Extending life for people with a terminal illness: a moral right or an expensive death?

Empirical, ethical and methodological issues

Neil McHugh, Helen Mason, Job van Exel, Rohan Deogaonkar

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Overview

• About the project
  • Background
  • Research objectives
  • Study design

• This session
  • Helen Mason – findings (experts)
  • Neil McHugh – methodological and ethical issues
  • Job van Exel – survey design
  • Open discussion and questions
UK MRC Methodology Panel funding 2011-2014

“Is ‘end-of-life’ care more valuable? Measuring societal views on health care resource allocation using the new Q2S method.”

Rachel Baker, Neil McHugh, Helen Mason, Cam Donaldson, Laura Williamson, Jon Godwin, Marissa Collins, Rohan Deogaonkar (GCU)

Job van Exel (Erasmus, Rotterdam)

Cathy Hutchinson (Beatson Cancer Centre, NHS Greater Glasgow & Clyde)
Scarcity...

... and health care resource allocation in publicly funded health systems
Are equal sized health gains ‘worth’ the same regardless of who benefits and in what ways?
Patients protest after kidney cancer drugs rejected

Peter Walker, David Batty and agencies

guardian.co.uk, Wednesday 27 August 2008 15:39 BST

Protesters storm the offices of the National Institute for Health and Clinical Excellence Photograph: Martin Argles

Dozens of kidney cancer patients and their families picketed the agency responsible for approving NHS treatments today over its decision to reject several new treatments.

Protesters gathered outside the headquarters of the National Institute for Health and Clinical Excellence (Nice) in Holborn, central London, saying that they "deserved the right to life".

Nice issued draft guidance earlier this month rejecting the drugs Sucent (sunitinib), Avastin (bevacizumab), Nexavar (sorafenib) and Torisel (temsirolimus), on the grounds that they are not cost-effective for patients with advanced and/or metastatic kidney cancer.

Although the medicines do not cure the cancer, they can extend a patient's life by several months.

After the demonstration outside the building, a small group of protesters went to see the chief executive of Nice, Andrew Dillon, with letters calling for a rethink of the guidance.
NHS end-of-life drugs rule change

Drugs which give terminally ill patients a few extra months to live have a better chance of being approved on the NHS under new rules.

The National Institute for Health and Clinical Excellence (NICE) is to extend the threshold at which the drugs are deemed cost-effective.

But this will only be in certain circumstances for instance in people who have less than two years to live.

The rules affect decisions for England, Wales and Northern Ireland.

It is thought one or two treatments a year will be affected by the change.

The charity Macmillan Cancer Support estimated 10,000 cancer patients a year could benefit.

The announcement follows a five-week public consultation and will come into effect in time for the January meetings of Nice advisory committees.

It will impact decisions made at the end of life for patients in England, Wales and Northern Ireland.

The NHS has a finite pot of money for treatments.
Specific criteria

- less than 2 years to live
- treatments would result in a gain of at least 3 months of increased life expectancy
- drug is licensed for a relatively small patient group
Objectives

i. To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;

ii. To develop methods to investigate the distribution of those views, including their association with other characteristics, in a nationally representative sample of the UK general public.
Methods

**Q methodology**
Empirical, qualitative

i. To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;

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**Survey methods**
Methodological, quantitative

ii. *To develop* methods to investigate the distribution of those views, including their association with other characteristics, in a nationally representative sample of the UK general public.
Methods

Q methodology

i. To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;

Survey methods

ii. To develop methods to investigate the distribution of those views, including their association with other characteristics, in a nationally representative sample of the UK general public.
**Respondent samples**

**Q methodology**
- 50 experts; 250 public; face to face Q sorts

1. **To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;**

**Survey methods**
- 5,000 online questionnaire respondents

2. **To develop methods to investigate the distribution of those views, including their association with other characteristics, in a nationally representative sample of the UK general public.**
Progress

Data collection complete, analysis preliminary

i. To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;

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Year 3 – to be completed Sept 2014
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• About the project
  • Background
  • Research objectives
  • Study design

• This session
  • Helen Mason – findings (experts)
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Extending life for people with a terminal illness: a moral right or an expensive death? Empirical, ethical and methodological issues.

