

ANZSPM

Australian and New Zealand Society of Palliative Medicine

CLINICAL INDICATORS FOR END OF LIFE CARE AND PALLIATIVE CARE

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INTRODUCTION

Clinical indicators (CIs) are one method of improving the quality of medical care provided for patients and their families/carers requiring end of life and palliative care. Clinical indicators can be used as the basis of self improvement in quality improvement cycles and can be used to inform policy and strategic direction.¹ However, at present in Australia there are few clinical indicators for end of life and palliative care. If process based CIs are specifically based on evidence based guidelines and target identified gaps in the “quality of best practice care” they can become potent effectors of quality improvement in service provision.

Palliative Care Australia promotes a needs based approach to palliative care and recognises that many people who die an expected death in Australia do not need to be cared for by a Specialist Palliative Care Service. They advocate that all health professionals will be engaged in end of life care, for example cardiologists, oncologists etc.²

To promote improvement of end of life care and palliative care in all settings, the CIs are applicable to generalists, non-palliative medicine physicians or palliative medicine specialists

These physician level performance indicators need to be part of a wider set of key performance indicators that measure the broader health system responses to the individual patient and family/carer needs when facing end of life issues. Physicians may not have control over the process or design of the health systems in which they work. However, these CIs do allow generalists, non-palliative medicine physicians or palliative medicine specialists to assess their own direct clinical care processes for patients they care for at the end of life.

For quality indicators to be useful they must be developed, piloted and implemented with scientific rigour. A process for general medical clinical indicators development and implementation process has been outlined.^{3,4,5}

- Identify area where there is potential for suboptimal care
- Identify the perspective from which to measure
- Focus on the transitions through the health sector
- Summarise and define CI set
- Pilot the indicator
- Identify quality improvement strategies
- Implement CIs
- Evaluate the changes and modify strategies

¹ Evans SM, Lowinger JS, Sprivulis PC, Copnell B, Cameron PA. 2009 Prioritizing quality indicator development across the healthcare system: identifying what to measure. *Internal medicine Journal* 39:1648-654.

² Palliative Care Australia (PCA)² has developed a glossary of terms that have been used in this proposal
End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.

Palliative care: Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

Specialist palliative care provider: Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes and hospices and palliative care units.

³ Scoot I & Phelps G 2009. Measurement of improvement: getting one to follow the other. *Internal medicine Journal* 39:347-51.

⁴ Brand C, Lam SKL, Roberts C, Gorelik A, Amatya B, Smallwood D and Russell D (2009) measuring performance to drive improvement: development of clinical indicator set for general medicine. *Internal medicine Journal* 39:361-369.

⁵ Evans SM, Lowinger JS, Sprivulis PC, Copnell B, Cameron PA. 2009 Prioritizing quality indicator development across the healthcare system: identifying what to measure. *Internal medicine Journal* 39:1648-654.

Recommendations for specific implementation strategies for improving pain management in a Palliative Care population

1. How “best practice” should look to overcome institutional barriers to routine, fastidious screening, assessment, quantification and development of a documented reassessment plan for management of pain is still not clear in the literature?
2. How “best practice” should look to monitor for adverse side effects of treatment is also not clearly defined as yet?

Currently the Palliative Care sector nationally has developed two data collection processes for Specialist Palliative Care by which we can monitor and benchmark the effects of changes we bring about in our pain management routines. Palliative Care Outcomes Collaborative (PCOC)⁶ data collection and benchmarking (that collects episodic data on phase, function, patient and carer distress and numerical scores for seven common symptoms including pain) is only available in Australia, however National Standards Assessment Programme (NSAP)⁷ data collection and benchmarking is also available for New Zealand. There have been discussions about extending use of NSAP at least to the generalist or non-specialist sectors for use as a Continuous Quality Improvement (CQI) process to monitor Palliative Care service delivery in all areas. We do not have enough high level evidence as yet about the robustness and comprehensiveness of these two quality improvement processes in terms of whether they are able to give us fairly complete and meaningful surrogate measures for assessing the quality of our Palliative Care service delivery to our patients and their families. However PCOC & NSAP do currently provide us with powerful tools by which we believe that we can both monitor and benchmark the quality of our service delivery. By benchmarking this data and entering into peer review processes we believe that clinicians in these services can be more confident of the quality of service delivery and give their fund providers and patients and their families meaningful feedback on the quality of their Palliative Care service delivery overall.

