

End of Life Care Definitions and Triggers for Assessment

A summary and discussion of the literature



AUTHOR:

Dr Stephen J.O'Connor

JULY 2016

Table of Contents	Page
	ABSTRACT
	2
	1.0 INTRODUCTION
	3
	2.0 METHODOLOGY
	3
	3.0 FINDINGS
	4
3.1 Distinguishing end-of-life care from palliative and supportive care	4
3.2 Definitions of end-of-life care	7
3.3 Further definitions from the literature	12
3.4 Death trajectories and ambivalence about end-of-life care discussion	16
	4.0 TRIGGERS TO END-OF-LIFE ASSESSMENT
	22
4.1 The problem with prognostication when death is ‘imminent’	22
4.2 Studies predicting mortality in the longer term	25
	5.0 CONCLUSIONS AND RECOMMENDATIONS
	28
	6.0 REFERENCES
	31
	7.0 APPENDICES
	38
7.1 Psychosocial indicators that death may be expected	38
7.2 Six-month MDS Mortality Risk Index	39
	LIST OF TABLES
Table 1: Summary of main end of life definitions	11
Table 2: Quality of life attributes ranked by order of importance	15
Table 3: Frequency and Scores for Variable Entry into the Algorithm Data Set	27

Abstract

This report was commissioned by the NHS National Programme Director for End of Life Care in 2008 to inform the development of national policy regarding end of life care prior to the controversy surrounding misuse of the Liverpool Care Pathway (Ellershaw and Wilkinson, 2003) and its subsequent discontinuation from use in clinical practice. It was situated on the Department of Health's webpages for end of life care until taken down following internal reorganisation of the website and the redistribution of responsibility for end of life care within the National Health Service some years later. The subject of end of life prognostication was as sensitive then as it is now, although in many respects, it is much more visible as a subject for social, political and academic debate these days, not least because of the many examples contained within subsequent reviews of the Liverpool Care Pathway's misuse by clinicians or practitioners who failed in some instances to fully understand the importance of 'diagnosing dying' before putting individuals onto the care pathway, and their failure to heed the very first rule of its use, namely; that such decisions should always be discussed with those who were dying and their close family members *before* putting them on the pathway wherever possible.

It is my view that the majority of clinical interventions contained within the Liverpool Care Pathway for the Dying were, and continue to be clinically sound when used appropriately; although the evidence base for some of them remains sparse, and it is an area of practice which continues to be massively under-resourced and under-researched even to this day. Rather, the problem in many publicised cases outlined in the wake of the Liverpool Care Pathway controversy lay in the inability of clinicians to prognosticate accurately which, when combined with a natural aversion to having difficult conversations with patients and family members, and the lack of investment or interest in palliative and end of life education led to inevitable mistakes occurring. I still recall the evident glee of one manager who called me to explain why she was withdrawing staff members from an end of life programme I was running because the 'LCP' was being introduced into her ward and that was all that was needed to provide good end of life care while reducing her training budget. We clearly know better now, but the clinical science of prognostication, or 'diagnosing dying' which I much prefer, is notoriously imprecise, not least because people die from myriad causes, each of which have their own unique dying trajectories although other biopsychosocial factors also play their part in the way and speed with which any given individual will deteriorate at the end of life.

The review undertaken was neither funded nor intended to be a comprehensive systematic review of the literature, but rather a twenty-page summary and starting point for discussion about the way in which we recognise that someone is dying and how we could or should respond to that fact. The need for discussion is as pertinent today as it was then, not least because of the fact that more patients and family members expect us to have answers to these questions, though clearly this is still a work in progress for many of us and will continue to be until we fully understand the benefits of having such conversations with them.

1.0 Introduction

It has been estimated that approximately 280 people per 100,000 die from cancer each year in the UK of whom 25–65% will require help from a palliative care support team and 15–25% will receive inpatient hospice care. Over twice this proportion (690 per 100,000) will die from non-malignant causes in the same time, and whilst a small proportion of these will die suddenly without warning, the majority will have predictable signs that their underlying circulatory, respiratory or neurological conditions are worsening (Murtagh et al., 2004). Whilst little may be done to reverse these conditions by this stage, there is considerable evidence that the symptoms associated with end-stage disease may be successfully alleviated after a thorough end-of-life care assessment and the provision of appropriate palliative or end-of-life interventions aimed at both these and the support needs of patients and their carers. There is little agreement however, as to what constitutes end-of-life care or the optimum time at which such an assessment should take place. This review of the literature was therefore commissioned by the National Programme Director for the NHS End-of-life Care Programme to provide a summary of the ways in which end-of-life care is currently defined, and to identify the factors currently used to trigger an end-of-life assessment.

2.0 Methodology

A series of searches using MEDLINE, CINAHL, CancerLit, PsychInfo and the Applied Social Science Index (ASSIA) from 1995 to 2008 was conducted using the search terms: *end-of-life, palliative, terminal, hospice, death and dying* connected by the Boolean operator 'or'. These search terms were combined using the Boolean operator 'and' with the following secondary search terms: *defin*, prognos*, diagnos*, predict*, identify*, indicat** again connected by the Boolean operator 'or'. These terms were used to identify papers using the terms: definitions, defining, prognosis, prognostication, diagnosing, diagnosis, predict, predicting, identify, identifying and indicators in relation to the first set of search terms in the title or abstract of the literature.

The search was undertaken between August and November 2008 and was limited to English language papers. An initial screening process looking at the papers' titles was then conducted. The vast majority of papers were rejected and no single paper claimed to have investigated existing definitions of end-of-life care as its sole focus. As a result of this, the abstracts of 568 papers were then sampled. Sixty-two papers were then chosen on a theoretical sampling basis as it was often impossible to determine whether the papers contained a definition of end-of-life care or not. Most did not, and many others alluded to the same few definitions, most notably those originating in the work of Lynn and colleagues (Lorenz et al., 2008; Lorenz et al., 2006; Lynn and

Goldstein, 2003; Lynn et al., 2002; Lunney et al., 2002; Lynn, 2000; Hoffman et al., 1997; Lynn et al., 1997). Twenty-nine papers looking at prognostication were selected with regard to the second objective of the review and a supplementary search of articles in press was also conducted on Elsevier's ScienceDirect and Wiley-Blackwell's WileyInterscience search engines to identify any papers currently in print using the same criteria. Review of the selected papers' reference lists revealed another 19 papers, and a search of the gray literature, including personal communication with the author of one set of papers identified a further four papers including the draft copy of an article not yet submitted for peer review.

3.0 Findings

3.1 Distinguishing end-of-life care from palliative and supportive care

Interest in end-of-life care as a separate and distinctive entity from palliative or terminal care has its origins in North America and in particular, the work of Joanne Lynn and her colleagues (Lorenz et al., 2008; Lorenz et al., 2006; Lynn and Goldstein, 2003; Lynn et al., 2002; Lunney et al., 2002; Lynn, 2000; Hoffman et al., 1997; Lynn et al., 1997). It is becoming increasingly influential in determining health policy for those with life-limiting illness (NHS Confederation, 2005), and for those whose life is coming towards its natural conclusion, particularly in the elderly (National Institute for Clinical Excellence, 2004; Department of Health 2003). However, the term itself is somewhat ambiguous, and has been variously used to describe the care given to patients in the last year, months, weeks, days, or even hours of life depending upon the nature of the care setting or the stance of individual researchers themselves (Payne et al., 2002). Froggatt and Payne (2006) point to the disparate nature of two common tools used within the UK to enhance the care of dying patients by way of an exemplar in this respect, the first being the Liverpool Care Pathway for the Dying (Ellershaw and Wilkinson, 2003) which outlines the care to be provided to dying patients in the last few hours or days of life in a variety of in-patient care settings, and the Gold Standards Framework which provides the basis for optimum care delivery in the community during the final weeks or months of life. Indeed, the authors of the Gold Standards Framework go further, suggesting that it is *'concerned with helping people to live well until the end-of-life and includes care in the final year of life for people with any end stage illness.'* (Gold Standards Framework accessed 24th October, 2008 <http://www.goldstandardsframework.nhs.uk>).

This ambiguity is not helped by recent policy documents on the subject, one end-of-life care strategy (National Council for Palliative Care, 2006) arguing that, *'it may be useful to regard 'end-of-life care' as simply an everyday expression that may be easily understood by the general public and in that context does not require formal definition'* (p2). In line with this there is little evidence

in the literature reviewed that any large-scale prospective studies have been carried out to ascertain whether the meaning of the term is 'easily understood' by the general public as the document suggests, or the degree to which lay conceptualisations of the term accord with those of health professionals. Such research would indeed be difficult to undertake given that there is so little agreement about the meaning of the term amongst professional carers, although to its credit, the report does go on to assert that, *'this does not lessen the need to produce a common understanding of its meaning for health and social care professionals'* (p2).

Notwithstanding this, the document studiously avoids any attempt to do so in detail, arguing instead that its onset depends upon a variety of factors including the nature of the patient's final illness (its onset varying between those with cancer, organ failure, dementia and age-related frailty for instance), the personal or emic perspective of individual patients; and differences in the clinical or prognostic opinions of individual professionals which may vary enormously depending upon their clinical experience or philosophical stance. Haematologists for example, may have very different conceptions of when end-of-life care is appropriate than someone working in palliative care, oncology or other settings, and there is evidence that the views of haematology nurses may vary markedly from those of their medical colleagues in this respect, indicating that interprofessional as well as lay/professional differences of opinion on the topic may exist (Zimmermann, 2007; McGrath and Holewa, 2007; McGrath and Holewa, 2006; Boyce et al., 2003). The report's authors point out that clinical indicators too have been suggested, including weight loss, frailty, poor appetite, breathlessness, poor performance status, dependence upon others for assistance with activities of daily living and pain (Porock and Oliver, 2007; Porock et al., 2005; Della Santina and Bernstein, 2004; Elkington et al., 2004; Jacobs et al., 2002; Wilson, 2002; Nikoletti et al., 2000; Morris et al., 1990). Lorenz et al. (2008), Knause et al. (1995) and Fox et al. (1999) demonstrate the paucity of physician's prognostic abilities however, many doctors estimating during the patient's last week of life that they may live for a further two or even six months.

As a consequence of this, the best definition that the National Council for Palliative Care proffers in their report is that, *'end-of life care is simply acknowledged to be the provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life'* (p3); although again, neither the 'last phase of life' nor the time at which this commences is defined with any certainty. The authors do argue however, that *'in most cases, end-of-life care does not begin earlier than one year before death'* (p3), although no evidence is provided to support this claim and it is difficult to determine why they arrive at such a conclusion if they genuinely believe that end-of-life care is primarily the *'provision of supportive and palliative care*

in response to the assessed needs of patient and family, given that these needs may (and often do) arise before this arbitrary cut-off date. Indeed, if one looks at supportive care for example, the National Institute for Clinical Excellence (NICE) (2004) supports the view of the National Council for Hospices and Specialist Palliative Care Services (NCHSPCS) that supportive care for people with cancer is *'the comprehensive care of patients and their families from the time of diagnosis, or even pre-diagnosis, throughout both curative and palliative treatments'* (Ahmedzai et al., 2004 p2199). The NCHSPCS state on their own website that supportive care *'helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease'*, and *'should be given equal priority alongside diagnosis and treatment'*. NICE (2004) argue therefore, that contrary to much of the published literature, supportive care *'is not a response to a particular stage of disease, but is based on an assumption that people have needs for supportive care from the time that the possibility of cancer is first raised'* (p18).

