

The Australian Best Care of the Dying Project (ABCD)

Phase One Report

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1. *What are the important gaps between evidence and clinical practice identified in the networks area of interest?*

The primary concern of the ABCD network is that the quality of dying in today's society is often poor. With the recent rapid advances in medical knowledge and technology and the explosion of new drugs, death is seen as a failure within many medical models. Death is no longer acknowledged as an inevitable part of life, but has been "medicalised, professionalised and sanitised" (Smith 2000). As a consequence, many patients still die alone, frightened and without dignity, having lost all control, feeling abandoned by health care professionals (Hardy 2004).

The hospice type model is considered the best model of care and for the minority who die under the care of palliative care teams, the experience may not be bad (Higginson 2003), but there is a suspicion that for many who die in acute hospitals or nursing homes the experience is not good (Smith 2000). In all locations, the particular needs of patients who are dying should be identified and addressed.

2. *What is the gap between evidence and practice that the network would propose to address first?*

Our network has attempted to identify short falls in the care of the dying across several settings and propose that these deficiencies in care are best addressed through system change; by the introduction of a care pathway program.

a) What is the best available evidence in this area?

Care pathways for the dying have been developed as a model to improve the end-of-life care of all patients. Care pathways are locally agreed multidisciplinary evidence-based practice guidelines for specific patient/user groups that can be adapted to all relevant settings (hospital, hospice, residential aged care facility or community). They are patient centred and address not only the physical but also the important psychosocial and practical issues that surround death.

The concept of care pathways for the dying was developed by a specialist palliative care team in Liverpool (Ellershaw et al 1997, Ellershaw and Wilkinson 2003). The Liverpool Care Pathway (LCP) defines 18 goals considered essential in the management of dying patients and for the care of their relatives/carers after death. These include initial assessment and care goals, on-going care goals as well as care after death goals ([appendix 1](#)). These goals address the issues identified from surveys, focus groups, expert opinion and consensus based best practice as being essential for the care of the dying patient.

Several other groups have adopted the care pathway concept but have adapted it according to their own specific needs or setting, for example the Palliative Care for Advanced Disease (PCAD) pathway from the Beth Israel Medical Centre (Beth Israel Medical Centre 2005) and that developed by the Welsh Collaborative Care Pathway Project (Fowell 2002).

All care pathways provide a template that describes the process of care necessary to achieve the set goals, and documents care given. The template is supported by evidence-based management guidelines.

While there is a body of evidence to support the management of some symptoms (eg pain (Expert Working Group of the EAPC 2001) and dyspnoea (Jennings 2001)) there is a paucity of “level 1” evidence to support the management of many of the symptoms commonly experienced by dying patients (for example fatigue, agitation, psychological distress). Many of these symptom control measures cannot be, or are very difficult to test within standard randomised control trial models (Grande 2000). Much of the evidence is thus of low grade.

Consensus practice in this specialty is supported by a wealth of experience and expert opinion however, as reflected by a number of “evidence-based” guidelines for symptom control (Ellershaw and Ward 2003, Panchal 2004).

The care pathway model is being used extensively in other disciplines and has been evaluated formally in some settings. For example, a Cochrane review of in-hospital care pathways for acute stroke has been published (Kwan 2002).

To review current evidence regarding the implementation and evaluation of end-of-life care pathways, a literature search of the Cochrane Library, MEDLINE, CINAHL, AMED, Scopus, Health Source, PsycINFO, PreCINAHL and the EMBASE databases was undertaken. Both keyword and subject headings were used to search each of the relevant databases. Search strategies were adapted to the requirements of individual databases but the following keywords in particular were searched: (care pathway* or critical path*) and (Liverpool or end of life or dying or terminal or palliative care). Additional search terms were employed in order to specifically identify

articles concerning the evaluation of the LCP and other related care pathways.

The search revealed several descriptive articles on the introduction and implementation of the LCP (or similar) for end-stage care in several settings (Bookbinder 2005, Counsell 2003, Jones 2004, Luhrs 2005, Mellor 2004, Pooler 2003).

