstrates the commitment of the Australian Government to develop the evidence base for palliative care in Australia.

It is encouraging that PCOC has been embraced by the specialist palliative care sector and the expectation at this point is that over 90% of services will join on a voluntary basis within the next year. Developments to date have involved broad consultation with the sector. For PCOC to be useful to these services, it is aiming to produce a data set that as far as possible complements data already being collected and that is used on a daily basis to inform practice and service planning. Work is underway to achieve this goal and thus for the first time data will be available to describe palliative care services being provided in Australia.

References

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