

AN EXPLORATION OF THE ECONOMICS OF END OF LIFE CARE

Joanna Coast,

Health Economics Unit, University of Birmingham

Sarita Lavender,

Health Economics Unit, University of Birmingham

Address for correspondence:

Joanna Coast

Professor of Health Economics

Health Economics Unit

School of Health & Population Sciences

Public Health Building

University of Birmingham

Birmingham

B15 2TT tel: 0121 414 3056

E-mail: j.coast@bham.ac.uk

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ABSTRACT

Background: An imperative to assess the health care needs and resource implication of care at the end of life is emerging in response to a globally increasing population of older people. National governments, including the UK government, are also focusing attention on end of life care as, for example, with the current UK End of Life Care Strategy. Economics, including health economics, however, seems to be primarily concerned with the living, giving little consideration to the process of dying or the consequences of death.

Aims: to explore the conceptualisation of death and dying in economics.

Methods: the paper uses a broad review of relevant literature from economics, health economics, thanatology and palliative care to explore and develop conceptual thinking in this area. Literature was obtained through selective database and citation searching and by contacting leading figures in the relevant fields.

Findings: The current conceptualisation of the end of life in economics and health economics is insufficient: it does not capture the preferences and goals of people approaching death, the significance of the family or the dynamic nature of the end of life. A new framework conceptualising end of life for economics is developed on the basis of existing empirical research from other disciplines.

Discussion: The paper ends with a research agenda for the economics of end of life care. The work is exploratory, and discussion around both the proposed conceptualisation and the ideas for future research will be extremely welcome.

INTRODUCTION

An imperative to assess the health care needs and resource implication of care at the end of life is emerging in response to a globally increasing population of older people. In the UK, for example, the number of people aged over 65 is projected to increase from nearly 11.4 million in 2006 to over 13.9 million by 2026 and exceeding 15.3 million by 2031.¹ Increases in healthy life expectancy have not, however, kept pace with improvements in total life expectancy and the number of people in need of greater care at the end of life is expected to rise.² This leads to concerns about higher costs, although recent research suggests that very high costs are related to proximity to death rather than age per se.³⁻⁵ These high costs associated with the dying process lead to accusations of futile care and calls for restraint in the use of high cost technologies at the

end of life – although there are some who believe that cost savings are illusory^{6,7} and that it is difficult to determine futility.⁸

National governments, including the UK government, are also focusing attention on end of life care as, for example, with the current UK End of Life Care Strategy,⁹ and the recently produced National Audit Office report on End of Life Care.¹⁰ One of the main foci of these reports is the choice of place of death, but they also allude to the need for evaluation of care strategies at the end of life, with the End of Life Care Strategy, in particular, pointing out the need for economic research in this area.⁹ To compete with other sectors for funds, End of Life (EoL) care programmes need to demonstrate their cost-effectiveness.¹¹ Some economic evaluations of EoL care have been attempted.¹²⁻¹⁴ These studies have, however, failed to present robust cost utility analyses, reporting issues in defining both costs and benefits of EoL interventions and calling for further development of research tools for use in this arena.¹⁵ One particular problem, as Menzel et al indicate is that ‘... conventional CEA underestimates the value of care in the face of death’ (Menzel et al,¹⁶ p.10).

This paper explores the economics of end of life care in the context of the current literature on this topic, with relevant literature from economics, health economics, thanatology and palliative care being used to explore and develop conceptual thinking in the area. A literature search was performed to identify publications concerned with the economics of the end of life and to identify significant research into preferences and outcomes at the EoL. Databases searched were Medline (up to 2007), Embase (1980-2007), PsychInfo (1985-2007), Econolit (1969-2007), CINAHL and Ageline. A variety of terms denoting the topic of interest (for example, ‘palliative care’, ‘hospice’, ‘good death’) were combined with terms relating to economics (for example, ‘economic evaluation’, ‘preferences’, ‘maximum endurable time’, ‘utility’). Citation searches produced a selection of useful articles. Senior health economists who had worked or published articles in the field, along with leading figures in outcomes research in palliative care were contacted in search of unpublished research and working papers, and searches on key authors in the field (e.g. Higginson, Normand) were conducted. The primary concern of the paper is decision making around the choice of interventions at the end of life, but it also has broader implications for how death may be incorporated into economic evaluation more generally.

