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Title: Development of a measure (ICECAP-CPM) 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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Abstract

Background: End of life care 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 suitable for use in economic evaluation that captures the benefits of end of life care to those close to the dying.

Design: To develop the descriptive system for the outcome measure. In-depth qualitative interviews were conducted with the participants and constant comparative analysis methods were used to develop a descriptive system for the measure.

Participants: Twenty seven individuals bereaved within the last 2 years or with a close person currently receiving end of life care were purposively recruited into the study. Participants were recruited through newsletters, adverts, snowball sampling and a local hospice.

Results: Twenty seven individuals were recruited. A measure of capability with six attributes, each with five levels was developed based on themes arising from the analysis. Attributes comprise: **good communication with services; privacy and space to be with the loved one; emotional support; practical support; being able to prepare and cope; and being free from emotional distress related to the condition of the decedent.**

Conclusion: This measure is designed to capture the benefits of end of life care to close-persons for use in economic evaluation. Further research should 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 evaluations typically focus on weighing costs against patient benefit. 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 within the capability paradigm designed for use in economic evaluation to capture the impacts of end of life care on those close to individuals at the end of life.

Implications for practice/theory:

Upon valuation, this measure enables close person benefits of end of life care to be captured for use within economic evaluation, thus aiding decision makers in best allocating resources.

Key Words:

Bereavement, Capability Approach, Palliative Care, Economic Evaluation, Outcome Assessment

Word count – 2973 (excluding abstract, tables and quotes)

Introduction

Evaluating the cost-effectiveness of end of life care (EoLC) is challenging. Recent years have seen increasing application of the capability approach within health economics¹⁻⁸. The capability approach provides an alternative framework for economic evaluation to the more usual approach of assessing cost per quality adjusted life year (QALY) gained⁹. The former focuses on what people are *able* to do or be in their lives, whereas the QALY approach focuses on health-related functioning⁹. Economic analyses conducted with QALYs tend to be narrow, both in the nature of benefits included (health functioning) and in their scope, in terms of those included (typically only patients). EoLC has been identified as an area where the capability approach is potentially valuable with strong arguments for the evaluation of EoLC to go beyond the usual narrow perspective¹⁰ both in what is measured and for whom. This broader perspective is aligned with the definition of EoLC used by the National Council for Palliative Care¹¹ and the Department of Health in the UK¹² 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)¹²

There is much evidence that bereavement and EoL can have significant impacts on those close to dying persons¹³⁻²⁸ (encompassing family and close friends, referred to here as 'close-persons'), yet economic evaluations typically ignore these impacts²⁹. The importance of close-persons has been highlighted within EoL reports globally^{12,30-32}. Although a growing body of research seeks to include informal carers within economic evaluation^{8,33-39}, this is

not yet the case for close-persons, yet the impacts of EoLC extend beyond carers to close-persons⁴⁰. 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 EoLC⁴¹.

Over the past decade, a suite of capability measures (known as ICECAP) has been designed for economic evaluation. These include the ICECAP-A³ for adults and ICECAP-O⁷ for older persons. 2014 saw the development of a new measure, the ICECAP-Supportive Care Measure (ICECAP-SCM)⁴², designed for use in economic evaluation of interventions at end of life (EoL)⁴². Although the ICECAP-SCM expands the breadth of focus for economic evaluation for individuals at the EoL, it only assesses impact on the dying person. A measure is needed for use alongside the ICECAP-SCM to capture impacts on close-persons as part of the framework for conducting economic evaluation at EoL^{10,43}.

Existing 'close-person' EoLC measures such as the FAMCARE,⁴⁴ CANHELP^{45,46}, and the SAT-FAM-IPC⁴⁷ focus on satisfaction of care for family members and are not suitable for use in economic evaluation. The large number of items within each measure (between 17 and 38) means they can be difficult to use in the trial setting where brevity is important to improve feasibility, response rates and completion rates⁴⁸, and that any attempt at valuation will be exceptionally challenging. Measures for use in economic evaluation need to incorporate a system that weights outcomes in relation to how valuable society feels the outcome is⁴⁹. 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 nine⁵⁰. 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.

