OPEN ACCESS

Diagnosing dying: an integrative literature review

Catriona Kennedy,[1] Patricia Brooks-Young,[2] Carol Brunton Gray,[3] Phil Larkin,[4] Michael Connolly,[5] Bodil Wilde-Larsson,[6] Maria Larsson,[6] Tracy Smith,[7] Susie Chater[8]

▶ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2013-000621).

For numbered affiliations see end of article.

Correspondence to
Professor Catriona Kennedy, Department of Nursing and Midwifery, University of Limerick, Health Sciences Building, Room HS3-037, Limerick, Ireland; catriona.kennedy@ul.ie

Received 6 November 2013
Revised 18 March 2014
Accepted 8 April 2014
Published Online First 29 April 2014

To cite: Kennedy C, Brooks-Young P, Brunton Gray C, *et al*. *BMJ Supportive & Palliative Care* 2014;**4**: 263–270.

ABSTRACT

Background To ensure patients and families receive appropriate end-of-life care pathways and guidelines aim to inform clinical decision making. Ensuring appropriate outcomes through the use of these decision aids is dependent on timely use. Diagnosing dying is a complex clinical decision, and most of the available practice checklists relate to cancer. There is a need to review evidence to establish diagnostic indicators that death is imminent on the basis of need rather than a cancer diagnosis.

Aim To examine the evidence as to how patients are judged by clinicians as being in the final hours or days of life.

Design Integrative literature review.

Data sources Five electronic databases (2001–2011): Cochrane Central Register of Controlled Trials (CENTRAL) on The Cochrane Library, MEDLINE, EMBASE, PsycINFO and CINAHL. The search yielded a total of 576 hits, 331 titles and abstracts were screened, 42 papers were retrieved and reviewed and 23 articles were included.

Results Analysis reveals an overarching theme of uncertainty in diagnosing dying and two subthemes: (1) 'characteristics of dying' involve dying trajectories that incorporate physical, social, spiritual and psychological decline towards death; (2) 'treatment orientation' where decision making related to diagnosing dying may remain focused towards biomedical interventions rather than systematic planning for end-of-life care.

Conclusions The findings of this review support the explicit recognition of 'uncertainty in diagnosing dying' and the need to work with and within this concept. Clinical decision making needs to allow for recovery where that potential exists, but equally there is the need to avoid futile interventions.

Improving end-of-life care is a key priority within current health and social care policy across European countries.[1 2] A shared focus is quality of care and provision based on need rather than diagnosis. Service providers are required to ensure that, when death is inevitable, every patient receives appropriate and timely end-of-life care, focused on comfort and dignity while avoiding futile and invasive interventions that prevent a peaceful death. The importance of preparing and supporting the family and those close to the patient is also recognised as directly influencing how they cope with and adapt to bereavement, with implications for their health and social well-being.[3–6]

Measures towards improving the quality of care in the last days and hours of life include the introduction of multiprofessional integrated care pathways to benchmark standards and support the delivery and evaluation of clinical care. The Liverpool Care Pathway (LCP) for the Dying Patient is the most widely recognised.[7] Originally developed within the UK in the mid-1990s as a vehicle to transfer the hospice model of end-of-life care for cancer patients into general care settings, the LCP came to be regarded as a model of best practice and is now used internationally.[8–10]

Identifying that the patient may be dying is, however, the crucial first step to planning and delivering effective end-of-life care, including the use of care pathways such as the LCP. Clinicians must accurately diagnose dying in order to ensure that a high standard of end-of-life care is provided for all those who need it and equally to identify when restorative treatment aims are appropriate.[11 12] This process is currently viewed as part art, part science and is often regarded as a skill of individuals rather than an objective assessment of signs and symptoms.[12 13]

The complexity of diagnosing dying has been highlighted within recent reviews of the LCP, which report some difficulties and misinterpretations in relation to the purpose and use of this framework in practice. A focus of attention is clinical decision making surrounding end-of-life care, with key recommendations including the development of clear guidance for professionals and further research in diagnosing dying.[14 15]

This integrative review was conducted to inform evidence-based practice in diagnosing dying, prompted by clinical members of the review team involved in supporting end-of-life care across hospital, hospice and community settings. The findings are also timely in relation to European policy requirements and relevant to informing the development and governance of end-of-life care internationally, reflecting priorities for improvement in other developed countries.[1 2 16]

METHODS

Aim

The aim of this integrative review was to examine the nature of evidence available to identify how patients are judged by clinicians as being in the final hours or days of life. The following questions formed the basis of the review:

- How do clinicians diagnose dying?
- What factors influence clinical decision making about dying?
- Can any related tools, triggers or guidance for clinicians be sourced?

