Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation

Canaway, Alastair ; Al-Janabi, Hareth; Kinghorn, Philip; Bailey, Cara; Coast, Joanna

DOI:

[10.1177/0269216316650616](https://doi.org/10.1177/0269216316650616)

License:

None: All rights reserved

Document Version

Peer reviewed version

Citation for published version (Harvard):

Canaway, A, Al-Janabi, H, Kinghorn, P, Bailey, C & Coast, J 2017, 'Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation', *Palliative Medicine*, vol. 31, no. 1, pp. 53-62.
<https://doi.org/10.1177/0269216316650616>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Checked 13/6/2016

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Download date: 26. Apr. 2023

Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation

Canaway, Alastair; Al-Janabi, Hareth; Kinghorn, Philip; Bailey, Cara; Coast, Joanna

DOI:

[10.1177/0269216316650616](https://doi.org/10.1177/0269216316650616)

Document Version

Peer reviewed version

Citation for published version (Harvard):

Canaway, A, Al-Janabi, H, Kinghorn, P, Bailey, C & Coast, J 2016, 'Development of a measure (ICECAP-Close Person Measure) through qualitative methods to capture the benefits of end-of-life care to those close to the dying for use in economic evaluation' *Palliative Medicine*., 10.1177/0269216316650616

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Checked for eligibility: 13/06/2016. © The Author(s) 2016. Publisher's version can be found at <http://pmj.sagepub.com/content/early/2016/06/01/0269216316650616.full.pdf+html>

av

DOI: 10.1177/0269216316650616

General rights

When referring to this publication, please cite the published version. Copyright and associated moral rights for publications accessible in the public portal are retained by the authors and/or other copyright owners. It is a condition of accessing this publication that users abide by the legal requirements associated with these rights.

- You may freely distribute the URL that is used to identify this publication.
- Users may download and print one copy of the publication from the public portal for the purpose of private study or non-commercial research.
- If a Creative Commons licence is associated with this publication, please consult the terms and conditions cited therein.
- Unless otherwise stated, you may not further distribute the material nor use it for the purposes of commercial gain.

Take down policy

If you believe that this document infringes copyright please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Title: Development of a measure (ICECAP-CPM) to capture the benefits of end of life care to those close to the dying for use in economic evaluation.

Authors: Alastair Canaway, Hareth Al-Janabi, Philip Kinghorn, Cara Bailey & Joanna Coast

Corresponding Author: Joanna Coast, University of Birmingham, Birmingham, United Kingdom.

Email: J.Coast@bham.ac.uk. Phone: +44 (0)121 414 3056. Fax: +44 (0)121 414 8969.

Background: End of life care often affects both the patient and those close to them. Typically those close to the patient are not considered within economic evaluation, which may lead to the omission of important benefits resulting from end of life care.

Aim: To develop an outcome measure for use in economic evaluation which captures the benefits of end of life care to those close to the dying.

Design: To develop the descriptive system for the outcome measure, 27 individuals who were bereaved within the last 2 years or had a close person who was at the time receiving end of life care were purposively recruited into the study. In-depth interviews were conducted with the participants and constant comparative analysis methods were used to develop a descriptive system for the measure.

Results: The analysis resulted in the development of a measure of capability with six attributes, each with five levels. The attributes cover: *being able to have **good communication** with services; being able to have **privacy and space** to be with the loved one; being able to get **emotional support**; being able to get **practical support**; being able to **prepare and cope**; and being **free from emotional distress** related to the condition of the decedent.*

Conclusion: This research has generated a tool that can be used to capture the benefits of end of life care for use in economic evaluation. Further research is required to value the measure and develop methods for incorporating outcomes for close persons into economic evaluation.

What is already known?

Typically, end of life care guidance suggests that care should target both the patient and those close to them. Economic evaluation methods focus on the patient and, on occasion, the informal carer.

There is a lack of measures designed for use within the end of life care setting to capture the experiences of those close to the dying for use in economic evaluation.

What this paper adds:

This paper develops a measure designed for use in economic evaluation that captures the impacts of end of life care on those close to individuals at the end of life.

Implications for practice/theory:

This measure will enable close person benefits of end of life care to be included within economic evaluation, thus aiding decision makers in best allocating resources.

