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Appropriate frameworks for economic evaluation of end of life care: A qualitative investigation with stakeholders

Abstract

Background: The use of quality-adjusted life years rests on the assertion that the objective of the healthcare system is to improve health.

Aim: To elicit the views of expert stakeholders on the purpose and evaluation of supportive end of life care, and explore how different purposes of end of life care imply the need for different evaluative frameworks.

Design: Semi-structured qualitative interviews, analysed through an economic lens using a constant comparative approach.

Participants: 20 professionals working in or visiting the UK or Republic of Ireland, with clinical experience and/or working as academics in health-related disciplines.

Results: Four purposes of end of life care were identified from and are critiqued with the aid of the qualitative data: to improve health; to enable patients to die in their preferred place; to enable the patient to experience a good death; to enable the patient to experience a good death, *and* those who are close to the patient to have an experience which is as free as possible from fear, stress and distress.

Conclusion: Managing symptoms and reducing anxiety were considered to be core objectives of end of life care and fit with the wider health service objective of improving/maximising health. A single objective across the entire health system ensures consistency in the way that resource allocation is informed across that entire system. However, the purpose of care at the end of life is more complex, encompassing diverse and patient-centred objectives which we have interpreted as enabling the patient to experience a good death.

Keywords: Palliative Care; Terminal Care; Economic Evaluation; Place of death; A good death; Quality-Adjusted Life Years

What is already known about the topic?

- Economic evaluation informs the efficient use of health and care resources.
- Competing options are typically assessed in terms of their costs and their impact, in terms of quality adjusted life years (health gain and life extension).

What this paper adds:

- We use qualitative accounts from expert stakeholders to explore the purpose of supportive end of life care, starting from the position that the criteria for evaluating supportive end of life care should match its purpose.

Implications for practice, theory or policy

- The views of stakeholders in terms of what supportive end of life care should ‘ideally’ be trying to achieve broadly equates to ensuring the ability to experience a good death.
- At best, quality adjusted life years and the policy agenda around place of death crudely relate to such an objective and hence an alternative evaluative framework should be explored.

1. Introduction

Scarcity is openly acknowledged in strategy and review documents relating to supportive end of life care (1, 2). Economists have an important role to play in providing evidence on the cost-effectiveness of health and social care interventions, to inform decision-makers and commissioners. However, as the MORECare statement (3) –which promotes consensus on methods for end of life care research– indicated, there are ‘strongly opposing’ views about the use of quality adjusted life years (QALYs) in the end of life care context. This lack of consensus is apparent from the relatively small literature in this area (4-8).

‘Reference cases’ are set for economic evaluation by regulatory bodies to facilitate comparison of cost-effectiveness results across a diverse set of competing healthcare interventions/services. The reference cases of regulatory bodies such as the National Institute for Health and Care Excellence (NICE) in the UK (9) and the ZorgInstituut Nederlands in the Netherlands (10) specify that QALYs should be calculated based upon an assessment of health functioning. Tariff values combine information from the five items of EQ-5D into a single score, reflecting societal preferences (11), which is then used to calculate QALYs.

Two alternative means of promoting efficiency across diverse sets of healthcare services are the use of cost-benefit analysis (the valuation of outcomes in monetary terms) and the use of generic measures of well-being within cost-effectiveness analysis. For social care, the NICE reference case provides for the use of broad well-being measures such as ASCOT and ICECAP (12). Tariff values are available to summarise states defined by ASCOT (13) and ICECAP measures (14, 15).

With any generic measure/framework, sensitivity may be compromised in order to facilitate comparability. Normand notes that the QALY is insensitive to the complex and multidimensional objectives of palliative care and that, because there is limited scope for

QALY gains, the QALY framework will tend towards bias against palliative care interventions (6). Palliative care interventions may not, therefore, be cost-effective, despite being valued by society; a phenomenon which has been dubbed the “QALY problem” (6), although the same issue could apply to any generic evaluative space which is insensitive to end of life care outcomes.