An important facet of this review was the inclusion of evidence from a range of chronic progressive conditions across the advanced disease trajectory. The outcomes of this review are presented in a conceptual map (figure 1) constructed using an inductive approach to illustrate the key concepts derived from the narrative synthesis of key literature and the relationships between these. This provides the reader with a conceptual framework that illustrates antecedents to clinical decision making in the complex process of diagnosing dying, when death can be anticipated.

Given the scope of the review questions, key aspects of the systematic review methods advocated by the Cochrane Collaboration and Scottish Intercollegiate Guideline Network (SIGN) were tailored to an integrative review design.[17 18] While the systematic review of randomised controlled trials is considered to be the gold standard in research synthesis, the integrative review is increasingly recognised as appropriate to inform evidence-based practice. The integrative review synthesises findings from a diverse range of primary experimental and non-experimental research methods to provide breadth of perspectives and a more comprehensive understanding of a complex healthcare problem.[19] Our review was based on the steps and processes in box 1 and informed by the PRISMA standards for reporting systematic reviews.[20]

Search strategy and results of search

The search of electronic databases was comprehensive and included the Cochrane Central Register of Controlled Trials (CENTRAL) on *The Cochrane Library*, MEDLINE (1950–2011), EMBASE (1980–2011), PsycINFO (1980–2011), CINAHL (1982–2011), Web of Science and Google (to September 2012*). Key search terms included combining *diagnosis (MeSH Diagnos*) with Death*, dying and care. End of life* was combined with Diagnos* and key words such as Recognis* and Instrument*. The search strategy is detailed in box 2. Results from Web of Science and Google were subsequently removed as the search of other databases was discriminating enough and these

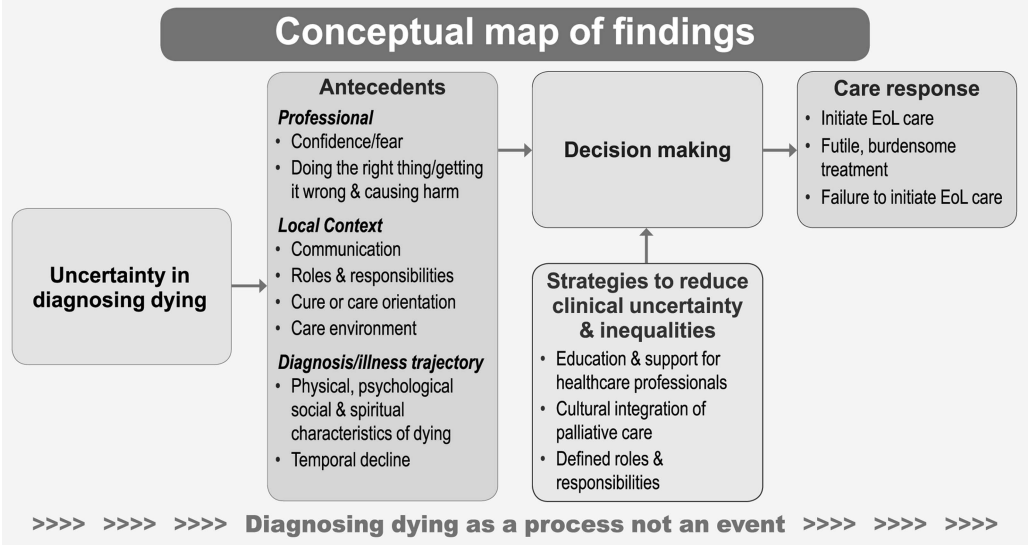

Figure 1 Conceptual map of findings.

Box 1 Methods of the integrative review

- Aims for the review are identified
- Criteria for including studies were identified
- Literature was identified according to an explicit and robust search strategy that was subject to ongoing refinement
- Studies were selected according to inclusion/exclusion criteria
- Studies were summarised using an agreed format and key messages were extracted
- Data extraction was undertaken by two reviewers
- We present a summary and synthesis of relevant studies
- Thematic analysis was an ongoing and iterative process involving all team members.

two databases did not allow us to combine the MeSH and key search terms resulting in an unmanageable numbers of irrelevant hits.