The paper begins by considering some definitions of death, dying and end of life care, that will be used throughout the rest of the paper. It then focuses on the small amount of literature that currently deals with this subject within economics, taking a broad remit and covering both positive and normative issues. The paper then examines normative issues in more depth, thinking particularly about economic evaluation of end of life care and (in a similar manner to the discussions around public health¹⁷) questioning whether end of life care is, in some way, ‘different’ to other health interventions that might be evaluated. The paper then goes on to justify the use of, and propose, a broader conceptual framework for evaluating end of life care in

economics. The paper concludes with a research agenda and a list of questions for discussion during the HESG meeting.

DEFINITIONS & CONCEPTS

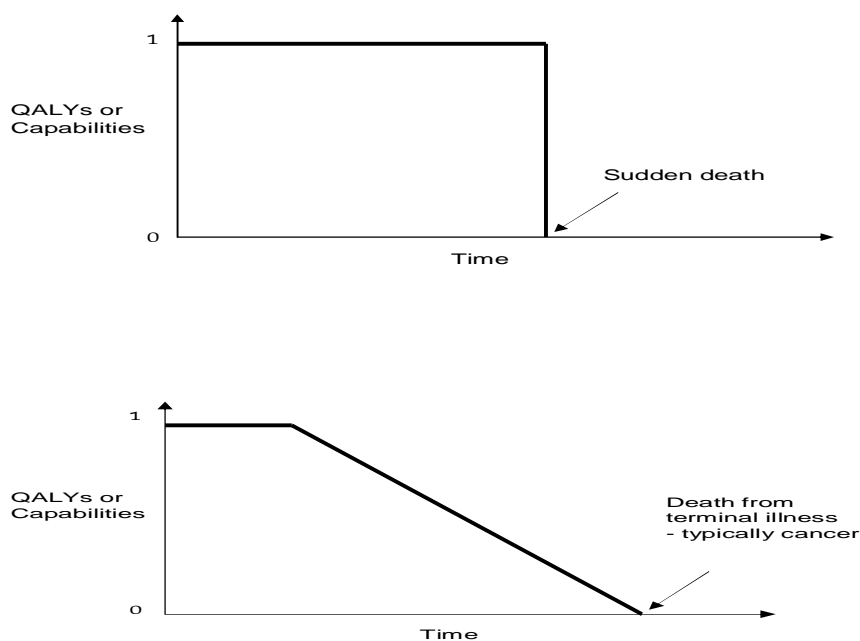
The terminology around end of life care is often used interchangeably and without explanation. It is worth being clear about how these concepts are being used within this paper. First, there are a number of terms for care at the end of life: end of life care, palliative care and terminal care are often used interchangeably but have slightly different meanings. The very recent NAO report uses a very general definition of end of life care indicating that these services are intended to support people approaching the end of life to live as a good a life as possible until they die.¹⁰ Palliative care, focuses on the physical, psychological and spiritual needs of the person, aiming to relieve suffering and control pain and symptoms.¹⁰ Palliative care is also sometimes referred to as comfort care. The terminology of terminal care is usually applied to care provided in the last few days or hours of life and focuses on alleviating distress and maintaining comfort. Both palliative care and terminal care services have largely been developed in the context of cancer. These particular services may not be available to all patients reaching the end of their lives, and there are some concerns about their applicability to, and broader use in, other populations without adaptation. This paper aims to be general in its focus, and so will refer to end of life care throughout, with the aim being to consider all specialist services for care at the end of life whatever the diagnostic context.