Supportive care is very different from palliative care therefore, which is the *'person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends'* (Ahmedzai et al., 2004 p2192). Moreover, NICE make clear that they consider end-of-life care is, in many instances, a sub-speciality of specialist palliative care (itself a sub-speciality of supportive care) when stating that *'although palliative care encompasses many of the elements identified as 'supportive care', there are well-defined areas of expertise within specialist palliative care to which patients and carers may need access, such as interventions to respond to unresolved symptoms and complex psychosocial issues for patients with advanced disease, complex end-of-life issues [and] bereavement issues'* (NICE, 2004 p21 emphases mine). It is also clearly apparent that NICE regard end-of-life care as the care provided to cancer patients in the very final stage of their disease as, for example, in their exhortation that *'Commissioners should ensure that continuous support can be provided for patients in their homes as end-of-life approaches, in compliance with the wishes of patients and carers'* (p114).

It should be noted however, that the NICE guidelines are concerned solely with the provision of supportive, palliative (and by definition, end-of-life) care to patients with malignant disease, in which it may be easier to define a stage at which end-of-life care should begin, the obvious failure of treatment to keep the disease in check, tumour growth, recurrence or widespread metastases making this more obvious than the gradual and more subtle deterioration likely to take place in end-stage cardiac or pulmonary disease, progressive neurological disorders such as amyotrophic lateral sclerosis and motor neurone disease; or the insidious onset of Alzheimer's or Parkinson's disease with advancing age. Writing from a gerontology perspective, Froggatt and Payne (2006)

argue that the initiation of end-of-life care is contingent upon knowing that someone is dying, a process which *'can vary from a very short time period of hours or days before an individual dies to the last few years of a person's life'*, a period they argue which is *'more easily defined retrospectively than prospectively'* (p346).

3.2 Definitions of end-of-life care

The US National Institutes of Health (2004) argue that there is no exact definition of the end-of-life, and consequently, no formal definition of end-of-life care. They suggest that both terms are used appropriately where chronic disease is present, although the symptoms of this may be permanent or temporary in nature. They specify however, that the underlying disease process should be irreversible, and that the symptoms or impairments resulting from it require either professional, or informal family or volunteer care in the time leading up to death. The guidelines point out that advancing age, frailty and comorbidity may be surrogates for a life-threatening illness, but argue that end-of-life care should not be defined by a specific timeframe unless reliable prognostic evidence is available to support such a decision (as might be the case with some cancer deaths). The World Health Organisation (1998) define end-of-life care as *'the active, total care of patients whose disease is not responsive to curative treatment'*, and argue that the aim of care in such cases is, *'to attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family'*. This definition is supported in respect of lung cancer patients by Griffin et al (2003), and it is appropriate perhaps, that a definition which addresses each of the biopsychosocial domains affected by this complex illness should be preferred by this group of researchers.

Writing about end-of-life care in cancer patients, Hewitt and Simone (1999) argue that end-of-life care *'extends beyond physical symptoms to include supportive, psychological, spiritual and emotional care'* (p25), and suggest that this occurs *'when the goals of care shift to the quality of life and symptom relief'* (p25). Citing Lynn et al's (1997) seminal work, they point out that it includes *'the management of physical or emotional symptoms and limitation on functions, the provision of pain relief and palliation to improve or maintain quality of remaining life, counseling on the potential harm or benefit of aggressive life extending treatments, respite, social support and other services to relieve caregiver burden, advance care planning and bereavement support'* (p26). The relationship between end-of-life care and counselling against *'aggressive futile measures'* (especially amongst US long term care residents) has been commented upon by a number of writers, most notably Kane (2003) in a WHO publication on health in the elderly who suggests that *'end-of-life care is closely related to rationing in that it offers a way to limit expensive, perhaps futile care in an ethical context driven by consumer empowerment'*, although

he notes that, *'to the surprise of many investigators, many older people are not anxious to cede access to potentially life saving technology, even if the likelihood of benefits is slim'* (p77). It is essential therefore, that end-of-life care does not become associated with any policy agenda aimed at restricting patients' life (or death) choices in such a way if it is to be accepted by the general public as a *bona fide* attempt to improve (rather than restrict) care at the end-of-life.

Another oncology perspective on end-of-life care is provided by the European Society of Medical Oncology who define it as, *'palliative care when death is imminent'*. These authors argue that it is provided to *'patients who are imminently dying and their families who have very special and often intense needs which commonly require individualized and intensive clinical care'* at such a time (Cherny et al., 2003). Here the relationship with palliative care is once again reiterated, although end-of-life care is conceptualised as a specific intervention offered in the period immediately preceding death. This contrasts sharply with a definition contained in the Oxford Handbook of Palliative Care however, which states that end-of-life care *'usually refers to the care of a person during the last part of their life'*, which they regard as commencing at the point at which, *'it has become clear that the person is in a progressive state of decline'*. Unlike Cherny et al. however, the authors of this definition argue that, *'end-of-life care is usually a longer period than the time during which someone is considered to be dying'*, and point out that in the UK, the term is almost exclusively used by health care professionals in contrast to patients and their families who still tend to refer to *'terminal illness'* or *'terminal care'* when discussing end-of-life issues. The preference for the new terminology may owe more to professional concerns than patient sensitivity therefore, the more so as it is clear that patients and their families are increasingly confused by the multiplicity of terms and definitions now used to describe what they consider to be the same thing.

A cardiac perspective on end-of-life care is provided by Zambrowski et al. (2005), who suggest that end-of-life care is *'delivered in order to provide symptom relief, comfort and support to patients and their families as they cope with managing an illness when optimal treatments have failed to halt progression of the illness or relieve symptoms'* (p569). Like Cherny et al (2003), they use the notion of imminence to determine when end-of-life care should start, arguing that it is appropriate when *'the likelihood is thought to be high that death is imminent within the coming weeks to months'* (p569), and consider palliative care services as part of this provision. The emphasis upon physical symptoms is in stark contrast to that provided by the US Department of Elder Affairs however, who take a more holistic approach, defining it as *'care provided to meet the physical, psychological, social, spiritual, and practical needs of terminally ill patients and their caregivers'*. This conceptualisation is more similar to the Gold Standards Framework in the UK

which also takes a more holistic view of its purpose when saying that, *'end-of-life care is concerned with helping people to live well until the end-of-life and includes care in the final year of life for people with any end stage illness'*, but is at odds with a definition contained in Ferrell and Coyle (2001) that end-of-life care refers *'explicitly to the final weeks of life when death is imminent'* (p28).

In recent years, the scope for further confusion has been raised in the UK by a desire to separate 'generic' end-of-life care (i.e. that provided by generalists in the primary care sector) from that provided by specialist palliative care services. Shipman et al. (2008) report the result of a national consultation exercise in the UK which elicited the views of 210 health care professionals, commissioners, academics, and representatives of user and voluntary groups on end-of-life care and 'generic end-of-life care' using a modified nominal group technique. The response rate to invitations was 74% of those invited (210/285). Short semi-structured questionnaires standardised for use across five locations were used, and these were followed up by interviews with selected respondents. Questions included views about the generalist's role, specific local concerns, access, education, training, and support. The consultation's facilitators defined generalist end-of-life care as *'care provided by health or social care professionals other than those whose remit was specialist palliative care, and proposed that end-of-life care consisted of care provided within the last year(s) of life to anyone with an advanced progressive disease that was likely to shorten their life'*. There was little consensus amongst respondents however, about what end-of-life care or indeed, generalist end-of-life care meant, each having different meanings for some respondents and none at all for others. There was considerable variation in respondents' definitions of generic palliative care and some dispute about when this ought to commence. Some respondents argued that it might include the last year or more of a patient's life whilst others considered that it only concerned the last few days of a patient's life. One respondent thought that it might incorporate the last two years of a patient's life. As a consequence, the researchers' definitions of end-of-life care were not fully accepted, and the personal views of respondents varied enormously in terms of what generic end-of-life care meant, when it should begin, and how long a period might be involved.

Writing from an ethical perspective, Brook-Hamilton (2000) argues that end-of-life care can be defined as *'medical and other supportive care given to a person during the final six months of life'*, but he also notes that *'end-of-life care is also defined by the expectations of the patients and family as to the final period of the patient's life, thus the boundaries of what constitutes end-of-life care are not definite'* (p73). This blurring of the boundaries is even more likely if one accepts the US Institute of Medicine's assertion that quality experience at the end-of-life is *'one that is free*

from avoidable distress and suffering for patients, families and caregivers; in general accord with patients and families' wishes; and reasonably consistent with clinical, cultural and ethical standards' (p516). Papers emanating from the UK say little about social or cultural determinants of its meaning, although a number of studies assessing the importance of culture, ethnicity and social factors have been undertaken in the United States (Carr and Khodyakov, 2007; Brody and Hunt, 2005; Gabbay et al., 2005), and a broader discussion of such issues can also be found in Kellehear (2008) and Kemp (2005). Table 1 overleaf provides a summary of the main definitions discussed above. These show the similarities and differences between different conceptualisations of the subject within the literature - especially in respect of when end-of-life care should begin. Criticisms that the topic is poorly and inconsistently defined appear to be true from the results of this review, but it is also apparent that one definition is unlikely to satisfy the multivariate needs of so disparate a community of practice or adequately explain the complex and highly individual care needs of different patients.

