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[Chan, Raymond Javan & Webster, Joan](#) (2011) A Cochrane review on the effects of end-of-life care pathways : do they improve patient outcomes? *Australian Journal of Cancer Nursing*, 12(2), pp. 26-30.

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Title:

A Cochrane review on the effects of end-of-life care pathways: Do they improve patient outcomes?

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Abstract:

Clinical pathways for end-of-life care management are used widely around the world and have been regarded as the gold standard. The aim of this review was to assess the effects of end-of-life care pathways (EOLCP), compared with usual care (no pathway) or with care guided by a different end-of-life care pathway, across all healthcare settings (e.g. hospitals, residential aged care facilities, community). We searched the Cochrane Register of Controlled Trials (CENTRAL), the Pain, Palliative and Supportive Care Review group specialised register, MEDLINE, EMBASE, review articles and reference lists of relevant articles. The search was carried out in September 2009. All randomised controlled trials (RCTs), quasi-randomised trials or high quality controlled before and after studies comparing use versus non-use of an EOLCP in caring for the dying were considered for inclusion. The search identified

920 potentially relevant titles, but no studies met criteria for inclusion in the review. Without further available evidence, recommendations for the use of end-of-life pathways in caring for the dying cannot be made. There are now recent concerns regarding the big scale roll-out of EOLCP despite the lack of evidence, nurses should report any safety concerns or adverse effects associated with such pathways.

* This paper is based on a Cochrane Review published in The Cochrane Library 2010, Issue 1 (see www.thecochranelibrary.com for information). Cochrane Reviews are regularly updated as new evidence emerges and in response to feedback, and The Cochrane Library should be consulted for the most recent version of the review.

Introduction:

It is well recognised that populations in developed countries are ageing (1). As populations age, the pattern of diseases that people die from also changes (2). With advanced ageing, there is an increased risk of death from chronic diseases such as cancer and heart failure (3) . For example, cancer was estimated to account for about 7 million deaths (12% of all deaths) worldwide in 2000 (3). Therefore, palliative care has been identified as one of the worldwide public health priorities due to the ageing population (2). Palliative care is concerned with "the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement" (4). End-of-life care focuses on the last days and hours of life (5) and the need to provide high quality care at this time is essential. The needs of dying people may include, but are not limited to, knowing when death is coming, understanding what can be expected, being able to maintain a sense of control and having their requests given preference, having access to information and excellent care, and having access to spiritual and emotional support as required (6). Quality end-of-life care may vary from person to person and may be difficult to define and accurately measure. However, such care should at least include the following domains: quality of life, physical symptoms, emotional and cognitive symptoms, advanced care planning, functional status, spirituality, grief and bereavement; satisfaction and quality of care, as well as caregiver well being (7). Obstacles to quality end-of-life care have also been identified and may include failure to recognise treatment futility, lack of communication among decision makers, no agreement on a course of end-of-life care, and failure to implement a timely end-of-life plan of care (8). In recent years, there has been a variety of initiatives developed worldwide to target such

issues by developing systemic approaches towards end-of-life care. These initiatives include programmes such as the National End of Life Care Programme (9), Gold Standards Framework in Care Homes (10) and the Liverpool Care Pathway (LCP) (11, 12).

Integrated care pathways are documents which outline the essential steps of multidisciplinary care in addressing a specific clinical problem. They can be used to introduce clinical guidelines and systematic audits of clinical practice (13). The LCP is an example of an integrated care pathway specifically for the dying phase of palliation.

Historically, dying patients receiving general hospital care tended to lack adequate attention from senior medical staff and nursing staff (14). The quality of symptom control and basic nursing care were considered to be inadequate (14). It was thought that much could be learned from the way patients were cared for in the hospice movement (14). The LCP was a model of best practice developed by the Royal Liverpool University Trust and the Marie Curie Centre Liverpool (11, 12), based on the care received by those in the hospice setting. Other objectives of the pathway were to promote cost-effective health care by appropriate prescribing, and avoiding crisis interventions and inappropriate hospital admissions. The document is patient-centred and focuses on the holistic needs of people who are dying. It incorporates the physical, psychological, social, spiritual and religious aspects of care (15). The LCP defines 19 goals considered essential in the management of dying patients and for the care of their relatives/carers after death (11, 12). These goals were

established with the issues identified from surveys, focus groups, expert opinion and consensus best practice.

Later, several other groups developed care pathways for the dying based on the concept of Ellershaw and colleagues (16-18). Whilst the professional conjecture is that end-of-life care pathways promote best possible patient outcomes (15), recent speculations have suggested possible adverse effects. These adverse effects included premature use of the pathway leading to death due to the premature diagnosis of imminent death, the care pathway masking the signs in improvement in patients and causing carers' dissatisfaction (19, 20). Therefore, a systematic review is warranted to substantiate claims as to whether the end-of-life care pathways are beneficial or harmful for dying patients and their carers.