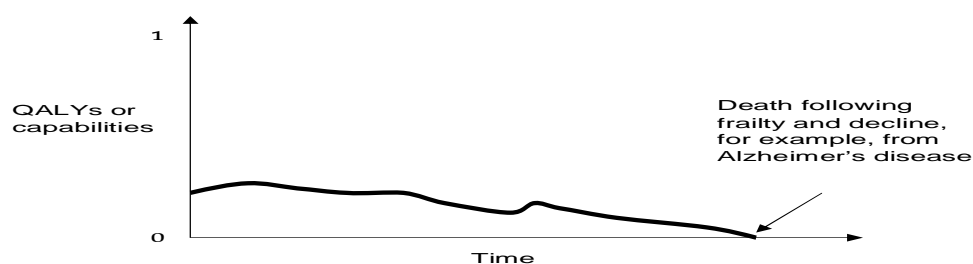
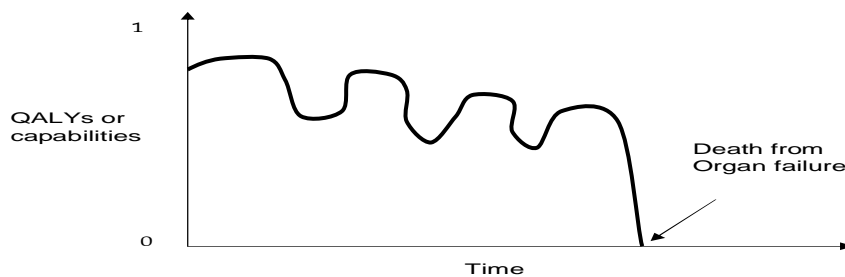
Second, the terms associated with mortality – dying, death and dead – may need some unpicking, to ensure that they are being used throughout the paper in a consistent manner, and to relate them to the notion of end of life care. Dying is a particularly tricky notion. In many ways we are all dying from the moment that we are born and clearly living and dying are concurrent. However, here the notion of a period of ‘dying’ can be thought of as the period in which the patient is suffering from advanced progressive disease in a known terminal condition or a condition from which it is likely that they will die. One useful way of thinking about this is the pragmatic approach used in the Supportive Care Pathway which aims to put end of life care in place for patients with a variety of different conditions, and where the move to end of life care is dependent upon whether the patient is expected to survive the next 12 months.¹⁸ Patients could be defined as ‘dying’ if the answer to this question were to be ‘yes’. Within the research literature there have been efforts to identify different ‘types’ of dying, referred to as ‘dying trajectories’, with the research of Lunney et al.^{19;20} confirming the existence of four main trajectories of dying, accounting for most patients final phases of life. Each of these differs in profile and length, with three trajectories starting from a position of high function and moving towards death in different ways. Although the originals are drawn in terms of high and low

function, they could also be thought of in terms of quality-adjusted life-years or capabilities, and are shown in this manner in figure 1. For the sudden death trajectory there is continued high function followed by a drop towards death. For progressive diseases such as cancer with a terminal phase there is high function followed by a steady decline. For organ failure there are a series of dips in terms of health or capability, on any of which a patient might succumb. And for patients with frailty and decline, as caused for example by Alzheimer's disease or Parkinsons disease, there is a long term decline, such as the period of end of life or dying may already find the patient with a very low health or capability, which continues to decline towards death.

Death comes later in the process of mortality and is concerned with the transition from being alive to being dead. Dead, in this conceptual framework follows the moments of death, and is the period in which the person is defined clinically as being no longer living.

Figure 1. Trajectories of dying, shown in relation to QALYs or capabilities (adapted from Lunney et al, 2002. ^{19;20})





CURRENT CONCEPTUALISATIONS WITHIN ECONOMICS

Economics has not traditionally had a strong focus on issues around death and dying. There are, however, aspects of economic theory that touch on issues around end of life. Perhaps the most obvious of these is Grossman's model considering consumption of health services throughout the life cycle.²¹ In this model, as a person ages, the return from their investment in health becomes increasingly short-lived and so they choose to invest less: 'death occurs when the [health] stock falls below a certain level, and ... individuals 'choose' their length of life' (Grossman,²¹ p.225). Other life cycle notions have flowed from this, following the assumption that, with age, the value of life decreases because of the limited returns on investment. Such notions suggest that the value of statistical lives drop sharply as older age is reached,²² a view that implies that less effort should be placed on life-saving as people reach the end of their natural life span.

There are, however, recent challenges to these life cycle theories that suggest a higher value of life at the end of life. These are based on empirical evidence that older people nearing the end of life do not choose to reduce their investment in health as would be expected on the basis of the life cycle theories.²³⁻²⁶ Instead they retain or even increase their investment. There are a

number of potential explanations for this deviation from expected behaviour. These include: a 'severing' of the relationship between age and demand because of insurance or state-funded care;²⁷ the notion that, if resources have no value once a person is dead, then they would use their entire wealth to extend life, no matter how short a period of time life was extended for;²⁸ that individuals overestimate life expectancy in older age;²⁹ and the idea that what drives decisions at these times is a concern to avoid 'regret' at not doing everything possible^{30;31} and retain hope that a chance of living remains.²⁸ Indeed, it seems logical that the young, who feel that they have abundant 'life' remaining may value life less than the old for whom the reality of scarcity of future life years becomes pertinent. It may be, that as the end of life approaches, there is a shift from the rational behaviour predicted under a traditional expected utility framework to behaviour explained by other theories of decision-making that become more pertinent to a person's end of life care decisions. This shift may be enhanced by the difficulty that seems to be experienced very often by decision makers in relation to denying care at the end of life – so called 'denial disutility'³² or 'denial aversion'.²⁸

In addition to these attempts to explain patterns of life saving and resource use, there has also been a focus amongst economists on the feasibility of reducing costs at the end of life.³³ Much of this work followed the publication in the US of studies showing that patients who die consume a disproportionate quantity of health resources (work by Lubitz and Prihoda,³⁴ for example), but because it is difficult to actually know whether a seriously ill person is in the last few days of life, the potential for resources savings is limited.^{7;35} Linked, is the more normative notion of the 'fair innings' associated with Alan Williams' work,³⁶ that older people at the end of life should no longer demand resources that could be used by others with many years of life ahead of them.