Key Words:

Bereavement, Palliative Care, Economic Evaluation, Outcome Assessment

Word count – 2916 (excluding abstract, tables and quotes)

Introduction

Evaluating the cost-effectiveness of end of life care (EoLC) is challenging. Analyses tend to be narrow, both in the nature of benefits included (health) and their scope in terms of individuals considered (typically patients). There are strong arguments for the evaluation of EoLC to go beyond this narrow perspective ¹, focusing on other important objectives such as dignity or preparation. This is reflected in the definition of EoLC used by the National Council for Palliative Care ² and the Department of Health in the UK ³, which defines EoLC as care that:

‘Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’ (p.4) ³

It is clear from this definition that EoLC extends beyond simply health, whilst explicitly including family suggests the need to broaden the evaluative scope beyond the patient.

A new measure, the ICECAP-SCM, has been developed for use in economic evaluation (EE) of interventions at end of life (EoL) ⁴, going beyond typical health-related quality of life instruments ⁵, and focusing on attributes around choice, love and affection, physical suffering, emotional suffering, dignity, being supported, and preparation. Although the ICECAP-SCM expands the breadth of focus for EE for individuals at the EoL, it does not deal with the issue of the focus on the patient alone. There is much evidence that bereavement and EoL can have significant impacts on those close to the dying person ^{6–21} (encompassing family and close friends, referred to here as ‘close persons’), yet EEs typically ignore these

impacts⁵. The importance of close-persons in respect to quality EoLC provision has been highlighted within EoL reports globally^{3,22-24}. Although a growing body of research seeks to include informal carers within EE²⁵⁻³², there is little available to capture the impacts on close persons. As close persons are also affected by EoLC, there are strong arguments to include impacts on them in the evaluation of EoLC interventions³³. Important aspects of EoLC for those close to the dying are likely to lie outside the health domain as reflected in a recent analysis of complaints from relatives about EoLC³⁴.

Measures for use in EE need to incorporate weights that relate to how valuable a particular attribute of outcome is³⁵. To facilitate such valuation, the measure should only include one item per attribute and the total number of attributes should not be too large - typically between five and nine³⁶. A short questionnaire with few attributes is also preferable in terms of feasibility and therefore response and completion rates³⁷. To achieve such a small number of questions/attributes whilst ensuring a measure is useful across different settings and types of care requires attributes to be relatively broad in scope.

Qualitative research with those whose health and lives are affected, is a useful means of generating content for the attributes of measures. Indeed, the US Food and Drug Administration³⁸ requires new measures to be developed with input from patient groups³⁹. Measures recently developed using these methods within health economics include the family of ICECAP measures^{4,40,41}, the Carer Experience Scale²⁷ and the CHU-9D utility measure for children⁴². Such measures should, because of their development, have pertinent language and terminology as well as improved content validity compared with measures developed from expert groups or literature⁴².

This paper aims to (1) develop conceptual attributes for a close-person measure of EoLC for use in EE and (2) develop a descriptive system (i.e. a self-complete questionnaire based on these conceptual attributes) for this measure.

Methods

The measure development consisted of two phases. The first phase involved ascertaining what was important to close persons to develop attributes for the measure. The second stage focussed on checking the coverage of the conceptual attributes and the meaning of the wording used to express these to ensure that the measure was interpreted as intended. These phases were not formally distinguished, with one stage running into the next as attributes were established at different paces^{43,44}.

The research was approved by the University of Birmingham's Life and Health Sciences Ethical Review Committee [ERN_12-1338] and North Wales NHS Research Ethics Committee - West [13/WA/0333].

Recruitment

Individuals included in this study were those who either had loved ones/relatives receiving EoLC, or were recently bereaved, and who had a range of experiences in terms of different death trajectories, different care settings and positive and negative experiences. There were two primary recruitment streams through (i) the University of Birmingham, and (ii) the Marie Curie Hospice, West Midlands. Recruitment through the University of Birmingham was chosen due to the ease of access, the broad spectrum of staff and students in respect of age and professions, and the lack of a specific death trajectory associated with this form of recruitment. Recruitment was achieved through posters and via a number of internal University publications. The Marie Curie Hospice, West Midlands was chosen to access older

participants who were less likely to be in the working population and who were receiving specialist care. Potential participants were recruited through a research nurse based at the hospice. Snowball sampling⁴⁵ was conducted to try to access a wider range of participants, via the initial participants, and to explore how perceptions varied within close-person networks.

For ethical reasons, participants were not recruited within six months of bereavement⁴⁶. It was, however, desirable that the bereavement was not too distant and so the maximum time from bereavement was two years. All participants received an information sheet describing the purpose and nature of the research prior to the interview. Informed consent was obtained from all participants. It was stressed during this process that the participants could stop the interview and withdraw from the study should they wish.