INTENDED PATIENT POPULATION

Age

These CIs are designed for patients over 18 years.

End of life population (last 6-12 months of life)

End of life population is defined by using three triggers for recognising that an individual is in the end of life population.⁸ Patients can be identified through any combination of the following 3 methods:

1. The surprise question: ‘Would you be surprised if this patient were to die in the next 6-12months’.

⁶ PCOC - is a voluntary quality initiative to assist palliative care service providers to improve practice and meet the "Standards for Providing Quality Palliative Care for all Australians".

http://chsd.uow.edu.au/pcoc/about_pcoc.html

⁷ NSAP - is a national framework (brief documentation audit and two structured interviews: first with patients and second with bereaved family members) for continuous quality improvement built on the Palliative Care Australia *Standards for providing quality palliative care for all Australians*

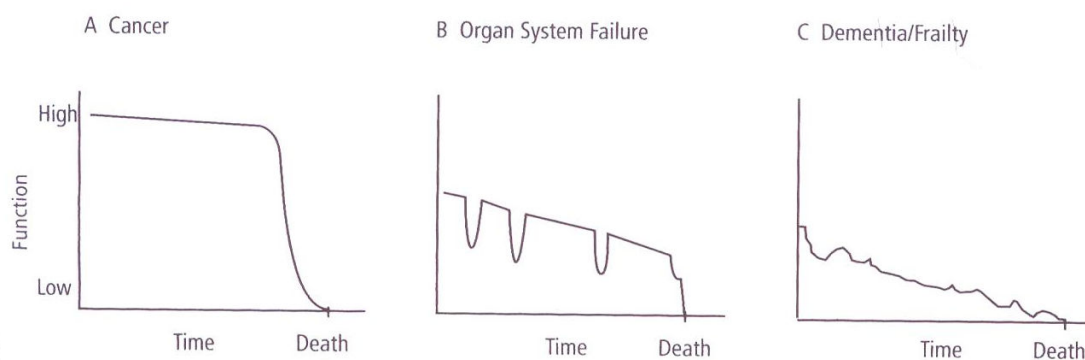
<http://www.standards.palliativecare.org.au/Default.aspx?tabid=1877>

⁸ Gold Standards Framework (2008) Prognostic Indicator Guidance version 5. Available at:

http://www.goldstandardsframework.nhs.uk/Resources/Gold%20Standards%20Framework/PIG_Paper_Final_revised_v5_Sept08.pdf. Accessed 15 March 2010

2. Choice / Need: The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment.
3. Clinical indicators: General and specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia. The trajectories for these end of life patient groups have been described in Figure 1

Figure 1: General trajectories to death for patients with cancer, organs system failure and dementia.



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Terminal population

The multidisciplinary treating team has agreed that the patient is dying when they are bed-bound with at least two other criteria present: (Any reversible cause for deterioration has been ruled out in line with patient and family wishes and cultural and religious needs).

- The patient is bed-bound.
- The patient is semi-comatose.
- The patient is only able to take sips of fluid.
- The patient is no longer able to take tablets.
- The patient is weak and drowsy for extended periods of time

Intended audience

These CIs are designed for use by medical practitioners including generalists, non-palliative medicine physicians or palliative medicine specialists for calculating reporting or performance measurement at the individual clinician level.

Clinical indicators

The document includes indicators for the following domains:

Symptom management - pain screening, assessment and management set.

- Pain intensity quantified
- Plan of care for pain
- Aperiets/laxatives initiated in patients on opioids

It is intended to develop indicators in other key domains as resourcing allows, such as:

- Other symptoms – dyspnoea, nausea, depression/anxiety, delirium etc.
- Terminal Care Pathways
- Advance Care Planning

- Continuity of Care
- Carer/Support Unit strain and bereavement risk assessment and management

The ANZSPM CI Working Group believes that there is ample evidence to support the three linked “Pain assessment and management indicators”.