The other main area of concentration of work by economists is in relation to theories of bequest. Traditional theories around bequest used the idea that older people might choose to accumulate wealth and goods to bequest to their survivors and thus continued saving in old age might be expected, but more recently the importance of bequests seems to have diminished.³⁷ Causes of this diminishing importance include pensions,³⁷ the decline of small-scale businesses passed down a family,³⁷ death taxes³⁸ and the expectation that wealth will be used to finance care.³⁹

The limited work that has been conducted has been in disparate areas. Although there is the suggestion that the preferences of the dying may differ from those of the living, there is little empirical economic research available to support the assumptions upon which the various arguments are based. Further, the traditional neoclassical basis of economics may be limited in addressing issues around death and dying. As Slemrod indicates 'economics... must address the most fundamental aspect of human life, its finitude, and how people deal with it. Models of rational behaviour may prove to be inadequate, inviting us to learn from psychology and thanatology' (Slemrod,⁴⁰ p.374). What economics of end of life care exists, furthermore, has been conducted mainly in an explanatory framework, rather than the normative framework

associated with economic evaluation. The next section of this paper aims to develop thinking in normative economics in relation to the economics of end of life care.

ECONOMIC EVALUATION OF END OF LIFE CARE: IS END OF LIFE ‘DIFFERENT’?

The main focus of normative economics is on what ‘should’ be done to achieve particular ends. Within welfare economics, the aim is to maximise utility (including utility through the consumption of health care); within extra-welfarism, the aim is, in practice (although not necessarily in theory⁴¹), the maximisation of health (usually, in practice, the maximisation of quality-adjusted life-years, or QALYs). Given that, in practice, most economic evaluation within the health and social care settings is conducted from an extra-welfarist perspective and most interventions in terms of end of life care are provided through health and social services, this section will focus mainly on whether the current extra-welfarist practice is sufficient for evaluating end of life care, and, in particular, whether patient measures of health benefit provide the appropriate evaluative space.

Although not clearly articulated, there is a clear sense in the economic contributions described in the section above that there might be something ‘different’ about care at the end of life, that might mean that it should be treated differently in relation to economic evaluation. There are, in fact, a number of potential differences, some of which might have greater importance than others in influencing a change in economic evaluation of end of life care.

The first of these, and one of the most obvious ways in which end of life care is clearly ‘different’, is that the concern is with ‘care’ and not with ‘cure’. The aim may not be to achieve improvements in ‘outcome’ because, in one sense at least, ‘outcome’ is already known with some degree of certainty: this outcome is death. Instead, the concern may be more with the process of care for the dying person and, perhaps, for their loved ones as well. This focus on process may itself lead to a rather different outcome: the idea of a ‘good death’, suggesting that the benefits that an economic evaluation of end of life care should be trying to illustrate are rather different to those of traditional health economic evaluations. Further, because of short life-expectancies, it has been noted that a policy of QALY maximisation will be unlikely to prioritise care for the dying.⁴²

A second area of potential ‘difference’ is that family and loved ones may assume greater importance than in most health care interventions. There is evidence that loved ones and caregivers of dying patients experience significant social and economic burden.⁴³⁻⁴⁵ Current extra-welfarist practice, however, focuses very much on the health outcomes of the patient

alone. End of life care is also centred on patients but the family and their needs may also be important and aspects of end of life care may be specifically aimed at caring for family and friends. Indeed, there is evidence that the person at the end of life may themselves be concerned to alleviate burden on family and may act accordingly.^{46;47} For those who die suddenly there may be different implications for family, not in terms of the need to take on a caring role, but in terms of lack of preparedness for the death. From the family's perspective it may be a poor death if they are unable to say goodbye, left without a will and so on. +

Third, survival may not be an appropriate outcome for patients at the end of life, making measures such as the QALY (in which quality of life is traded against quantity of life) potentially inappropriate in evaluating end of life provision. The use of death as an anchor point, at zero, may be largely meaningless in relation to end of life care. The meaning and valuation of death, and being dead, may also vary depending on socio-economic status, family circumstances and religious beliefs.⁴⁸ One of the difficulties here, however, is that, for many people living and dying may be going on concurrently – in the sense that both treatment and palliative interventions may be pursued at the same time. For treatment interventions, it may be important to evaluate in standard ways, whilst at the same time evaluating end of life care on its own terms. An interesting example here is the work of Arnesan and Norheim,⁴⁹ which found that more than half of a sample of metastatic cancer patients refused to trade a single day of life for perfect health. Whilst the preference of these patients was to remain amongst the living, this does not mean that interventions to enable a good death should not have been put in place.