Normand suggests that the appropriate solution to the “QALY problem” depends upon whether the need is to make comparisons between end of life care and other forms of health and social care or to make optimal use of end of life care resources (6). In the latter case, cost-effectiveness analysis (where there is a single, natural unit of outcome) will be adequate. There are a wide range of outcomes which could be selected as the (single) focus of cost-effectiveness analysis, such as pain score, place of death, or the patient’s broader wishes being recorded and realised.

Finally, work has been undertaken by health economists within recent years to develop context specific measures for evaluating supportive end of life care, one example of which is the ICECAP-SCM (Supportive Care Measure) (16). Such measures potentially offer greater sophistication than reliance on a single policy variable. A choice of evaluative space, aligned to any of the frameworks introduced here is as much of a choice as to what to *exclude* from analysis as it is about what it is that should be *included*.

The starting point for the study outlined in this paper is that, in determining the framework for economic evaluation in the end of life context, the purpose of end of life care should first be established. Otherwise, economic evaluation risks perversely and adversely influencing resource allocation.

2. Methods

This research utilised a qualitative approach to understanding the perceptions of expert stakeholders on the purpose of end of life care, adopting a subtle realist philosophical perspective (17) and analysing data through an economic lens (18). Qualitative interviews were conducted with academic stakeholders with expertise relevant to the topic of economic evaluation and end of life care. Ethical approval for the research was obtained from the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham [ERN_11-1293].

2.1 Sample & Recruitment

Sampling aimed to draw on a wide variety of perspectives in a form of maximum variation sampling (19), with variation across and within (clinical and non-clinical) academic disciplines, as reported elsewhere (20). It was anticipated that a sample size of around 20 would be sufficient to capture the main perspectives.

Stakeholders currently working in, or visiting, the UK or Republic of Ireland were identified through: searches of conference programmes and public websites of key research institutions; known contacts of the research team and advisory group; publicly listed membership of NICE Technology Appraisal Committees; snowball sampling. Stakeholders were invited via email; with one email reminder if appropriate. An information leaflet detailed the aims of the study, together with funding and the methods to be used for data collection.

2.2 Data Collection

Semi-structured one-to-one interviews were conducted during 2012/3 by PK. Interviews lasted between 45 and 80 minutes and were audio-recorded. A topic guide was followed, including: participant's background and experience; purpose and current provision of care at the end of life; context for economic evaluation at end of life; general outcomes of

importance; economic outcomes; timing and defining the 'end of life period'; assessment of outcomes. Appendix A contains the topic guide and further detail relating to data collection.

2.3 Analysis

Audio recordings were transcribed verbatim. Transcripts were analysed in batches of between three and six, using constant comparison and the writing of analytic accounts.

Transcripts were coded by both authors, themes were identified inductively, drawing on the economic disciplinary 'mode of thinking' of both authors (21), and were refined and modified as analysis progressed and analytic accounts were formed, compared and refined (22).

In the quotations reported, participants are identified by study number and discipline: Health Economics (HE); Nursing and Allied Health (NA); Health Psychology (HP); Physician (DR); Philosophy/Ethics (PE).

3. Results

Thirty three individuals were invited to participate; 20 interviews were conducted.

Participants were: HE (n=6); NA (n=6); HP (n=3); DR (n=3); PE (n=2). Characteristics of participants are reported in Table 1.

Table 1: Characteristics of Participants:

Participant Background/Experience	Number of Participants
Institutional Affiliation	
<i>Academic</i>	16
<i>NHS with honorary academic contract</i>	3
<i>Non-University Research-focused Organisation</i>	1
Academic/Clinical Discipline	
<i>Ethics/Philosophy</i>	2
<i>Health Economics</i>	6
<i>Health Psychology</i>	3
<i>Medical Doctor</i>	3
<i>Nursing/Allied Health</i>	6
Direct Clinical Experience/Healthcare Delivery	
<i>Yes</i>	8
<i>No</i>	12

3.1 Summary of the themes arising

Ten initial themes emerged and reflect the full breadth of the qualitative data. These themes and a diagrammatical representation of the interaction between them is summarised in Figure one. Where there is significant interaction between themes, these have been grouped together within a dotted outline (for example, it was sometimes artificial to distinguish between outcomes for the patient and outcomes for the family).