Methods

The primary objective of this review was to assess whether end-of-life care pathways improve outcomes of the dying across all healthcare settings (hospitals, residential aged care facilities, community). In particular, we aimed to assess the effects on symptom severity and quality of life of people who are dying and/or those related to the care such as families, caregivers and health professionals.

Search strategies

The standard methodology of the Cochrane Collaboration was used. We searched the Pain, Palliative and Supportive Care Review Group Specialised Register (Sept 2009), the Cochrane Central Register of Controlled Trials (Issue 4, 2009), Medline, EMBASE, CINAHL and PsycINFO. All databases were searched September 2009).

The following search terms were used: 'palliative care'; 'end-of-life'; 'terminally ill'; 'hospice\$'; 'end-stage'; 'dying'; 'critical pathways'; 'guidelines'; 'protocol'; 'professional standard'; 'care plan\$ or map\$'; 'clinical or critical or care path\$'. The dollar sign was used to retrieve all possible derivations of the root words. Hand searching of palliative care journals and relevant conference proceedings were performed. There was no restriction by language or date of publication. Reference lists of all retrieved articles were searched for additional studies.

Inclusion and exclusion criteria

Two authors reviewed each paper independently. We considered randomised controlled trials, controlled clinical trials controlled before and after studies meeting explicit inclusion and quality criteria used by the Cochrane Effective Practice and Organisation of Care (EPOC) group. To be eligible for review, controlled before and after studies had to include (1) contemporaneous data collection, (2) appropriate choice of control site and (3) a minimum of two intervention sites and two control sites. We did not plan to include any non-controlled studies (21). Participants in the included studies were to be patients and families who received care guided by an end-of-life care pathway. Participants included may have had different diseases such as cancer or organ failure. However, participants who received interventions must have been receiving care guided by an end-of-life care pathway for their last days and hours of life. There was to have been no restriction on age of the patient, diagnosis or setting (hospital, home, nursing home). There was to have been no age limit for participants included in this review.

Results

In total, 920 titles and abstracts were retrieved in electronic format and assessed.

Included studies

No studies fulfilled the study eligibility criteria.

Excluded studies

Twenty eight papers were retrieved in full text and were excluded because the study designs did not meet the criteria for included studies. Twenty papers were audits, letters or reviews, and were not experimental studies. Eight experimental studies were excluded because they did not meet the minimum criteria to be included in this review. Table 1 summarises the characteristics of the excluded studies.

INSERT TABLE 1

Discussion

No RCTs, quasi-experimental studies or controlled before and after studies meeting our eligibility criteria were identified for this review. The results of a number of case series and non-eligible controlled before-and-after studies indicate that end-of life care pathways may have the potential to improve symptom management (22, 23), clinical documentation and assessment (16, 23, 24), knowledge of end-of life care amongst internal medicine students (25), prescription of medications for end-of-life (22, 26), and bereavement levels of relatives (27). However, the effects of pathways are difficult to ascertain from these designs. It is also worth noting that no studies reported adverse effects of any EOLCP.

In the UK, the registered users of the LCP reached over 1800 health care institutions across all settings including hospitals, hospices, care homes and community services (28). Further, a publication endorsed by the Australian Government (titled: Supporting Australians to live well at the End of Life- National Palliative Care Strategy 2010), recommended a national roll out of EOLCP across all sectors (primary, acute and aged care) in Australia (29). The use of EOLCP has been accepted as the gold standard/national end-of-life care policy, despite the fact that there is a lack of sound evidence supporting such practice (30). This may be because of the ethical issues around randomising patients to a study arm that does not include an intervention, which many clinicians, irrespective of the lack of RCTs, believe to be effective. However, it is important for policy makers and clinicians to note that, such a large scale roll-out of the EOLCP will make good quality research ethically impossible (30).

Designing and conducting trials involving the dying is difficult and challenging due to methodological and ethical issues (31, 32). These issues may include difficult patient recruitment due to the patient being too ill to participate or unable to give informed consent, or the heterogeneous nature of palliative populations (33). However, a range of other strategies may be considered to make clinical trials possible. These include designing shorter term studies, limiting the number of outcomes, undertaking frequent follow-ups, advanced consent and proxy consent where appropriate for studies involving this population (34).

Although there have not yet been any formal reports of harm associated with the EOLCP, there is no guarantee, unless formal measurement has occurred, that

implementing EOLCP does not cause harm (35). Therefore, palliative care researchers should attempt to investigate end-of-life interventions with the most rigorous research methodology possible. It is encouraging to note that one Italian cluster randomised trial is now under way to investigate the effects of the EOLCP on patients (36).