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

Methods

A qualitative approach for measure development was chosen^{51,52} to ensure pertinent language and terminology as well as improved content validity compared with measures developed from expert groups or literature⁵³. Measure development consisted of two phases: i) eliciting and developing conceptual attributes for the measure; ii) checking the coverage and interpretation of attributes, and the meaning of the wording used to express them. These phases were not formally distinguished, with one phase running into the next as attributes were established iteratively and at different paces^{52,54}.

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 either had loved ones/relatives receiving EoLC, or were recently bereaved. Recruitment was purposive in aiming to include a wide 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) adverts targeted at University of Birmingham members, 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. 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 sampling⁵⁵ aimed to access further participants through the initial participants, to explore how perceptions varied within close-person networks.

For ethical reasons, participants were not recruited within six months of bereavement⁵⁶. It was, however, desirable that the bereavement was not too distant and so the maximum time from bereavement was two years. Participants received an information sheet describing the purpose and nature of the research and informed consent was obtained prior to interview. It was stressed throughout that participants could stop the interview and withdraw from the study at any point.

Sampling continued until saturation was reached in terms of the generation of the conceptual attributes and the development of appropriate wording^{52,54}. Saturation was discussed on an ongoing basis by the research team as analysis progressed.

Data collection

Interviews were conducted by AC (Male/MSc./Doctoral Researcher). AC had previous experience conducting research with a vulnerable group and received specific interviewer training for this research. Each participant was interviewed on one occasion and knew the research was contributing towards EoLC research. Interviews were conducted in a location of the participant's choice; locations included participants' homes, university premises and hospice premises. No individuals other than AC and the participant were present during interviews. Interviews started with warm up and 'content mapping' questions about the participant and their relationship to the decedent, providing context⁵⁷, before moving onto

questions about EoLC and bereavement experiences. A topic schedule, updated on an ongoing basis, ensured that participants' experiences were covered fully during the interview. In later interviews, as conceptual attributes were confirmed, the latter part of the interview checked coverage of the attributes and explored possible wording for the descriptive system, with drafts of the measure being tested with participants.

Interviews were digitally audio-recorded, transcribed verbatim and anonymised; field notes were made following each interview. Transcripts and field notes were not returned to participants and were only seen by the research team.

Data analysis

Analysis was based on constant comparison^{52,58} and conducted on batches of between three and six transcripts. 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 emerged⁵⁹. To ensure consistency in the interpretation and application of codes, newly coded sections were compared to similarly coded sections⁶⁰ and descriptive accounts were created to synthesise the data⁶¹. Through this process, and discussion of descriptive accounts, themes and sub-themes were developed that became 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 (JC, HA, PK, CB). The research team included those with disciplinary backgrounds in economics (JC, PK, HA, AC), nursing (CB), as well as experience in the topics of EoLC (JC, PK,

CB, HA), informal caring (JC, HA) and chronic pain (PK, CB) and these varied experiences helped differing 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 final batches of interviews checked for saturation, coverage and tested wording.

Participants were asked to identify anything they felt was missing from the attributes and descriptors and asked to relate them to their own situation. This enabled the opportunity to offer suggestions for improvement and allowed the researcher to assess whether the attributes and descriptors were being understood as intended.

The process was iterative and attributes were updated after each interview as suggestions were made. Analysis continued until wording for the measure was fully established. NVivo version 10⁶² was used to aid the conduct of the analysis.

Findings

Interviews took place between June 2013 and July 2014. Twenty two participants were recruited through the University, four through the hospice and one through snowballing.

Not all who initially expressed interest participated. The most common reason for excluding individuals was the time period since bereavement; several chose to withdraw prior to interview for undisclosed reasons.

Participant characteristics are given in Table 2 and decedent health conditions are given in Table 3. Interviews covered a broad set of death trajectories in a number of contexts.

Interviews lasted between 25 minutes and 80 minutes with a mean of approximately 45 minutes.