[Insert figure 1 here]

Information revealing participants' views on the purpose of end of life care crossed through each of the ten initial themes. Possible contradictions could be identified across interviews, for example some who were critical of place of death as an outcome had used this outcome in their own research, and two participants in particular who advocated the use of QALYs nevertheless listed non-health outcomes they envisaged would be important to patients. Complex concepts were sometimes expressed through recalling experiences (stories). Four purposes of end of life care were identified:

1. To improve (or maximise) the health of patients.
2. To enable patients to die in their preferred place.
3. To enable patients to experience a good death.
4. Positions one, two or three with the inclusion of the impact upon family and informal carers.

3.2 Health Gain

Most participants referred to controlling/relieving symptoms (most frequently pain) as a key element of end of life care. However, there was also explicit acknowledgement by many that end of life care is unlikely to significantly improve health, and thus some suggested that to assess end of life care in terms of health improvement was to set services up to fail:

In palliative care your input is an ill patient and your output is a dead patient

(13NA)

...we know a number of things: one is, by the very nature of it, the person's going to die; so if you're saying what's their health status at six months or whenever? Dead.

... so if you're using as an outcome measure how sick they are, all of our studies are going to, as it were, fail... (04HP)

Others expressed varying degrees of concern about the relevance and sensitivity of particular health-related quality of life instruments in the end of life context. Participants also focused on process elements such as the importance of communication with patients and family and broader support. These were seen as clearly distinct from health gain and thus not measured under this approach.

Instruments such as EQ-5D or even SF-36 are not adequate... palliative care interventions tend to be complex ... they're trying to affect a whole range of things from ... physical symptoms to trying to provide a broader support to the individual, family and friends... (09HE)

I don't think that health-related quality of life is necessarily the right generic measure. It's not broad enough. (02HE)

One view here was that the weaknesses associated with the QALY are, far from being specific to end of life care, merely more apparent in this context.

...the issues that arise when you're trying to develop evidence in palliative care are actually very generic ones ...it's just rather more stark... (09HE)

They're [QALYs] a useful tool but they clearly aren't useful in all areas of medicine and palliative care is perhaps the clearest example of when they're not useful. (17PE)

There were also differing views about the appropriateness of combining health status and survival within the QALY.

I don't think QALYs are right because that's looking at survival (01HP)

... as far as I'm aware, every attempt to come up with a practical alternative to the QALY –with respect to trade-offs with time– ... have never really reached success... [the QALY] is a pragmatic tool, I'm not aware of any areas, decisions by say NICE,

where the nature of those trade-offs between time and quality have clearly generated results which are perverse... (12HE)

Two arguments emerged in favour of assessing the consequences of interventions at the end of life in terms of health gain. First, if health gain is the legitimate objective of the health system and if care at the end of life is provided by the health system, then health gain, by default, becomes the objective of end of life care. From the normative viewpoint that health alone is of importance as the output of the health system (epitomised by 12HE), it would be inappropriate to factor wider impacts into economic evaluation; they would, instead, be seen as being either “derived from health” (12HE) or irrelevant.