DRAFT

METHOD

A multi-faceted approach was employed to define the indicator set:

- Expert opinion from the ANZSPM CI Working Group and consultation process
- Clinical indicators from Australia and overseas
- Clinical guidelines from Australia and overseas
- Level of evidence

Results

Table 2: Subset of 'process' indicators

Indicator	Value Based Judgements			
	Indicator	Consumer relevance	Level of evidence	Clinical relevance
Pain intensity quantified	Yes	High	Level 1	High
Plan of care of pain	Yes	N/A	Level 1	High
Aperients/laxatives initiated in patients on opioids	Yes, but use 72 hours	N/A	Consensus opinion	High

PAIN SCREENING, ASSESSMENT AND MANAGEMENT SET

Summary of the Evidence Base for Pain Clinical Indicator set

(adapted from CareSearch⁹ Physical Symptoms Web Page – last updated March 2010
<http://www.caresearch.com.au/caressearch/ClinicalPractice/Physical/Pain/tabid/746/Default.aspx>)

Key messages (references are on second page of this modified CareSearch extract)

- The majority of pain in palliative care patients can be effectively treated with available drugs and best practice management strategies, which include: appropriate and adequate investigation to establish a diagnosis and mechanism for the pain, regular multidisciplinary assessment of pain, mood and function with validated assessment tools and a documented plan for timely review.¹⁰
- Strong evidence supports treating cancer pain with non-steroidals, opioids, radionuclides and radiotherapy.¹¹ Bisphosphonates are effective in the treatment of malignant bone pain.¹²
- Whilst many opioid formulations are available and are effective, the recommended first line treatment for cancer pain continues to be oral morphine.¹³
- Recent evidence-based guidelines for neuropathic pain^{14,15} suggest that two groups of medications may be used as first line adjuvant treatment – of the antidepressants, either tricyclics or venlafaxine, and of the anticonvulsants, either gabapentin or pregabalin (due to their better side-effect profile, although head-to-head studies against carbamazepine and sodium valproate are still missing). Opioids and tramadol

⁹ CareSearch (Palliative Care Knowledge Network database) - an online resource of palliative care information (contextualized for the Australian setting) and evidence from the international literature. All materials included in this website are regularly reviewed for quality and relevance.

¹⁰ Azevedo Sao Leao Ferreira K., Kimura M, Jacobsen Texeira M. The WHO analgesic ladder for cancer pain control, twenty years of use. How much pain relief does one get from using it? Supportive Care in Cancer. 2006 Nov;4(11):1086-93.

¹¹ Lorenz K, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for improving palliative care at the end of life: a systematic review. Annals of Internal Medicine. 2008 Jan 15;148(2):147-159.

¹² Qaseem A, Snow V, Shekelle P, Casey DR Jr, Cross JT Jr, Owens DK, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. Annals of Internal Medicine. 2008 Jan 15;148(2):141-146.

¹³ Hanks GW, Conno F, Cherny N, Hanna M, Kalso E, McQuay HJ, et al., Morphine and alternative opioids in cancer pain: the EAPC recommendations. British Journal of Cancer. 2001 Mar 2;84(5):587-93.

¹⁴ Finnerup NB, Otto M, McQuay HJ, Jensen TS, Sindrup SH. Algorithm for neuropathic pain treatment: An evidence based proposal. Pain. 2005 Dec 5;118(3):289-305.

¹⁵ Dworkin RH, O'Connor AB, Backonja M, Farrar JT, Finnerup NB, Jensen TS, et al. Pharmacological management of neuropathic pain: Evidence-based recommendations. Pain. 2007 Dec 5;132(3):237-251.

are also effective in neuropathic pain, and are suggested to be co-administered first line in neuropathic cancer pain.¹⁶

Pain is a frequent complication of cancer, and is common in many other life-limiting illnesses and chronic co-morbid illnesses. Pain that is not well controlled causes significant distress and disability and can result in increased carer distress and requests for physician assisted suicide. The effective management of pain is therefore a core element of palliative care practice. Most pain can be effectively treated using standard care according to the WHO analgesic ladder and non-pharmacological approaches.¹⁷ Resistant pain can usually be adequately managed with additional therapies such as interventional pain management, palliative radiotherapy and/or chemotherapy, bisphosphonates etc. in addition to non-pharmacological measures.