Table 1: Summary of main end of life definitions

Source	Definition
Oxford Handbook of Palliative Care	<i>'the care of a person during the last part of their life [when] it has become clear that the person is in a progressive state of decline.'</i>
US Department of Elder Affairs	<i>'care provided to meet the physical, psychological, social, spiritual, and practical needs of terminally ill patients and their caregivers'</i>
World Health Organisation (1998)	<i>'the active, total care of patients whose disease is not responsive to curative treatment [intended] to attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family.'</i>
UK Gold Standards Framework	<i>'end-of-life care is concerned with helping people to live well until the end-of-life and includes care in the final year of life for people with any end stage illness.'</i>
An oncology perspective (European Society of Medical Oncology - Cherny et al, 2003)	<i>'delivered in order to provide symptom relief, comfort and support to patients and their families as they cope with managing an illness when optimal treatments have failed to halt progression of the illness or relieve symptoms [appropriate for] patients who are imminently dying and their families who have very special and often intense needs which commonly require individualized and intensive clinical care.'</i>
A cardiac perspective (Zambrowski et al., 2005)	<i>'care delivered in order to provide symptom relief, comfort and support to patients and their families as they cope with managing an illness when optimal treatments have failed to halt progression of the illness or relieve symptoms [when] 'the likelihood is thought to be high that death is imminent within the coming weeks to months.'</i>
A long-term care perspective (Lynn et al., 1997)	<i>'the management of physical or emotional symptoms and limitation on functions, the provision of pain relief and palliation to improve or maintain quality of remaining life, counseling on the potential harm or benefit of aggressive life extending treatments, respite, social support and other services to relieve caregiver burden, advance care planning and bereavement support.'</i>
A 'generic' end-of-life care perspective (Shipman et al., 2008)	<i>'care provided by health or social care professionals other than those whose remit was specialist palliative care, and proposed that end-of-life care consisted of care provided within the last year(s) of life to anyone with an advanced progressive disease that was likely to shorten their life.'</i>
An ethical perspective (Brook-Hamilton, 2000)	<i>'medical and other supportive care given to a person during the final six months of life [which] is also defined by the expectations of the patients and family as to the final period of the patients life.'</i>

3.3 Further definitions from the literature

Many papers studied during the course of this review failed to define what they meant by end-of-life care even as they bemoaned the absence of a clear definition. One early paper by Asch et al. (1997) which elicited the views of 468 critical care nurses in US hospitals found that the subject was a 'gray area' to 32% of the respondents questioned, although the paper itself offers no help by way of a definition of the term; and few others make any real attempt to define this important concept or variable in their papers. Mularski et al (2007) point out however, that end-of-life care encompasses many possible courses of action in order to arrive at an agreed plan of care, and claim to have used a 'broad definition' of the term in their review of 99 end-of-life outcome measures, although this definition is not to be found in their paper, a problem inherent in any search for end-of-life care definitions within the literature. They point out however, that prognostication is poor and imprecise for most non-malignant conditions, and argue that different diseases show different patterns of functional decline as the patient moves towards the end-of-life, indicating perhaps, their reluctance to define so elusive a concept in too precise a way. Steinhauser et al. (2000) argue meanwhile that whilst physicians focus upon the physical aspects of a patient's deteriorating condition, patients and their families tend to imbue the end-of-life with broader psychosocial and spiritual meanings which are shaped by a lifetime of experience and interwoven with personal and symbolic as well as spiritual meaning.

One paper by Nolan and Mock (2004) which considers the development of a new framework for end-of-life care uses instead, a definition contained within the US Institute of Medicine Report, *Describing Death in America* carried out by Lunney et al. (2003). This describes the end-of-life as *'the period of time during which an individual copes with declining health from an ultimately terminal illness, from a serious though perhaps chronic illness, or from the frailties associated with advanced old age – even if death is not clearly imminent'* (p22). This definition makes clear that end-of-life care needs to include the care of those with an identifiable terminal illness such as recurrent cancer, those illnesses regarded as chronic (though life threatening), such as pulmonary or cardiac disease, and those considered to be at an age (or approaching such an age) where death from as yet undiagnosed causes might reasonably be expected to occur. This is a very broad definition however, and the assumption that everyone covered in the list has similar end-of-life care needs is to be avoided wherever possible.

When discussing the provision of palliative care for people with chronic obstructive pulmonary disease (COPD) for example, Murray et al. (2006) point out that there is a *'stark contrast between the experiences and services available for people with advanced cancer and COPD'*, arguing that *'in the last year of life, patients with COPD have worse quality of life, greater limitation of activity,*

and more anxiety and depression than patients with lung cancer' (p363). Citing work by Gore et al. (2000), these authors draw attention to the fact that over 80% of patients with COPD are house-bound whilst a third of them are also chair-bound. In spite of this however, less than half of them have the mobility aids that might reduce their social isolation; and very few recognised as being at the end-of-life are offered an opportunity to discuss their prognosis or make informed decisions about their end-of-life care as cancer patients are likely to be. COPD is a good example therefore, of an illness in which gradual organ failure is marked by frequent, potentially severe exacerbations of the illness or superimposed infections, any of which may prove fatal (Murray et al., 2005; Lynn and Adamson, 2003). In such circumstances, Murray and his colleagues argue that death may occur suddenly and unexpectedly, long before a terminal prognosis has been made by doctors who are more likely to overestimate their patient's survival than underestimate it (Christakis and Lamont, 2000), and thus deny them the opportunity to discuss end-of-life issues with family members and those providing their medical and nursing care.

Describing this situation as 'prognostic paralysis' (Murray et al., 2005), these authors provide some helpful questions to help professional carers broach such issues with their patients including:

- What is the most important thing in your life right now?
- What keeps you going?
- You seem cheerful at present, but do you ever feel down?
- If things got worse, where would you like to be cared for?

To which I would also add, 'if things got worse, how far would you like us to go in maintaining your life knowing that these are unlikely to be successful or have unforeseen consequences?' They also advocate use of the 'surprise' question, i.e. '*would it surprise me if this patient were to die within the next six months*', and point out that the uncertain disease trajectory in COPD may help to facilitate conversations of this sort given that these questions can be asked relatively early within the last likely year of life without necessarily alarming the patient or making them feel that death is imminent. Unlike many other authors, Murray et al. (2006) also outline some clinical risk factors which should alert those caring for such patients to the need for such a conversation including:

- Hospital admission for severe exacerbation of COPD
- Being house or chair bound due to COPD
- Having a FEV1 of 30% or less
- Requiring long-term oxygen therapy
- A diagnosis of depression or poor quality of life

- Co-morbidities such as heart failure or diabetes
- A low body mass index.

One systematic literature review on the evidence base for improving palliative care outcomes at the end-of-life conducted by Lorenz et al. (2008) pointed out that there is inconsistent use of terminology when defining the end-of-life, and a variety of methods used to assess its onset, including clinician assessment that the patient is 'actively' dying, clinical characteristics, survival indices, and psychological preparedness or 'patient readiness' for death. These authors also point out that no precise definitions or performance characteristics of these terms have been published, and argue that clinicians may prefer to define the end-of-life as '*having a fatal condition, risking death with the next exacerbation*' or when the patient is, '*beginning to acknowledge the seriousness of the situation*' (p149-150). They suggest however, that waiting for near certainty would fail to identify most dying people and argue that an end-of-life care assessment needs to be conducted much earlier for many people living with serious life-threatening illness, and advocate that clinicians ask themselves the so-called 'surprise question' i.e. '*would it be a surprise if this patient were to die within the next six months*', a question which is being advocated widely, but also lacks rigorous testing although some anecdotal evidence for its utility exists.

One prospective cohort study made use of this question together with the Charlson Comorbidity Index and Karnofsky Performance Status scores to assess the likelihood of death occurring within a six month period in 147 haemodialysis patients (Moss et al., 2008). The study found that the mortality rate for the group least expected to die within six months was 10.6% compared to 29.4% for those expected to die within this timeframe. Although the numbers of patients dying was quite small (22 patients or 15% of the sample), those thought likely to die were 3.5 times more likely to do so than those expected to live (odds ratio 3.507, 95% CI 1.356 to 9.067, $P = 0.01$), leading the authors to conclude that the 'surprise' question is an effective identifier of mortality risk for patients undergoing dialysis. In general, patients expected to die were older (72.5 ± 12.8 versus 64.5 ± 14.9) and had a higher comorbidity score (7.1 ± 2.3 versus 5.8 ± 2.1) as well as a lower performance status score (69.7 ± 17.1 versus 81.6 ± 15.8), which indicates that clinician's intuitive judgements when asked this question may have some basis in objective measures of patients' age, comorbidity and functional status. However; another survey of 274 second year nephrology fellows of the American Medical Association found that 12% of respondents underestimated the annual mortality rate (20-29% per annum) of dialysis patients whilst 21% overestimated it; indicating that much needs to be done before those caring for renal patients feel competent to assess annual mortality risk in their patients (Holley et al., 2003), most respondents saying that

they felt significantly better prepared to manage haemodialysis than initiate discussions about end-of-life care or determine when this might be appropriate.

This finding is supported by the *Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments* (Knaus et al., 1995), which suggested that many renal patients die prolonged and sometimes painful deaths after receiving unwanted interventions long after these have become futile, physicians all too often appearing ill-equipped or lacking sufficient confidence to prevent this from occurring (Garvin and Chapman, 1995), and unaware that patients' priorities had changed by the time that treatment cessation became necessary (Steinhauser et al., 2000). The study by Steinhauser et al. asked patients (n=340), bereaved family members (n=332), physicians (n=361) and other care providers (n=429) to rate the importance of 44 quality of life attributes using a 5-point Likert scale. They also asked respondents to rank in order of importance 9 attributes derived from earlier focus group work. The study demonstrated that patients' psychosocial and spiritual end-of-life needs were consistently underestimated by physicians (Table 2). These differences persisted after multivariate analyses were performed to control for sex, race, socioeconomic status, household, composition, religion, and religiosity.

Table 2: Quality of life attributes ranked by order of importance by patients and physicians at the end of life (Steinhauser et al, 2000)

Attributes	Participants agreeing the importance of the attribute	
	Patients	Physicians
Being mentally aware	92%	65%
Being at peace with God	89%	65%
Not being a burden to family members	89%	58%
Being able to help others	88%	44%
Being able to pray	85%	55%
Able to plan own funeral	82%	58%
Not being a burden to society	81%	44%
Feeling one's life to be complete	80%	68%

P = .001 for all comparisons

Notwithstanding these differences, more than half of the survey items showed consensus between all 4 groups including pain and symptom management and the importance of preparing for the end-of-life. These echo the results of another study that many renal patients wanted to plan ahead for their death when this became inevitable (Christakis and Iwashyna, 1998), a process which requires clear communication in order to facilitate shared decision and the primacy of patients' wishes at this time.

The views of care home managers were elicited by one postal survey of 261 suitable care homes¹ selected from a list of registered institutions in one English county by Froggatt and Payne (2006). Responses were received from 115 (46%) of the homes sampled, of which only 81 (33%) were suitable for analysis. Responses indicated that there is a marked lack of clarity as regards end-of-life care, one manager describing it as '*a continuation of existing care*' (p344) whilst others related it to the care provided to residents in the '*last days*' or the '*final stages*' of life whilst another added somewhat quizzically that it is provided when '*the end is near*' (p344). Unlike many settings, post-mortem care featured highly in their definitions of end-of-life care, one manager regarding it simply as verifying that death had occurred whilst another defined it as the performance of last offices. A third manager suggested that it simply consisted of checking the pulse and phoning the GP to certify the death whilst another included the dignified departure of the deceased to the care of a funeral director as being included within this remit.

Interestingly, only one manager spoke about end-of-life care in relation to the provision of palliative care for dying residents, and most related it to the events leading up to and immediately following the death event. This is interesting given that the majority (505 or 70%) of deaths reported in the study occurred within the care home, only 214 (29%) taking place in hospital and 8 (1%) in hospice settings. Moreover; 85% (564 deaths) were from causes other than cancer, a situation in stark contrast to the majority of deaths occurring in specialist palliative care settings or acute environments where most end-of-life care research takes place (Eve and Higginson, 2000). Unlike specialist palliative care settings however, the study indicates that patients dying in nursing homes are likely to experience a broader range of illnesses and consequently experience many different death trajectories in settings which are not focused on the care of the dying and invariably have fewer qualified staff than either hospices or hospitals. This warrants further consideration, as does the continuing ambivalence of many older people to discuss end-of-life care issues with health care professionals, which is in stark contrast to the aims of the philosophy and may not simply be due to people's fears that attempts will be made to ration their access to more intensive interventions as discussed previously (Kane, 2003).