‘The Experts’
Outline

• Expert Study
• Development of Q set
• Data collection
• Factors
What is the Expert Q study?

- Study includes two different P-sets in the first phase; Experts and General Public
- Purposive sample of people who are ‘data rich’
- Specifically individuals who have expertise in ‘End of Life’ in a professional or personal capacity
- Allow us to compare the results with those found in the general public
Who are the experts?

- 49 Q sorts completed

<table>
<thead>
<tr>
<th>Area of expertise</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td>14</td>
</tr>
<tr>
<td>Health Service</td>
<td>20</td>
</tr>
<tr>
<td>Pharmaceutical Company</td>
<td>6</td>
</tr>
<tr>
<td>Religious leaders</td>
<td>3</td>
</tr>
<tr>
<td>Patient or patient family</td>
<td>10</td>
</tr>
<tr>
<td>Others</td>
<td>7</td>
</tr>
</tbody>
</table>

* Does not sum to 49 as respondents can be categorised in more than one area
Q set

• Statements taken from
  – Media review (readers’ comments)
    • 45 articles
  – Public consultation – NICE EoL policy
    • 850 comments from 300 respondents
  – 16 depth-interviews
  – 3 Focus groups (20)
• Resulted in 49 statements
Example Statements

We all have the right to life

It is not worthwhile devoting more and more NHS money to someone who is going to die soon anyway.

Real help and compassion should be about providing a death with dignity instead of more drugs to get a few more weeks or months out of a very sick body.
Data Collection

• Collected by the research team in face to face interviews
• Introduction to the topic
  – Limited health care budget
  – Defining end of life in this context
• Sorting from most agree to most disagree (+5 to -5)
• Followed by interview lasting 20-50 minutes
Analysis

• PQ Method
• Centroid followed by Varimax
• 3 factor solution
  – F1 Health Systems
  – F2 Individual Patient Choice
  – F3 Quality of Life
Factor 1
Factor 1

• Taking a system level approach
• Maximising the health of the whole population
• Consideration of costs and benefits and the opportunity cost to all patients
• Patient choice for expensive treatments not supported – don’t have a right to all treatments
• QoL and death with dignity but potentially wrapped in the size of potential benefits
If the means of helping someone live longer exists, it is morally wrong to deny them the treatment.

Patients should have the right to refuse life-extending treatments if they choose.

We all pay for the NHS so we should have a right to life-extending treatment when we need it.

People who will die prematurely deserve to take priority over those who have non-life-threatening illnesses, even if it's not such a 'good' use of NHS money.

Everyone has a right to basic healthcare but there has to be limits and expensive, end-of-life, drugs are not basic care.

Not giving access to life-extending medicine to a person with a terminal illness is the same as killing them.

If somebody wants to keep fighting until the last possible moment, they should be allowed to do so, regardless of cost.

Real help and compassion should be about providing a death with dignity instead of more drugs to get a few more weeks or months out of a very sick body.

The health system should be about getting the greatest benefit overall for the population.
“NHS is always about priorities, and picking priorities is very difficult. People’s personal circumstances may be very different which makes it hard for doctors to choose, but **overall health policy has to be decided in a very rational way about the greatest good for the greatest number of people**”

“money isn’t just money it’s somebody else’s opportunity for easement of pain or suffering or prolongation of perhaps a better quality of life. **That money is never infinite so it always means taking it from somewhere else**”
Factor 2
Factor 2

