Rationing: should it be implicit or explicit?

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Conference on priority setting in health care, Vasterås, Sweden, October 2011
A framework for rationing

Explicit rationing
- Political processes
  - Lay participation
  - Medical paternalism
- Technical methods
  - Equity
  - Efficiency

Implicit rationing

(Coast et al, Priority setting: the health care debate, John Wiley, 1996)

Joanna Coast: Implicit or explicit rationing?
Outline

- Defining explicitness
  - Advantages of explicitness
- Disutility associated with explicitness
  - Deprivation disutility
  - Denial disutility
- Evidence for & implications of deprivation disutility
- Evidence for & implications of denial disutility
- Discussion
Defining explicitness
Explicit & implicit

- Explicit priority setting:
  - Making clear the decisions that have been made about resource allocation and the basis upon which these decisions have been made

- Implicit rationing:
  - The unacknowledged limitation of care
  - Care is limited, but neither the decisions, nor the bases for those decisions are clearly expressed
Moves towards more explicit rationing

- Oregon plan – USA
- Core services – New Zealand
- NICE – UK
  - Seen as successful in introducing systematic & accountable priority setting to the NHS
Moves towards more explicit rationing

- Development of A4R framework
  - ‘accountability for reasonableness’
  - Proposed by Daniels & Sabin, & increasingly influential
  - Focuses on the process of priority setting & has four requirements:
    - Publicity – decisions & rationales accessible
    - Relevance – ‘fair-minded’ individuals should agree
    - Appeals – should be mechanism for dispute & review
    - Enforcement – regulation of the first three criteria
Advantages of explicit rationing

- Generally favoured in theory because:
  - Enables technical priority setting methods to proceed
    - e.g. health maximisation, as in NICE in the UK
  - Legitimacy & accountability of public decision-making bodies
  - Honesty & respect for patient autonomy at the consultation level
  - Ensuring use of ethically defensible criteria in resource allocation at the consultation level
  - Appeals are possible
  - With availability of information in the media & through the internet, implicit rationing is increasingly unsustainable
With explicit rationing people will be very aware of their rights and their rationing status:

- Do people want to know if their care is rationed?
- Do doctors want to ration explicitly?
- What happens to the health care system when you have explicit rationing?
Disutility from explicit rationing
Disutility from explicit rationing

- Two potential sources of disutility
  - Deprivation disutility
    - Patients / family
  - Denial disutility
    - Doctors / politicians / public / society
Deprivation disutility (1)

- Notion developed by Mooney & Lange, 1993, in relation to antenatal screening
  - Loss in utility for women ineligible for screening who subsequently bear child with disability
- Adapted to rationing situation by Coast, 1997
  - Loss in utility through knowing that others can access treatment that I cannot
  - Associated with both resentment & loss of hope
Deprivation disutility (2)

- "it is easier to bear inevitable disease or death than to learn that remedy is possible but one's personal resources, private insurance coverage or public programme will not support it“
  - (Evans & Wolfson, in Mooney, 1994)

- Preference for implicit rationing “not through a belief in medical imperialism or paternalism but through a concern about the anguish that patients and their relatives might feel if they knew that they are being denied services that others had received explicitly because of cost”
  - (Hoffenberg, in Smith, 1993)
Denial disutility (1)

Denying treatment may cause considerable disutility to those who have to make this decision.

“The greatest source of anguish in the implementation of the plan will come in learning how to live with, and to rationalise, its failure to cover some people whose condition will pull at our sympathies... We will, for one thing, always wonder if we are doing the right thing. We will always wonder, for another, if it might be possible to relieve the pain by some stratagem we have not yet devised.”

– (Callahan, 1991)

“...for physicians to have to face these trade-offs explicitly is to assign to them an unreasonable and undesirable burden.”

– (Fuchs, 1984)
Denial disutility (2)

- Implicit rationing
  - Denial disutility minimised by justification on medical grounds & decision ‘conveyed’ by variety of means
    - Options for treatment not mentioned e.g. no referral
    - Options for treatment stated as inappropriate & justified on medical grounds

“Doctors gradually redefine standards of care so that they can escape the constant recognition that financial limits compel them to do less than their best”
  - (Aaron & Schwarz, 1984)

- Patients who are not referred will not be rejected & the doctor does not then have to face the rejected patient.
Denial disutility (3)

