Developing a new end-of-life instrument for use in economic evaluation

Joanna Coast

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Overview
End of life care & economics

- Increases in healthy life expectancy have not kept pace with improvements in length of life
  - Number of people in need of care continues to rise

- Policies to improve care at end of life have economic implications
  - Potentially high costs for governments, health services, charities
  - Limits to unpaid care provided by families or wider social networks

- May be more successful/less costly policies that would enhance the ability of society to provide care for all
To compete with other sectors for funds, end of life programmes need to demonstrate cost-effectiveness

- ‘conventional CEA underestimates the value of care in the face of death’ (Menzel et al, 1999)

Economic evaluations of aspects of end of life care have failed to present robust analyses

- Issues in defining costs & benefits
- Calls for further development of research tools
QALY = quality-adjusted life-year
Current approach to economic evaluation of end of life care

- Disease-directed therapy
- Functional goals
- QoL
- Patient-centred
- QALYs

Entry to Death
Multidimensional framework for economic evaluation

- Disease-directed therapy
- Functional goals
- QoL/Health
- Patient-centred

- Palliative/comfort care
- Spiritual/existential goals
- QoD
- Family-focused

- Active Dying

- Grief & bereavement

Increasing functional decline

Entry

Death
Capability approach

GOOD: hospice provision

UTILITY: pleasure obtained from receiving the care

HEALTH: improvements in morbidity and mortality

CAPABILITY: what you are able to do or be e.g. ability to make preparations
Economic measures within the framework

- Generic capabilities (for older people)
- Patient capabilities at end of life (SCM)
- Family capabilities at end of life
Economic measures within the framework

Generic capabilities (for older people)

Patient capabilities at end of life (SCM)

Family capabilities at end of life

Entry

Death
Generating attributes for inclusion in the measure
Aims

☐ To discover older peoples’ preferences at the end of life

☐ To develop distinct attributes of care at the end of life

☐ To develop a measure to be used in economic evaluations of health and social care interventions at the end of life
Methods

- First phase
  - 23 Interviews with those at various stages along dying trajectory
    - General population aged over 65 (11)
    - Older people living in residential care or sheltered housing (7)
    - Older people receiving palliative care (5)
  - (Aged 65 – 97 years, mean age 78 years, 15 female, 8 male)
  - explored what informants felt was important about end of life care, dying and death
  - constant comparative analytical methods

- Second phase
  - repeat interviews with 12 informants
  - checked attributes & generated wording
ICECAP-SCM - conceptual attributes (1)

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

- **Autonomy** – having a say in decisions that affect your life and care
  - *I don’t want to be kept alive if I’m not fit enough to enjoy it.* (Female, 81, RC)
ICECAP-SCM - conceptual attributes (2)

- **Physical suffering** – freedom from pain or discomfort
  - *I just wouldn’t want to be in pain all the time* (Female, 72, PC)

- **Emotional suffering** – freedom from worry or distress
  - *My discomfort is emotional rather than physical … if I have a very down period … it’s just the emotional thing really really …* (Female, 83, PC)
ICECAP-SCM - conceptual attributes (3)

- **Affection** – being with people who care about you
  - She [daughter] comes round here nearly every day to see me. She’s adorable she is … (Female, 68, PC)

- **Support** – having the help and support you need
  - Support plays a big part in some people’s lives, well most people’s lives really, if they got the support it makes them feel better. (Female, 74, GP)
ICECAP-SCM - conceptual attributes (4)

- **Completion** – having an opportunity to make the preparations you want to make
  - *I want to be cremated with my wedding ring on.* (Female, 97, RC)
  - *If I wanted to, the opportunity is there to make all the preparations I need. But as far as I’m concerned I have done all I need to, or all I want to at the moment.* (Female, 83, PC)
ICECAP-SCM – wording for measure

- **1) Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
- **2) Being with people who care about you** (Being with family, friends or caring professionals)
- **3) Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
- **4) Emotional suffering** (Experiencing worry or distress, feeling like a burden)
- **5) Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
- **6) Being supported** (Having help and support)
- **7) Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)
Need for valuation
ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship
   - I can have all of the love and friendship that I want [4]
   - I can have a lot of the love and friendship that I want [3]
   - I can have a little of the love and friendship that I want [2]
   - I cannot have any of the love and friendship that I want [1]

2. Thinking about the future
   - I can think about the future without any concern [4]
   - I can think about the future with only a little concern [3]
   - I can only think about the future with some concern [2]
   - I can only think about the future with a lot of concern [1]

3. Doing things that make you feel valued
   - I am able to do all of the things that make me feel valued [4]
   - I am able to do many of the things that make me feel valued [3]
   - I am able to do a few of the things that make me feel valued [2]
   - I am unable to do any of the things that make me feel valued [1]

4. Enjoyment and pleasure
   - I can have all of the enjoyment and pleasure that I want [4]
   - I can have a lot of the enjoyment and pleasure that I want [3]
   - I can have a little of the enjoyment and pleasure that I want [2]
   - I cannot have any of the enjoyment and pleasure that I want [1]

5. Independence
   - I am able to be completely independent [4]
   - I am able to be independent in many things [3]
   - I am able to be independent in a few things [2]
   - I am unable to be at all independent [1]

The ICEpop CAPability Instruments
(– O, –A and –SCM )

State: 44123

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Issues for valuation
1. Who should value?