In the palliative care setting, some of the important contributors to pain to consider and treat specifically are:

- Emergencies such as: pulmonary emboli, spinal cord compression and bowel obstruction
- Bony metastases & pathological fractures
- Malignant wounds
- Infection or inflammation
- Capsular pain, visceral pain
- Radiotherapy / chemotherapy effects (usually short term)
- Lymphoedema & cerebral oedema
- Depression / anxiety / fear
- Frailty, decreasing mobility or becoming bed-bound
- Constipation and urinary retention.
- Active research areas / controversies

Much of the evidence about pain management comes from studies in populations quite different from palliative care patients.¹⁸ Studies of acute pain, single dose studies of particular analgesics, and studies in non-malignant pain syndromes like post herpetic neuralgia and diabetic neuropathy all contribute to the evidence, but must be treated with care when extrapolated to palliative care.

Further research is needed to identify the most effective pain assessment tools for use in palliative care, especially in the terminal and/or confused palliative population¹⁹ and to improve processes of routine care and timely review so that pain is managed most effectively.²⁰

Head to head trials of adjuvants in neuropathic pain are needed to strengthen the evidence base.²¹

¹⁶ Dworkin RH, O'Connor AB, Backonja M, Farrar JT, Finnerup NB, Jensen TS, et al. Pharmacological management of neuropathic pain: Evidence-based recommendations. *Pain*. 2007 Dec 5;132(3):237-251.

¹⁷ Azevedo Sao Leao Ferreira K., Kimura M, Jacobsen Texeira M. The WHO analgesic ladder for cancer pain control, twenty years of use. How much pain relief does one get from using it? *Supportive Care in Cancer*. 2006 Nov;4(11):1086-93.

¹⁸ Carr, D., et al., Evidence report on the treatment of pain in cancer patients. *J Natl Cancer Inst Monogr.*, 2004. 32: p. 23-31. [Reference added in update, October 2009]

¹⁹ Holen JC, Hjermstad MJ, Loge JH, Fayers PM, Caraceni A, De Conno F, et al. Pain assessment tools: is the content appropriate for use in palliative care? *Journal of Pain & Symptom Management*. 2006 Dec;32(6):567-80.

²⁰ Carr, D., et al., Evidence report on the treatment of pain in cancer patients. *J Natl Cancer Inst Monogr.*, 2004. 32: p. 23-31. [Reference added in update, October 2009]

²¹ Finnerup NB, Otto M, McQuay HJ, Jensen TS, Sindrup SH. Algorithm for neuropathic pain treatment: An evidence based proposal. *Pain*. 2005 Dec 5;118(3):289-305.

Ketamine is widely used in the context of rapidly escalating opioid use and for uncontrolled complex pain. As the level of evidence for efficacy is poor, randomised controlled trials are currently under way in Australia to assess the effectiveness of ketamine as an adjuvant in poorly controlled pain, and to identify safe and effective breakthrough doses and orders for “as required” regimens of opioids.

Clinical indicators for pain

Although there are few clinical indicators in the area of pain screening, assessment and management, many sets of clinical guidelines have been produced here and overseas that provide evidence for the development of guidelines in this area.

- Guidelines for a Palliative Approach in Residential Aged Care (2004)
- Pain in Residential Aged Care Facilities: management strategies (2005)
The Australian Pain Society
- Draft National Pain Strategy

Evidenced based clinical indicators have been drafted for pain intensity and developing a plan of care²²

The evidence from these guidelines clearly indicates that patients in Australia are not being treating adequately for pain.

²² National committee for Quality Assurance/physician Consortium for performance Improvement 92008) Palliative Care Clinician Performance measurement Set.

End of life care (last 6-12 months of life)

Three clinical indicators:

4. Pain intensity quantified
5. Plan of care for pain
6. Aperients/laxatives initiated in patients on opioids

1. Pain intensity quantified

Percentage of patients with advanced chronic or serious life threatening illness who have pain intensity quantified.