A number of primary themes emerged from interviews 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 generated and were further developed through the analytic process. Illustrative quotes are provided for each attribute. The gender, age range of the participant, and the relation of their decedent are shown in square brackets.

Although the sample size for the hospice patients was not sufficiently large to conduct a detailed and meaningful comparison between the two groups, no additional themes were identified from the hospice sample that were not already identified.

Attribute Development

Communication with those providing care services: The importance of good communication was a significant theme. 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.

CDX1 [female, 40-49, father]: *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 participants who had experienced a prolonged death trajectory. Important factors included support that

helps in caring for the person at EoL, allowing some normality in close-persons' lives as well as a broader sense of being supported to deal with the bereavement.

CDX9 [male, 20-29, father in-law]: *...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 [female, 30-39, father]: *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 their experience had improved where they had access to emotional support, including through their own close person network and avenues such as religion.

CDX16 [male, 40-49, father]: *...immediate family, you couldn't really manage without them.*

CDX17 [female, 20-29, grandmother]: *...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 [female, 40-49, father]: *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 [female, 50-59, friend]: *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 close-persons and decedents, 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 participants. This emotive topic caused several participants to become upset as they recounted their experiences. The three main issues of concern were pain and suffering, dignity, and attentiveness.

CDX19 [female, 50-59, father]: *...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 [female, 20-29, grandfather]: *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 participants, being able to prepare for death and bereavement appeared to have improved their experience. Although less widespread across the participants, for those who discussed it the theme seemed particularly salient.

CDX5 [female, 40-49, mother and father]: *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 were used to ensure no important items were omitted and the terminology was understood as intended. This process led to several changes including examples being added to the communication attribute and the use of lay terms replacing terms such as 'close persons' in the measure.

CDX28 [male, 20-29, grandmother]: *...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 [female, 30-39, grandmother]: *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 is in Table 1 with the complete measure in figure 1 in the Appendix.

Table 1: The Attributes with Descriptors

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; 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.

2. *Practical Support*. 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.

3. *Privacy and Space*. 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.

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.

5. *Preparing and Coping*. 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.

6. *Emotional Distress, 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.

Discussion

This paper has described the development of attributes for a measure to capture the impact of EoLC on close-persons for use in economic evaluation within the capability approach¹⁰.

The development process involved in-depth interviews with bereaved individuals and individuals close to somebody receiving EoLC. The resulting measure, the ICECAP-Close Person Measure (ICECAP-CPM) contains six broad attributes covering issues that participants felt were important as their close person experienced 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 the health measures standardly used in economic evaluation, but are important impacts of EoLC.

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^{63 41}, 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 themes show considerable overlap with the attributes identified for the ICECAP-CPM. The two attributes of the measure that are less prominent in the complaints review relate to support for the close person. These may have been 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 complain about treatment of their loved one than their own support.

There are no existing measures directly comparable to the one developed here. The closest are the FAMCARE-2 ⁴⁴, a scale of family satisfaction of care developed in the context of advanced cancers, and the QOLLTI-F ⁶⁴, designed to measure the quality of life of the carer to someone at EoL. The QOLLTI-F and the FAMCARE-2 contain 16 and 17 items respectively and are unlikely to be suitable for valuation for economic evaluation. Furthermore, the new measure is broader than the QOLLTI-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 ⁴⁴ and the QOLLTI-F including items on emotional wellbeing, privacy and place ⁶⁴.

The work presented here has strengths and limitations. The new measure 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 within economic evaluation^{3,7,8,10,42}. There may be limitations associated with the University community as a

focus for 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. A further limitation of recruitment through advertising, is that participants effectively self-selected for interview and 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. This may have been due to the sensitivity and privacy of this topic area. People within the UK tend to be uncomfortable talking about dying and death⁶⁵ and this may have resulted in participants being reluctant to recruit others into the study. There were also more women than men in the final sample, possibly reflecting the burden of caring⁶⁶ and the more intense experiences that might result from the closeness of this role.