- Explicit rationing
  - A general reluctance to specify services to be denied
    - Programme budgeting & marginal analysis (PBMA) exercises across the board show lack of willingness to specify services for explicit disinvestment
    - Reluctance to deny services noted in the initial consultation on core services in New Zealand
    - NICE threshold seems to be maintained at a level where denial is relatively limited
Empirical evidence for, & implications of, deprivation disutility
Empirical evidence

- Two qualitative studies with in-depth interviews
  - 1996-8 – UK, exploratory element to find out if citizens & health professionals wanted to know about rationing of their own care
    - 24 interviews – health professionals & members of the public
  - 2005-2007 – UK, focus on whether patients want to know about rationing of their own care
    - Acknowledgement: Amanda Owen-Smith, Research Fellow, University of Bristol for some of the material included here
    - 2 case-studies of patients with breast cancer and morbid obesity
    - 52 interviews – patients & health professionals
Study 1 - Findings (1)

- Members of the public & health professionals similar views
- Vast majority wanted to know about rationing
- Tendency to suggest ways in which the health care might be achieved
- Knowing that you know about any rationing gives implicit reassurance that care is not being rationed otherwise
Study 1 - Findings (2)

- People wanted to know for two main reasons
  - To understand
    - “I’d like to maybe have some understanding why that decision was made, in terms of the technical side of it… and then so maybe I could weigh it up and decide whether they were right…” (Male, 31)
  - To alter the decision
    - “Well if I know about it perhaps I could kick up a fuss and get it.” (Male, 65)

- But, this work was hypothetical

- What happens when real rationing situations are encountered?
Study 2 – Findings (1)

- Complex pathways for reacting to rationing across both case-studies

- Choice:
  - Accept rationing decision
  - Contest rationing decision
  - Opt out of public system and pay privately
Study 2 – Findings (2)

☐ In theory…

- … Almost all informants were aware of resource shortages
- … well over half accepted the inevitability of rationing
- … several said they would be prepared to accept rationing of their own care
Study 2 – Findings (3)

☐ In practice...

- ... only one of fifteen patients whose care was rationed through explicit denial of a particular treatment did not try either to contest the decision or seek care privately
- ... awareness of inconsistency between theoretical view and actual behaviour
- Acceptance of denial only once all other options exhausted

 Everything must be rationed up to a point, because there is a finite pot, and I appreciate that. I can see where they’re coming from, but when you’re on the end of it, that’s not really what you care about – you just want to get the money and the drug. (Breast cancer patient)
Study 2 – Findings (4)

- Contesting rationing decisions
  - Only 2 out of 8 successful
  - Rejection difficult & hurtful for patients who tended to be surprised
  - Appeal process deeply distressing
    It was a farce… it was so patronising it was unbearable… it was a bloody forgone conclusion, we weren’t going to win the appeal. (Breast cancer patient)
  - Some struggled to understand the appeal process
    The difficulty I’ve got is, well, who do I complain to? (Morbid obesity patient)
Study 2 – Findings (5)

- Two patients who continued to be denied Herceptin publicised their plight through the local & national press

- Many expressed admiration for those patients who made a stand for all patients:
  
  It must be awful for these people having to fight their illness, and fight the authorities… but a lot of good comes out of these cases… I admire them tremendously (Breast cancer patient)

- Legal proceedings started by one informant
  
  - Others decided against legal challenges as too expensive

- Attempts to influence politicians not seen as helpful
  
  I wrote to my MP [Member of Parliament]… she was about as much use as a chocolate teapot. (Breast cancer patient)
Study 2 – Findings (6)

☐ Paying privately

- Seen as important option by all patients denied care
- Sometimes payment a final option once other attempts failed
- For others it was a first response, preferable to contesting decisions
- All informants concerned about inequity of allocating healthcare on the basis of capacity to pay

*It’s sad isn’t it for people out there who really can’t get this loan or get money. It is a life of misery they’re going to end up living.* (Morbid obesity patient)
Study 2 – Findings (7)

- Deprivation disutility greater with explicit denial
  - Only 1/15 accepted explicit rationing
  - No patients contested rationing through waiting & only 2 paid
  - Patients prepared to accept rationing by dilution

- Nearly all patients who contested decisions or paid for care said that they could not tolerate care being withheld because they were so anxious about their health
  - Especially where this was perceived as potentially life-saving

  *I have to have [surgery], I’m not living, I’m going to die… I have a right to a life.* (Morbid obesity patient)

- Decisions seen as particularly unfair if patients in other locations could access the denied treatment
Conclusions