- Individual patient perspective
- Life is important – we all have the right to life
- Supporting individual/patient choice for treatment, giving the patient and their family time together and to prepare for death
- Provide treatments even if they are not a cure
- Rejection that costs should be a reason why treatments not provided No importance placed on system level health maximisation through consideration of costs and benefits
<table>
<thead>
<tr>
<th>F2 Individual Patient choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>48</td>
</tr>
<tr>
<td>I think life-extending treatments for people who are terminally ill are of less value as people get older.</td>
</tr>
</tbody>
</table>

| 33                             |
| End-of-life drugs are not a cure, they are life-prolonging. There is no point in delaying the inevitable for a short time. |

| 32                             |
| People with a diagnosis of a terminal illness know that they will die early. Other people may not know in advance that they will die (e.g. patients with heart problems). It is unfair to give priority to those whose time of death is more likely to be known. |

| 1                              |
| It is not worthwhile devoting more and more NHS money to someone who is going to die soon anyway |

| 36                             |
| Treatments that provide a short life extension are not worth it - they are only prolonging the pain for the patient’s family/friends. |

| 11                             |
| It is important to give a dying person and their family time to prepare for their death, put their affairs in order, make peace and say goodbyes |

| 37                             |
| All human life is precious |

| 8                              |
| Patients should have the right to refuse life-extending treatments if they choose |

| 20                             |
| We all have the right to life. |

| 18                             |
| It may not sound like much, but a few extra weeks or months might mean an awful lot to a family affected by a terminal illness. |

Brighter futures begin with GCU
“I think that if a system such as the NHS is to be truly compassionate, the patient choice and family choice has to be one of the premier things that we consider. And so I think if it is important to a patient to try to do whatever within the realms of being realistic then I think they should have that option”

“It has to be a decision made not just on the basis of a new drug or a costly treatment but something that would help meet the needs of somebody who wants to live as long as they can”

“I think life should be prolonged if that is the wish of the patient and the family”
Factor 3
Factor 3

- QoL during the last few months is important
- Only extending life if QoL is good, otherwise giving time for people to prepare with their family and having a ‘good death’
- Do not agree that we should be preserving life at all costs; this could be because of QoL during this last few months but also because of the cost to the NHS and other patients
- Cannot keep spending to provide treatments, not an automatic right to have treatment
### F3 Quality of life

<table>
<thead>
<tr>
<th>28</th>
<th>If the means of helping someone live longer exists, it is morally wrong to deny them the treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>40</td>
<td>Life is sacred and if it is possible to preserve life, every effort should be made to do so</td>
</tr>
<tr>
<td>23</td>
<td>A year of life is of equal value for everyone.</td>
</tr>
<tr>
<td>29</td>
<td>Not giving access to life-extending medicine to a person with a terminal illness is the same as killing them.</td>
</tr>
<tr>
<td>6</td>
<td>If somebody wants to keep fighting until the last possible moment, they should be allowed to do so, regardless of cost</td>
</tr>
</tbody>
</table>

**Centre of factor array omitted**

<table>
<thead>
<tr>
<th>22</th>
<th>Real help and compassion should be about providing a death with dignity instead of more drugs to get a few more weeks or months out of a very sick body</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>Life should only be extended if the patient’s quality of life during that time will be good.</td>
</tr>
<tr>
<td>8</td>
<td>Patients should have the right to refuse life-extending treatments if they choose.</td>
</tr>
<tr>
<td>11</td>
<td>It is important to give a dying person and their family time to prepare for their death, put their affairs in order, make peace and say goodbyes.</td>
</tr>
<tr>
<td>41</td>
<td>I wouldn’t want my life to be extended just for the sake of it - just keeping breathing is not life</td>
</tr>
</tbody>
</table>

Brighter futures begin with GCU

GCU
Glasgow Caledonian University
“Because quality of life is what it is all about, life itself is not the be all and end all”

“It's pretty un-contentious that ‘death with dignity’ is the really crucial thing”

“I’m not sure I think there is a right to life because in that case we would be spending our entire worldwide research funds to keep people in a suspended state and that's not a quality of life and I think life is about quality as well as length”
Next steps

Work in progress

• Further analysis
  • Judgemental rotation
  • Examining other data collected
Methodological and Ethical Considerations