3.4 Death trajectories and ambivalence about end-of-life care discussions

The concept of death trajectories has long been used to illustrate similarities and dissimilarities in patient experience as they approach death (Field and Cassel, 1997; McCormick and Conley, 1995; Glaser and Strauss, 1965). Those credited with developing the term noting that '*the dying*

¹ In order to be eligible for the study, care homes had to be registered for the care of adults > 65 years of age by the Commission for Social Care Inspection and provide personal or nursing care to those with 'old age', 'dementia', 'physical impairment', 'mental impairment', 'sensory impairment' and/or 'terminal illness'.

trajectory of each patient has at least two outstanding features and variable properties... duration and shape' (Glaser and Strauss, 1965 p6). It is clear that at least three distinctive death trajectories are acknowledged within the early literature on this topic. Glaser and Strauss (1968) described these as *abrupt* or *surprise* deaths, *expected* deaths (which may be long and lingering or of relatively short duration), and *entry-re-entry* deaths, in which individuals may enjoy a comparatively good quality of life between episodic bouts of worsening ill-health or disease.

One much cited paper by Lunney et al (2003) reporting the results of a US cohort analysis on data gathered as part of a prospective, longitudinal interview study of 14,456 respondents aged 65 years or more (Comoni-Huntley et al., 1990) found that 'frail' decedents (classified by entry into a nursing home for all or part of the period preceding annual interview) were 8 times more likely to have functional deficits than those dying suddenly, one and a half times more likely to die than those dying with cancer, and three times more likely to die than those with organ failure after controlling for age, sex, race, education, marital status and other demographic variables including time from final interview to death. Their study supported the findings of others that older frail decedents are more likely to experience a sharp decline in functional status² than age-matched survivors (Wolinsky et al., 1996; Lawton et al., 1990) notwithstanding the fact that specific medical conditions also influence functional ability in the dying, cancer patients experiencing a sharper decline in functional status in the last months than those dying from more chronic illnesses (Teno et al., 2001).

As a consequence of this, and earlier analyses conducted by the same authors on data from Medicare claimants Lunney et al, (2002) and Lunney et al (2003) proffer four theoretical death trajectories which are *sudden death*, *terminal illness* (including end-stage cancer), *organ failure* (defined for the purposes of the study as congestive heart failure and chronic lung disease or similar) and importantly, given recent demographic changes within most developed countries, *frailty* – a concept which is increasingly considered within the literature when determining the point at which end-of-life care should begin. One possible weakness of the study is that whilst 99% of decedents (n=4,871) participated directly in the interview process at baseline, only 74% did so in their last year of life due to cognitive or physical impairment, researchers relying upon the proxy reporting of decedents functional status at this time (Kutner et al., 2006; McPherson and Addington-Hall, 2003), although 316 of the decedents were interviewed within the last month of their life, which is one of the largest ante-mortem data sets encountered in the literature reviewed.

² Functional status was assessed using 7 activities of daily living (ADL), namely bathing, walking across a small room, grooming, dressing, eating, transferring from bed to chair and using a toilet in addition to other activities such as kneeling, crouching, climbing a flight of stairs, walking half a mile and respondents' ability to do 'heavy' housework such as vacuuming and washing a floor.

In addition to objective measures of disability using the ADLs listed below, the researchers also found that a diagnosis of cancer, heart disease, diabetes, hip fracture or stroke also predisposed the individual to death in comparison to age matched survivors (0.76 versus 0.44; $P < .001$), cancer deaths tending to be more common among the youngest age group³ (mean age 78.7 years, SD 6.9) in comparison to sudden death (80.4 years SD 7.8), organ failure (82.3 years SD 7.7) and frailty (85.1 years SD 7.2), with 77% of the latter group being 80 years or older when they died. Where overlap existed, it was more likely to include frailty (also identified in 320 or 8% of organ failure decedents and 202 or 5% of cancer decedents). Sex differences in the level of disability were apparent, women reporting consistently higher levels of functional disability than men, although the trajectory of the decline in both men and women, and in each if the age cohorts was similar to the projected trajectory for each group, the mean functional ability of each gradually diminishing over the last year of life.

When the disability trajectories for each group were analysed, cancer patients were found to have a lower level of functional disability than those in the organ failure or frail groups in the early months of their final year of life, but experienced a marked decline in their functional ability in the last three months of life. This is consistent with expected disease trajectories and patterns of death in malignancy, particularly where metastases are present. The functional ability of decedents in each of the non-sudden death groups were markedly worse in the last three months of life however, indicating that a sudden decline in functional ability may be an appropriate prognostic indicator in determining when death is likely to occur and when end-of-life care should commence. However, whilst the researchers were able to confirm their hypothesis that death trajectories demonstrated predictable differences in the onset, severity and prognostic value of functional disability in each of their groups, there was a more marked variation in individual differences within these groups, and some overlap between frailty as a variable. Those dying with frailty, cancer, or from organ failure made up 20%, 21% and 20% of the sample respectively, 24% of the deaths being attributed to causes other than these or sudden death, which made up 15% of the sample.

The existence of so large a group ($n=990$) dying without malignancy, organ failure or apparent frailty in the months leading up to their non-sudden deaths is interesting in so far as this group had a higher incidence of co-morbidities ($n=1.45$ SD 0.66) in comparison to all other groups (mean 1.05 for cancer, 1.04 for organ failure and 1.08 for frail decedents), and a baseline of zero in the referent (sudden death) group who were more likely to be males between the ages of 65 and 74 years who had the lowest rates of ante-mortem disability calculated by functional status. The

³ The age groups were 65-74 years, 75-84 years and 85 years or more.

researchers conclude however, that *'only short-term expected deaths such as may occur with cancer decedents, are likely to have a predictable terminal period that meets the public expectation of dying, and the health care requirements for hospice [or end-of-life] care'* (p2390-2391). The vast majority of people do not die from expected deaths however, but from *'acute complications of an otherwise chronic condition, most likely without a discrete terminal illness phase'* (p2391) which may preclude their being assessed for hospice or specialist palliative care provision, or even having a comprehensive assessment of their end-of-life care needs made. Frogatt and Payne (2006) reiterate this point when arguing that fewer than 10% of those dying in care homes do so with a recognisable terminal illness, more than 50% dying after a prolonged period of general deterioration (Seymour et al., 2005; Davies and Higginson, 2004). The knowledge and skills needed to care for care home residents at the end-of-life are very different therefore, from those required to care for patients in acute or specialist palliative care settings, but older people's understanding and views about end-of-life care are only now beginning to be investigated by researchers (Seymour et al., 2005) whilst still less is known about the perspectives of family members in respect of such issues.

Studies since the phrase *'death trajectory'* was first coined clearly demonstrate that many of those entering the final stages of their lives (and those who care for them) have some forewarning about their impending death and may manifest signs of physical, functional, psychological and/or social deterioration which are gradual and predictable. Others, perhaps the majority, are less likely to exhibit such a clear or predictable decline however, and may live for many months in what Field and Cassel (1997) called a *'Living-Dying Interval'*, McCormick and Conley (1995) describe as the *'Chronic Living-Dying Period'* and van Gennep (1965) describes as the *'Liminal Phase'* of life. This period may be considerably longer than that traditionally associated with end-of-life care, particularly where some measure of treatment is available for the underlying condition such as cardiac, pulmonary and renal disease. Others, such as those with life-long conditions such as cystic fibrosis, neurodegenerative disorders or sickle cell disease may face the prospect of a relatively sudden (though predictable) death at an unknown point during their lives. It is difficult to know when EOLC should begin in such circumstances, since any attempt at prognostication is fraught with difficulty and likely to be inaccurate in such cases. Many attempts have been made to use statistical probability when determining survivorship over a specified time period such as six or twelve months (Lynn et al., 1997), but the propensity for patients to die from sudden or otherwise unanticipated conditions such as treatment failure (in cancer for instance) or a superimposed infection may hasten death considerably.

Medical technology may also obfuscate the living-dying trajectory for many (Field and Cassel, 1997), and there is considerable debate within the literature about the efficacy or futility of measures such as the use of dialysis, mechanical ventilation, antibiotics, parenteral feeding, intravenous fluids or cardiac resuscitation during the final phase of a patient's life. We have moved a long way indeed since Montaigne (1575) commented that to die of old age is a privilege rarely to be seen. The majority of those dying in any one year will be elderly (Field and Cassel, 1997). These individuals are more likely to live alone, with an elderly or infirm carer, or in a residential home than any other group, whilst increasing geographical mobility may accentuate the problem of loneliness or isolation felt in relation to other members of their family. During this time, patients may be fully aware that they have a progressive disease which is likely to kill them, but may not regard themselves as actively dying. In this respect, they demonstrate behaviours similar to those described by Patterson (2003; 2001) in her 'shifting perspectives' model of chronic illness which will now be discussed.

Derived from a meta-analysis of 292 qualitative research studies on patient experiences of chronic illness, the model rejects the linearity of traditional chronic illness (or even living-dying) trajectories espoused by those such as Corbin and Strauss (1992), and posits one based upon two dialectic relationships, one between illness and wellness, and another between the internal self and the external world. Individual perspectives, health beliefs, coping mechanisms and cognitive appraisal of the threat posed to them by their worsening condition all play a part in the individual's perception of themselves as a chronically sick (and potentially dying) individual as well as one who is still living through the last phase of their life. Thus the patient's perceptions of their own lived reality, rather than those of the clinician are the most important factors in determining how they interpret, report and respond to changes in their condition as they enter the end-of-life. Patients may experience periods where their illness (and possible death) is in the foreground of their consciousness, during which time both theirs, and their carer's attention is focused towards the life-limiting burden of the illness and any suffering, losses or treatment related to it. This is likely to be balanced by periods of comparative wellness, in which the patient's internal and social self, rather than the increasingly incapacitated body becomes the source of the patient's identity, and some may move from being victims of circumstance to managers of their situation with a renewed appreciation for life and others as they enter its final phase.

In either case, carers need to assist the patient in finding meaning in their illness (Cumbie et al., 2004) conscious that both its meaning and severity are constantly subject to re-evaluation (Stuifbergen et al., 1990). Whether one agrees with the shifting perspectives model or not, the need for patients to balance their need for support against the quest for normality or ordinariness

is well documented (Kralik, 2002). This is clearly demonstrated by Gott et al. (2008) whose in-depth interviews with 40 elderly end-stage cardiac patients (median age 77) showed that older people's views often conflicted with the values upon which most palliative or end-of-life care is predicated, many respondents saying that whilst they would like the opportunity to put their affairs in order, they did not want to discuss the imminence of their death, assuming that this was as much a consequence of their advanced years as their underlying condition. Citing earlier work by Seymour et al. (2005; 2004) about the reservations or ambivalence older people sometimes show when asked to consider their own deaths, Gott et al. observe that, *'such ambivalence was apparent in the attitudes of the participants in our study who, whilst in the main acknowledging their likely limited prognosis, did not want to dwell upon this [since] they felt so doing destroyed the hope they needed to enjoy their day-to-day lives'* (p1119).