Implications for practice and research

This review was unable to find any evidence of effect or harm with the use of end-of-life pathways in caring for the dying. Without sufficient evidence for improving patient outcomes, organisations should await further high quality evidence before the roll-out of the EOLCP. With the recent concerns regarding potential harms associated with the use of the EOLCP, it is important that clinical nurses document and report any suspected safety concerns or adverse effects associated with the pathways to their nursing directors or the safety and quality committee in their organisations. Until further formal investigation is conducted, documented harms in an organisation may suggest further quality and safety measures or discontinuation of the pathways. RCTs or other well designed controlled studies are needed for the evaluation of the use of end-of-life care pathways in caring for dying people. In future studies, outcome measures should include the outcomes of interest in this review in relation to patients, families, caregivers and health professionals. These may include patients' symptom control, harms, communication between health care team and families, caregivers well being, grief and bereavement, staff and caregivers' satisfaction, staff confidence, cost of intervention, cost of care, medication use and harms. Further, investigations of the effects of such pathways for specific

populations are warranted. These specific populations may include, but are not limited to, children and patients with end-stage organ failure or dementia.

Acknowledgements

The authors would like to acknowledge the contribution of the Cochrane Pain, Palliative and Supportive Care Review Group and the Cochrane Effective Practice and Organisation of Care Review Group. In particular, we would like to thank Professor Christopher Eccleston, Jessica Thomas, Laila Tyrrell, Caroline Struthers and all the referees for their valuable input (Peer reviewers: Bridget Candy and Alain Mayhew) (Consumer referees: Kathy Smith and Clare Jeffrey).

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Table 1. Characteristics of excluded experimental studies

Excluded studies	Reasons of exclusion	Other characteristics
Bailey 2005, USA (22)	Before and after study (without control)	Participants: pre=108, post=95 (patients with cancer and end stage disease) Pathway: End of life care plan Main outcomes: Increased mean number of documented symptoms, number of care-plans, opioid medication availability, do-not-resuscitate orders, and the use of restraints in the post intervention group. Notes: Changes in the proportion of deaths that occurred in intensive care units and the use of nasogastric tubes were not statistically significant. The end of life care plan was part of a larger intervention with a focus of improving processes of care.
Bookbinder 2005, USA (16)	Controlled before and after study: Non-contemporaneous data collection, non-comparable sampling	Participants: Pre=101, post =156 (patients with cancer and end stage disease) Pathway: The Palliative Care for Advanced Disease pathway (PCAD) Main outcomes: Patients in the experimental units were more likely to have not for resuscitation orders, the comparison units were more like to have morphine infusions and cardiopulmonary resuscitation
Luhrs 2005, USA (24)	Controlled before and after study: Non-contemporaneous data collection, non-comparable sampling and does not have at least 2 intervention and 2 control sites	Participants: pre=28, post=29 (patients from a medical and an oncology unit) Pathway: The Palliative Care for Advanced Disease pathway (PCAD) Main outcomes: Patients on the PCAD were more likely to have documentation of care goals and plans of comfort care, fewer interventions and more symptoms assessed, more symptoms managed as per guidelines.
Okon 2004, USA (25)	Controlled before and after study: does not have at least 2 intervention and 2 control sites	Participants: 54 internal medicine residents (medical officers) Pathway: Integrated end-of-life clinical pathway: the PEACE tool Main outcomes: Mean end-of-life care knowledge scores of the internal medicine residents were 46% higher in the intervention group compared to the control group.
Taylor 2007, New Zealand (37)	Before and after study (without control)/ audit	Participants: pre=20, post=10 (patients in a residential aged care facility) Pathway: Liverpool Care Pathway Main outcomes: There was an increase in pre-emptive medication prescription within one residential aged care facility Notes: The pre-post comparison included only medication prescriptions.
Thompson-Hill 2009, UK (38)	Before and after study (without control)/ audit	Participants: 20 patients Pathway: Supportive care plan Main outcomes: Increased documentation and discussion of place of preferred death.
Veerbeek 2008, Netherlands (27)	Before and after study (without control)	Participants: pre=219, post= 253 (patients with cancer and end stage disease) Pathway: Liverpool Care Pathway

**Veerbeed 2008,
Netherlands (23)**

Before and after study (without
control)

Main outcomes: Documentation of care was significantly more comprehensive compared with the baseline period, and the average total symptom burden was significantly lower in the intervention period.
Participants: pre=131, post =141 (patients with cancer and end stage disease and relatives)
Main outcomes: The relatives had declined levels of bereavement
Pathway: Liverpool Care Pathway
Notes: Only 59% of relatives filled in the questionnaires. Relatives who filled in the questionnaires may be those who had higher satisfaction with the use of the pathway and the service.