Neil McHugh

Rachel Baker, Helen Mason, Job van Exel, Rohan Deogaonkar
Contents

• Sampling and Study Design
• Reasons for P set selection
• Similarities and differences between factor solutions
• Options for Survey Design
• Ethical Issues
Sampling and Study Design
Phase 1 P Sets
• ‘Experts’ 50 Q sorts
  • Purposively selected
  • Sample includes:
    • Health and health policy professionals, patients groups, charities, hospice volunteers, bereaved families, cancer research scientists, pharmaceutical industry, health economists, ethicists, religious leaders...
• General Public 250 Q sorts
  • Survey company
  • 10 regions across 4 countries in UK

<table>
<thead>
<tr>
<th>Quota Sampling</th>
<th>Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Religion</td>
</tr>
<tr>
<td>Gender</td>
<td>Ethnic group</td>
</tr>
<tr>
<td>Employment status</td>
<td>Health</td>
</tr>
</tbody>
</table>
Reasons for P set selection

• ‘Experts’
  • P-set selected according to accepted Q methods

• General Public
  • Phase 1 Research Objective:
    • “To identify and describe societal perspectives on the (relative) value of life-extending, end-of-life technologies by eliciting the views of both members of the public and experts in relevant fields”
  • NHS-publicly funded health care system
  • NICE End of Life Supplementary Guidance
  • “The Institute recognises that the public, generally, places special value on treatments that prolong life – even for a few months – at the end of life, as long as that extension of life is of reasonable quality (at least pain-free if not disability-free . . . .” (Rawlins et al., 2010, p348)
  • Decision makers explicitly seek the views of the public
Similarities and differences between factor solutions

• Do the ‘expert’s’ views then reflect those of the general public?
  • GP F1 highly correlated with Ex F2 (0.85)
  • GP F2 correlated with Ex F1 (0.78) and Ex F3 (0.62)
  • No correlation between GP F3 and any of the Ex Factors

• One uncorrelated factor – GP F3
  • Rejection of price on life; life is precious; not natural to extend life when someone is going to die soon but if gain to be had then individuals should be given that chance; not prolong agony/pain

• What does this mean for designing the Phase 2 survey?
Options for Survey Design

- 2 factor solutions from Phase 1
- 2 Phase project
  - Q methodology (Phase 1) → Survey Methods (Phase 2)
- So what factor solution should we take forward to Phase 2?
  1. ‘Expert’s’ factor solution
  2. General Public’s factor solution
  3. Pooled factor solution
  4. Super factors
  5. Use both factor solutions

- Who are the ‘experts’???

- Are the ‘experts’ then just a subset of the general public?
• Ethical Issues
  • Q allows us to *describe* shared views
    - Understand and represent the factors without judgement

• How might/should the information generated in this research be used in policy?
  • For policy use views have to be judged
    - Assess the quality of the arguments
  • For example,
    - Factor 1 from General Public – denial of scarcity
    - Publicly funded health care system

• What is the normative relevance of societal perspectives derived in this way?
  - An empirical ethics approach
Survey design
Objectives

i. To identify and describe societal perspectives on the (relative) value of end of life technologies by eliciting the views of both members of the public and experts in relevant fields;

ii. To develop methods to investigate the distribution of those views, including their association with other characteristics, in a nationally representative sample of the UK general public.
Overview

- Different ways to investigate the distribution of the views identified in a Q study → how to collect & analyse data
- Pros and cons
- Discussion
Q survey methods - Data collection

- Talbott’s Q block (Talbott, 1963)
  - blocks of statements, ranking

- Brown’s standardized factor index score (Brown, 2002)
  - statements, rating

- Self-categorisation to abbreviated factor descriptions
  - self-categorisation to abbreviated factor descriptions, rating and/or ranking

*Question*: What information about factor membership / factor association do these approaches give us?
Approach 2

This study is about decision making in health care. No matter how large the health care budget will ever be, the list of services and treatments will be too long to do everything that could possibly be done. There are constraints that must be made about which health services and treatments to provide and, therefore, which not to provide. Different choices will mean that some patients get treatments (because they are provided) and other patients will not (because treatments are not provided).