Sampling was continued until saturation was reached in terms of the generation of the conceptual attributes and the development of appropriate wording^{43,44}. The reaching of saturation was discussed on an ongoing basis by the research team as analysis progressed.

Data collection

Data collection was undertaken by AC (Male/MSc./Doctoral Researcher). AC had previous experience conducting research with a vulnerable group and received specific interviewer training prior to this project. Each participant was interviewed on one occasion. Interviews were conducted in a location of the interviewee's choice by AC; locations included participants' homes, university premises and hospice premises. Interviews started with straightforward 'content mapping' questions about the informant and their relationship to the decedent, providing context to the interview⁴⁷, before moving onto questions about experience of EoLC and bereavement. A topic schedule was used to ensure that the

experiences of the participants were thoroughly examined during the interview. This included warm up questions to generate rapport before exploring the individual's experience of bereavement. In later interviews, as conceptual attributes were confirmed, the latter half of the interview checked the overall coverage of the attributes and explored the interpretation of possible wording for the descriptive system with drafts of the measure being tested with the participants.

All interviews were digitally audio-recorded, transcribed and anonymised; field notes were made following each interview which aided the analysis process.

Data analysis

Constant comparative analytic methods were used, as recommended for this type of measure development^{39,43}. Analysis was iterative, being conducted in batches of between three and six transcripts as data collection progressed. Analysis began with a general reading of transcripts, and then more detailed application of a coding structure, developed from the data, to sections, paragraphs or sentences. New codes were added as necessary. Repeated systematic searching of the data was conducted until no new themes emerged⁴⁸. To ensure consistency in the interpretation and application of the codes, newly coded sections were compared to other similarly coded sections⁴⁹ and descriptive accounts were created to synthesise the data⁵⁰. Through this process, themes and sub-themes were developed that were to become the basis for the attributes and descriptors of the measure. Interviews continued until saturation whereby no new themes were emerging from the data. Analysis was conducted primarily by AC with support from all research team members. The research team included those with disciplinary backgrounds in economics, social medicine and nursing, as well as experience in the topics of EoLC, informal caring and

chronic pain, and these varied experiences helped different interpretations of the data to emerge as findings were discussed.

Terminology used by participants in the early interviews was used to inform the initial wording for the descriptors of the attributes that were presented back to new participants. The process was iterative and the attributes were updated after each interview as suggestions were made. Analysis continued until the wording for the measure was fully established. NVivo version 10⁵¹ was used to aid the conduct of the analysis.

Findings

Interviews took place between June 2013 and July 2014. Twenty two interviewees were recruited through the University, four through the hospice and one through snowballing. Characteristics of informants are given in Table 2. The interviews covered a broad set of death trajectories in a number of different contexts. All interviews took place solely with the participant with no non-participants present. Interviews lasted between 25 minutes and 80 minutes with the average interview lasting approximately 45 minutes.

A number of primary themes emerged from the interviews during the attribute development phase which then developed into attributes for the measure. These attributes were: *communication with those providing care services; practical support; privacy and space; emotional support; preparing and coping; and emotional distress*. After the first two batches of analysis, all six themes had been touched upon at some stage and they were further developed through the analytic process.

Attribute Development

Communication with those providing care services: A strong theme to emerge from the initial qualitative interviews was the importance of good communication. This included communication between the patient network and service providers around health, prognosis and care plans, and focused on both quality of communication and availability of staff. It also included perceptions of communication between service providers.

CDX7: so actually more communication, God it's always the same isn't it, communication every time...With staff.

CDX1: I think the doctors need to be more frank. There's an awful lot of 'pussy footing about' you know, there's an awful lot... they used terms like 'Oo there's something we don't like there, there's a mass there'. But they didn't say, 'this is cancerous', and they didn't really explain the consequence or the meaning of palliative care...

Practical support: Practical support was particularly important to those informants who had experienced a prolonged death trajectory. Factors that were important to informants included support that helps in caring for the person at EoL, allowing some normality in their lives as well as a broader sense of being supported to deal with the bereavement.

CDX9: for my father in law...[there was] absolutely no support outside the hospital, no social support at all within the community so everything...fell on his daughter...on my wife, and the mother to look after him and whenever he was in hospital that meant almost 24 hour vigils really

CDX10: In the end we got the support from the undertaker...you just need a friendly face who knows what they're doing

Emotional Support: A number of participants discussed the importance of emotional support. There was a feeling for many that experience had been improved where they had access to emotional support, including through their own close person network and avenues such as religion.

CDX16: ...immediate family, you couldn't really manage without them.

CDX17: ...I think that gave us a bit of comfort, that a priest had been in to see her.