I'm not clear whether health systems SHOULD, from a normative perspective, be trading those types of broader benefits with other people's health... (12HE)

Many participants acknowledged the need for comparability in terms of the results of economic evaluation:

*...there's... lots of debate about how appropriate QALYs are for end of life care...
I'm quite critical of QALYs [but] I still think that commissioners need some metric like that. (07HE)*

Indeed, some felt that comparability was sufficient reason to settle for health gain/QALYs:

...if you're to argue for funding against other healthcare activities...it's perfectly reasonable to demonstrate the benefit only in terms of health care... (20DR)

Hence, whilst there was a divergence of views between those who regarded health gain as the sole and legitimate objective of the health system and those advocating a broader focus, there was significant agreement that the opportunity cost of investing resources in end of life care must (somehow) be compared to the opportunity cost of investing across the rest of the health sector. If health gain can be considered to be a legitimate objective of end of life care, this

definition of benefit/outcome clearly facilitates such comparison. The question that exercised informants was just how ‘poor a fit’, in terms of the relevance and realistic opportunity for health gain in the case of end of life care, can be tolerated to achieve consistency and comparability.

Factors differentiating care at the end of life included the overlap with social care, the inevitable worsening health of the patient, and the shift away from curative intent. For some informants, this meant that the purpose and objectives of end of life care simply do not fit the mould that is standard for health economic evaluation.

3.3 Preferred place of death

The environment in which death occurs is one ‘process’ element that many participants considered important and policy relevant. Participants discussed particular characteristics of preferred place of death. They used ‘comfortable’ and ‘safe’ as positive terms when referring to the care environment, and ‘fear’ and ‘distress’ as negative terms.

there’s ...an aversion for people to ...be in a high intensity environment, where it’s noisy, the lights are bright, they’re in an over-crowded situation with strangers, compared to somewhere where it’s ...peaceful, comfortable... and you’re with the people you want to be there with... (19HE)

supporting the process of dying in a way that enables the patient to have a death which is ... in a place... that doesn't add stress and harm (13NA)

Dying in acute care was generally seen as a poor outcome, with dying at home or in a hospice seen as positive. In part this seemed to relate to the lack of opportunity in an acute environment to develop trusting relationships with staff and for staff to understand patients’ wishes:

In the acute environment ... [care] is very poor, it's marginalised, it's frightening to everybody concerned. (11NA)

Patients often arrive on their own... very often patients aren't able to communicate... information's lacking, time is of the essence ... it's not until there's the time and the information that you sometimes realise that this isn't what they wanted (10NA)

Some participants, however, expressed scepticism about research suggesting a common preference for dying at home, and a number expressed the view that patient preferences change over the course of the dying trajectory as their condition progresses. Participants frequently acknowledged that the reality of dying at home may be very different from the expectation, and that setting unrealistic expectations seems “cruel” (3NA):

... they're people who are answering a hypothetical question ... So far away from death people choose home and they're really unrealistic... (06DR)

[the acute setting is] an open door...patients know they can get help there ...even when they have community services, they still chose emergency departments to get help and support (10NA)

There was also concern that a sole focus on place of death could have unwanted consequences for others in the family, both in providing unpaid care and broader impacts on family life.

... if home needs adapting, that affects the entire household... (13NA)

Despite the simplicity of preferred place of death as an outcome, and its use by policy-makers, there was little support for its use as an outcome in economic evaluation. Rather, what appeared to be important was to acknowledge heterogeneity between patients and to enable each individual patient to experience as good a death as possible. Place of death appears, at best, to be a crude proxy for this more complex aspiration.

The purpose is different for everybody you look after ... when it comes to end of life care, you don't know what a patient wants and so you have to negotiate with them (06DR)

3.4 “A good death”

Some participants explored alternatives to the QALY, which involve broadening the evaluative space but seeking to maintain some means of comparability. A relatively small number of non-health outcomes were mentioned by participants, including social isolation/engagement, spirituality and meaning-making, dignity and respect, putting affairs in order, good communication with staff, the environment, and some concept of achievement/closure.

...a more general characterisation of quality of life would include for example their ability to be with family, their ability to put their financial affairs straight... do those last ...things that they want to do before they 'shuffle off' (12HE)

I would hope that people had done what they wanted to do... those tasks that people feel they wish to accomplish (05NA)

Indeed, when participants gave examples of effective care at the end of life it was often in a context in which staff had time and experience, and care was the focus rather than health gain.