You will now see ten statements about how to make those choices in health care. We are interested in how much you agree with each of these statements. Please indicate your agreement by ticking a box.

1. Patient characteristics such as age, gender or income should play no role in prioritizing between people.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

2. In a treatment adds one month to the life of a patient and costs $30,000, one should consider whether the money could have been better spent on other health care.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

3. Patients should be given to people whose quality of life is better than those whose quality of life is lower when treatment can only improve their quality of life by a small amount.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

4. There is no sense in having kids if the quality of life of the parents will be seriously be degraded.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

5. Younger people should have a greater priority than older people because they haven’t lived as long as other groups of health units.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

6. People should not be allowed to buy health care or to buy health care.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

7. People who are in some way responsible for their own illness should receive lower priority than people who are not.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

8. People who are healthier when treated, because they are more effective than, should receive greater priority than people who benefit from lower priority.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

9. People who in some way responsible for their own illness should receive lower priority than people who are not.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

10. It is more important to provide treatments that prolong life than treatments that improve the quality of life.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree

Approach 3

This study is about decision making in health care, i.e. how resources is divided between people in general, and between those who are treated in different health care settings. We are interested in how much you agree with each of these points of view. Please indicate your agreement by ticking the boxes.

1. People should be allowed to buy health care at any time.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

2. People should be given to people whose quality of life is better than those whose quality of life is lower when treatment can only improve their quality of life by a small amount.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

3. Younger people should have a greater priority than older people because they haven’t lived as long as other groups of health units.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

4. People who are in some way responsible for their own illness should receive lower priority than people who are not.
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   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

5. People who are healthier when treated, because they are more effective than, should receive greater priority than people who benefit from lower priority.
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   - Disagree
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   - Agree
   - Strongly agree

6. People who in some way responsible for their own illness should receive lower priority than people who are not.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

7. It is more important to provide treatments that prolong life than treatments that improve the quality of life.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

8. Someone who is the only person in the world with a condition should not be treated any differently than someone who is the only person in the world with a condition even if they are not treated any differently.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

9. If someone who is the only person in the world with a condition should not be treated any differently than someone who is the only person in the world with a condition even if they are not treated any differently.
   - Strongly disagree
   - Disagree
   - Neither agree nor disagree
   - Agree
   - Strongly agree

10. It is more important to provide treatments that prolong life than treatments that improve the quality of life.
    - Strongly disagree
    - Disagree
    - Neither agree nor disagree
    - Agree
    - Strongly agree
Q survey methods - Data analysis

• Talbott’s Q block (Talbott, 1963)
  – Sum-score of factor ratings per block

• Brown’s standardized factor index score (Brown, 2002)
  – Brown’s standardized factor index score
  – Confirmatory factor analysis
  – Latent class analysis

• Self-categorisation to abbreviated factor descriptions
  – Descriptive statistics per factor
Some pros and cons

- Talbott’s Q block (Talbott, 1963)
  - Ranking of statements more similar to Q
  - Based on sub-set of statements, selection of statements (per block), framing, scoring

- Brown’s standardized factor index score (Brown, 2002)
  - Common way to collect data, low respondent burden
  - Based on sub-set of statements, selection, analysis

- Self-categorisation to abbreviated factor descriptions
  - Respondents evaluate factors as a whole
  - Higher respondent burden, summary
Some points for discussion

• Which approach is most ‘faithful’ to Q methodology?

• What should we do?
  – Match respondent to a single factor
  – Look at strength of association with all factors

• What are (dis)advantages of the different approaches?
  – Separate statements vs. factor as a whole
  – Ranking versus rating
  – Survey data vs. combination with Q data

• Experiences or different ideas to share?
Discussion
Discussion Questions

• So what factor solution should we take forward to Phase 2?
• Are the ‘experts’ just a subset of the general public?

• What is/should be Q’s role in empirical ethics?
• (How) Should the quality of factors be interrogated/evaluated?