This ambivalence has also been demonstrated in relation to the formulation of advance directives (Seymour et al., 2004) and communication about end-of-life care in general (Hoffman et al., 1997) in this client group, both of which have been much advocated in an attempt to improve end-of-life care planning (Murray et al., 2007; Winter and Parker, 2007; Becker et al., 2007; Davison and Torgunrud, 2007). Seymour and her colleague's UK study demonstrates that advance directives are primarily understood in terms of their capability to increase personal autonomy and assist the family of the deceased in the period immediately surrounding the death, but concerns about the inappropriate use of such directives and the possibility that the patient's preferences may change over time have led to their being largely discounted in this client group (Seymour et al., 2004). The research showed that in contrast to current guidelines on their use (General Medical Council, 2001; British Medical Association, 1995), elderly patients saw them primarily as a non-binding guide to relatives at a difficult time of transition, and not as a bilateral arrangement between the patient and their physician which ought not to be vetoed by family members.

Furthermore, little consideration was given to their capacity to safeguard the moral autonomy of patients, a finding supported by that of Gott et al (2008), which suggested that older patients have a much narrower concern for autonomy than bioethicists, published guidelines, or those advocating their use as an aid to end-of-life care planning would like. Seymour and her colleagues point instead, to the profound sense of mutual interdependency which arises between a person coming to the end of their life and those in their immediate family circle, a complex biopsychosocial dynamic which may often be underestimated by professional carers, as has already been suggested in relation to the concerns of end-stage renal patients which are often underestimated by health care professionals (Steinhauser et al., 2001; 2000). These indicate that a

change in the goals of care is needed if patients are to die a dignified and socially integrated death irrespective of the setting in which they die (Hov et al., 2007; Kaufman, 2000; Fins et al., 1999).

4.0 Triggers to end-of-life assessment

Various attempts have been made to develop prognostic or diagnostic tools which will reliably indicate that death is now probable. Measures which rely upon probability, and in particular, upon demographic or non-clinical variables are less likely to provide reliable data than those related to the patient's physical condition – albeit in many cases, no less accurate. Attempts have been made however to develop such tools using actuarial, demographic or health indices to predict the probability of death occurring for specific groups of patients in any given period. These shall now be considered, providing as they do, instruments of varying reliability, sensitivity and specificity for such a purpose. They are posited as exemplars of some of the exciting work currently taking place to improve end-of-life prognostication and not as an exhaustive analysis of every available tool as the size and scope of this review preclude such an analysis.

4.1 The problem with prognostication when death is 'imminent'

In order to provide appropriate end-of-life care in the last days or hours of life it is first necessary to identify that the patient is actively dying since quality end-of-life care is unlikely to be achieved if an accurate diagnosis that death is imminent cannot be made (Leland, 2000). Accurate prognostication is notoriously difficult however, and there is some dispute as to the optimum time at which this is both clinically feasible and socially acceptable given the impact of such news on the individual concerned and the members of his or her family. The need to distinguish between the likely imminence of death (whether stated in days, weeks or months), and the mere possibility that death may occur at some unforeseen point in the future has been the subject of considerable debate for many years. However, if one envisages that communication of the patient's transition from active or curative treatment to end-of-life care is necessary in order to elicit necessary changes in the patient's management plan and the withholding of interventions considered futile, it is incumbent upon health professionals to do this accurately as well as sensitively, whether in the days leading up to an imminent death, or at the time when a patient's gradual decline is predicted some months in advance of their death (as may happen in cancer or to a lesser extent, end-stage cardiac or pulmonary disease).

The literature search identified relatively few papers which investigated nurses' ability to recognise dying in the last days or hours of life, including Parker-Oliver et al. (2004) and Porock

and Parker-Oliver (2007). In the latter study, the researchers interviewed 14 staff from both urban and rural long-term care settings and found that nurse recognition that the resident was entering the terminal phase of life was initiated by a mixture of 'ambiguous clues', 'decision clues', 'ready to go clues', 'withdrawal clues', and 'visible clues'. Ambiguous clues included falls, diminishing appetite or infections which may indicate deterioration in the patient's condition, but might also be preventable or reversible. Ambiguous clues also included psychosocial events such as the passing of a significant event (such as a birthday or the birth of a grandchild which the resident had been particularly looking forward to) and the sense that these marked the beginning of life closure in some way. Decision clues included the residents questioning the efficacy of long-term medications or other health interventions and expressing a preference for these to stop. Respondents in the study noted that this decision often precipitated a calm acceptance on the part of the resident and a sense of relief that they had exerted their autonomy – perhaps after many years of unquestioningly accepting the advice of their physician or the indignities of medical interventions now thought futile.

Ready to go clues included residents asking about legal assistance for writing a will or considering the arrangements for their funeral, but might also include conversations about the completeness or finality of a resident's life, or their lack of fear about the 'inevitable' and what may lay ahead. Withdrawal clues included small 'leave-taking' comments or the expression of thanks for services rendered, followed by psychosocial withdrawal. This stage may be accompanied by requests not to join others at meal times or to participate in group activities. Even normal conversation may be muted or stifled. Visible clues leave no question that the patient is now actively dying and include pallor, cyanosis, oedema or mottling of the skin. Most respondents admitted that they seldom thought about end-of-life or palliative care interventions until this latter phase because of the apparent lack of urgency in earlier stages of the dying process which may precede death by many days or a matter of weeks. The authors noted however, that referral to hospice was not considered appropriate at this time.

The authors of a separate paper on 'turning points' in end of life prognostication (Jakobsen et al., 2006) argue that clinical identification of dying is irretrievably linked to a reorientation in the goals of care provided to patients who are dying, but found that few studies examined when – or indeed whether such a decision was actually taken by clinicians in practice. These authors therefore examined the health care records of 229 people who had died at home or in hospital in Sweden during 2001. Analysis of the medical records showed that there were several significant turning points in clinician's evaluations of patient mortality risk which led to a deliberate change in

the patient's plan of care. These included phrases such as, 'no longer feasible to treat', 'the patient is beyond active therapy', 'continue with best possible palliative care', 'for withdrawal of life prolonging therapies' and 'decreasing blood pressure despite IV hydration. No CPR, palliative care only'. Such turning points were found in 160 patient records and in most cases, a deliberate change in the goals of care was subsequently prescribed. The mean time interval between recorded turning points and the death of the patient was 19 days (median 5 days). For individuals without cancer the interval was almost 11 days (median 3 days). Thus the time interval between the turning point and death differed significantly between patients with cancer and other conditions, supporting the notion that cancer patients have significantly longer to prepare for death than other patient groups, and confirming the impression that cancer tends to follow a predictable death trajectory in comparison to other illnesses. This is consistent with other studies which show that there remains a great deal of uncertainty in identifying which acute exacerbations of a non-malignant illness are likely to be the last as the death trajectories for such conditions can be so variable (Nolan and Mock, 2004; Lunney et al., 2002).

Elliott et al (2007) point out that the majority of methods used to calculate a patient's prognosis are based on biological, physiological or functional indicators which are primarily by the physicians themselves. Many of these tools, such as the Karnofsky Performance Status scale are one-dimensional, observer-rated scales that have modest predictive value although used extensively in the studies cited in this review. In contrast, health-related quality of life (HRQOL) instruments based on patient's own perceptions of their health status tend to have stronger theoretical underpinnings than disease status or subjective medical judgements (Cella, 1995), but most were not designed specifically for the assessment of end-of-life patients. In their study, Elliott and his colleagues attempted to determine the utility of the Missoula-Vitas Quality of Life Index (MVQOLI) in end-of-life (hospice) patients in order to determine whether the MVQOLI accurately measures HRQOL and could be used to predict patient survival times.

The MVQOLI contains 16 items in five domains including the perceived level of physical symptom distress, function, interpersonal relationships, personal well-being and transcendence/spirituality. Patients are asked to rate their satisfaction in each domain on a 5-point scale ranging from agree strongly to disagree strongly. In addition, patients' global quality of life is ranked on a single item 5-point scale ranging from worst possible to best possible. Cancer was the most common terminal diagnosis (59.6%) in the sample of 1,047 patients admitted to the hospice although the most common cause of comorbidity was end-stage cardiac disease. The median survival time from admission to hospice and the patient's eventual death was 17 days (range 0 to 925 days).

Unfortunately, however, the MVQOLI demonstrated no prognostic utility in their study and performed worse than the observer rated Karnofsky Performance Status scale and the modified activity of daily living score (MADLS) which performed better in showing associations with survival time. Meanwhile, more research is needed into psychosocial factors which might indicate that death can be expected soon (Appendix 1).

4.2 Studies predicting mortality in the longer term

In their rationale for the development of the INTERMED palliative care assessment tool, Mazzocato et al. (2000) argue that documentation of patient need is still often restricted to the assessment of physical and psychological symptoms or quality of life, even in palliative care settings. Whilst some exceptions exist, such as the Support Team Assessment Schedule (STAS) (Higginson and McCarthy, 1993; Higginson et al., 1992), which evaluates current physical and psychological symptoms, expressed care needs, financial concerns, communication among health care professionals and family members; most still do not address broader issues of relevance to those in the final stages of their disease process such as psychological adjustment and social or spiritual concerns, in spite of evidence provided by Vernooij-Dassen et al. (2007) that explicit clarification of patient concerns frequently identified new areas of need in the psychosocial and spiritual domains of care.

INTERMED was developed therefore, to assess and document information concerning these needs in an integrated manner, and to see whether the needs of specific subgroups requiring intensive palliative care involvement could be identified in order to tailor the delivery of these services appropriately. The other aim of the project was to ensure that clinical decision making with regard to the type, setting, duration and appropriateness of treatment was better managed. The tool specifically addresses patient prognosis, social vulnerability and perceived threat to life in patients accessing palliative care services, and whilst not tailored specifically towards end-of-life care, the authors point out that the tool is more stable over time than the STAS model and importantly, complements decision making processes in periods of transition whilst taking account of diagnostic and prognostic complexity, residential instability and problems accessing appropriate health care services which may be crucial when developing an appropriate management plan for those entering the final stage of life.

