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Eileen J Sutton¹ and Joanna Coast²

Abstract

Background: An imperative to assess the economic impact of care at the end of life is emerging in response to national policy developments in a number of settings. Current focus on health benefits in economic evaluation may not appropriately capture benefits of interventions at the end of life. No instruments are available for measuring such benefits for economic evaluation of end-of-life care.

Aim: To develop a descriptive system for a measure for use in economic evaluation of end-of-life care.

Design: An initial phase of in-depth interviews was conducted to develop conceptual attributes for inclusion in a measure; a second phase of semi-structured repeat interviews with a subsample of informants was carried out to clarify and confirm the final set of attributes and to develop meaningful wording for a measure.

Setting/participants: In total, 23 older people from three groups across the dying trajectory: older people (1) within the general population, (2) living in residential care and (3) receiving palliative care.

Results: Interviews suggested that the important domains to include within this framework from the perspective of those approaching the end-of-life are choice/having a say in decision-making, love and affection/being with people who care, freedom from physical suffering, freedom from emotional suffering, dignity and self-respect, support, and preparation. A full descriptive system comprising seven questions, each representing one attribute, was developed.

Conclusion: Economic evaluation should reflect the broader benefits of end-of-life care. Although the supportive care measure developed here requires validation and valuation, it provides a substantial step forward in appropriate economic evaluation of end-of-life care.

Keywords

End-of-life care, cost-effectiveness, outcome measures, aged

Introduction

An imperative to assess resource implications for care at the end of life (EoL) is emerging, through national policy documents, in many nations.^{1–4} One focus is place of death, but reports also allude to the evaluation of care strategies and requirements for economic research.¹ To compete with other sectors for funds, EoL care (EoLC) programmes need to demonstrate efficiency. Economic evaluations have been attempted,⁵ but there are methodological issues in defining costs and benefits, with need for further development of research tools.⁶

Previous research has noted limitations with the quality-adjusted life-year (QALY)⁷ approach to palliative care (PC)⁸ and difficulties in measuring outcomes at the EoL.⁹ One problem in applying QALYs to EoL interventions results from the nature of this ‘quality’ adjustment. In essence, measures used for this adjustment are measures of

health, thus the focus of benefit assessment is purely health improvement: either health status improvement or extending length of life. This may not be appropriate for EoLC, where the concern may be providing care rather than health improvement. EoLC may have more in common with interventions traditionally provided through social services; the evaluative framework may need to encompass the broad

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methods advocated for evaluating social service interventions¹⁰ where health outcomes are not routinely the focus.¹¹

Current literature on older people's preferences for EoLC has largely originated from the United States and focused on treatment decisions – including advance care directives and life-sustaining treatments – although what constitutes a good death or quality EoLC has been explored.¹² Some efforts to conceptualise quality of dying have identified important domains for a 'good death'.^{13–15} These notably contain attributes beyond health, suggesting the inadequacy of a sole focus on health in decision-making frameworks for EoLC. For economic decision-making, however, it is important that the domains can be linked with meaningful values that reflect the relative importance that these domains have for people. To be able to do this with existing methods requires measures with a small number of single-item domains. This work aimed to explore what factors older people consider important at the EoL to (1) identify distinct attributes that could be included in an economic measure of EoLC and (2) develop a descriptive system for an appropriate measure for this setting.

Methods

The research was designed in two phases: (1) initial interviews to determine conceptual elements of a good death and (2) follow-up interviews to check that resultant attributes were meaningful to participants, capturing all relevant issues. This approach has been used previously.¹⁶ Consolidated criteria for reporting qualitative research (COREQ) guidelines are followed in reporting.¹⁷

In phase 1, in-depth qualitative interviews were conducted with 23 informants at various stages along the dying trajectory,^{18,19} aiming to obtain a diverse sample within three groups of individuals with varying 'closeness' to death, from older people who were currently healthy, through frail older people, to those already diagnosed with an EoL condition:

- People aged over 65 years recruited from a general population (GP) sample who had previously taken part in a survey on long-term care ($n = 11$);
- People aged over 65 years living in residential care (RC) facilities ($n = 7$);
- People aged over 65 years receiving PC ($n = 6$).