Fourth, the attributes contained in measures that are primarily concerned with the living may be less relevant for those who are dying. Those faced with imminent death may define quality of life differently from healthier individuals, and health status itself may assume less relevance than, for example, spiritual dimensions and preparation for death. Generic health instruments have, for example, been criticised by palliative care researchers for their sparse descriptive capacity.^{50;51}

Fifth, there is the problem that preferences and valuations around end of life care may not be stable. For each of us, our own death is a new experience and for many of us there may not be extensive experience of the death of others. Thus, whilst in the Arnesan and Norheim work many refused to trade quality of life for quantity, others have found that individuals with very poor health and limited life expectancy may prefer to live only a very limited amount of time – that there may be, in fact, a maximum endurable time (MET) that people wish to face in particularly poor health states. Clearly, this potential lack of stability around preferences at this time may have implications for the possibilities (or lack thereof) of (useful) empirical estimation of preferences.

Finally, the end of life may have greater weight in evaluating a life as a whole than the period in which it takes place,⁵² with empirical research by Diener et al suggesting that '... a life's ending is weighted especially heavily in judging quality of life' (Diener et al,⁵³ p.124). This work

indicates that the benefit that good care at the end of life can bring may be an addition to the value of that life as a whole, rather than as an improvement in one ‘slice’ of that life.

To conclude this section, there are clearly a number of ‘differences’ between the evaluation of end of life care and the evaluation of health improving interventions. It is a matter of debate, as in, for example, the evaluation of public health interventions, whether these differences are sufficient to require a new or different toolkit for the economic evaluation of end of life care. It is asserted here that this is the case, not least, because the evidence is that the standard health economics methodological toolkit is not currently used in the economic evaluation of palliative and end of life care (see for example, work by Douglas and Normand,¹²⁻¹⁵). Such a new or different toolkit, however, requires a clear conceptual basis or framework: as George states ‘conceptual clarity is a limiting factor in all research... every aspect of research design and implementation is inextricably affected by the conceptual foundation that underlies the research question’ (George,⁵⁴ p.87).

A NEW FRAMEWORK FOR EVALUATING END OF LIFE CARE?

How should a framework for evaluating end of life care look? If health is not the appropriate evaluative space, then what is? And at what point in the patient journey or care pathway should this ‘different’ evaluative space become relevant. The most naïve position (other than the current position in which no different evaluative space would be advocated at all) might look something like figure 2.

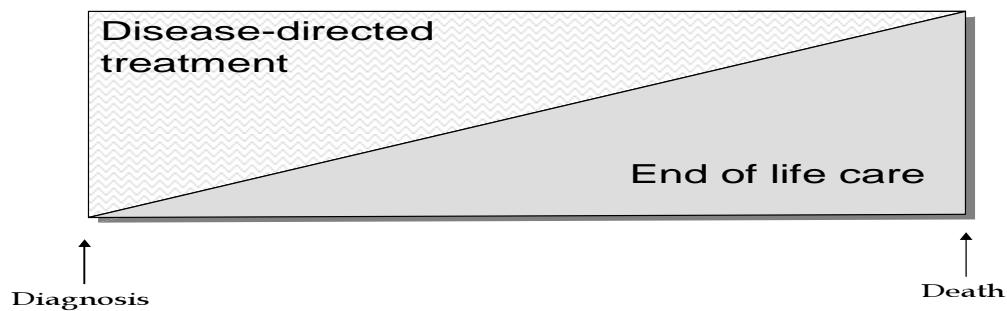
Figure 2: A naïve view of the change in evaluative space



In this approach, which reflects the traditional clinical model of care, a shift in treatment intention would be recognised at the point at which curative care was no longer deemed effective and patients received care focusing on comfort and well being. However, as indicated in the discussion of dying trajectories above, and as pointed out by Lloyd, ‘... there may be no definable moment when a person can be said to be dying rather than living with a disease’ (Lloyd,⁵⁵ p.241). In practice this sort of division is rarely seen* and the boundaries are blurred, increasingly reflected in clinical practice where curative and palliative interventions may be delivered concordantly,^{58;59} suggesting that the proposed framework should be more akin to that in figure 3.