In their cluster analysis of the INTERMED scores on different patient groups, the authors found that the tool provided a reliable way of accurately assessing the palliative care needs of patients demonstrating higher levels of psychological and social comorbidity who might benefit from a

comprehensive psychosocial as well as physical assessment, and consideration of their complex discharge needs when returning home from the acute care setting. The study did have some weaknesses however as the authors only included patients with a cancer diagnosis (n=82) and deliberately excluded those with nonmalignant disease. Notwithstanding these issues, the tool has been positively evaluated in the Netherlands, where it has been used to consider the care needs of those with complex co-morbidities (Latour et al., 2007), and tested in relation to its reliability and stability when assessing the complex biopsychosocial care needs of patients with multiple sclerosis (de Jonge et al., 2004). These same authors have also used the tool to assess quality of life and predict one-year survival in end-stage renal patients (de Jonge et al., 2003) and found that age (>65 years), co-morbid diabetes and the INTERMED score were the three variables most likely to identify those patients with a poor quality of life and significantly (from an end-of-life perspective), patient mortality in the early stage of treatment. The report's authors suggest therefore, that the tool provides a useful reminder to health care professionals to initiate end-of-life discussions about patient's future care preferences, fears and concerns at an earlier point on the disease trajectory, and to refer patients with end-of-life care needs to the appropriate services in a timely manner. It should be noted however, that these and other papers evaluating the tool's effectiveness tend to come from the same stable of researchers responsible for developing and disseminating the tool (the Stichting INTERMED Foundation), including some involved in the study by Mazzocato et al. (2000).

Admission to long-stay care signals the beginning of end-of-life care for many older people. It is not always possible however, to predict with any certainty the trajectory that may lead to their ultimate death, or whether their remaining life span will be short or long. One well-conceived study making use of data from the Minimum Data Set (MDS) designed by Morris et al. (1990), a comprehensive and well evaluated assessment instrument (Phillips et al., 1996; Hawes et al., 1995; Hawes et al., 1992) of more than 400 items compulsorily applied to all nursing home residents in the United States for Medicare and Medicaid funding purposes was conducted by Porock et al. for the calendar year 1999 (Porock et al., 2005; Porock et al., 2003). The complete instrument is completed for each nursing home resident within 14 days of admission, and an abbreviated form administered at 90 day intervals, on each anniversary of the admission, and again when a significant change in the resident's health status occurs. The researchers selected the 50 MDS items most likely to accurately predict death within a six-month period on the basis of previously published research findings and analysed data on these from the MDS scores of 43,510 nursing home residents in the state of Missouri against death registrations of nursing home residents in the state over the same twelve-month period.

The 50 variables considered most likely to predict death from the MDS fell into four main categories: demographics such as age and sex, clinical pathology such as a diagnosis of cancer, chronic obstructive pulmonary disease, congestive cardiac failure, clinical signs and symptoms such as shortness of breath, weight loss, cognitive impairment, pain and deficits in residents' activities of daily living; and adverse events such as falls, infections, hospitalisation or the loss of a spouse or partner. Data from the 43,510 residents were randomly divided into 20 subsamples in order to avoid overestimating the clinical significance of small but statistically significant differences in this huge sample, and to avoid known problems associated with using a step-wise selection of predictor variables. This ensured that only those variables identified as significant ($p=0.01$) in every subsample were included in the prognostic algorithm subsequently developed. A significance level of 0.01 rather than 0.05 was used to offset the relatively large power of the still large subsamples, and to ensure that only clinically significant variables were identified by the analysis of the data. Twenty-six of the 50 variables were subsequently found to have a significant relationship with 6-month mortality (as calculated from the death certificates), but these were then subjected to a step-wise logistic regression analysis to see which of them remained after this procedure. Each variable received a ranked score dependent upon how often it was selected by the stepwise procedure and the step at which it was selected. Total scores and the frequency with which each variable appeared in the 20 subsamples were used to determine the predictive reliability of each variable (see Table 3 below).

Table 3: Frequency and Scores for Variable Entry into the Algorithm Development Data Set

Ranking	Variable Name	Frequency of model entry	Total score of ordered entry
1	Requiring assistance with ADLs (0-7)	20	379
2	Shortness of breath	20	338
3	Cancer diagnosis	20	328
4	Recent admission to nursing home	20	322
5	Poor appetite	20	287
6	Male sex	20	277
7	Deteriorating condition	20	274
8	Weight loss	20	249
9	Chronic heart failure	20	236
10	Age	20	190
11	Renal failure	20	180
12	Cognitive performance scale score <6	19	119
13	Alzheimer's disease or dementia	18	97
14	Dehydrated	17	129

It became clear that 14 variables were far more reliable indicators of six-month mortality, of which two, cancer and age, and recent admission and deterioration were consistently related to each other. The interaction between admission to the nursing home and deterioration suggested that these two variables were not simply additive (or causal) in nature whilst interestingly; the risk of dying of cancer in a six-month period was greater the younger the nursing home resident, thus the points allocated for this mortality risk actually decrease the older the resident is (Appendix 2).

The 14 most frequently occurring variables together with the two interactive variables (cancer and age, and recent admission and deterioration) were then selected for the development of a 6-month predictive MDS Mortality Risk Index (MMRI) which was used to estimate the 6-month mortality of Missouri nursing home residents in the original sample against national data from the 1997 National Health Survey (Gabrel and Jones, 2000). Kaplan-Meier survival curves illustrated a close resemblance to the 6-month probability of dying when calculated using the MMRI and compared back to the death certificate data. In practice however, the tool was too complex to be completed in the clinical setting although a simplified version of both the tool and the scoring sheet has now almost been completed and will be published shortly (personal communication D. Porock 25th October 2008).

5.0 Conclusions and recommendations

In their end-of-life care strategy, the National Council for Palliative Care (2006) suggest that it may be 'useful to regard end-of-life care as simply an everyday expression that may be easily understood by the general public', and eschew 'importing' definitions from abroad as 'these do not necessarily fit well with current supportive and palliative care policy and health care system in this country' (p2). There are several problems with this statement however. In the first instance, this review of the literature clearly demonstrates that the nature, scope and duration of end-of-life care, together with the factors which trigger its initiation are far from understood, and still less agreed by health care professionals, whilst the 'general public' are scarcely aware that it exists as a separate entity from the broader remit of palliative (and to a lesser extent, supportive) care provision. There can be little doubt however, that improvements in end-of-life care services provided to dying patients and their families need to be greatly improved; but these need to be conceptualised and developed with the greatest possible consensus if cracks are not to appear in the edifice that is currently being constructed. Greater clarity is certainly needed if both the general public and health care professionals are to share a common coin of communication when discussing and negotiating care outcomes at life's end, and this consensus needs to begin with those offering these services.

In seeking this clarity, it is crucial that both home-grown and imported definitions of end-of-life care are subjected to careful scrutiny, and a full analysis of the concept undertaken in order to determine the scope of practice of all those engaged in the delivery of such services. Furthermore, international consensus is needed on this subject if international comparisons of care provision and effectiveness are to be made, and both policy makers and health care professionals held to account for the decisions they make in allocating finite resources to those with complex and often ongoing needs. Imported definitions on end-of-life care are no less useful than those on health or palliative care, both of which were developed as a result of international consensus and were subsequently adopted in the UK. If this is not done, it will be difficult for researchers to develop prognostic tools which have external validity outside their own borders as each will be working to different definitions of what end-of-life care is or ought to be.

Of somewhat more fundamental importance however, is the question 'should the care of dying people in the twenty-second century be driven by the 'current supportive and palliative care policy and health care system in this country' as the authors of the submission suggest, or should it, like the goals of care established with individual patients, derive from a thorough and comprehensive assessment of need. It would appear from this very brief review of the literature that very little consideration has been given to listening to the views of those in need or receipt of such services although Macmillan's Cancer Voices initiative may provide one such example for this exercise. Form it is said, should follow function, and any temptation to mould end-of-life care services around current systems is likely to result in fragility given that systems and services are subject to constant redefinition and reform. Conversely, it is clear from the literature that patients' end-of-life concerns remain the same across different client groups, racial, social and ethnic divides, as well as international borders and historical epochs. This is hardly surprising given that one is dealing with the most basic of human concerns when considering end-of-life care, including man's frailty, vulnerability, anxiety and quest for dignity in the face of his own mortality. A better understanding of these concerns will provide a surer foundation for the establishment of a service than the 'current supportive and palliative care policy and health care system in this country' currently allows, and prevent some of the unfounded assumptions made by health care professionals about dying peoples' genuine concerns, fears and needs as they approach death.

These concerns are not best served by attempts to appropriate particular disciplinary territories or boundaries, and it is encouraging that the literature acknowledges the necessary interplay between palliative, supportive and end-of-life care. On the whole, the literature does not appear to have addressed the question of whether these are in fact the same thing however, and we

must be careful of tailoring a new set of clothes which leave our conceptual and professional nudity clearly open to the gaze of the general public, our patients and their carers. They clearly see few of the demarcations which are currently being created by policy makers and service providers within this area of care, and their concerns revolve much less around semantics than equality of access, dignity, sensitivity, and the availability of appropriate resources to assist them in their time of greatest need. To this end, it is important that renewed attempts are made to prognosticate accurately, treat effectively and care appropriately as and when the need arises. The need for further research into the area of end-of-life care is clearly apparent, and should exercise the minds of clinicians, service commissioners and academics alike. Large scale, international studies should be set up to establish the parameters of such valuable research and to arrive at consensus in respect of the terminology used, as well as developing comprehensive databases on morbidity and mortality such as that designed by Morris et al. (1990) in the United States. These will provide vital data for researchers and clinicians alike, and should address current gaps in our knowledge base on this most vital of subjects.

6.0 References

- Ahmedzai, S., Costa, A., Blengini, C., Bosch, A., Sanz-Ortiz, J., Ventafridda, V. and Verhagen, S. (2004) A new international framework for palliative care. *European Journal of Cancer Care*, 40: 2192-2200.
- Asch, D., Shea, J., Jedrzewski, M. and Bosk, C. (1997) The limits of suffering: Critical nurses' views of hospital care at the end of life. *Social Science & Medicine*, 11: 1661-1668.
- Becker, G., Sarhatlic, R., Olschewski, M., Xander, C., Momm, F. and Blum, H. E. (2007) End-of-Life Care in Hospital: Current Practice and Potentials for Improvement. *Journal of Pain and Symptom Management*, 33: 711-719.
- Boyce, A., McHugh, M. and Lyon, P. (2003) Proactive palliative care choices for haematology day unit patients. *Int J Palliat Nurs*, 9: 544-50.
- British Medical Association (1995) *Advance Statements About Medical Treatment*. London: BMA.
- Brody, H. and Hunt, L. (2005) Moving beyond cultural stereotypes in end-of-life decision making. *American Family Physician*, 71: 515-522.
- Brook-Hamilton, J. (2000) Chapter 8. The ethics of end of life care. In: Poor, B. and Poirrier, G. (Eds) *End of Life Nursing Care*. Sudbury, MA: Jones and Bartlett, pp. 73-104.
- Carr, D. and Khodyakov, D. (2007) End-of-life health care planning among young-old adults: an assessment of psychosocial influences. *Journal of Gerontology Series B Psychological Sciences and Social Sciences*, 62: S135-141.
- Cella, D. (1995) Measuring quality of life in palliative care. *Seminars in Oncology*, 22: 73- 81.
- Cherny, N., R, C., P, K. and and Members of the ESMO Taskforce on Supportive and Palliative Care (2003) ESMO takes a stand on supportive and palliative care. *Annals of Oncology*, 14: 1335-1337.
- Christakis, N. and Iwashyna, T. (1998) Attitude of self-reported practice regarding prognostication in a national sample of internists. *Archives of Internal Medicine*, 158: 2389-2395.
- Christakis, N. and Lamont, E. (2000) Extent and determinants of error in doctor's prognosis in terminally ill patients: prospective cohort study. *British Medical Journal*, 320: 469-472.
- Comoni-Huntley, J., Blazer, D. G., Lafferty, M., Everett, D., Brock, D. and Farmer, M. (1990) *Established Populations for Epidemiologic Studies of the Elderly. Volume II. Research Data Book*. Bethesda, MD: National Institutes for Health.
- Corbin, J. and Strauss, A. (1992) A nursing model for chronic illness management based upon the trajectory framework. In: Woog, P. (Ed) *The Chronic Illness Trajectory Framework*. New York: Springer.
- Cumbie, S., Conley, V. and Burman, M. (2004) Advanced practice nursing model for comprehensive care with chronic illness: Model for promoting process engagement. *Advances in Nursing Science*, 27: 70-80.