Box 2 Search strategy

1. (Death AND (Sign* OR symptom*))
2. (Dying AND (Sign* OR symptom*))
3. 1 OR 2
4. 3 AND Diagnos*
5. 3 AND Recognis*
6. 3 AND Assess*
7. 3 AND Tool
8. 3 AND Instrument*
9. 3 AND Criteria
10. 3 AND Pathway*
11. 3 AND Care
12. 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11
13. End of Life AND Diagnos*
14. End of Life AND Recognis*
15. End of Life AND Assess*
16. End of Life AND Tool
17. End of Life AND Instrument*
18. End of Life AND Criteria
19. End of Life AND Pathway*
20. End of Life AND Care
21. 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20
22. 12 AND 21
23. 22 AND Palliative
24. 22 AND Terminal*
25. 22 AND Final
26. 22 AND Cancer*
27. 22 AND Coronary
28. 23 OR 24 OR 25 OR 26 OR 27
29. Limit 28 to Human, English Language, 2001–2011, and Primary Studies, Meta-Analyses, Systematic Reviews, RCTs, Europe, North America, Australasia.

We included systematic reviews, qualitative and quantitative studies that explored how patients are judged by clinicians as being in the final hours or days of life. The population investigated was adult patients with progressive life-limiting illness in hospital, hospice, community or care home settings. Our focus was to establish what factors influence clinical decision making by health professionals in determining when a patient is in the dying phase, including any tools, triggers or guidance. Papers that focused on the transition to palliative care and prognostication were excluded, as beyond our aim to extract data relevant to the last hours or days of life. Literature about the LCP was included where this considered diagnosing dying and therefore met the inclusion criteria for the review.

The search included literature published since 2001 in English from Europe, North America and Australasia as these were judged to be culturally relevant to a European context. A 10-year timescale was considered sufficient to ensure comprehensive coverage and currency of relevant literature given the increasing emphasis during this timeframe on planning end-of-life care. The initial search strategy generated 576 titles. In total, 245 titles were excluded due to being duplicates or not relevant to the overall aims of the review by three reviewers (CK, CG and PBY) who screened the original yields from the searches. These three reviewers independently reviewed 331 abstracts and agreed initial inclusion of papers in the review at a consensus meeting. In addition to the place and year of publication, papers had to explore diagnosing dying (the dying phase: last hours or days of life) in adults rather than the transition to palliative care where prognosis was a longer term. At this stage, 42 papers were identified and further scrutinised. Nineteen papers were excluded because they did not present data about the last hours and days of life and this rendered 23 papers for inclusion (figure 2). Searches of grey literature identified a number of conference posters and some work in progress. Authors were contacted where possible, but this yielded insufficient or no further data for inclusion.

Review process and quality assurance

Once the 23 papers for inclusion were identified, the eight reviewers were paired and each pair reviewed 5–6 studies through extracting key data and findings using a preformatted table (see online supplementary table S1). This was an important part of the quality assurance process as ensuring all reviewers used a consistent approach to data extraction. Reviewers first read their allocated studies independently then agreed findings with a partner, which were presented in a summary table. This produced 23 summaries, one for each included study. We used the SIGN hierarchy of evidence to assign a quality rating to the papers in order to allow us to draw conclusions and make an

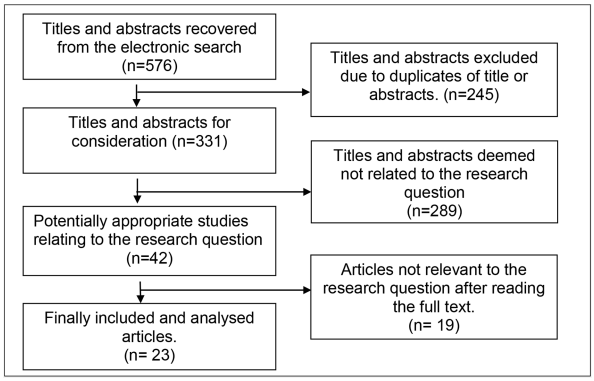

Figure 2 Search results.

overall judgement about the quality of evidence available in the field. All reviewers received detailed summaries of all the included papers and then participated in the refinement of themes and a conceptual framework initially developed by three reviewers (CK, CG and PBY). Robust methods were employed throughout the review, with analysis an ongoing and iterative process involving all team members. This included two full-team consensus meetings via teleconference, in addition to ongoing dialogue and feedback via email.

RESULTS

A central overarching theme of uncertainty in diagnosing dying emerged, alongside two subthemes, *characteristics of dying* and *treatment orientation*. What follows is the presentation of the thematic and conceptual findings from the review process.