There are a number of uncontrolled studies that have attempted to evaluate care pathways. Mirando and colleagues identified several areas in which there was improved conformance to pathway goals in a post implementation pathway audit and several areas where further improvement was needed (Mirando et al 2005). In an analysis of 168 patients dying over a one year period, Ellershaw and colleagues have shown the LCP to be an effective method of measuring symptom control in the dying patient (Ellershaw et al 2001). Qualitative evidence has indicated that nurses and hospice-based doctors feel it has a positive impact for patients, carers and health professionals (Jack et al 2003). The Navigate Care Model (NCM) specifies clinical pathway assignments for hospice patients based on the anticipated outcomes of death, discharge home, or discharge into residential care. A study, evaluating the effects of NCM indicated better symptom management, along with improved patient and family satisfaction (Nightingale 2003). Knowledge of end-of-life care by interns was significantly improved following the intervention of an integrated, end-of-life clinical pathway tool (Okon 2004). A small study describing the impact of the LCP in a stroke unit has also demonstrated a marked improvement in the documentation of patient care (Jack 2004).

A systematic review of all studies evaluating the pathway to date is indicated. There is considerable variation between published studies to date with respect to methodology and outcome measures and currently no review or randomised controlled evidence to support the end-of-life pathway concept.

The hospice model of care of the dying is espoused as a model of excellence however and the LCP provides a means of transferring this care into hospitals and other care institutions (Ellershaw and Ward 2003). The LCP has been recognised as a model of good care by the NHS Beacon Programme (NHS Beacon) and has been highlighted as a mechanism for improving the care of the dying in the UK. It now forms part of standard management in over one hundred UK hospitals. One of the key recommendations of the UK National Institute for Health and Clinical Excellence guidance for improving supportive and palliative care for adults with cancer is that in all locations, the particular needs of patients who are dying should be identified and addressed (www.nice.org.uk). The LCP for dying patients is highlighted as a mechanism for achieving this.

b) What evidence is there to demonstrate a gap between evidence and practice both in general and within your network

What constitutes a “good death”? The principles of a good death identified following a debate of an Age, Health and care study group (Debate of the Age, Health and Care study group) centred on control, autonomy and independence. This was not only for issues such as pain and symptom control, but also for place of death, who should be present at the time of death and the maintenance of privacy. The importance of access is also stressed, not only to information and

expertise, but also to spiritual and emotional support and to hospice type care across all settings. Pain and symptom management, clear decision making, preparation for death, achieving a sense of completion, contributing to others and affirmation of the whole person have been cited as the six main components of a good death by patient, relative and provider focus groups (Steinhauser, Clip 2000). In a cross-sectional, stratified random national survey of seriously ill patients, recently bereaved families, physicians and other care providers undertaken by the same group, (Steinhauser, Christakis 2000) pain and symptom control, communication with doctors, preparation for death and the opportunity to achieve a sense of completion was found to be important across all groups. Other factors important to the quality of life at the end of life differed by role and by individual. For example, patients rated being mentally aware, having funerals planned, not being a burden, helping others and coming to peace with God as very important.

What is a “bad death”? An observational study of patients dying in a hospital in Scotland (Mills 1994) describes disturbing scenes of neglect and poor care of patients dying on busy medical wards. A similar study from the United States highlights short-comings in the care of patients with life-threatening illnesses, namely around issues of communication, continuation of inappropriate treatment, and ignorance of patients’ end-of-life wishes (SUPPORT 1995). Several other observational studies have pointed to the variance in care of patients dying in the hospital setting (Rogers 2000, Clark 2002). Most Australians die in hospital and there is evidence here to suggest that the care of these patients is not always optimal. Late implementation of end-of-life management plans and active treatment up to and including the day of death has been described and may be common place (Middlewood 2001). These

deficiencies continue to 'fuel' to the euthanasia movement in Australia (Kelly 2004).

Issues that contribute to the sub-optimal care of patients dying in hospital are said to include a lack of open communication, difficulties in accurate prognostication and a lack of planning of end-of-life care (Edmonds 2003). Furthermore, there is evidence of significant symptom burden at the end of life (Hockley 1988, Kutner 2001)

Referral to a palliative care teams results in improved outcomes and a small benefit has been demonstrated in a meta-analysis assessing the benefit to patient care of palliative care teams (Higginson 2003).