* Note, however, that such a sharp transition can often be observed in the US where Medicare criteria for entry to hospice programmes require, as well as poor prognosis, that individuals forego any intervention other than supportive and comfort care.^{56;57}

Figure 3: Current clinical view of end of life care

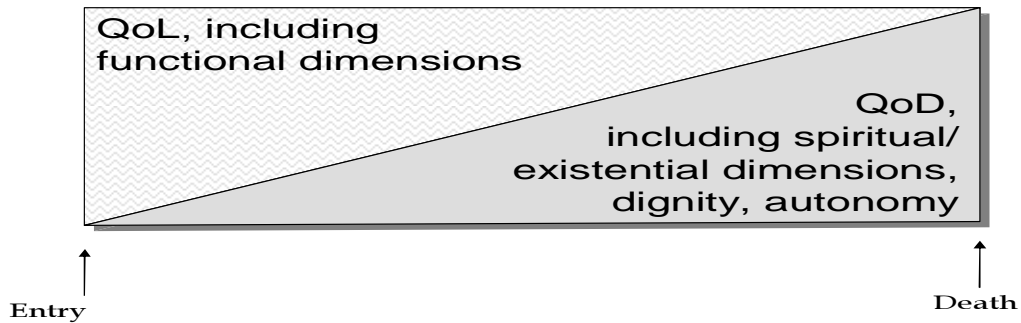


Clearly, the depiction of this figure with a straight line separating disease-directed treatment from end of life care, does not reflect the disease trajectories outlined in earlier sections of the paper but, for the purposes of exposition, this straight line will be retained in the framework although in practice this relationship may take a number of forms.

Currently the framework is developed in terms of the clinical care provided. For the purposes of economic evaluation, however, it needs to be concerned with the measurement of patient benefit and the appropriate evaluative spaces. Figure 4 therefore amends the diagram to show the potential factors that might be taken into account within this framework. The figure also reflects a move away from the clinical notion of diagnosis as the entry point to this framework, towards a more ambiguous point labelled 'entry' that might reflect the sort of expectation of life expectancy used by Main et al.¹⁸

Unfortunately, however, the complexity of this framework might increase further, with the addition of a period of active dying, a point towards the very end of life when those who are dying become more homogenous. At this time the patient may be non-communicative and care of the family may become increasingly important – although clearly not to the detriment of care for the patient. Indeed, the importance of care for the family as well as the patient may be anticipated to increase during the dying period generally, as indicated in the discussion in the section above. These changes are shown in figure 6.

Figure 5: Appropriate evaluative spaces for end of life care



Clearly, there are a number of dynamic dimensions that are important in shaping end of life care. These are illustrated fully in figure 7 by a continuum demonstrating the shifting relevance of different factors, starting with a potential increase in health care use, followed by a period characterised by the dying trajectory where the relevance of dimensions changes as death approaches, itself followed by a period of ‘active dying’ that culminates in death. After death, a period of bereavement and grief for loved one is shown. This framework clearly provides a departure from the somewhat naïve view illustrated in figure 2, but it also begs the question of how, or even whether, this framework is possible to operationalise. Figure 8 shows one means by which this framework might be operationalised: with the use of standard health or quality of life measures (QALYs or capabilities, for example) for the ‘living’ element of patients’ lives and the concurrent use of new measures in new evaluative spaces for the ‘dying’ elements: essentially measures that, as far as possible, relate to a ‘good death’.

Figure 6: The framework showing a shift in the focus of care and an active dying phase