Review findings on 'characteristics of dying'

Thirteen papers identified characteristics of dying: one systematic review,[21] seven retrospective chart reviews,[22–27] two qualitative studies,[28 29] one structured interview study,[30] one quantitative study,[31] one literature review[32] and one survey.[33] The review by Plonk (2005) included all research relevant to death, terminal care and bereavement available on Medline between 1990 and 2004; two studies focused on older people in the nursing home setting[29 30] and four studies focused on cancer (Ethunandan *et al* 2005):[24 25 27 31] one on patients with stroke (Mazzocato *et al* 2010)[26] , three on both cancer and other long-term conditions (Goodman *et al* 2002)[23 28 32], one on amyotrophic lateral sclerosis (ALS)[22] and one on medical decision making at the end of life.[33]

Findings from these studies demonstrate dying trajectories that incorporate physical, social, spiritual and psychological decline towards death and the extent to which each study dealt with these varied.

Physical characteristics included symptoms such as dyspnoea, which was correlated with shorter survival across cancer and other diagnoses such as ALS and may be a marker of the final phase of the dying process.[22 23] Chart reviews of 42 patients with stroke showed multiple causes of dyspnoea such as aspiration pneumonia or cardiac failure, which were a major or a contributing cause of death in 78% of these patients.[26] Physical decline and symptoms such as pain, loss of appetite and increased dependency are also reported as more prevalent shortly before death in patients with cancer.[31]

Glioma patients have particular physical rather than psychosocial symptoms such as decreased level of consciousness, dysphagia, neurological deficit and seizures in the last phase of life. Tailored guidelines may then be required for this group of patients to inform anticipatory care planning and treatment decisions at the end of life.[25 27]

A number of studies identified that for both cancer and non-cancer patients psychosocial characteristics were present but received less attention at the end of life. These included issues with coping, struggling with the meaning and purpose of life, impaired cognition and conscious level.[28–31] While the relationship between physical and psychosocial symptoms such as pain and existential or psychosocial suffering remains poorly studied, there is increasing evidence of medical interventions at the end of life.[21 33]

The relationship between physical and psychosocial symptoms also emerged in a UK study of patients with heart failure (n=24) and patients with lung cancer (n=24). Issues relating to the meaning and purpose of life may be perceived by patients as more important than physical well-being, symptoms or support near the end of life. As physical symptoms increased, there was a parallel decline in social well-being, with social withdrawal identified as an independent marker of the immanence of death. In patients with lung cancer, the physical and social care trajectories were interlinked with psychological and spiritual issues and this became more evident at times of transition, including to the final phase of the illness. Similarly, for patients with heart failure, social and psychological decline ran in parallel with physical deterioration.[28] As noted for patients with head and neck cancer (N=32), insufficient recording of the psychosocial and spiritual aspects of care means that the 'complete quality of dying' experience cannot be assessed.[24]

The influence of perceived suffering on medical decision making was revealed in a large survey (n=20 480) of doctors across six European countries.[33] The proportion of deaths preceded by decisions made in response to suffering (as perceived by the doctors rather than an explicit request from the patient) varying between 23% (Italy) to 51% (Switzerland). Sudden and unexpected death occurred in about a third of cases in all six countries. The administration of drugs with the explicit intention of hastening death varied between countries: about 1% or less in Denmark, Italy, Sweden and Switzerland; 1.82% in Belgium and 3.40% in the Netherlands.

Residents in nursing homes experience high rates of physical and emotional symptoms at the end of life, which may not be well-managed, as in this setting the interpretation of 'comfort care' can vary and end-of-life care needs may not then be recognised or addressed.[29 30] In the frail elderly, physical indicators were identified as anorexia, increased pain, greater frailty or weakness, weight loss, altered breathing patterns (including apnoea), mottled skin and a distinctive odour. Behavioural indicators include personality and mood changes, with increased restlessness, anxiety or agitation described as characteristics of the final decline to death. Withdrawal from conversation with staff and a new tendency to decline social interaction with other residents or family members was also identified. For people with dementia, an integrative literature review highlighted a range rather than definitive characteristics of dying and little consensus regarding the value of prognostic indicators.[32]

One study explored the application of the Palliative Performance Scale (PPS) to predict death/length of survival in a hospital setting for patients with cancer (n=157) and other diagnoses (n=104). Health professionals were more likely to regard cancer as a terminal illness than other groups, and while the PPS was useful in describing mortality risk across populations, it is less useful for predicting death in individual patients.[23]

The included studies identified a range of physical and psychosocial characteristics of dying. There was variability in recording and measurement including factors such as severity and progression rate. No definitive criteria for diagnosing dying were identified across all patient groups. Professional decision making may also be influenced by the diagnosis of the patient and care setting. A cancer diagnosis may prompt the health professional to look for confirming evidence that death may be imminent as opposed to other life-limiting conditions, particularly in frail older people who may receive comfort, rather than end-of-life care. Evidence also suggests that a focus on physical symptoms may also support the tendency towards ongoing biomedical interventions despite the imminence of death. This is explored further in the second subtheme; treatment orientation.