Denominator

Denominator Statement: Patients with a substantial risk of death within one year, based on the physician's clinical judgment integrating the patients co-morbidities, health status, social and other factors OR patients with advanced disease whose goals of care prioritize comfort OR patients with incurable cancer, organ system failure, or severe progressive neurological conditions.

Denominator Inclusions/Exclusions: For ICD-9 Codes or GSF Prognostic Guidance, see Appendix 1: Denominator Codes.

Numerator

Numerator Statement: Number of patient visits in which pain intensity is quantified. Pain intensity should be quantified using a standard and relevant instrument, such as a 0-10 numerical rating scale, a categorical scale (e.g. none, mild, moderate and severe – as for the Australian National - Subacute Non-Acute Patient – AN-SNAP, data collection around the Palliative Care Outcomes Collaboration), or a pictorial scale (e.g. Wong-Baker Faces Pain scale or for delirium and severe cognitive impairment – ABBEY Pain Scale or PAINAD).

Rationale

Rationale: Quantification of pain intensity allows clinicians to determine appropriate interventions for the treatment of pain, should it be present. Currently, inadequate quantification of pain intensity is widely prevalent among the EOL care population. Clinical guideline evidence supports the assessment of pain intensity, and deems pain related care as one of the critical elements for palliative care.

2. Plan of care for pain

Percentage of patients with advanced chronic illness or serious life threatening illness who have a documented plan of care to address pain.

Denominator

Denominator Statement: Patients with a substantial risk of death within one year, based on the physician's clinical judgment integrating the patients co-morbidities, health status, social and other factors OR patients with advanced disease whose goals of care prioritize comfort

OR patients with incurable cancer, organ system failure, or severe progressive neurological conditions.

Denominator is all those who have pain as measured by a standard and relevant instrument in *Indicator 1: Pain intensity quantified*.

Denominator Inclusions/Exclusions: For ICD-9 Codes or GSF Prognostic Guidance, see Appendix 1: Denominator Codes.

Numerator

Numerator Statement: Patient visits that included a documented plan of care to address pain. A documented plan of care includes: a plan for treatment of the pain: use of opioids, non-opioid analgesics, other measures eg radiotherapy, chemotherapy, interventional pain therapy, psychological support, patient and/or family education, or a statement about why no intervention was taken, AND a plan for reassessment of pain including a planned reassessment time or interval.

Rationale

Rationale: Inadequate development of pain care plans is widely prevalent among the palliative care population. As a result, the patient may be harmed and or further costly treatments may be incurred. Clinical guideline evidence supports the creation of a pain care plan and deems it as one of the critical elements for palliative and end of life care.

3. Aperients/laxatives initiated in patients on opioids

Percentage of patients with advanced chronic illness or serious life threatening illness who have been prescribed opioids and are prescribed aperients/laxatives within 24 hours as a plan of care to address constipation.

Denominator

Denominator Statement: Patients prescribed opioids for pain.

Denominator is all those who have pain as measured by a standard and relevant instrument in *Indicator 1: Pain intensity quantified* and have a plan of care that includes the use of opioids in *Indicator 2: Plan of care for pain*.

Denominator Inclusions/Exclusions: For ICD-9 Codes, see Appendix 1: Denominator Codes.

Numerator

Numerator statement: Patients prescribed opioids for pain who are also prescribed aperients/laxatives for constipation within 24 hours of their opioid prescription, where aperients/laxatives are not contra-indicated.

Rationale

Rationale: Many patients who are prescribed opioids are not given aperients/laxatives until they become constipated. The treatment of constipation as a side effect of opioid administration was addressed in a recent systematic review. The review found that 25-50% of cancer patients have constipation and that it is the most frequently occurring adverse effect of opioid use in advanced cancer. Other Adverse Events that are probably also necessary to bear in mind and screen for

are: nausea +/- vomiting, drowsiness and cognitive impairment
(both of which can be dangerous for driving or using heavy
machinery etc.)

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APPENDIX 1 – DENOMINATOR CODES

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APPENDIX 2 PAIN SCALES

Abbey pain scales

PAINAD

Faces

0-10 numerical scale

Visual analog scale

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