This paper describes the first stage in generating a close-person measure for use, alongside the ICECAP-SCM (with those at end of life) in economic evaluation of end of life care. Further research is needed to value the measure and this is a priority for future research. With such valuation, the measure will be able to meaningfully assess the relative value of different capability states given by the measure. Using deliberative valuation has been suggested as an important method for exploring future valuation work within the capability paradigm¹⁰. Future research is also required to assess the feasibility, validity and reliability of the measure with different groups. Other areas for exploration relate to the close-persons with whom the measure should be used within economic evaluation, and the relative weights to be given in the decision making process to those at the end of life and close-persons. This is being investigated as part of a wider European Research Council funded study⁶⁷.

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 economic evaluation and suggest that current methods will fail to capture 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 economic evaluation. This will enable close-person benefits of EoLC to be included within economic evaluation, thus aiding decision makers in allocating resources to achieve most benefit.

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

Characteristics		Number*
Age range of participants (years)	20-29	7
	30-39	4
	40-49	6
	50-59	6
	60-69	2
	70-79	2
Gender	Female	22
	Male	5
Ethnicity	White British	23
	Indian	1
	Mixed race	2
	Greek	1
Months since bereavement	Pre-bereaved	6
	6-12 months	8
	12-18 months	2
	18-24 months	14
Relation of decedent to participant	Mother	9
	Father	8
	Grandmother	5
	Grandfather	1
	Spouse	2
	Sibling	1
	Friends	3
	Father in law	1
Age range of decedent (years)	40-59	2
	60-79	11
	80+	13
	Not-specified	4
Recruitment method	Newsletter	22
	Marie Curie Hospice	4
	Snowball	1

*Total number of decedents = 30 as three participants reported two bereavements.

Table 3: Decedent health conditions

Decedent end-of-life conditions included
<p>Cancers:</p> <ul style="list-style-type: none"> - Lymphoma - Oesophageal - Lung - Colon & liver - Back & spine - Mesothelioma <p>Neurodegenerative disorders:</p> <ul style="list-style-type: none"> - Alzheimer's - Dementia - Parkinson's disease - Multiple system atrophy - Motor neurone disease <p>Heart conditions:</p> <ul style="list-style-type: none"> - Heart Failure - Sudden death via heart attack - Coronary heart disease - Elective surgery complications <p>Pulmonary conditions:</p> <ul style="list-style-type: none"> - COPD - Pneumonia <p>Stroke:</p> <ul style="list-style-type: none"> - Stroke & TIA <p>Frailty:</p> <ul style="list-style-type: none"> - Hospital acquired infections following falls <p>Others:</p> <ul style="list-style-type: none"> - Sarcoidosis - Undiagnosed chest complaint

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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 all of the time.....	5
B. I have been able to have good communication most of the time.....	4
C. I have been able to have good communication some of the time...	3
D. I have been able to have good communication a little of the time..	2
E. I have been able to have good communication none 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 all of the time.....	5
B. I have been able to have privacy and space most of the time.....	4
C. I have been able to have privacy and space some of the time.....	3
D. I have been able to have privacy and space a little of the time.....	2
E. I have been able to have privacy and space none 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 fully able to get practical support.....	5
B. I have been mostly able to get practical support.....	4
C. I have been somewhat able to get practical support.....	3
D. I have been mostly unable to get practical support.....	2
E. I have been completely unable 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 fully able to get emotional support.....	5
B. I have been mostly able to get emotional support.....	4
C. I have been somewhat able to get emotional support.....	3
D. I have been mostly unable to get emotional support.....	2
E. I have been completely unable 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 fully able to prepare for and cope with, the person's death.....	5
B. I have been mostly able to prepare for, and cope with, the person's death.....	4
C. I have been somewhat able to prepare for, and cope with, the person's death.....	3
D. I have been mostly unable to prepare for, and cope with, the person's death.....	2
E. I have been completely unable 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 fully able to be free from emotional distress.....	5
B. I have been mostly able to be free from emotional distress.....	4
C. I have been somewhat able to be free from emotional distress.....	3
D. I have been mostly unable to be free from emotional distress.....	2
E. I have been completely unable to be free from emotional distress.....	1

Thank you for your help with this research