Review findings on 'treatment orientation'

Ten papers reported findings on the factors influencing end-of-life decision making including diagnosing dying, care and symptom management. Methodologies were two case reviews,[34 35] one exploratory interview study,[36] two mixed methods,[37 38] one quantitative study,[39] one retrospective cross-sectional survey of bereaved relatives,[40] one qualitative study,[41] one action research study[42] and one case review of patients on LCP.[43]

Findings from these papers suggest that while nurses and doctors may diagnose dying or report being able to do so, medically futile interventions may be continued in the very last phase of life.[36–38] Where poor prognosis and the dying phase was recognised and documented, there was still little evidence of systematic planning for end-of-life care. Consequently, diagnostic testing and unnecessary interventions were continued in the last 24 h of life.[37] A German study of medical and nursing practice in caring for dying patients (n=252) in a large hospital identified that plans for end-of-life care were implemented rarely and late. Fifty-two per cent of patient died in ICU with a focus on life-prolonging interventions evident.[34] In Italy, a review of the medical and nursing records of the last 3 days of life for 370 patients reported that patients were exposed to invasive treatments despite close proximity to death and with palliative care expertise sought in only 7% of cases.[38] Large variations have also been recorded regarding the extent to which decisions are discussed with patients, relatives and other caregivers and the need for much greater involvement of patients and families in end-of-life decision making acknowledged.[33]

The influence of diagnosis on professional responses was also identified from a survey of bereaved carers.[35] In contrast to patients with cancer, those with other life-limiting illnesses were less likely to be diagnosed as dying and more likely to be moved to hospital prior to death.[40] Older patients in the end stages of heart failure or dementia admitted through accident and emergency departments (n=102) have been reported as disadvantaged in relation to timely end-of-life care.[35]

Three included papers were linked to implementation of the LCP.[41–43] A retrospective review of patient data (n=168) in one hospice reported the LCP entry criteria as appropriate for a cancer population; combining multiprofessional team agreement that the patient is dying with additional criteria including bedbound, semi-comatose and only able to take sips of fluid.[43] These criteria were supported by a phenomenological study of hospice doctors and nurses (n=10), which also highlighted the influence of additional factors. These included understanding the individual patient's history, the experience of the clinician and the views of family and carers. Staff experienced anxiety over potential misiming of the LCP and causing distress for patients and families. The authors suggest the risk that clinicians may then avoid difficult conversations with families struggling to accept the reality of dying.[41] An action research study in eight UK nursing homes identified a functional rehabilitative culture and that staff lacked knowledge and skills related to diagnosing dying and end-of-life care that made implementation of the LCP challenging, requiring a cultural shift, change to care processes and facilitative education.[42]

Implementation of the Inpatient Comfort Care Program (ICCP) (preintervention n=108;

postintervention n=95) suggests it may be possible to introduce palliation in hospital units focused on curative interventions that positively impacts on end-of-life care, although the primary outcomes stated are linked to physical as opposed to psychosocial symptoms. The primary process of care, presence of an order for opioid medication at the time of death, showed a highly significant change from 57.1% to 83.2%. Presence of a do not resuscitate order at the time of death increased from 61.9% to 85.1%, with indicators that most of the dying patients were recognised and their preferences for end-of-life care documented to 90.8%. Improved documentation suggested that the intervention was successful in stimulating staff to recognise symptoms and better identify patients who are dying.[39]

It is noteworthy that seven of the papers focus on acute hospital settings, and despite the limited number of studies, decision making related to diagnosing dying in this setting may remain focused towards biomedical interventions rather than systematic planning for end-of-life care. There is some evidence, however, that while factors such as the context of care and the diagnosis of the patient may influence decision making, measures including education and supportive care processes can facilitate appropriate end-of-life care.