Davies, E. and Higginson, I. (2004) *Better Palliative Care for Older People*. Copenhagen: World Health Organisation.

Davison, S. N. and Torgunrud, C. (2007) The Creation of an Advance Care Planning Process for Patients with ESRD. *American Journal of Kidney Diseases*, 49: 27-36.

de Jonge, P., Hoogervorst, E., Huyse, F. and Polman, C. (2004) INTERMED: A measure of biopsychosocial case complexity: one-year stability in Multiple Sclerosis patients. *General Hospital Psychiatry*, 26: 147-152.

Della Santina, C. and Bernstein, R. H. (2004) Whole-patient assessment, goal planning, and inflection points: their role in achieving quality end-of-life care. *Clinics in Geriatric Medicine*, 20: 595-620.

Elkington, H., White, P., Addington-Hall, J., Higgs, R. and Pettinari, C. (2004) The last year of life of COPD: a qualitative study of symptoms and services. *Respiratory Medicine*, 98: 439-445.

Ellershaw, J. and Wilkinson, S. (2003) *Care of the Dying: A Pathway to Excellence*. Oxford: Oxford University Press.

Elliott, T., Renier, C. and Palcher, J. (2007) The Prognostic Value of Measuring Health- Related Quality of Life in Hospice Patients. *Journal of Palliative Medicine*, 10: 696-704.

Eng, C. (2002) Future consideration for improving end-of-life care for older persons: Program of All-Inclusive Care for the Elderly (PACE). *Journal of Palliative Medicine*, 5: 305-309.

Eve, A. and Higginson, I. (2000) Minimum dataset activity for hospice and hospital palliative care services in the UK 1997/98. *Palliative Medicine* 14: 395-404.

Ferrell, B. and Coyle, N. (2001) *Textbook of Palliative Nursing*. Oxford: Oxford University Press.

Field, M. J. and Cassel, C. (1997) *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press.

Fins, J., Miller, F., Acres, C., Bacchetta, M., Huzzard, L. and Rapkin, B. (1999) End-of-Life Decision-Making in the Hospital: Current Practice and Future Prospects. *Journal of Pain and Symptom Management*, 17: 6-15.

Forest, P. (2004) Being there: The essence of end-of-life nursing care. *Urologic Nursing*, 24: 270-280.

Fox, E., Landrum-McNiff, K., Zhong, Z., Dawson, N., Wu, A. and Lynn, J. (1999) Evaluation of prognostic criteria for determining hospice eligibility in patients with advanced lung, heart, or liver disease. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Journal of the American Medical Association*, 282: 1638-1645.

Froggatt, K. and Payne, S. (2006) A survey of end-of-life care in care homes: issues of definition and practice. *Health & Social Care in the Community*, 14: 341-348.

Gabbay, B., Matsumura, S., Etzioni, S., Asch, S., Rosenfeld, K., Shiojiri, T., Balingit, P. and Lorenz, K. (2005) Negotiating end-of-life decision making: a comparison of Japanese and U.S. residents' approaches. *Academic Medicine: Journal of the Association of American Medical Colleges*, 80: 617-621.

Garvin, J. and Chapman, C. (1995) Clinical management of dying patients. *Western Journal of Medicine*, 163: 268-277.

General Medical Council (2001) *Withholding and Withdrawing Life Prolonging Treatments: Good Practice in Decision-making*. Guidance from the Standards Committee of the General Medical Council. London: General Medical Council.

Glaser, B. and Strauss, A. (1965) Temporal aspects of dying as a non-scheduled status passage. *American Journal of Sociology*, 71: 48-59.

Glaser, B. and Strauss, A. (1968) *Time for Dying*. Chicago: Aldine.

Gore, J., Brophy, C. and Greenstone, M. (2000) How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*, 55: 1000-1006

Gott, M., Small, N., Barnes, S., Payne, S. and Seamark, D. (2008) Older people's views of a good death in heart failure: implications for palliative care provision. *Social Science & Medicine*, 67: 1113-1121.

Griffin, J., Nelson, J., Koch, K., Niell, H., Ackerman, T., Thompson, M. and Hammond Cole, F. (2003) End-of-Life Care in Patients with Lung Cancer. *Chest*, 123: 312S-331S.

Hawes, C., Morris, J., Phillips, C., Mor, V., Fries, B. and Nonemaker, S. (1995) Reliability estimates for the minimum data set for nursing home assessment and care screening (MDS). *Gerontologist*, 35: 172-178.

Hawes, C., Phillips, C., Mor, V., Fries, B. E. and Morris, J. (1992) MDS data set should be used for research. *Gerontologist*, 32: 563-564.

Hewitt, M. and Simone, J. (1999) *Ensuring Quality Cancer Care*. Washington DC: National Academies Press.

Higginson, I. and McCarthy, M. (1993) Validity of the support team assessment schedules: do staffs' ratings reflect those made by patients or their families? *Palliative Medicine*, 7: 219-228.

Higginson, I., Wade, A. and McCarthy, M. (1992) Effectiveness of two palliative support teams. *Journal of Public Health*, 14: 50-56.

Hoffman, J., Wenger, N., Davis, R., Teno, J., Connors, A. F., Desbiens, N., Lynn, J. and R, P. (1997) Patient preferences for communication with physicians about end of life decisions. *Annals of Internal Medicine*, 127: 1-12.

Holley, J., Carmody, S., Moss, A., Sullivan, A., Cohen, L., Block, S. and Arnold, R. (2003) The Need for End-of-Life Care Training in Nephrology: National Survey Results of Nephrology Fellows. *American Journal of Kidney Diseases*, 42: 813-820.

Hov, R., Hedelin, B. and Athlin, E. (2007) Good nursing care to ICU patients on the edge of life. *Intensive and Critical Care Nursing*, 23: 331-341.

Jacobs, L. G., Bonuck, K. and Burton, W. (2002) Can "Palliative Care Reports" Improve End-of-Life Care for Hospitalized Patients? *Journal of Pain and Symptom Management*, 24: 299-311.

Jakobsen, E., Bergh, I., Gaston-Johansson, F., Stolt, C. and Öhlen, J. (2006) The Turning Point: Clinical Identification of Dying and Reorientation of Care. *Journal of Palliative Medicine*, 9: 1348-1358.

Kane, R. (2003) The interface of long-term care and other components of health and social services systems in North America. In: Brodsky, J., Habib, J. and Hirschfield, M. (Eds) *Key Policy Issues in Long Term Care*. Geneva: World Health Organisation Collaborating Centre for Research in Health in the Elderly, pp. 63-90.

Kaufman, S. (2000) Senescence, decline, and the quest for a good death: Contemporary dilemmas and historical antecedents. *Journal of Aging Studies*, 14: 1-23.

Kellehear, A. (2008) Dying as a social relationship: A sociological review of debates on the determination of death. *Social Science & Medicine*, 66: 1533-1544.

Kemp, C. (2005) Cultural issues in palliative care. *Seminars in Oncology Nursing*, 21: 44- 52.

Knaus, W., Harrell, F., Lynn, J., Goldman, L., Phillips, R. and Connors, A. (1995) The SUPPORT prognostic model. Objective estimates of survival for seriously ill hospitalized adults. Study to understand prognoses and preferences for outcomes and risks of treatments. *Annals of Internal Medicine*, 122: 191-203.

Kralik, D. (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* 39: 146-154.

Kutner, J. S., Bryant, L. L., Beaty, B. L. and Fairclough, D. L. (2006) Symptom Distress and Quality-of-Life Assessment at the End of Life: The Role of Proxy Response. *Journal of Pain and Symptom Management*, 32: 300-310.

Latour, C., Huyse, F., de Vos, R. and Stalman, W. (2007) A method to provide integrated care for complex medically ill patients: the INTERMED. *Nursing and Health Sciences*, 9: 150-157.

Lawton, M., Moss, M. and Glicksman, A. (1990) The quality of the last year of life of older persons. *The Milbank Quarterly*, 68: 1-28.

Leland, J. (2000) Death and Dying: Management of patients with end-stage disease. *Clinics in Geriatric Medicine*, 16: 875-893.

Lorenz, K. A., Lynn, J., Dy, S. M., Shugarman, L. R., Wilkinson, A., Mularski, R. A., Morton, S. C., Hughes, R. G., Hilton, L. K., Maglione, M., Rhodes, S. L., Rolon, C., Sun, V. C. and Shekelle, P. G. (2008) Evidence for Improving Palliative Care at the End of Life: A Systematic Review. *Annals of Internal Medicine*, 148: 147-W28.

Lorenz, K. A., Shugarman, L. R., Lynn, J., Arnold, R. M. and Liao, S. (2006) Health Care Policy Issues in End-of-Life Care. *Journal of Palliative Medicine*, 9: 731-748.

Lunney, J., Lynn, J. and Hogan, C. (2002) Profiles of older Medicare decedents. *Journal of the American Geriatric Society*, 50: 1108-1112.

Lunney, J. R., Foley, K. M., Smith, T. J. and Gelband, H. (2003) *Describing Death in America: What we need to know*. Washington, DC: National Academies Press.

Lynn, J. (2000) Finding the Key to Reform in End-of-Life Care. *Journal of Pain and Symptom Management*, 19: 165-167.

Lynn, J. and Adamson, D. (2003) Living well at the end of life. Adapting health care to serious chronic illness in old age. Santa Monica, CA: Rand.

Lynn, J. and Goldstein, N. E. (2003) Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering. *Annals of Internal Medicine*, 138: 812.

Lynn, J., Nolan, K., Kabacoff, A., Weissman, D., Milne, C. and Berwick, D. M. (2002) Reforming Care for Persons Near the End of Life: The Promise of Quality Improvement. *Annals of Internal Medicine*, 137: 117.

Lynn, J., Teno, J., Phillips, R., Wu, A., Desbiens, N., Harrold, J., Claessens, M., Wenger, N., Kreling, B. and Connors, A. (1997) Perceptions by Family Members of the Dying Experience of Older and Seriously Ill Patients. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *Annals of Internal Medicine*, 126: 97-106.