Privacy and Space: The setting for the person at the end of their life appeared to be an important factor for close persons, whatever the death trajectory. This perhaps reflects that the end result of all death trajectories is a place of death.

CDX1: And also it gave us privacy as well...you don't really [want] to be on display when somebody you care about is disappearing out the world.

CDX6: it was a lovely place for her to be... it made it easier to think that she was going to spend her last days somewhere beautiful...

Emotional distress: Due to the empathetic and emotional ties between the close persons and the decedents, the quality of care appeared to impact by causing emotional distress to close persons. Issues relating to the care and condition of the decedent were frequently raised by informants. This emotive topic caused several participants to become upset as they recounted their experience. The three main issues of concern were pain and suffering, dignity, and attentiveness.

CDX19: ...awful for him, awful to go like that...we knew from the way he was about his life that he wouldn't have wanted a death like that...and that was what made it painful.

CDX24: *It makes me really angry...it's really bad because I only focus on the last couple of weeks of his life and I don't think he was treated very well in that time and I know how much pain he was in...*

Preparing and coping: For some informants, being able to prepare for the death and bereavement appeared to have improved their experience. Although less widespread across the informants, for those who discussed it, the theme seemed to be particularly salient.

CDX5: *I think that's important, very important to some people, very important to my dad. And it helped me and it helped us knowing what he wanted to happen to his things, to his home, to his money.*

The Conceptual Attributes – checking the attributes and understanding

The final six interviews contributed to the checking of the attributes and the development of meaningful terminology. This was to ensure that the measure was not omitting anything of importance and to check that the terminology was being understood as intended. This process led to several changes being made to the measure. For example, the first quote below led to examples being added to the communication attribute, whilst the second led to the replacement of the technical term 'close persons' with a lay term within the measure.

CDX28: *...you could have expressed that a bit clearer...what 'communication with those providing care services', like, who do you mean by providing care services...*

CDX23: *I had to read the second point twice...having your 'close-persons' post bereavement affairs and funeral arrangements...*

The final set of attributes and corresponding descriptors can be found below in Table 1 with the complete measure in figure 1 in the Appendix.

Table 1: The Attributes with Descriptors

<p>1. <i>Communication with those providing care services</i> (e.g. doctors, nurses and carers). This includes things like: being able to get information about the person's health and care; being able to have a say in the care that the person receives; being able to ask questions, have them answered and have views respected; being able to have rapport with those providing care.</p>
<p>2. <i>Practical Support</i>. This includes things like: being able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family; being able to get practical support from employers such as time off when needed; being able to get practical support with bereavement processes and dealing with the person's affairs.</p>
<p>3. <i>Privacy and Space</i>. This includes things like: being able to have time with the person in private; being able to be in a peaceful location with pleasant facilities.</p>
<p>4. <i>Emotional Support</i>. This includes things like: being able to get emotional support through family, friends or colleagues; being able to get emotional support through other services including charities and religion if applicable.</p>
<p>5. <i>Preparing and Coping</i>. This includes things like: being prepared for the person's death; having your person's post-bereavement affairs and funeral arrangements in order, being free from guilt and regrets.</p>
<p>6. <i>Emotional Distress, <u>related to the condition</u> of the person</i>. This includes things like being free from emotional distress resulting from: seeing the person in pain and discomfort; seeing the loss of dignity, or a lack of respect given to the person; seeing a lack of care and attention given to the person.</p>

Discussion

This paper has described the development of attributes for a measure to capture the impact of EoLC on close persons for use in EE within the capability paradigm¹. The development process involved in-depth interviews with bereaved individuals and with those close to

somebody who was receiving EoLC. The resulting measure, the ICECAP-Close Person Measure (ICECAP-CPM) contains six broad attributes covering issues that informants felt were important to them as their close person experienced the EoL: communication; practical support; privacy and space; emotional support; preparing and coping; and emotional distress related to the condition of their close person. This measure is helpful in moving beyond an exclusive focus on health in this context; many of these important aspects would not be captured by focusing exclusively on health, as is often the case in EE.

Other work in the UK, in different contexts, suggests that similar issues are important to family and friends. The Neuberger report and associated analysis of complaints around EoLC, published in June 2013 ^{52 34}, suggested that six themes were important. These were: *awareness of approaching EoL, communication and being caring, symptom management, the environment, concerns around clinical care, and fundamental medical and nursing care.* These show considerable overlap with the attributes obtained with the attributes identified for the ICECAP-CPM. The two attributes of the measure that are less prominent in the complaints review are those relating to support for the close person. It is likely that these were less prominent in the analysis of complaints both because that analysis focused on hospital care and because close persons may have been more likely to go to the effort of complaining about treatment of their loved one than their own support.