Unfortunately, the provision of palliative care services in Australia falls well short of published standards (Palliative Care Australia) perhaps not surprising in a country where palliative medicine is still not recognised as a specialty in its own right. Furthermore, there is a documented paucity of the palliative approach to care in specific sectors eg residential aged care facilities (Fox 1999, Travis 2001) and non-malignant disease (Auret 2003).

c) Why is this gap a priority?

Australia has an aging population and a paucity of specialist palliative care services. Current data on cancer and non-cancer deaths in Australia indicate that there are approximately 187 deaths from cancer and 187 expected deaths from other progressive predictable life limiting illnesses per 100,000 population (Palliative Care Australia 2003).

There is an increasing awareness of issues surrounding the quality of death and dying. This has been highlighted by the recent emphasis on clinical governance, patient centred care and patient choice, coupled with an increase in the number of complaints about issues related to death in hospitals. The way a patient dies remains as a lasting memory for those relatives and carers left behind and is becoming a common cause of complaint within hospitals. It is not uncommon to find anecdotes of bad deaths under the Australian Health Care system in local and national newspapers (Stammers 2004).

d) How will closing this gap improve patient outcomes?

The ultimate aim of an end-of-life pathway is to improve the care of the dying. Furthermore, there is evidence that psychological distress and morbidity in the bereaved can be reduced if quality of life in dying is maximised (Parkes 1990)

e) What challenges are anticipated in addressing this gap?

The barriers to a “good death” as identified from a multidisciplinary network focus group are listed in [appendix 2](#).

The barriers to implementation of care of the dying pathways as identified from the literature include those relating to symptom control (Johnson 2005), cultural differences (Murray 2005), community issues (Groot 2005), health systems (Feeg 2005, Yabroff 2004) and health professionals (Auret 2003). There are also barriers related specifically to the implementation of a care pathway project (Ellershaw and Wikinson 2003, Bookbinder 2005, Okon 2004, Mirando 2005, Jones 2004, Mellor 2004, Mirando 2005, Jack 2003) where difficulties around sustainability and compliance to the pathway are common themes.

3. How did we go about identifying these evidence-practice gaps?

Deficiencies in the care of the dying were identified by audit of current practice in a network of eight health care institutions in Queensland within the remit of the Australian Best Care of the Dying (ABCD) Project.

Methods

The audit was carried out according to the protocols of the Liverpool Care Pathway (LCP) using the standard audit proforma (www.lcp-mariecurie.org.uk). The project has been registered with the LCP central office. Members of the LCP project team provided audit guidance, baseline review forms and external review. Audit guidelines from the LCP were sent to all centres to ensure consistency. Regular network meetings were held to guide and inform participants.

Permission from the Chief Executive Officer or equivalent was sought in each unit prior to audit. The audit was exempt from full ethics review as it met all the criteria of a quality assurance review. For the purposes of confidentiality, all patients, wards, units and institutions were de-identified and referred to by letter only.

Twenty consecutive sets of notes of patients who had died in each of eight institutions within the network were reviewed. Patients had to have been admitted for a minimum of 48 hours prior to death to be included. The 18 goals set out in the LCP ([appendix 1](#)) were taken as the standard for optimal care of the dying. On-going care goals were also assessed. The audit assessed the documentation of achievement of each of these goals within each unit. Goals were recorded as met

only if there was supporting documentation in the notes eg from clinical notes, prescription charts, and nursing or allied health records.

Results

The network comprised 4 hospitals, 3 hospices and 1 nursing home in Queensland. Within the hospitals, patients had died on oncology wards (2) and general medical wards (2). The notes of 160 patients were reviewed. One case was subsequently excluded as the patient had died within 48 hours of admission. There was no missing data in the remaining 159 audit forms.

The audit population included 88 males and 71 females with a median age of 71 (range 29-100). The majority of patients (76 %) had died from malignant disease. The most common cancers were lung (12%), colon (10%), prostate (7%), breast (6%) and female genital organs (6%). Twenty-four percent of the audit sample had died from non-malignant disease, most commonly following a cerebrovascular accident (6% of all cases). The median in-patient stay prior to death was 15 days (range 2-3040 days).