Ethical approval for the study was granted by South West Multi-Centre Regional Ethics Committee (06/MRE06/12) and written consent was gained from participants who were provided with information about the purpose of the research. Pseudonyms for participants are used throughout. A distress protocol was developed for use if participants became upset during interviews.

Invitation letters and study information sheets were distributed by post (GP), via care home managers (RC) and

via health-care professionals at hospices (PC). Those wishing to participate returned a completed reply slip. From the GP group, 32 individuals were contacted; as access to the RC and PC groups was facilitated through professionals, numbers approached are unknown.

The researcher conducting the interviews (E.J.S., PhD) had previously worked on studies examining sensitive issues and is trained in basic counselling. Interviews took place in participants' homes (GP), residents' rooms/vacant communal rooms (RC) or vacant hospice rooms (PC). One informant wanted her daughter to be present during the interview; all other interviews included only interviewer and informant.

Initial interviews were largely informant-led, enabling participants to articulate important issues in their own words. Informants were first asked whether they had experienced the death of a loved one, and if so, what was good or less good about the way that person had died. They were subsequently asked what would be important to them when they were dying. A topic guide was devised following review of relevant literature¹² to aid probing of underlying attributes. Interviewing older people on EoL issues is shaped by constructions of this group as vulnerable;²⁰ nevertheless, all interviewees were willing to discuss EoL. The researcher made short reflexive field notes at the end of interviews; these were useful during the analytical process. The different backgrounds of the two researchers (economics and social policy) allowed for different interpretations of the data to emerge and helped to challenge preconceptions of the researchers and the more general interpretation.

Data collection and initial data analysis proceeded concurrently, with issues raised by participants followed up in subsequent interviews iteratively. Data saturation was discussed between E.J.S. and J.C. regularly; saturation for the GP and RC groups was relatively easily achieved but within the PC group was more challenging because of gatekeeping issues. Nevertheless, both researchers were satisfied that by the end of the first round of interviews, no new major themes were arising.

Interviews were audio-recorded with participants' permission and transcribed verbatim. Interviews took place between June 2006 and November 2008 and lasted between 40 and 105 min. Analysis had two distinct stages. The first stage drew out the main issues raised in the initial interviews. Interview data were analysed using constant comparison^{21,22} with the aid of ATLAS.ti. Transcripts were coded by E.J.S. with a sample from each group coded by J.C.; these were cross-checked and codes amended following discussion. The second stage took these issues and documented how they contributed to a good death, grouping them into mutually exclusive attributes of EoLC – a challenging exercise owing to its necessarily reductive nature. Feedback from delegates at the 7th Palliative Care Congress was also incorporated.

A second interview was conducted with 12 participants to (1) check that the attributes developed were meaningful, capturing all the relevant issues and (2) check that the wording used in the attributes was easily understandable. In the early second-stage interviews, the main focus was the first aim; participants were given a showcard listing draft attributes, and the interviewer questioned informants about each area in turn, inviting them to explain in their own words what it represented, for example, 'If we start with suffering, what sort of things come to mind?' Data were analysed using constant comparison, and amendments made to the topic guide for subsequent interviews in line with participants' recommendations. A draft supportive care measure was devised, wherever possible using participants' language. In later interviews, acceptability of wording and possible attribute levels were also tested. E.J.S. presented the draft measure to a local hospital PC group for expert feedback. Further amendments were made in light of findings and feedback.

Findings

Analysis stage 1: identifying issues that are important to older people at the EoL

Following analysis of the initial 23 interviews, eight broad categories emerged: *Suffering, Maintaining identity, Independence, Choice, Dignity, Love and affection, Being supported* and *Preparation*. There was no clear divergence in views between the different groups, and therefore, the analysis is presented for all groups together.

Suffering. Participants highlighted factors like being free of pain and not having a long or lingering death:

I just wouldn't want to be in pain all the time. (Female, 72 years, PC)

When the time comes, let's hope it's quick. (Male, 81 years, GP)

These examples emphasise both positive and negative attributes, for example, not being in pain was contrasted with having a quick or peaceful death; this later presented difficulties in developing the measure's wording.