...crucial conversations happen when someone's lying awake at two o'clock in the morning and the nurse happens to go in to do the observations (11NA)

One participant referred to evidence that patients are (or at least indicate that they are) willing to trade-off health in order to achieve better quality of life generally, suggesting that a broader outcome is feasible:

Patients – caregivers to a lesser extent – were still [in Discrete Choice Experiments] willing to trade months of survival for those... non health-related benefits... (19HE)

In terms of consistency, there was some suggestion that additional items could be added around a core outcome set, depending upon the condition being studied. For end of life care, those additional outcomes could be thought of as assessing factors which enable ‘a good death’ such as communication, environment, having those people around who are important to you, spiritual support and a sense of closure/accomplishment:

I think there has to be a core set of outcomes to inform the decision making process but then arguably for any clinical area you might want to have separate measures that are specific to that area (07HE)

A more radical suggestion was that different outcomes be used in different contexts and that a more sophisticated means of comparison be established (an “exchange rate”).

...if we’re serious about being able to support resource allocation, one of the objectives has to be comparability between palliative and curative intent ...rather than saying let’s have a single measure that you apply across all settings, you have a system of validated comparison between measures in different settings... rather like the pound-dollar-euro rates, we don’t have a single currency... but we do at any given time know how to interpret one currency in terms of another. (09HE)

A third alternative was to maintain a consistent, universal measure but ensure that it is sufficiently broad.

...I strongly believe that the framework upon which we base economic evaluation, currently, can be applied to anything, but the detail is inadequate... Particularly since the development of NICE, there’s a serious lack of flexibility... health economists have

just walked away from the theoretical underpinnings of what they do... just kind of dumped utility ... for a very narrow measure of health-related quality of life... (02HE)

As well as a broadening of outcomes, it was suggested by one participant that time might be considered in terms of the “nature of the trajectory”, rather than “counting the days”. In other words, outcomes could be related to an entire experience and not sequences of time; a good death or a satisfactory death could perhaps be such an outcome.

People’s view of the quality of an experience is not simply related to how long it lasts, indeed in some cases people would describe as a better experience something that is shorter in duration... it’s not that it [time] is irrelevant, it’s just that it can’t be added up like that... (09HE)

A number of options were therefore suggested by informants for taking account of the different outcomes that are seen as important in relation to a good death. Inevitably, this would make evaluation more complex but could avoid the problem identified by one participant that “we often make the things which are least meaningful measurable” (05NA).

If a different framework is to be used for evaluation of end of life care, however, there are difficult questions about when a person would move onto the new framework. This issue was discussed with participants although they found it challenging. Suggestions from participants included: a prognosis of less than a year and an awareness of that prognosis; the first point at which the health system engages with a person on the fact that they will soon be dying; the point at which it is known that the disease is terminal; the point at which the Liverpool Care Pathway would have been initiated (the last few days of life); when people come to realise themselves that they are approaching end of life; the point at which palliation becomes the treatment priority. Uncertainty around the trajectory was stressed by most health professionals.

3.5 “A good death” with a broad perspective

Some participants additionally strongly favoured incorporating outcomes for family and others close to the patient and indeed some explicitly referred to support for the family when summarising the purpose of end of life care.

...providing end of life care isn't just to the person, it's important to provide care to their family as well... (06DR)

Participants tended to think about those close to the patient in two ways, as informal care providers who should be supported in caring for the patient and as people who are emotionally involved and bear a lasting memory.

...whether the carer felt well supported, because I think that's indivisible from outcomes, that IS an end of life care outcome actually cos you see the patient and family as an indivisible unit (08NA)

...it can be so difficult, you know, dying in an ambulance or in a hospital, or in A&E, and that lives with those families for many, many years (16HP)

There was, however, concern expressed about the need to integrate properly any inclusion of non-patient outcomes into the economic analysis.