The full audit results showing the percentage of goals achieved as combined data and data per site are presented in [appendix 3](#) and [appendix 4](#).

Discussion

The audit highlighted deficiencies in the care of the dying and striking differences in practice in different institutions. As expected, in hospice units, goals were achieved in a higher percentage of cases in many areas. This was particularly evident in those goals relating to communication and care after death.

Most patients were prescribed medications in anticipation of pain and agitation whereas only two-thirds were prescribed “as required” drugs for the other common symptoms in the dying (nausea or retained secretions). About 20% of patients were continued on intravenous fluids or antibiotics or continued to have blood tests up until the time of death. The necessity to withdraw active treatment eg IV fluids or antibiotics was rarely an issue in hospices, whereas it is often a major issue in hospital units.

Orders regarding resuscitation (NFR) were documented in only 50% of cases overall. There was a marked discrepancy between hospitals and hospices/nursing home in this respect however. NFR was documented on most occasions in the hospitals but almost never in the hospices and nursing home routinely where the assumption of NFR is implicit.

Documentation regarding awareness of family/carers to both diagnosis and impending death was relatively good, whereas discussions regarding these issues with patients themselves were less often documented.

The paucity of documentation regarding spiritual support highlighted several issues. In one hospital, pastoral care workers are prevented from writing in the notes on the grounds of patient confidentiality. In another hospital, pastoral care workers record their visits routinely. During the period of the audit however, the pastoral care representative from unit A was on vacation, highlighting the need for leave cover.

It was clear in most notes how relatives were to be contacted of a patient’s impending death but there was little documentation of the provision of any written information to relatives. This demonstrates a

limitation of the audit in that the distribution of such information would not necessarily be recorded. In many cases however, we are aware that this printed information is not available routinely and the audit has highlighted a need.

As has been demonstrated by many units undertaking the LCP, there is rarely documentation in hospital units that the GP has been informed of the patient's death, or that family/carers have received information/instructions on procedures/services available after death. Conversely, the GP was informed in all cases in the hospice units and nursing home.

The documentation of regular assessment of symptoms common in the terminal phase was generally poor, with the exception of bowel care and the monitoring of syringe drivers.

Summary

The audit has limitations in that it assessed documentation of achievement of goals as specified by the LCP. The audit was not altered in any way to conform to the Australian health system or local unit practice. In some cases, it may be standard practice within a unit to carry out some of these goals (eg informing a GP following death) but if this was not recorded in the notes, it was not scored as having been done. Similarly, the systems in place to monitor many of these issues may differ from those specifically audited according to the LCP guidelines eg symptom assessment pathways.

However, the audit has highlighted many deficiencies in the care of the dying in individual units and across the entire network. As expected, the hospice units performed better in many aspects of goal achievement but areas for improvement were still identified. Striking

differences in practice were noted between different units in some aspects of care.

One of the major areas for improvement is in the provision of written information for relatives and carers. Similarly, documentation of regular symptom assessment during the terminal phase was poor.

4. How does the network propose to fill the evidence-practice gaps?

We propose that the care of the dying can only be improved following a system change. The LCP (or equivalent care pathway program modified to suit requirements of individual units) provides a model to address current deficiencies in the care of the dying. It was designed to identify variances (as highlighted in this audit) and offers a framework for improving these deficiencies. It is a powerful educational tool and a means of empowering generic health care workers to achieve best practice.

The network model supports other units interested in applying a care pathway program. Dissemination of the findings of this project may highlight sub-optimal care units outside the network and encourage others to adopt a similar model of care.

5. How do we propose to continue to review the evidence-base gaps?

The use of Integrated Care Pathways for the dying provides a mechanism for the continuous evaluation of clinical practice. They define the optimal goals expected in the best care of a dying patient and form part of the clinical record. The pathway template provides a

measure for the evaluation of outcomes ie how many of the essential goals are being met. All variations from the pathway are documented, and the reasons for the variations analysed. Solutions are developed to address the causes of potentially avoidable variation, and the pathway is revised to incorporate these improvements. Integrated Care Pathways thus provide a powerful audit tool, as all aspects of the process and outcome of clinical practice can be constantly monitored.

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