There are no other measures directly comparable to the one developed here. The two closest measures within the literature are the FAMCARE-2 ⁵³ which is a scale of family satisfaction of care developed in the context of advanced cancers and the QOLTI-F ⁵⁴ which is designed to measure the quality of life of the carer to someone at EoL. The QOLTI-F and the FAMCARE-2 contain 16 and 17 items respectively and are therefore unsuitable for

valuation for EE. Furthermore, the measure developed here focusses on all those close to the decedent and is broader than the QOLTI-F in terms of scope (all close persons rather than carers) and the FAMCARE-2 conceptually (focusing on all impacts rather than just satisfaction). Nevertheless there are clear overlaps in the concepts covered by the three measures, with FAMCARE-2 including questions on information, dignity, practical assistance, and emotional support⁵³ and the QOLTI-F including items on emotional wellbeing, privacy and place⁵⁴.

The work presented here has both strengths and limitations. The measure developed is unique in focusing on the capture of benefits of EoLC to close persons. It has been developed within the capability paradigm, adding to an emerging research area^{1,4,27,40,41}. There may be limitations associated with using a University community as the main focus for the sampling, but the associated strength of this untargeted approach (in terms of health care setting) is that it enabled the work to capture a variety of death trajectories and both positive and negative experiences of care. All informants recruited through advertising effectively self-selected themselves for interview and therefore may have different views on what is important at EoL than those who do not self-select. Snowball sampling was ineffective with only one participant being recruited using this method. It is hypothesised that this may be due to the sensitivity and privacy of this topic area. People within the UK tend to be uncomfortable talking about dying and death⁵⁵. If people are uncomfortable talking about death and bereavement then this may result in people being reluctant to recruit others into the study. There were also more women than men in the final sample, possibly reflecting the burden of caring and the more intense experiences that might result from the closeness of this role.

Future research will be required to assess the feasibility, validity and reliability of the measure with different groups. For use in EE, there is also the need to value the measure

and this is a priority for future research. A further area for exploration relates to the close persons with whom the measure should be used within EE.

The findings of this paper suggest that there are a number of attributes of EoLC that are important to those close to the dying. These attributes have broader coverage than those typically included within EE and suggest that the incumbent methodology is inappropriate for the capturing the impacts of EoLC for those close to the dying. The research in this paper provides a measure that, once valued, is concise and amenable to EE, and that could be used alongside the ICECAP-SCM patient measure to ensure that the benefits of EoLC are captured for all those impacted. This will enable close-person benefits of EoLC to be included within EE, thus aiding decision makers in best allocating resources.

Table 2: Descriptive characteristics of participants (n=27)