- Societal values from the general population?
  - As a starting point?
  - But may have little understanding of the issues

- Values from those at end of life themselves?
  - Something each of us experience only once for ourselves and may be genuine changes in values that should be taken into account
  - Willingness/feasibility of participation
  - Difficulties in accessing this group

- Possible to design task that enables the general population to provide all required information that is linked with a task that is potentially feasible for those at the end of life?
2. Four or five levels for ICECAP-SCM

- Qualitative work suggested that people saw having something most of the time as the top level that was realistic.

- Conceptually as an economist it feels more ‘comfortable’ to have ‘all of the time’ as a top level.

- Any benefits or losses in these options from the valuation perspective?
1) Having a say – Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you

I can make decisions that I need to make about my life and care **most of the time**

I can make decisions that I need to make about my life and care **some of the time**

I can make decisions that I need to make about my life and care **only a little of the time**

I can **never** make decisions that I need to make about my life and care

---

1) Having a say – Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you

I am able to make decisions that I need to make about my life and care **all of the time**

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I am able to make decisions that I need to make about my life and care **only a little of the time**

I am **never** able to make decisions that I need to make about my life and care
3. ‘Standard’ or ‘opaque’ version?

- Some people may not know they are at the end of life
  - First external study to use the questionnaire queried the possibility of a less ‘explicit’ version
  - Focus on question 7 – Being prepared

- If the questionnaire is less explicit, does this affect values?
7) Being prepared – Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will

- I have had the opportunity to make **most** of the preparations I want to make
- I have had the opportunity to make **some** of the preparations I want to make
- I have **only** had the opportunity to make a **few** of the preparations I want to make
- I have **not** had the opportunity to make **any** of the preparations I want to make
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7) **Being prepared** – Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will

I have had the opportunity to make most of the preparations I want to make
I have had the opportunity to make some of the preparations I want to make
I have only had the opportunity to make a few of the preparations I want to make
I have not had the opportunity to make any of the preparations I want to make
Methods
Methods (general)

- Three pilot studies (n=204, 100, 102)
  - Ethics approval from University of Birmingham

- DCE incorporating Case 2 best-worst scaling (BWS) exercise
  - Additional socio-demographic, health, capability questions
  - Recording of time taken to complete survey

- Web-based panel

- Conditional logit regression analysis & plotting of variance scale factor
Set 3 of 16

Imagine living in the end of life state presented and decide which aspect you think would be most acceptable, and which aspect you think least acceptable? Please select one answer per column.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Most</th>
<th>Least</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to have the help and support that I need only a little of the time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I sometimes experience significant physical discomfort</td>
<td></td>
<td></td>
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<tr>
<td>I am able to maintain my dignity and self-respect some of the time</td>
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</table>
Imagine you are able to choose between the current end of life state (A) and a "middling" end of life state (B), which would you choose?

<table>
<thead>
<tr>
<th>End of life state A</th>
<th>End of life state B</th>
</tr>
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Select End of life state A or End of life state B.
Methods (issue 1)

- Novel “nesting” structure of the tasks for multiple layers of complexity
  - Most complex multi version one for general population (16 choice sets)
  - Simpler one for potential use with patients (8 choice sets and simplified task)

- Pilot 1
  - BWS limited to choices between top and bottom levels; DCE in ‘middling’ state

- Pilot 2
  - Checking for artefacts arising from previous RCT

- Pilot 3
  - Randomised to half of full OMEP in 32 - more complex task
Methods (issues 2/3)

- Respondents randomly assigned to four or five level version of the ICECAP-SCM (pilot 1)
- Respondents randomly assigned to ‘standard’ or ‘opaque’ version of ICECAP-SCM (pilot 3)
Results
Issue 1

- BWS much easier task than DCE

\[ y = 0.2417x - 0.4304 \]
\[ R^2 = 0.8965 \]
### Issue 1

<table>
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|                                |             |              |                      |
| Log pseudolikelihood           | -943.4162   |              |                      |
| Pseudo R2                      | 0.1407      |              |                      |
| Wald chi2(8)                   | 93.21       |              |                      |

* Significant at the 10, 5 and 1% level.

[^] Robust standard errors to account for clustering at respondent level.

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Joanna Coast: Valuing ICECAP-SCM

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Issue 2

- 5 level version of ICECAP-SCM seemed to result in use of simplifying heuristics
  - 6/102 individuals always chose middling state with 4 level version
  - 29/102 always chose middling state with 5 level version
- Pilot 2 (with 4 level version but ‘opposite’ middling state)
  - Choice of middling state did not have any significant or systematic effects
- Valuation task supports initial qualitative research to stick with 4 levels
Issue 3

- Virtually no effects associated with use of ‘standard’ or ‘opaque’ versions
- Suggests values for the two versions of the measure will be interchangeable
Discussion
Conclusions

- Main valuation study (n approx 6,000)
  - Novel ‘nesting’ approach appropriate
  - Choice of 4 level version of ICECAP-SCM
  - ‘Standard’ version for use in main valuation study
    - Use ‘standard’ and ‘opaque’ versions of ICECAP-SCM interchangeably

- Further work
  - Main study will consider heterogeneity – limited ability to consider this here
  - Additional work planned to generate values from patients / agents of patients
Acknowledgements:

Research team
Kathy Armour
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Alastair Canaway
Terry Flynn
Phil Kinghorn
Rosanna Orlando

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Funding: European Research Council

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