Conceptual map of key findings

Synthesis of the findings revealed a number of antecedents to decision making and possibilities for action. The conceptual framework (figure 1) provides a visual representation of the possible relationships between decisions, responses and strategies that are influenced by the clinical context. The evidence of active medical intervention rather than end-of-life care reported in several studies we interpreted as resulting from 'uncertainty in diagnosing dying' due to a number of factors that can influence decision making and responses. Care orientation in an acute hospital is more likely to result in active treatment as opposed to the nursing home, where comfort or rehabilitative care may be the focus. Our findings demonstrate that diagnosis is important, with cancer linked to more explicit recognition of dying than other life-limiting illnesses. Professionals' expertise in end-of-life care is also important in determining their course of action.

DISCUSSION

The overarching theme of 'uncertainty in diagnosing dying' is representative of the current discourse within literature and echoes our limited understanding of what constitutes a 'good death'.[24] It also reflects a tendency towards continued unnecessary interventions and treatment into the last days of life, even when nurses and doctors recognise death is imminent.[44]

The complexity of identifying clinical indicators of dying across different diseases supports the drive towards care based on needs rather than diagnosis.[21 37] However, expanding our understanding of the characteristics of dying for different patient groups is important to support thorough and comprehensive clinical assessments, determining whether reversible causes for decline are present and can be addressed or whether death may be imminent.[45] Of consideration, however, is the need for consensus regarding terminology. A range of terms may be used for the final phase of life, with varied and often implicit rather than clearly stated definitions, which can confound synthesis of evidence and cause ambiguity in relation to care goals.[46]

Of relevance to the current discourse regarding the LCP, this review has highlighted a range of contextual factors that may influence diagnosing dying reflecting calls for research in this area.[14 47] The first randomised controlled trial to assess the effectiveness of the LCP reported no significant difference in the overall quality of end-of-life care for people with cancer and highlighted the influence of contextual factors.[9] The authors also question whether focusing only on the last few hours or days of life may influence optimum management for those with difficult symptoms and communication with the family. This reflects earlier discourse from 2001 and further supports the need for clarification of current definitions to reflect the temporal nature of dying.[43]

For patients and families, planned care in place of choice, time with loved ones to say goodbye and being prepared to die are recognised as important at the end of life.[31] Yet, even when death may be imminent, there remains a tendency for professionals to avoid or postpone related conversations, reflecting the reality that many care decisions are informed by role and personal world views.[36]

The importance of exposing uncertainty in diagnosing dying cannot be overly emphasised. It is an important consideration for the individual clinician and the healthcare team, but equally for patients and carer(s). Allowing the possibility of death to be acknowledged and any plan of treatment to be discussed realistically gives precious time for the patient and family to express their preferences. This facilitates an individualised plan of care, particularly where no restorative treatment is possible or further decline would herald the end of life. Paradoxically, being open about uncertainty may support planning and build trust with the patient and their carer(s), removing the need to rely on a 'tick box' approach to diagnosing dying.[14 45]

Thus, strategies used to reduce uncertainty should reflect that decision making is influenced by clinical skills, professional judgement and clinical wisdom. In this context, clinical wisdom describes a depth of intuitive expertise, reflective of a strong skill base, which frames the decision-making process. Clinical wisdom is evident when symptoms are potentially reversible or

when the reality of dying is in evidence and a decision on the right course of action is needed. Clinical wisdom assists in determining appropriate goals of care and interventions to ensure that the patient's wishes are met and a dignified death is achieved.[48]

CONCLUSION

The findings of this review support the explicit recognition of 'uncertainty in diagnosing dying' and the need to work with and within this concept. Clinical decision making needs to allow for recovery where that potential exists, but equally there is the need to avoid futile interventions. This requires contextual factors to be addressed, reliable care processes and systems and education for healthcare professionals alongside raising public awareness of issues related to death and dying.

Most of the included studies were based on retrospective case reviews or small qualitative studies and scored low/moderate quality ratings, and the findings should be viewed in this context. The search strategy and methods for synthesising a disparate collection of studies have limitations. However, we have reported our methods in detail and consistent patterns emerged to illustrate important insights into diagnosing dying. The conceptual map requires further testing and refinement but provides a basis for further exploration. It also has the potential to provide a framework for discussion in clinical teams around strategies for improvement in diagnosing dying.