Participant ID	Participant's Age Range (years)	Participant's Gender	Participant's Ethnicity	Months Since Bereavement	Relation of decedent to participant	Decedent's terminal condition	Decedent's age group (years)	Recruitment Method
CDX1	40-49	Female	White British	18-24	Father	Pancreatic Cancer	60-79	Via Newsletter
CDX4	40-49	Female	Indian	18-24	Sibling	Lymphoma	40-59	Forwarded Newsletter (external)
CDX5	40-49	Female	White British	6-12; 18-24	Mother and Father	Alzheimer's, Heart Failure + COPD	60-79, 80+	Via Newsletter
CDX6	50-59	Female	Mixed	18-24	Friend	Oesophageal Cancer	40-59	Via Newsletter
CDX7	50-59	Female	White British	18-24	Mother	COPD and Alzheimer's/Dementia	80+	Via Newsletter
CDX8	30-39	Male	White British	18-24	Father	Sudden Death - Heart attack	60-79	Via Newsletter
CDX9	20-29	Male	White British	6-12, 12-18	Father in law, and Grandmother	Cancer, Stroke	60-69, 80+	Via Newsletter
CDX10	30-39	Female	White British	18-24	Father	Death following elective heart surgery complications	Not-specified	Via Newsletter
CDX13	30-39	Female	Greek	Pre-bereaved	Mother	Motor Neurone Disease	60-79	Via Newsletter
CDX14	50-59	Female	White British	Pre-bereaved	Mother	TIA/Dementia	80+	Via Newsletter
CDX15	50-59	Female	White British	18-24 (both)	Friends x 2	Death/decline following extended period in hospital	80+, 80+	Via Newsletter
CDX16	40-49	Male	White British	6-12	Father	CHD - Death following heart surgery complications	80+	Via Newsletter
CDX17	20-29	Female	White British	6-12	Grandmother	Pneumonia	80+	Via Newsletter
CDX18	60-69	Female	White British	6-12	Mother	Pneumonia	80+	Snowball
CDX19	60-69	Female	White British	6-12	Father	Lung Cancer	80+	Via Newsletter
CDX20	40-49	Female	White British	6-12	Mother	Cancer - Colon/Liver	60-79	Via Newsletter
CDX21	50-59	Female	White British	6-12	Father	Undiagnosed - chest complaint	80+	Via Newsletter
CDX22	20-29	Female	Mixed Race	18-24	Grandmother	Heart Disease	Not-specified	Via Newsletter
CDX23	30-39	Female	White British	18-24	Grandmother	Post-fall infections in hospital	80+	Via Newsletter
CDX24	20-29	Female	White British	18-24	Grandfather	Lymphoma	60-79	Via Newsletter
CDX25	20-29	Female	White British	18-24	Father	Cancer - back/spine	60-79	Via Newsletter
CDX26	70-79	Female	White British	Pre-bereaved	Spouse	Multiple System Atrophy	60-79	Marie Curie Hospice
CDX27	40-49	Female	White British	Pre-bereaved	Mother	COPD	60-79	Marie Curie Hospice
CDX28	20-29	Male	White British	12-18	Grandmother	Parkinson's Disease	80+	Via Newsletter
CDX29	50-59	Male	White British	Pre-bereaved	Mother	Sarcoidosis (inflammatory cells clumping around body)	60-79	Marie Curie Hospice
CDX30	70-79	Female	White British	Pre-bereaved	Husband	Mesothelioma (cancer of the lining of the lung)	Not-specified	Marie Curie Hospice
CDX31	20-29	Female	White British	18-24	Mother	Viral Pneumonia + sudden heart attack	Not-specified	Via Newsletter

Acknowledgements

The authors would like to acknowledge the help and support received by Dr Kathy Armour, and Rachel Perry at the Marie Curie Hospice, West Midlands.

Funding Acknowledgements

This work was supported by the European Research Council [grant number: 261098 EconEndLife].

Conflicts of interest

No conflicts of interest to declare.

References

1. Coast J. Strategies for the economic evaluation of end-of-life care: making a case for the capability approach. *Expert Rev Pharmacoecon Outcomes Res* 2014; 14: 473–82.
2. The National Council for Palliative Care. Commissioning end of life care. 1–12, <http://www.ncpc.org.uk/sites/default/files/AandE.pdf> (2006).
3. Department of Health. End of Life Care Strategy - promoting high quality care for all adults at the end of life. Guidance D: 1–173, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf (2008).
4. Sutton EJ, Coast J. Development of a supportive care measure for economic evaluation of end-of-life care using qualitative methods. *Palliat Med* 2014; 28: 151–7.
5. NICE. Guide to the methods of technology appraisal 2013, <https://www.nice.org.uk/article/PMG9/chapter/5-The-reference-case> (2013, accessed 28 July 2014).
6. Van den Berg G, Lindeboom M, Portrait F. Conjugal bereavement effects on health and mortality at advanced ages. *J Health Econ* 2011; 30: 774–794.
7. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet* 2007; 370: 1960–1973.
8. Williams JJ. Depression as a Mediator Between Spousal Bereavement and Mortality from Cardiovascular Disease: Appreciating and Managing the Adverse Health Consequences of Depression in an Elderly Surviving Spouse. *South Med J* 2005; 98.
9. Bradbeer M, Helme RD, Yong HH, et al. Widowhood and Other Demographic Associations of Pain in Independent Older People. *Clin J Pain* 2003; 19.
10. Song J, Floyd FJ, Seltzer MM, et al. Long-term Effects of Child Death on Parents' Health Related Quality of Life: A Dyadic Analysis. *Fam Relat* 2010; 59: 269–282.
11. Song JI, Shin DW, Choi JY, et al. Quality of life and mental health in the bereaved family members of patients with terminal cancer. *Psychooncology* 2012; 21: 1158–1166.
12. Rebollo P, Alonso J, Ramon I, et al. Health-related quality of life during the bereavement period of caregivers of a deceased elderly person. *Qual Life Res* 2005; 14: 501–509.
13. Boelen P, Bout J va. den., Keijser J d. Traumatic Grief as a Disorder Distinct From Bereavement-Related Depression and Anxiety: A Replication Study With Bereaved Mental Health Care Patients. *Am J Psychiatry* 2003; 160: 1339–1341.