- There is some deprivation disutility from explicit rationing
  - Most try to circumvent explicit denials of care
- Both professionals & patients were concerned about the pressure such protests might put on the NHS as a whole & worried about inequity
- Inconsistency between theoretical and actual reactions to rationing
Implications: potential instability

- Both studies resonate with a major problems of explicit rationing as identified by Mechanic:
  - Individual strength of preference not considered
  - People will feel deprived of care & there will be a lack of acceptance of explicit rationing
  - Challenges to health system
    - Appeals, media, legal
  - Weakening resolve of health system
  - Return to more implicit rationing
    - Rationing by waiting rather than rationing by explicit denial?
Empirical evidence for, & implications of, denial disutility
Empirical evidence – Findings (1)

- Study 1 – main focus on citizen-agent relationship in health care provision
- Reluctance to deny care

*It is just so hard to say ‘no’ to somebody … you would feel awful if you knew that you were turning that one person down.* (Female citizen informant, aged 29)

*It’s very painful … if you look at any individual case it’s always absolutely heart tugging and you would say “well this can’t be allowed to happen” …* (Male service informant, aged 70)
Findings (2)

- Role of Commissioners of health care to have a societal perspective…

- … But constraints on what they decide from Government (above) and clinicians below
  - Governments don’t want to be seen to be denying care
  - Clinicians present issues as ‘life and death’ to influence decisions

*It tends to be presented as this is life or death, the classic sort of shroud waving. And unfortunately we do give in to them. We allow that to influence our decisions, perhaps more than we ought to.*

(Male, aged 39)

- Once decisions are made, denial disutility influences implementation
Findings (3)

- Continuous dilution of societal decisions as decisions become closer to patient care:
  - You find money. You transfer money in as legal a way as possible, so that the budget for [speciality] for instance, would tend to run short because we were having to use so much of it for patients [with life saving illness]... All hospitals do it... Especially if you’ve got an acute service where people are dying.  
    (Male, aged 70)
  
  - A nurse or a doctor is there to care for an individual and do everything that is necessary.  
    (Female, aged 35)
Findings (4)

☐ This dilution happens with the collusion of the societal decision makers:

The health authority's but one grouping in a whole constellation of them. We don't make the real decisions about where the money gets spent. The individuals it gets spent on. That's a matter for the trust.

(Male, aged 39)

We don't say to the [clinicians] you may not prescribe [treatment], what we've said is we are not able to provide additional funds for the [clinical] service in recognition of the increased costs that would arise if you did prescribe [treatment]… But if you can do it within your budget, that is your business not ours.

(Male, aged 62)
System of equivocation

Constraints

“Health Authority” as agent for the citizen

Trust Board

Trust Management

Hospital Doctors

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Strategies for dealing with denial disutility

... if you say there is a local policy, that somebody in your situation will not get a wheelchair, and I can say, “Yes, this is a policy that has been evolved by local GPs and I have been involved in making that policy, but it is not me, it is decided as the best way of spreading the resource amongst everybody, and everybody in your situation who goes to see a GP will get the same message.” So if I can say that, then that is what I am comfortable with.

(GP)
Strategies for dealing with denial disutility

...there's a 22 year old who tried to commit suicide because he was so obese, and he was getting teased and can't get a job... And I had to say “well I'm really sorry but I can't offer you this operation,” and I just come out from the end of the clinic feeling... in tears almost... And then you can have three or four people like that in a clinic if you let them come. I'm just having to write back now without seeing them in clinic because I just can't bear to have to make that decision... It's desperate." (Consultant surgeon)

(Amanda Owen-Smith)
Implications of denial disutility

- Impact of decisions taken on a societal basis may ultimately be small.

- System of equivocation with collusion to minimise distress arising from the responsibility for denying care.

- Impact of making care explicit is potentially to increase denial disutility, but this may again be minimised through responses of health professionals.
Discussion
Conclusions

- Clear potential for both deprivation and denial disutility in resource limited systems

- Qualitative evidence suggests that (avoidance of) these forms of disutility is an important motivation for both patients’ and doctors’ actions

- Both forms of disutility may impact on the process of rationing
Implications

- Return to implicit rationing?
  - May be politically unacceptable – at least in rhetoric
  - Practically difficult given availability of information

- Be aware of these motivations, and account for them as systems develop to avoid unintended effects
  - Develop methods for minimising disutility
    - E.g. Panel decisions to minimise denial disutility
    - E.g. National rather than local priority setting to minimise deprivation disutility
  - Deal explicitly with the disutility?
    - Training & support for doctors?