... what's fundamentally important about any broadening of the perspective on benefits and dis-benefits is that we deal with them symmetrically in terms of evaluating new technologies, but also on the opportunity cost side (12HE)

... And if you did it for end of life care, would you have to do it for all types of care? And that could end up putting a lot of burden on analysts... (18HE)

Whilst from a health economics perspective the inclusion of family and persons close to the patient is a normative question, from a care perspective, it may be somewhat artificial to differentiate between support for the patient and support for those closest to the patient.

4. Discussion

4.1 Main findings

Participants confirmed that there are elements of the common (health economics) conceptualisation of health that are relevant and important in the end of life context, namely pain, discomfort and anxiety. However, attributes relating to the planning and delivery of care, as well as broader factors more personal to the patient, were also identified as important, indicating there may be a case for altering the evaluative space typically adopted within economic evaluation.

In the economics literature, those favouring the QALY framework stress that it is intended to incorporate information (in addition to utility) relating to the characteristics of people (7); the fact that some important (non-health) characteristics of people “such as spirituality or preparedness for death” [7 p523] are not included within current instruments (such as EQ-5D) does not mean they couldn’t be included. This argument is weakened, however, if the rejection of broader outcomes relates to the view, expressed by some participants here, that the legitimate objective of the health system is solely to improve health, as well as fear of the resulting lack of transparency in terms of displacement (23).

Single proxy outcomes such as preferred place of death could be used in cost-effectiveness analysis and, in particular, participants noted the importance given to place of death within the policy literature. However, preferred place of death represents a narrow element of the

overall picture: a person could die at home as their preferred place of death, yet also die in great pain. Many strategy and policy documents do refer to dying at home, drawing upon evidence that suggests many people (56%-65% in the UK, 74% in the Republic of Ireland) have a prior preference to die at home (1, 24). Dying at home, or more generally in a preferred place, is often seen as one, or even 'the', important outcome of end of life care in non-economic analysis (25, 26). However, current research indicating a common preference for dying at home fails to quantify the associated trade-offs, and was generally regarded as unreliable by participants. A more nuanced outcome which could be used in cost-effectiveness analysis, which has been explored in the published literature (27) is that patients' preferences are known and adhered to.

Several participants suggested ways of ensuring some degree of consistency/transparency across the healthcare system as a whole, whilst facilitating a broader (or alternative) outcome space. One solution is to expand the current QALY, i.e. expand the scope of the current QALY, but still have one standardised framework. Perhaps a more appropriate suggestion is to add additional end of life care outcomes around the core/generic outcome space (as a context-specific bolt-on). Expanding the QALY framework does not, however, overcome issues associated with time and survival.

A more radical solution involves a stand-alone metric for evaluation in the context of end of life care, which conceptualises a 'good death'. This position supports recent suggestions for using the Capability Approach as a framework for the economic evaluation of end of life care, possibly utilising a new capability-based supportive care measure, the ICECAP-SCM (4, 28). Capability is a concept associated with the work of Amartya Sen and Martha Nussbaum (29-31). Sen advocates defining well-being with respect to the ability or freedom that a person has to achieve the things that they have reason to value.

Although the ICECAP-SCM was developed through qualitative work with those approaching the end of life, it still involves assessing outcomes using a standardised set of questions. Hence whilst it is at least context-specific, there is limited scope for such a measure to promote truly patient-centred outcomes and some exchange-rate type mechanism would still need to be developed if end of life care services are to be compared with more general health services.

4.2 Strengths and Limitations

This work has strengths and limitations. A clear strength is the focus on an under-researched area. Because of the desire to generate a broad understanding of the area from a number of perspectives, the number of ‘voices’ in any one disciplinary area is limited. Nevertheless, drawing on the perspectives of clinically qualified academics, psychologists and philosophers, in addition to economists, ensured that the analysis was grounded in end of life care, as well as conceptual frameworks for economic analysis. Although the work was largely limited to the UK, policy statements internationally state similar priorities for end of life care and a minority of participants brought an international perspective.