Author affiliations
[1]Department of Nursing and Midwifery, University of Limerick, Edinburgh Napier University, Limerick, Ireland
[2]Edinburgh Napier University NHS, Edinburgh, UK
[3] Edinburgh Napier University, Edinburgh, UK
[4]University College Dublin, Dublin, Ireland
[5]All Ireland Institute for Hospice and Palliative Care/University College Dublin, Dublin, Ireland
[6]University of Karlstad Universitetsgatan 2, Karlstad, Sweden
[7]University of Karlstad Universitetsgatan 2, Karlstad, Sweden
[8]Department of Palliative Medicine, St Columba's Hospice, Edinburgh, UK

Contributors CK planned the review. CBG, PB-Y and CK scrutinised the searches and agreed papers for inclusion in the review. All authors participated in the review of papers. CK constructed the initial conceptual framework, and this was subsequently refined in discussions with all team members. CK drafted the manuscript with the exception of the section on uncertainty that was drafted by PL and MC. All authors agreed on the content of the final manuscript.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

1 Clark D, ten Have H, Janssens R. Common threads? Palliative care service developments in seven European countries. *J* Palliat Med 2000;14:479–90.
2 Flores A, Brasch S, Giordano A, *et al*. Facts and indicators on palliative care development in 52 countries of the WHO European region. *J Palliat Med* 2007;21:463–71.
3 National Audit Office. End of Life Care: Report by the Comptroller and Auditor. http://www.endoflifecareforadults.nhs.uk (accessed Jun 2013).
4 Scottish Government. Living & Dying Well: Building on Progress. http://www.scotland.gov.uk (accessed Jun 2013).
5 Department of Health. End of Life Care Strategy: Third Annual Report. http://www.dh.gov.uk (accessed Jun 2013).
6 Scottish Government. Shaping Bereavement Care: A Framework for Action. http://www.scotland.gov.uk (accessed Jun 2013).
7 Marie Curie Palliative Care Institute. The Liverpool Care Pathway for the Dying Patient. http://www.mcpcil.org.uk (accessed Jun 2013).
8 Marie Curie Palliative Care Institute. LCP: International Programme. http://www.mcpcil.org.uk (accessed Jun 2013).
9 Constantini M, Romoli V, Di Leo S, *et al*. Liverpool care pathway for patients with cancer in hospital: a cluster randomised trial. *Lancet* 2014;383:226–37.
10 Horey D, Street A, Sands A. Acceptability and feasibility of end-of-life care pathways in Australian Residential aged care facilities. *Med J Aust* 2012;197:106–9.
11 Marie Curie Palliative Care Institute. National Care of the Dying Audit Hospitals. http://www.mcpcil.org.uk/liverpool-care-pathway/national-care-of-dying-audit.htm (accessed Jun 2013).
12 Ellershaw J, Ward C. Care of the patient in the last hours of life. *BMJ* 2003;326:30–4.
13 Taylor P. Recognizing dying in terminal illness. *Br J Hosp Med (Lond)* 2011;72:446–50.
14 Government UK. A Review of the Liverpool Care Pathway. More Care, Less Pathway. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (accessed Jul 2013).
15 Scottish Government. The Liverpool Care Pathway. http://www.scotland.gov.uk/Topics/Health/Quality-Improvement-Performance/Living-Dying-Well/Liverpool-Care-Pathway (accessed Dec 2013).
16 Department of Health Australia. The National Palliative Care Strategy—Supporting Australians to Live Well at the End of Life. https://www.health.gov.au/internet/main/publishing.nsf/Content/A87BC5583161BEBFCA257BF0001D3AF6/$File/NationalPalliativeCareStrategy.pdf (accessed Dec 2013).
17 The Cochrane Collaboration. Cochrane Handbook for Systematic Reviews of Interventions. http://www.tectutorials.com/Resources/AHRQ%20Modules/UoCTrainingMaterials/CochraneHB/booktext.pdf (accessed July 2013).
18 SIGN. Policy Statement on the Grading of Recommendations in SIGN Guidelines. http://www.sign.ac.uk/pdf/SIGN_grading.pdf (accessed July 2013).
19 Whittlemore R, Knafl K. The integrative review: updated methodology. *J Adv Nurs* 2005;13:546–53.