14. Li J, Laursen TM, Precht DH, et al. Hospitalization for Mental Illness among Parents after the Death of a Child. *N Engl J Med* 2005; 352: 1190–1196.
15. Surtees P. In the shadow of adversity: the evolution and resolution of anxiety and depressive disorder. *Br J Psychiatry* 1995; 166: 583–594.
16. Easterlin RA. Explaining happiness. *Proc Natl Acad Sci* 2003; 100: 11176–11183.
17. Broman CL, Riba ML, Trahan MR. Traumatic Events and Marital Well-Being. *J Marriage Fam* 1996; 58: 908–916.
18. Blanchflower DG, Oswald AJ. Well-being over time in Britain and the USA. *J Public Econ* 2004; 88: 1359–1386.
19. Oswald AJ, Powdthavee N. *Death, Happiness, and the Calculation of Compensatory Damages*. University of Chicago Press: The Journal of Legal Studies, 2008.
20. Clark AE, Diener E, Georgellis Y, et al. Lags And Leads in Life Satisfaction: a Test of the Baseline Hypothesis. *Econ J* 2008; 118: 222–243.
21. Holdsworth LM. Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': A qualitative study. *Palliat Med* 2015; DOI: 10.1177/0269216315584865.
22. PCA. *Standards for Providing Quality Care for all Australians: 4th Edition*. 2005.
23. CHPCA. *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice - Revised and Condensed Edition*. 2013.
24. Hospice New Zealand. *Hospice New Zealand Standards for Palliative Care - quality review programme and guide 2012*. 2012.
25. Dixon S, Walker M, Salek S. Incorporating Carer Effects into Economic Evaluation. *Pharmacoeconomics* 2006; 24: 43–53.
26. Al-Janabi H, Flynn TN, Coast J. QALYs and Carers. *Pharmacoeconomics* 2011; 29.
27. Al-Janabi H, Coast J, Flynn TN. What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up. *Soc Sci Med* 2008; 67: 111–21.
28. Brouwer W, van Exel N, van Gorp B, et al. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Qual Life Res* 2006; 15: 1005–21.
29. Hoefman R, van Exel J, Brouwer W. Measuring the impact of caregiving on informal carers: a construct validation study of the CarerQol instrument. *Health Qual Life Outcomes* 2013; 11: 173.

30. Van den Berg B, Brouwer W, Koopmanschap M. Economic valuation of informal care. An overview of methods and applications. *Eur J Health Econ* 2004; 5: 36–45.
31. Van den Berg B, Brouwer W, van Exel J, et al. Economic valuation of informal care: the contingent valuation method applied to informal caregiving. *Health Econ* 2005; 14: 169–83.
32. Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. *Value Health* 2012; 15: 975–81.
33. Haycox A. Optimizing Decision Making and Resource Allocation in Palliative Care. *J Pain Symptom Manage* 2009; 38: 45–53.
34. NHS. Snapshot Review of Complaints in End of Life Care, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212480/Review_of_complaints_end_of_life_care.pdf (2013, accessed 1 July 2014).
35. Williams A. 'Should QALYs be programme specific?' *J Health Econ* 1990; 8: 485–487.
36. Brazier J, Deverill M. A checklist for judging preference-based measures of health related quality of life: learning from psychometrics. *Health Econ* 1999; 8: 41–51.
37. Higginson IJ, Evans CJ, Grande G, et al. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Med* 2013; 11: 111.
38. Farnik M, Pierzchała WA. Instrument development and evaluation for patient-related outcomes assessments. *Patient Relat Outcome Meas* 2012; 3: 1–7.
39. Stevens K, Palfreyman S. The use of qualitative methods in developing the descriptive systems of preference-based measures of health-related quality of life for use in economic evaluation. *Value Health* 2012; 15: 991–8.
40. Grewal I, Lewis J, Flynn T, et al. Developing attributes for a generic quality of life measure for older people: preferences or capabilities? *Soc Sci Med* 2006; 62: 1891–901.
41. Al-Janabi H, Flynn TN, Coast J. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Qual Life Res* 2012; 21: 167–76.
42. Stevens K. Assessing the performance of a new generic measure of health-related quality of life for children and refining it for use in health state valuation. *Appl Health Econ Health Policy* 2011; 9: 157–69.
43. Coast J, Al-Janabi H, Sutton EJ, et al. Using qualitative methods for attribute development for discrete choice experiments: issues and recommendations. *Health Econ* 2012; 21: 730–41.