Maintaining identity. Participants raised issues concerning cognitive awareness and having religious beliefs recognised, contributing to their personal identity or sense of self:

If, heaven forbid, I get to the state where I'm non-compos mentis, sort of thing, I don't want to be kept alive. (Female, 86 years, GP)

I'm Jewish to start with ... I'm very fortunate that I've got strong religious beliefs. (Female, 90 years, RC)

Independence. Informants related the importance of being able to do things that they enjoyed and maintaining their independence for as long as possible:

If I want to go and dig the garden I can say: 'Oh I'll go and do ten minutes in the garden'. (Female, 86 years, GP)

I can do everything I want to do, and I don't have to rely on people. That's important, not having to rely ... Well I wouldn't like other people in my home, you know ... I do like company but somebody, you know, doing all the intimate things, like doing my ... cleaning the house for me, and that's my job. (Male, 81 years, GP)

Choice. Informants identified choice as important, for example, being able to make decisions about things that affected their lives like the place that they would live or be cared for:

I'm staying here until I get carried away. I've worked hard and paid for it, and this is my abode and I'm quite happy with it. (Male, 72 years, GP)

I don't want to be kept alive if I'm not fit enough to enjoy it. (Female, 81 years, RC)

In contrast to some evidence from the literature,¹² participants did not place great emphasis on the importance of treatment decision-making and advance care planning, although other aspects of autonomy such as being able to choose place of care or death were emphasised.²³

Dignity. Another vital issue for participants was being able to maintain their dignity. This involved being able to look after their personal needs for as long as possible, having good nursing or personal care, if or when needed, and not feeling indebted to others:

Being clean, number one, not being in any of your own mess whatsoever. (Female, 68 years, GP)

You wouldn't want to be a burden mentally or physically on people. (Male, 68 years, GP)

Love and affection. Participants across all three groups drew attention to the importance of good relationships, particularly with family:

I don't think I'd be the same if I never had a family. (Male, 69 years, RC)

She [daughter] comes round here nearly every day to see me. She's adorable she is ... and gives me chocolate. (Female, 68 years, PC)

Being supported. Closely linked to the previous category was having people in your life whom you can call on if needed and who support the decisions you make:

When I came out of hospital he [husband] done everything I mean, he cooked the food and he's never cooked in his life [laugh] ... And all the washing, ironing he did. (Female, 72 years, PC)

My closest friend who came ... has been all I've got ... and she would be the same now if I needed her. (Female, 83 years, PC)

Preparation. Most study participants had funeral, burial or cremation plans in place. Other issues included having financial affairs in order and being able to say goodbye to loved ones/friends:

I want to be cremated with my wedding ring on. (Female, 97 years, RC)

I've left my will to [friend] cos I haven't got any family. (Male, 81 years, RC)

Second-stage interviews and analysis stage 2: refining attributes

Clarifying attributes. The second-stage interviews revealed problems with coverage of some initial attributes. The attribute *Suffering* was easily understood by participants, who related this to experiencing pain, discomfort or fatigue, although there was some concern regarding distinguishing everyday aches and pains associated with getting older from the severe physical discomfort of particular diseases or conditions:

I think as you get older you all, well, you all suffer pain one way or another ... the knees go, the hips go ... (Male, 68 years, GP)

Another issue raised was the separation of physical from emotional pain:

I mean my discomfort is emotional rather than physical and I have days when I feel really good, and don't worry, but if I have a very down period ... I mean nobody wants to experience pain but I'm quite sure these days they can do things to relieve you of pain, but it's just the emotional thing really which is more, especially when you've got nobody to talk it through with ... (Female, 83 years, PC)

These findings highlighted the importance of capturing both physical and emotional components of suffering, the latter encompassing worry and distress. Two distinct attributes were therefore created, to ensure that both elements were accounted for. These were described as *Physical suffering* and *Emotional suffering*.