Mazzocato, C., Stiefel, F., de Jonge, P., Levorato, A., Ducret, S. and Huyse, F. (2000) Comprehensive Assessment of Patients in Palliative Care: A Descriptive Study Utilizing the INTERMED. *Journal of Pain and Symptom Management*, 19: 83-90.

McCormick, T. and Conley, B. (1995) Patients' perspectives on dying and on the care of dying patients. *Western Journal of Medicine*, 163: 236-43.

McGrath, P. and Holewa, H. (2006) Missed opportunities: nursing insights on end-of-life care for haematology patients. *International Journal of Nursing Practice*, 12: 295-301.

McGrath, P. D. and Holewa, H. A. (2007) Description of an Australian model for end-of-life care in patients with hematologic malignancies. *Oncology Nursing Forum*, 34: 79-85.

McPherson, C. J. and Addington-Hall, J. M. (2003) Judging the quality of care at the end of life: can proxies provide reliable information? *Social Science & Medicine*, 56: 95-109.

Morris, J. N., Hawes, C., Fries, B. E., Phillips, C. D., Mor, V., Katz, S., Murphy, K., Drugovich, M. L. and Friedlob, A. S. (1990) Designing the national resident assessment instrument for nursing homes. *The Gerontologist*, 30: 293-307.

Moss, A. H., Ganjoo, J., Sharma, S., Gansor, J., Senft, S., Weaner, B., Dalton, C., MacKay, K., Pellegrino, B., Anantharaman, P. and Schmidt, R. (2008) Utility of the "Surprise" Question to Identify Dialysis Patients with High Mortality. *Clinical Journal of the American Society of Nephrology*, 3: 1379-1384.

Mularski, R. A., Dy, S. M., Shugarman, L. R., Wilkinson, A. M., Lynn, J., Shekelle, P. G., Morton, S. C., Sun, V. C., Hughes, R. G., Hilton, L. K., Maglione, M., Rhodes, S. L., Rolon, C. and Lorenz, K. A. (2007) A Systematic Review of Measures of End-of-Life Care and Its Outcomes. *Health Services Research*, 42: 1848-1870.

Murray, S., Boyd, K. and Sheikh, A. (2005) Palliative care in chronic illness. We need to move from prognostic paralysis to active total care. *British Medical Journal*, 330: 611-612.

Murray, S., Pinnock, H. and Sheikh, A. (2006) Palliative care for people with COPD: we need to meet the challenge. *Primary Care Respiratory Journal*, 15: 362-364.

Murray, S. A., Kendall, M., Grant, E., Boyd, K., Barclay, S. and Sheikh, A. (2007) Patterns of Social, Psychological, and Spiritual Decline Toward the End of Life in Lung Cancer and Heart Failure. *Journal of Pain and Symptom Management*, 34: 393-402.

Murtagh, F., Preston, M. and Higginson, I. (2004) Patterns of dying: palliative care for non-malignant disease. *Clinical Medicine*, 14: 39-44.

National Council for Palliative Care (2006) End of Life Care Strategy: The National Council for Palliative Care Submission. London: NCCP.

National Institute of Clinical Excellence (2004) Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. London: NICE.

National Institutes of Health (2004) Statement on Improving End-of-Life Care. National Institutes of Health State-of-the-Science Conference: 6-8 December 2004.

Nikoletti, S., Porock, D., Kristjanson, L. J., Medigovich, K., Pedler, P. and Smith, M. (2000) Performance status assessment in home hospice patients using a modified form of the Karnofsky Performance Status scale. *Journal of Palliative Medicine*, 3: 301-311.

Nolan, M. T. and Mock, V. (2004) A conceptual framework for end-of-life care: A reconsideration of factors influencing the integrity of the human person. *Journal of Professional Nursing*, 20: 351-360.

Parker-Oliver, D., Porock, D. and Zweig, S. (2004) End-of-life care in US nursing homes: A review of the evidence. *Journal of American Medical Directors Association*, 5: 147-155.

Paterson, B. (2001) The shifting perspectives model of chronic illness. *IMAGE: Journal of Nursing Scholarship*, 33: 21-26.

Paterson, B. (2003) The Koala has claws: Applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research*, 13: 987-994.

Payne, S., Sheldon, F., Jarrett, N., Large, S., Smith, P., Davis, C. L. and et al. (2002) Differences in understanding of specialist palliative care amongst service providers and commissioners in South London. *Palliative Medicine*, 16: 395-402.

Phillips, C., Hawes, C., Mor, V., Fries, B. and Morris, J. (1996) Evaluation of the nursing home resident assessment instrument: Executive Summary. Report to Health Care Financing Administration by the Research Triangle Institute.

Porock, D. and Oliver, D. P. (2007) Recognizing dying by staff in long-term care. *Journal of Hospice & Palliative Nursing*, 9: 270-278.

Porock, D., Oliver, D. P., Zweig, S., Rantz, M., Mehr, D., Madsen, R. and Petroski, G. (2005) Predicting death in the nursing home: development and validation of the 6-month Minimum Data Set Mortality Risk Index. *Journals of Gerontology Series A: Biological Sciences & Medical Sciences*, 60A: 491-498.

Porock, D., Oliver, D. P., Zweig, S. C., Rantz, M. and Petroski, G. F. (2003) A profile of residents admitted to long-term care facilities for end-of-life care. *Journal of the American Medical Directors Association*, 4: 16-22.

- Porock, D. and Parker-Oliver, D. (2007) Recognizing dying in nursing home residents. *Journal of Hospice and Palliative Nursing*, 9: 270-278.
- Seymour, J., Gott, M., Bellamy, G., Ahmedzai, S. and Clark, D. (2004) Planning for the end of life: the views of older people about advance care statements. *Social Science & Medicine*, 59: 57-68.
- Seymour, J., Witherspoon, R., Gott, M., Ross, H., Payne, S. and Owens, T. (2005) *End-of- Life Care: Promoting Comfort, Choice and Well-Being for Older People*. Bristol: Polity Press.
- Shipman, C., Gysels, M., White, P., Worth, A., Murray, S., Barclay, S., Forrest, S., Shepherd, J., Dale, J., Dewar, S., Peters, M., White, S., Richardson, A., Lorenz, K., Koffman, J. and Higginson, I. (2008) Improving Generalist End of Life Care: National consultation with practitioners, commissioners, academics, and service user groups. *British Medical Journal*, 337: a1720
- Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L. and Tulsky, J. (2000) Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *Journal of the American Medical Association*, 284: 2476-2482.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., Grambow, S., Parker, J. and Tulsky, J. A. (2001) Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers. *Journal of Pain and Symptom Management*, 22: 727-737.
- Stuifbergen, A., Becker, H., Ingalsbe, K. and Sands, D. (1990) Perceptions of health among adults with disabilities. *Health Values*, 14: 18-26.
- Teno, J. M., Casey, V. A., Welch, L. C. and Edgman-Levitan, S. (2001) Patient-Focused, Family-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family Members. *Journal of Pain and Symptom Management*, 22: 738-751.
- van Gennep, A. (1965) *The Rites of Passage*. London: Routledge and Kegan Paul.
- Vernooij-Dassen, M., Groot, M., van den Berg, J., Kuin, A., van der Linden, B., van Zuylen, L., Crul, B. and Grol, R. (2007) Consultation in palliative care: the relevance of clarification of problems. *European Journal of Cancer*, 43: 316-322.
- Wilson, D. M. (2002) The duration and degree of end-of-life dependency of home care clients and hospital inpatients. *Applied Nursing Research*, 15: 81-86.
- Winter, L. and Parker, B. (2007) Current health and preferences for life-prolonging treatments: An application of prospect theory to end-of-life decision making. *Social Science & Medicine*, 65: 1695-1707.
- Wolinsky, F., Stump, T., Callahan, C. and Johnson, R. (1996) Consistency and change in functional status among older adults over time. *Journal of Aging and Health*, 8: 155-182.
- Zambrowski, C., Roser, L. and Moser, D. (2005) Chapter 41 End of life care in the acute heart failure patient. In: O'Connor, C., Stough, W., Gheorghide, M. and Adams, K. (Eds) *Managing Acute Decompensated Heart Failure*. Chichester: Taylor Francis, pp. 569-603.
- Zimmermann, C. (2007) Death denial: obstacle or instrument for palliative care? An analysis of clinical literature. *Sociology of Health and Illness*, 29: 297-314.

Appendix 1: Psychosocial indicators that death may be expected

- social withdrawal and disinterest
- increased contemplation and revisiting memories
- expressions of regret or sadness
- evaluating life and achievements
- reassuring others that death is not feared or death anxiety
- engaging in the 'five tasks of the dying'
 - asking forgiveness
 - offering forgiveness
 - offering thanks and gratitude
 - offering sentiments of love
 - saying goodbye
 - letting go

Appendix 2: 6-month MDS Mortality Risk Index (after Porock et al, 2005)

6-month MDS Mortality Risk Index			
Age without cancer			
≤ 69 yrs	1 point		
70-78 yrs	2 points		
79-88 yrs	3 points		
89-98 yrs	4 points		
≥ 99 yrs	5 points	Age score (non cancer)	<input style="width: 80px;" type="text"/>
Age with cancer			
≤ 74 yrs	8 points	or	
75-84 yrs	7 points		
85-94 yrs	6 points		
≥ 95 yrs	5 points	Age score (with cancer)	<input style="width: 80px;" type="text"/>
CPS score			
0-1	0 points		
2-4	1 point		
5-6	2 points	CPS Score	<input style="width: 80px;" type="text"/>
Admission and/or deteriorating score			
Admission only	3 points		+
Deteriorating	3 points		
Admitted & deteriorating	4 points	Admission score	<input style="width: 80px;" type="text"/>
Activity of daily living score*			
		ADL Score (maximum 7)	<input style="width: 80px;" type="text"/>
Shortness of breath			
	3 points	Breathlessness score	<input style="width: 80px;" type="text"/>
Poor appetite			
	2 points	Appetite score	<input style="width: 80px;" type="text"/>
Male			
	2 points	Gender score	<input style="width: 80px;" type="text"/>
Weight loss			
		Weight score	<input style="width: 80px;" type="text"/>
Chronic heart failure			
	2 points	CHF score	<input style="width: 80px;" type="text"/>
Renal failure			
	2 points	Renal score	<input style="width: 80px;" type="text"/>
Dehydrated			
	2 points	Dehydration score	<input style="width: 80px;" type="text"/>
			Sub-Total
			<input style="width: 80px; border-top: 3px double black;" type="text"/>
Alzheimer's disease	subtract 1 point	Alzheimer's score	- <input style="width: 80px;" type="text"/>
			TOTAL
			<input style="width: 80px; border-top: 3px double black;" type="text"/>

* add 0-5 points for deficits in each of the following ADLs: bed mobility, inability to transfer between surfaces, dressing, ambulation, eating, personal hygiene, elimination depending upon severity.

ISBN 978-1-909067-59-2