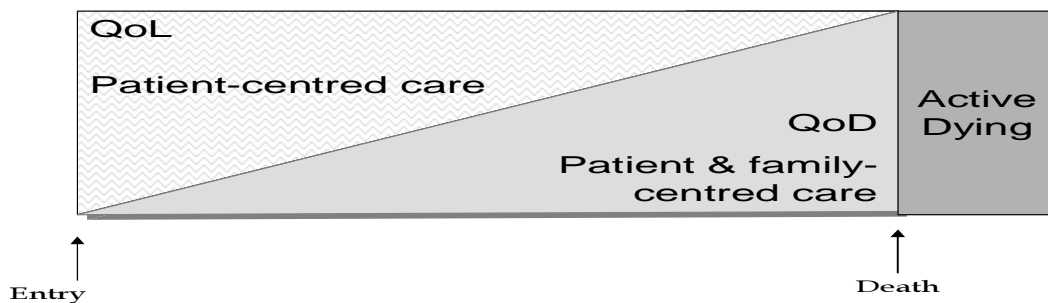


Figure 7: A full multidimensional framework for end of life care

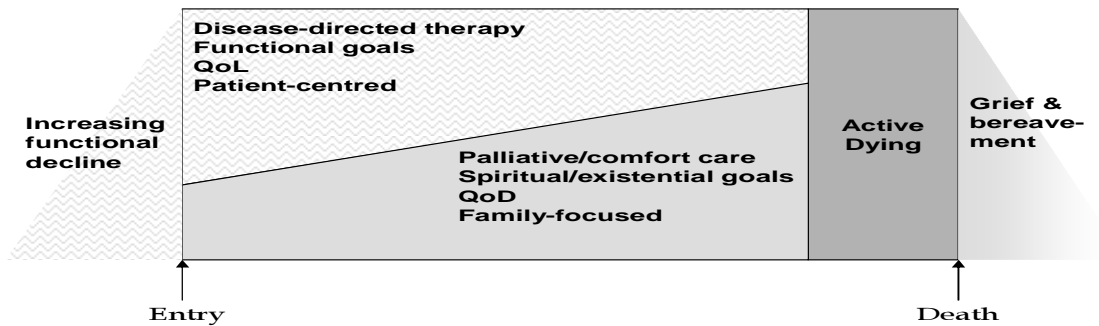
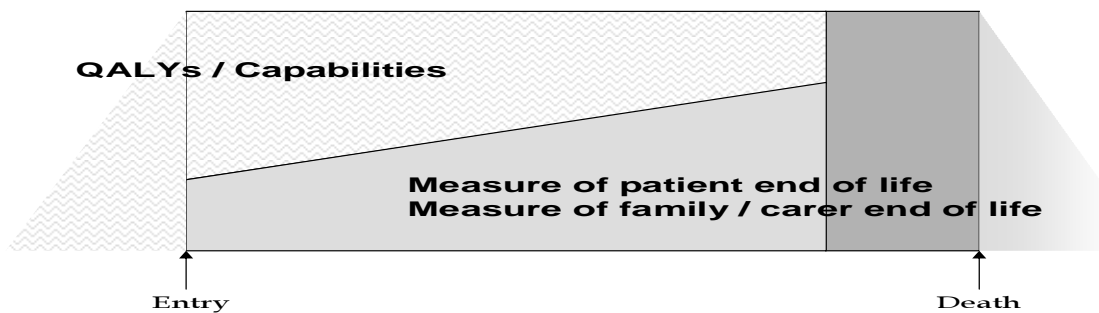


Figure 8: Measures within the framework



Clearly, this work provides only a framework for discussion; to be able to use this framework research in a number of areas would be required. The nature of this research is discussed below.

DISCUSSION: A RESEARCH AGENDA

Economics, including health economics, seems to be primarily concerned with the living, giving little consideration to the process of dying or the consequences of death. There is a dearth of health economics research into end of life care. At a time when the cost of dying attracts so much attention, and policies to improve the quality of end of life care are being put in place, it seem not only appropriate, but essential, that health economists develop more concern with

issues of death and dying. The tools available to health economists are, however, inappropriately specified for use in an older population approaching death. Although recent economic research has suggested a higher value for life as death approaches and has called for further empirical research, it has failed to turn to the extensive empirical data from fields such as palliative care and nursing, and is unable to help in the development of new approaches within economic evaluation. This paper has therefore aimed to redress this balance somewhat, by using these literature to assist in developing a framework and, hopefully, beginning a debate about how the economic evaluation of end of life care should be conducted, and, in particular, in what evaluative space.

The suggested framework brings with it a number of important research questions that remain to be tackled. The first is concerned with how ‘entry’ to the end of life framework is defined. ‘Entry’ could be defined in terms of the health care process – by diagnosis or prognosis – or by the person themselves through, for example, decisions to discontinue curative treatment. For many patients there may not, however, ever be such a clear terminal diagnosis. Patients entering long-term care and dying in care homes, for example, may never be clearly defined in this way. Dying patients may be defined retrospectively of course, but in practice this means that patients who would never have been considered for end of life care would be included and this might bias evaluations.⁶⁰ Clearly further research is needed to define ‘entry’ to a framework such as this, but as indicated earlier, the expectation of a particular life expectancy may be an appropriate method.