It was clear from the start that participants found the attribute *Maintaining identity* difficult to comprehend as a separate entity. Some interpreted it as being treated as an individual (e.g. by health professionals), while others interpreted it as being autonomous or as maintaining dignity:

Of course there comes a stage dependent on the first one, suffering, and depending on your dignity how you maintain your own identity ... so the three are somewhat linked in my mind ... I don't know what you can do really. Maybe I'm not grasping the word right ... You want to stay as long as possible in your own home ... you could class that as maintaining your identity I suppose ... because I am actually struggling with it. (Male, 68 years, GP)

I think some people get the wrong idea when they get these people who've got this Alzheimer's that they wanna be directed and pushed – they don't want that do they? (Female, 74 years, GP)

The ability to maintain a sense of self was therefore viewed as related to the overall latent (or underlying) construct for the entire measure and dependent on the possession of other attributes. Therefore, having a high level in other attributes such as dignity or choice would enable a person to maintain their identity. The team therefore decided that this attribute should be dropped from later iterations and others expanded to ensure that they encompassed all issues originally associated with *Maintaining identity*.

The attribute of *Independence* presented similar difficulties as participants related this to being able to decide where they would live or be cared for:

I went in for this flat because it's wheelchair friendly ... I'm hoping that I'd lay here in a box, because it was a very deliberate act of me to look for somewhere where I can be independent for as long as possible. (Female, 67 years, GP)

Links with worry or distress were also evident as participants discussed not wanting to call on, or be indebted to, family or friends:

I hate being dependent upon my son, my grandson ... but there's no other support at all. (Female, 86 years, GP)

The research team therefore decided that while maintaining independence was vitally important for participants, the key elements mentioned were already encapsulated in other attributes, including *Choice*, *Emotional suffering* and *Being supported*, so it was dropped from later iterations.

Clarifying wording. The attribute *Dignity* was understood by participants to encompass factors such as being clean, having privacy, having religious beliefs recognised and being treated with respect. As outlined above, elements of self-identity were also captured. The wording 'I can maintain my dignity and self-respect' was tested and found to incorporate elements important to participants:

Making sure ... things like your bodily functions, to make sure that's done and to make sure you don't lie in a wet bed and things like that. (Female, 74 years, GP)

I've got my self-respect, she [carer] doesn't stand there if I'm having a shower and all that, she just makes sure the windows are covered ... we all want our self-respect no matter who we are. (Female, 68 years, PC)

Discussions regarding *Choice* raised interesting issues around the attribute levels. The kinds of decisions mentioned by participants included where they would live or be cared for at the EoL and regarding medical treatments. However, participants believed that at the EoL, it would be unrealistic to have choice and input in 'all decisions', 'all of the time' or 'always' due to issues including availability of service provision, health state and cognitive capacity:

I'm not always able because circumstances won't allow me to always make decisions. (Female, 68 years, PC)

You might say 'right I have to go into a nursing home', but I haven't really got a choice which one I go to. (Male, 68 years, GP)

Following the analysis, the attribute was therefore renamed *Having a say* and wording for the top-level attribute was amended to 'most of the time'.

Testing the attribute *Love and affection* revealed problems with wording. The first-stage interviews had highlighted the importance of relationships, especially with family. However, in the second-stage interviews, it was evident that in relation to EoLC, this wording was problematic:

What is love? Difficult isn't it, love and affection. Well I mean, it's good enough love and affection for people to be doing what they think you want, right, and looking after you to the best of their ability. At the EoL that must be what love and affection is. (Female, 74 years, GP)

In this way, love and affection were viewed as associated with aspects of caring. The wording of this attribute was subsequently amended to '*Being with people who care about you*' to take into account participants' concerns that the attribute should be relevant for people who did not have family or, for example, if they were living in RC or being cared for in hospital or a hospice.

The remaining two attributes proved less problematic and, rather than radical alterations, required fine-tuning of wording in order to make them more meaningful. The attribute *Being supported* was well understood, with participants relating it to the availability of practical help and emotional and decision-making support:

I think support plays a big part in some people's lives, well most people's lives really, if they got the support it makes them feel better. (Female, 74 years, GP)

There were suggestions that wording should take account of the needs of the individual, as people require

varying levels of support depending on their circumstances, or their personality; therefore, this was subsequently amended to 'I am able to have the help and support that I need'.