4.3 Implications

The diversity of views about the conduct of economic evaluation of end of life care and the clear need for further research for almost all frameworks, suggests that a major implication arising from this work is that more research resource is required to generate a greater evidence base in this area. One factor that was identified as important was the need to assess the impact of care on those close to the person at end of life and work has recently been undertaken to explore this issue (32).

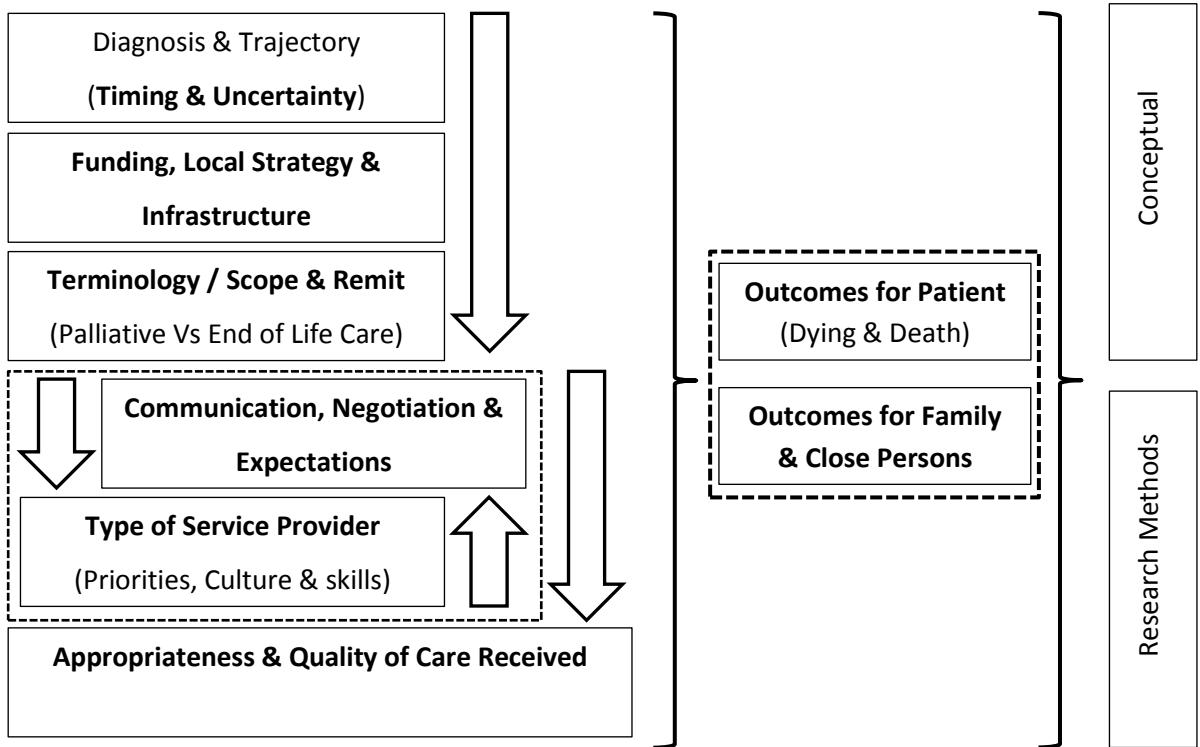
Many health economists regard the maximisation of health gain as the system-level objective of the National Health Service, but if what participants in this study who are healthcare

professionals reported trying to achieve for patients and families, and what the wider sample listed as being important to patients and family members is interpreted as the objective of end of life care, that objective broadly aligns to what we have termed ‘a good death’.

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Data Management & Sharing: The conditions of ethical approval require that data be stored on a secure network at the University of Birmingham. The likelihood of identifying expert stakeholders from complete transcripts means that full data sharing will compromise anonymity. Excerpts of the transcripts will be shared upon request. Requests should be sent to: icecap-data-access@contacts.bham.ac.uk

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