

# 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

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**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.**

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***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 <sup>1</sup>, 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 <sup>2</sup> and the Department of Health in the UK <sup>3</sup>, 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) <sup>3</sup>*

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) <sup>4</sup>, going beyond typical health-related quality of life instruments <sup>5</sup>, 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 <sup>6–21</sup> (encompassing family and close friends, referred to here as ‘close persons’), yet EEs typically ignore these

impacts<sup>5</sup>. The importance of close-persons in respect to quality EoLC provision has been highlighted within EoL reports globally<sup>3,22-24</sup>. Although a growing body of research seeks to include informal carers within EE<sup>25-32</sup>, 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 interventions<sup>33</sup>. 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 EoLC<sup>34</sup>.

Measures for use in EE need to incorporate weights that relate to how valuable a particular attribute of outcome is<sup>35</sup>. 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 nine<sup>36</sup>. A short questionnaire with few attributes is also preferable in terms of feasibility and therefore response and completion rates<sup>37</sup>. 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 Administration<sup>38</sup> requires new measures to be developed with input from patient groups<sup>39</sup>. Measures recently developed using these methods within health economics include the family of ICECAP measures<sup>4,40,41</sup>, the Carer Experience Scale<sup>27</sup> and the CHU-9D utility measure for children<sup>42</sup>. 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 literature<sup>42</sup>.

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<sup>43,44</sup>.

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 sampling<sup>45</sup> 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 bereavement<sup>46</sup>. 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<sup>43,44</sup>. 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 interview<sup>47</sup>, 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<sup>39,43</sup>. 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 emerged<sup>48</sup>. To ensure consistency in the interpretation and application of the codes, newly coded sections were compared to other similarly coded sections<sup>49</sup> and descriptive accounts were created to synthesise the data<sup>50</sup>. 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 10<sup>51</sup> 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 paradigm<sup>1</sup>. 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 <sup>52 34</sup>, 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 <sup>53</sup> which is a scale of family satisfaction of care developed in the context of advanced cancers and the QOLTI-F <sup>54</sup> 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 support<sup>53</sup> and the QOLTI-F including items on emotional wellbeing, privacy and place<sup>54</sup>.

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<sup>1,4,27,40,41</sup>. 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 death<sup>55</sup>. 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

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### **Conflicts of interest**

No conflicts of interest to declare.

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## 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 <b>all</b> of the time.....   | 5 |
| B. I have been able to have good communication <b>most</b> of the time....   | 4 |
| C. I have been able to have good communication <b>some</b> of the time....   | 3 |
| D. I have been able to have good communication <b>a little</b> of the time.. | 2 |
| E. I have been able to have good communication <b>none</b> 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 <b>all</b> of the time.....      | 5 |
| B. I have been able to have privacy and space <b>most</b> of the time.....     | 4 |
| C. I have been able to have privacy and space <b>some</b> of the time.....     | 3 |
| D. I have been able to have privacy and space <b>a little</b> of the time..... | 2 |
| E. I have been able to have privacy and space <b>none</b> 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 <b>fully able</b> to get practical support.....        | 5 |
| B. I have been <b>mostly able</b> to get practical support.....       | 4 |
| C. I have been <b>somewhat able</b> to get practical support.....     | 3 |
| D. I have been <b>mostly unable</b> to get practical support.....     | 2 |
| E. I have been <b>completely unable</b> 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**