The final attribute *Preparation* was thought to be concerned with making a will or other financial arrangements such as power of attorney, making funeral plans or having opportunity to say goodbye to family and friends. However, one participant thought it might be helpful to clarify this in the wording:

Really under a heading of preparation you could write lots of things, even as a reminder of what sort of things that people should be considering. (Male, 68 years, GP)

Other participants recognised that some people may want to put off these types of preparations until absolutely necessary:

If I wanted to, the opportunity is there to make all the preparations I need. But as far as I'm concerned I have done all I need to, or all I want to you see, at the moment. (Female, 83 years, PC)

The wording for the measure was amended to account for these suggestions by adding the phrase 'I want to make'. The attribute was also renamed *Being prepared* and an explanatory list added.

The final measure. In summary, following stage 2, two draft attributes (*Maintaining identity* and *Independence*) were subsumed into other attributes, while one draft attribute (*Suffering*) was expanded to encompass both physical and emotional elements. The final seven attributes were as follows:

1. *Choice* – expressed in the questionnaire as 'Having a say' with questions worded as 'being able to make decisions about my life and care'.
2. *Love and affection* – expressed as 'Being with people who care about you' with questions worded as 'being able to be with people who care about me'.
3. *Physical suffering* – expressed as 'Physical suffering' with questions worded as 'experiencing significant physical discomfort'.
4. *Emotional suffering* – expressed as 'Emotional suffering' with questions worded as 'experiencing emotional suffering'.
5. *Dignity* – expressed as 'Dignity' with questions worded as 'being able to maintain my dignity and self-respect'.
6. *Being supported* – expressed as 'Being supported' with questions worded as 'being able to have the help and support that I need'.
7. *Preparation* – expressed as 'Being prepared' with questions worded as 'Having had the opportunity to make the preparations I want to make'.

For each attribute, further clarification is given about meaning through use of examples. For example, under 'being prepared' are aspects such as 'having financial affairs in order' and 'saying goodbye to family and friends' (see Supplementary Appendix 1).

Discussion

This article has described the development of a measure for use in economic evaluation of EoLC interventions using qualitative in-depth interviews with older people. The measure contains seven attributes covering issues cited by informants at different stages along the trajectory towards death as being important to them. These attributes comprise physical suffering, emotional suffering, choice/having a say, being supported, being with people who care, dignity and preparation. The majority would not be captured within an evaluative space of 'health' – this offers reassurance to those concerned that proposing an alternative basis for assessing outcome in economic evaluation for EoLC is a (somewhat underhand) means of making these interventions seem more cost-effective relative to other interventions. Rather, it suggests that this approach is convincing and appropriate for evaluating EoL interventions.

The attributes determined here are similar to many identified across measures of quality of life/death for use in EoLC.^{12,24} Past work has included themes such as the importance of family and carers, control of symptoms, spiritual well-being, emotional or psychological well-being, preparation for death, control or independence, location of death and the importance of service provision. This past work has not tended to distinguish between aspects of a good death (e.g. emotional well-being) and means of achieving that good death (e.g. service provision). Here, the conceptual focus was on the attributes of a good death and not the means by which a good death is achieved.

The work presented here has both strengths and limitations. It has captured views of individuals at varying points across the dying trajectory to whom EoL issues are directly relevant. There were, however, no respondents from ethnic minority backgrounds, and all could speak English.

This work has provided the first step in developing methods for economic evaluation of EoLC by developing an appropriate descriptive system. Two further steps are needed. First, the descriptive system needs to be validated in varying groups of individuals at EoL, both in terms of construct validity and sensitivity to change. There are also important questions about who completes the measure to be explored. Second, the measure needs to be valued using appropriate techniques such that, as with other economic measures, the values meaningfully represent the extent of change captured by the measure. Discrete choice techniques²⁵ may be appropriate and have previously been used in populations at EoL.²⁶

This research suggests that what is important to people at the EoL goes beyond health and that the current exclusively health-focused paradigm for economic evaluation is inappropriate. Indeed, the focus on care, rather than cure, suggests that EoLC shares important characteristics with social care, and in the same way, tools for evaluation should focus on appropriate benefits. This research takes the first step towards providing a practical means of measuring benefits of interventions at the EoL for economic decision-making.

Supplementary material

The appendix mentioned in this paper is available online at www.birmingham.ac.uk/icecap.

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Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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