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

Empirical and Methodological Issues
Outline

• Background to the project
  – Topic
  – Objectives
  – Study design
• Q methodology
• Phase 1 findings
• Discussion
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.”

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Cathy Hutchinson (Beatson Cancer Centre, NHS Greater Glasgow & Clyde)
Relative value of end of life care and resource allocation

- 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?

1 QALY = 1 QALY = 1 QALY?

e.g. 1 year in full health
Patients protest after kidney cancer drugs rejected

Peter Walker, David Batty and Agencies
Guardian.co.uk, Wednesday 27 August 2008 15:35 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Nice issued draft guidance earlier this month rejecting the drugs Sutent (sunitinib), Avastin (bevacizumab), Nexavar (sorafenib) and Torisel (temsirolimus), on the grounds that they are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 by the National Pharmaceutical Advisory Committee (NPAC) and the National Institute for Health and Clinical Excellence (NICE) in their decisions about the use of new cancer drugs.

The Institute is also conscious of its responsibility to support the development of novel treatments for smaller patient groups that provide innovative benefits over and above existing NHS care.
NICE End of life Supplementary guidance

• 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
“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). NICE has therefore provided its advisory bodies with supplementary advice about the circumstances under which they should consider advising, as cost-effective, treatments costing >£30,000 per QALY.” p 348
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

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Q Methodology
What is Q methodology?

• ..is a set of connected techniques designed to enable the study of ‘subjectivity’
  – (views, opinions, beliefs, values, tastes, ...)

• “Only subjective opinions are at issue in Q, and although they are typically unprovable, they can nonetheless be shown to have structure and form, and it is the task of Q technique to render this form manifest for purposes of observation and study.” (Brown, 1986) page 58

• Combines qualitative and quantitative techniques
Q methodology

• Data generation
  – Statements (Q-set)
  – Card sort (Q-sort)
  – Qualitative data (comments/ interviews)

• Data analysis
  – ‘by person’ factor analysis

• Results
  – A number of ‘factors’
  – Each factor representing a point of view
Q sorting
The Q set

• Concourse:
  – *The running or flocking together of people; the condition or state of being so gathered together.*
  – *The running, flowing together, or meeting of things (material or immaterial); confluence. (OED)*
  – universe of subjective viewpoints around a topic

• Q set:
  – Representative of the concourse
Selection of respondents (the P set)

• **Size of sample?**
  – Cannot be predetermined ..but
  – Typically a sample of between 40 and 60 respondents will be plenty. Often fewer.

• **Who to sample?**
  – Similar to qualitative approaches to sampling
  – Theoretical sampling
  – Purposive not representative
Analysis

• (by person) Factor Analysis

• Groups together Q sorts which have been completed in a similar way

• Aim to identify and describe subjectivities: the range of views on a topic (not to make a claim about percentage or characteristics of people expressing them)
Interpretation

- Interpreting factors focusing on the most salient (i.e. most agree/disagree statements)
- And distinguishing statements
- And respondents’ comments
- To create a holistic, rich narrative for each factor
Phase 1

A Q methodological study of the relative value of life-extensions for patients with terminal illness
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)

• Decision on what to rule out based on research question

• Resulted in 49 statements
Example Statements

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

We all have the right to life

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.
Respondent samples

• 57 purposively sampled “data rich” individuals
  • Interviewed by research team
  • Health/policy professionals, patient groups, charities, hospices, bereaved families, cancer research scientists, pharma industry, health economists, ethicists, religious leaders...

• 250 members of the UK population
  • Quota sampled by IPSOS MORI (age/gender/employment)
  • 10 regions, 4 UK countries
Data Collection

• Introduction to the topic *(see animation)*
  – Limited health care budget
  – Defining end of life in this context

• Guided Q sort, onto a grid labelled most agree to most disagree

• Followed by interview lasting 20-50 minutes

• Socio-demographic questionnaire
Animated intro to online survey

setting the scene – condition of instruction

http://www.youtube.com/watch?v=gPNdGUSdRtg
Analysis

- PQ Method software
- Centroid>Varimax
- ‘Purposive Sample’ plus factors from our General Public sample

- 3 Factors
  - F1 Maximising population health
  - F2 Individual patient perspective
  - F3 Balancing cost effectiveness with patient values
Factor 1

“Greatest benefit for all, no special cases”
Factor 1

- System-level (rather than individual patient) approach
- Awareness of the budget constraint
- Maximising the health of the whole population
- Consideration of costs and benefits and the opportunity cost to all patients
- QoL and death with dignity but potentially wrapped in the size of health benefits

<table>
<thead>
<tr>
<th><strong>MOST AGREE</strong></th>
<th><strong>Factor 1</strong></th>
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<tbody>
<tr>
<td><strong>4</strong></td>
<td>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.</td>
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<tr>
<td><strong>5</strong></td>
<td>NHS provision of life-extending treatments should be decided on the basis of their cost and health benefits</td>
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<td>At the end of their life, patients should be cared for at home with a better quality of life rather than have aggressive and expensive treatments that will only extend life for a short period of time.</td>
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<td>The health system should be about getting the greatest benefit overall for the population</td>
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<td></td>
<td>Patients should have the right to refuse life-extending treatments if they choose</td>
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GCU Glasgow Caledonian University
## Factor 1

- Patient choice for expensive treatments not supported – we don’t have a right to all/any treatments.

- Patients with terminal illness don’t take priority, cost and value for money are important.
“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

Individual patient perspective - the value of life should be central, not cost
Factor 2

- Individual patient perspective
- Rights-based arguments
- Life is precious – 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

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.

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.

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

We all have the right to life.

All human life is precious.
Factor 2

- Provide treatments even if they are not a cure - they are worthwhile.

- 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

Treatments that are very costly in relation to their health benefits should be withheld.

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

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

I think life-extending treatments for people who are terminally ill are of less value as people get older.

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

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

Balancing cost effectiveness with quality of life and patient values
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
- A ‘good death’

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.

NHS provision of life-extending treatments should be decided on the basis of their cost and health benefits.

Patients at the end of life will grasp any slightest hope but that is not a good reason for the NHS to provide costly treatments that may extend life by a short time.

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

I wouldn’t want my life to be extended just for the sake of it - just keeping breathing is not life.
Factor 3

- We should not preserve life at all costs
- A year of life in poor health is not equal to a year of life in good health.
- Cannot keep spending to provide treatments, not an automatic right to have treatment

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

A year of life is of equal value for everyone.

Life is sacred and if it is possible to preserve life, every effort should be made to do so.

If the means of helping someone live longer exists, it is morally wrong to deny them the treatment.

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

• So....?

• Factor 1 – would not support QALY weights/ NICE end of life policy, a QALY is a QALY

• Factor 2 – would provide life extension at any cost

• Factor 3 – might support EoL QALY weights, contingent on other things such as quality of life and not at any cost.

• ... views are divided
Empirical and Methodological Issues

• Theoretical sampling (n=57) versus general population (n=250)...

• ...gave us different, overlapping factor solutions
  • tension?
  • Critical/ ethical analysis of factors? (e.g. f2)

• Study Design
  • From phase 1 to phase 2 (survey methods)
  • From ‘rich accounts’ to short descriptions/ key statements
Discussion

• How might viewpoints/perspectives relate to choices (future research)

• What does this mean for NICE/SMC?

• Value based pricing (appraisal) and EoL