44. Coast J, Horrocks S. Developing attributes and levels for discrete choice experiments using qualitative methods. *J Health Serv Res Policy* 2007; 12: 25–30.
45. Frank O, Snijders T. Estimating the Size of Hidden Populations Using Snowball Sampling. *J Off Stat* 1994; 10: 53–67.
46. Ingleton C, Morgan J, Hughes P, et al. Carer satisfaction with end-of-life care in Powys, Wales: a cross-sectional survey. *Heal Soc Care Community* 2004; 12: 43–52.
47. Ritchie J, Lewis J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. SAGE Publications, 2003.
48. Hewitt-Taylor J. Use of constant comparative analysis in qualitative research. *Nurs Stand* 2001; 15: 39–42.
49. Strauss A, Corbin J. *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: US: Sage Publications, 1990.
50. Ritchie J, Lewis J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. 2nd ed. London: SAGE Publications, 2013.
51. QSR Interntational Pty Ltd. NVivo qualitative analysis software. 2012.
52. Department of Health. More Care, Less Pathway, A Review of the Liverpool Care Pathway for dying patients, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf (2013).
53. Edmonton Zone Palliative Care Program. FAMCARE and FAMCARE-2 Guidelines of Use, [http://palliative.org/NewPC/_pdfs/tools/FAMCARE Guidelines_v2 0_12Dec2012 \(2\).pdf](http://palliative.org/NewPC/_pdfs/tools/FAMCARE%20Guidelines_v2%200_12Dec2012(2).pdf) (2012, accessed 1 July 2014).
54. Cohen R, Leis AM, Kuhl D, et al. QOLTI-F: measuring family carer quality of life. *Palliat Med* 2006; 20: 755–67.
55. Dying Matters Coalition. NCPC: Dying Matters Public Survey, <http://www.comres.co.uk/poll/1173/ncpc-dying-matters-survey.htm> (2014).

Appendix

Figure 1: The Close Person Measure

End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- having been able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being at ease with those providing care.

A. I have been able to have good communication <u>all</u> of the time.....	5
B. I have been able to have good communication <u>most</u> of the time....	4
C. I have been able to have good communication <u>some</u> of the time...	3
D. I have been able to have good communication <u>a little</u> of the time..	2
E. I have been able to have good communication <u>none</u> of the time....	1

2. Privacy and Space. This includes things like:

- having been able to have time with the person in private (e.g. a private room in hospital);
- having been able to be in a peaceful location with pleasant facilities;
- having been able to be with the dying person at the end of their life.

A. I have been able to have privacy and space <u>all</u> of the time.....	5
B. I have been able to have privacy and space <u>most</u> of the time.....	4
C. I have been able to have privacy and space <u>some</u> of the time.....	3
D. I have been able to have privacy and space <u>a little</u> of the time.....	2
E. I have been able to have privacy and space <u>none</u> of the time.....	1

3. Practical Support. This includes things like:

- having been able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

A. I have been <u>fully able</u> to get practical support.....	5
B. I have been <u>mostly able</u> to get practical support.....	4
C. I have been <u>somewhat able</u> to get practical support.....	3
D. I have been <u>mostly unable</u> to get practical support.....	2
E. I have been <u>completely unable</u> to get practical support.....	1

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

A. I have been <u>fully able</u> to get emotional support.....	5
B. I have been <u>mostly able</u> to get emotional support.....	4
C. I have been <u>somewhat able</u> to get emotional support.....	3
D. I have been <u>mostly unable</u> to get emotional support.....	2
E. I have been <u>completely unable</u> to get emotional support.....	1

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having the person's post-bereavement affairs and funeral arrangements in order;
- being free from guilt and regrets.

A. I have been <u>fully able</u> to prepare for and cope with, the person's death.....	5
B. I have been <u>mostly able</u> to prepare for, and cope with, the person's death.....	4
C. I have been <u>somewhat able</u> to prepare for, and cope with, the person's death.....	3
D. I have been <u>mostly unable</u> to prepare for, and cope with, the person's death.....	2
E. I have been <u>completely unable</u> to prepare for, and cope with, the person's death.....	1

6. Emotional Distress to you, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

A. I have been <u>fully able</u> to be free from emotional distress.....	5
B. I have been <u>mostly able</u> to be free from emotional distress.....	4
C. I have been <u>somewhat able</u> to be free from emotional distress.....	3
D. I have been <u>mostly unable</u> to be free from emotional distress.....	2
E. I have been <u>completely unable</u> to be free from emotional distress.....	1

Thank you for your help with this research