20 Moher D, Liberati A, Tetzlaff J, *et al*. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009;151:264–9.
21 Plonk W, Arnold R. Terminal care: the last weeks of life. *J Palliat Med* 2005;8:1042–54.
22 Mandler RN, Anderson FA, Miller RG, *et al*. The ALS patient care database: insights into end of-life care in ALS. *Amyotroph Lateral Scler Other Motor Neuron Disord* 2001;2:203–8.
23 Oludamilola O, Hanson L, Usher B, *et al*. Validation of the palliative performance scale in the acute tertiary care hospital setting. *J Palliat Med* 2007;10:111–17.
24 Ethuandan M, Rennie A, Hoffman G, *et al*. Quality of dying in head and neck cancer patients: a retrospective analysis of potential indicators of care. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 2005;100:147–52.
25 Sizoo E, Braam L, Tjeerd J, *et al*. Symptoms and problems in the end-of-life phase of high-grade glioma patients. *Pub and Neuro-Onc* 2010;12:1162–6.
26 Mazzocato C, Michel-Nemitza J, Anwara D *et al*.The last days of dying stroke patients referred to a palliative care consult team in an acute hospital. *Eur J Neurol* 2010;17:73–7.
27 Pace A, Di Lorenzo C, Guariglia L, *et al*. End of life issues in brain tumor patients. *J Neurooncol* 2009;91:39–43.
28 Murray S, Kendall M, Grant E, *et al*. Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. *J Pain Symptom Manage* 2007;34:393–402.
29 Waldrop D, Kirkendall A. Comfort measures: a qualitative study of nursing home-based end-of-life care. *J Palliat Med* 2009;12:719–24.
30 Reynolds K, Henderson M, Schulman A, *et al*. Needs of the dying in nursing homes. *J Palliat Med* 2002;5:719–24.
31 Georges J-J, Onwuteaka-Philipsen BD, van der Wal G, *et al*. Symptoms, treatment and "dying peacefully" in terminally ill cancer patients: a prospective study. *Supp Care Canc* 2005;13:160–8.
32 Goodman C, Evans C, Wilcock J, *et al*. End of life care for community dwelling older people with dementia: an integrated review. *Int J Geriatr Psychiatry* 2010;25:329–37.
33 Van der heide A, Deliens L, Faisst K, *et al*. End-of-life decision-making in six European countries: Descriptive study. *Lancet* 2003;362:345–50. http://image.thelancet.com/extras/03art3298web.pdf
34 Becker G, Sarhatlic R, Olschewski M, *et al*. End-of-life care in hospital: current practice and potentials for improvement. *J Pain Symptom Manage* 2007;33:711–19.
35 Formiga F, Olmedo C, Lopez-Soto A, *et al*. Dying in hospital of terminal heart failure or severe dementia: the circumstances associated with death and the opinions of caregivers. *J Palliat Med* 2007;21:35–40.
36 Johnson DC, Kutneri JS, Armstrong JD. Would you be surprised if this patient died?: Preliminary exploration of first and second year residents' approach to care decisions in critically ill patients. *BMC Palliat Care* 2003;2:1.
37 Jacobs LG, Bonuck K, Burton W, *et al*. Hospital care at the end of life: an institutional assessment. *J Pain Symptom Manage* 2002;24:291–8.
38 Toscani F, Di Giulio P, Brunelli C, *et al*. How people die in hospital general wards: a descriptive study. *J Pain Symptom Manage* 2005;30:33–40.
39 Bailey AF, Burgio KL, Woodby LL, *et al*. Improving processes of hospital care during the last hours of life. *Arch Intern Med* 2005;165:1722–7.
40 Burt J, Shipman C, Richardson A, *et al*. The experiences of older adults in the community dying from cancer and non cancer causes: a national survey of bereaved relatives. *Age Ageing* 2010;39:86–91.
41 Dee JF, Endecott R. Doing the right thing at the right time. *J of Nurs Man* 2011;19:186–92.
42 Watson J, Hockley J, Dewar B. Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *Int J Palliat Nurs* 2006;12:234–40.
43 Ellershaw J, Smith C, Overill S, *et al*. Care of the dying: setting standards for symptom control in the last 48 hours of life. *J Pain Symptom Manage* 2001;21:12–17.
44 Haig S. Diagnosing dying: symptoms and signs of end-stage disease. *End of Life Care* 2009;3:4:8–13.
45 Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. *Clin Med* 2004;4:39–44.
46 Junger S, Payne S, Brearley S, *et al*. Consensus building in palliative care: a Europe-wide Delphi Study on Common understandings and Conceptual Differences. *J Pain Symptom Manage* 2012;44:192–205.
47 McConnell T, O'Halloran P, Porter S, *et al*. Systematic realist review of key factors affecting successful implementation and sustainability of the Liverpool care pathway for the dying patient. *Worldviews Evid Based Nurs* 2013;10:218–37.
48 Francis R. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf (accessed Aug 2013).