A second, and very important question, concerns what outcomes are relevant to the model in terms of a good death. It is important to determine what dimensions might be more appropriate than those contained in current QALY or capability measures. It should be noted that ‘[t]here is no single formula for a ‘good death’ (Steinhauser,⁶¹ p.825) for providing such dimensions. There is considerable, and long-running debate on this issue and there has been little consensus on the best evaluative approach in the field. Some researchers have chosen to focus on individual domains such as pain⁶² but it has been noted that many use location of care as a proxy for a good death⁶³ although there is empirical evidence that not all patients consider home death as desirable,⁶⁴ that preference for place of death may vary over the dying trajectory⁵⁹ and that other factors, such as not being lonely, may dominate.⁶⁵ There have been some efforts to conceptualise quality of dying by identifying domains considered important contributors to a ‘good death’ by patients and families.⁶⁶⁻⁶⁸ Work is currently ongoing to develop, using qualitative methods with individuals at various stages along the dying trajectory, a set of attributes for use in a measure for economic evaluation.⁶⁹

Third, there is the important question of how to weight and anchor any measure that is developed. Standard techniques, such as time trade-off and standard gamble, may not be appropriate here if death does not provide a sensible anchor point. An alternative might be the use of methods such as discrete choice experiments to obtain weights for questionnaires. As with other areas there are then important questions about whose weights should be incorporated

– those of the general population, as is generally suggested in the extra-welfarist approach, or those of dying patients themselves. Using general population preferences could be subject to the accusation that this group has insufficient knowledge to be able to make these choices; using the preferences of dying patients clearly produces logistical problems (ethics, sensitivity, and patients being well enough to complete lengthy survey instruments) and if preferences are rapidly changing and therefore unstable, current techniques may not produce helpful findings, particularly if there is no clear way to group individuals according to stage of disease or other factors. It should be noted, however, that discrete choice experiments have been able to be used in at least some groups in this population.⁷⁰ It may even be, that weights should be defined not according to some sort of aggregation of individual preferences as is the usual practice both within extra-welfarism and welfarism, but that they should be obtained through deliberation and debate, in methods more akin to those suggested within the capabilities literature.

A fourth question concerns who precisely should enter the model in relation to families and carers, and how benefits to them might be captured. Single interventions may deliver different benefits to multiple recipients, for example, providing clinical and psychosocial care to the dying individual, but also respite time for carers.¹² This difficulty may be particularly acute in terms of considering the impact of death on loved ones after the death event. This after-death period has received little attention from economists and there is a need for preliminary research to define the relevance of burdens as well as the duration and profile of this section of the model.

Fifth, there is the important issue of how to weight different dimensions (QALYs, QoD for patients, QoD for family) across the end of life continuum. The framework developed here implies that a patient may still have quality of life issues whilst quality of dying considerations also become important, and that patients' shifting perceptions and expectations may lead to different goals becoming more or less prominent along the dying trajectory. One of the most challenging issues for health economists working in the context of the continuum presented here is how to ascertain the relative weights of quality of life and quality of dying measures, capturing the shifting relevance of different goals along different dying trajectories. Clearly this is a complex area. Whilst methods might be available through the use, for example, of discrete choice experiments to determine relative weights, such experiments would need careful planning and clearly come further down the line than attempts to develop relevant outcome measures for economic evaluation.

Finally, and linked, there is the question of how to conceptualise the use of different frameworks at different phases of people's lives.* Here the distinction has been made between health in the living and end-of-life care in the dying, but this may not be the most appropriate 'split' and it

* Thanks to Hareth Al-Janabi for this point.

may be that a life-course approach could be used to emphasise different goals at different stages of life, with for example, a good upbringing (safety, development) at the beginning of life, experiences and opportunities in early adulthood, a focus on dependents in later adulthood and so on. Clearly, the extent to which goals differ at different phases of people's lives is an empirical question: information about this issue could then be linked to measures of well-being or quality of life.

One issue that has not been tackled here is the placing of this framework within a non-welfarist approach. Clearly the framework is more aligned with an extra-welfarist (albeit at the theoretical level⁴¹ rather than its current practical expression as a concern with health maximisation⁷¹) or capability view of the world, than with a welfarist view. The welfarist might reasonably ask whether this makes the whole debate considerably more complex than it might otherwise be. Within welfarism, after all, the measurement of all benefits can be done in the same way – on the basis of willingness to pay. The concern about retreating to a welfarist framework is that for the most part, those receiving end of life care are a vulnerable population who may not be the best judges of their own welfare and for whom resources may well be scarce. In the authors' view, this therefore makes the welfarist approach inappropriate.

We would welcome discussion on any issues prompted by the paper, but would particularly like some discussion around:

- Whether there is important economic literature that we have inadvertently missed.
- Whether economic evaluation in end of life care does merit a 'different' approach
- Issues around situating this work within a non-welfarist perspective
- Whether the proposed framework is appropriate/useful. If not, why not?
- What next?

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