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Public views on health care rationing: a group discussion study

Richard Cookson [a,*], Paul Dolan [b]

[a] *LSE Health, London School of Economics, Houghton Street, London WC2A 2AE, UK*
[b] *School of Health and Related Research and Department of Economics, University of Sheffield, Sheffield, UK*

Abstract

This small-scale study develops a new methodology for investigating which ethical principles of health care rationing the public support after discussion and deliberation. In ten groups of about six people, members of the public are asked to discuss a hypothetical rationing choice, concerning four identified patients who are described in general terms but without detailed information. It is explained to respondents that the purpose of the exercise is to find out what general ethical principles they support. Discussions are chaired by an academic specialising in health policy, whose role is to encourage debate but not actively to participate. On the basis of an innovative qualitative data analysis, which translates what people say into ethical principles identified in the theoretical literature, the public appear to support three main rationing principles: (1) a broad 'rule of rescue' that gives priority to those in immediate need, (2) health maximisation and (3) equalisation of lifetime health. To our knowledge, this pluralistic viewpoint on rationing has never been developed into a coherent theoretical position, nor into a quantifiable model that health care managers can use for guidance.

Keywords: Citizen's jury; Equity; Focus group; Medical ethics; Public opinion; Rationing

1. Introduction

What ethical principles should govern decisions about the distribution or 'rationing' of limited health care resources [1]? Academics and health care profession-

* Corresponding author. Tel.: +44-171-955-6376; fax: +44-171-955-6803.
E-mail address: r.cookson@lse.ac.uk (R. Cookson)

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als have proposed a number of different and potentially conflicting principles, including distribution according to need [2], distribution so as to maximise the health of the community [3] and distribution so as to reduce health inequalities [4]. However, there is now an increasing interest in finding out which of these principles are supported by the general public, on whose behalf rationing decisions are being made [5].

Much of the existing evidence comes from questionnaire surveys and opinion polls [6]. This conventional way of consulting the public has its limitations, however, since respondents are not given time to consider their answers in any depth, and may be unduly influenced by the way that questions are framed. The study reported in this paper takes a more 'deliberative' approach to consulting the public, which gives respondents an opportunity to discuss the issues and to develop their views during the process of consultation.

The study was based on small group discussions about a hypothetical rationing exercise designed to raise a wide range of ethical issues. Respondents had to choose which of four identified patients should be treated, assuming there is only enough money to treat one of them. In order to focus discussion on general principles, rather than particular details of the case, respondents were deliberately not presented with detailed information about the four patients and their suggested treatments. The aim was to elicit generalisable principles that can be applied to a wide range of decisions.

In this respect, this study departs from the 'citizen's jury' approach described by Lengahan [7], which typically presents respondents with detailed information about the particular case being discussed, including the opportunity to cross-examine expert witnesses. The study also departs somewhat from the usual 'focus group' approach used by market researchers and sociologists [8], since (1) discussion leaders took a more pro-active role to encourage debate about general rationing principles and (2) in the qualitative analysis, respondents' views were translated into general principles identified from a review of the theoretical literature.

2. Methodology

2.1. The sample

In this study, 60 members of the general public from the York area of England took part in two separate group discussions, involving questionnaires and discussions about a wide range of issues of fairness in health care. The aim was to recruit ten groups of six people who would meet for about 2 h on two separate occasions with a fortnight between each meeting. Letters of invitation were sent out to 1000 people who were randomly chosen from two general practitioners' lists in York. They were given a list of times and venues and asked to indicate which pair(s) of dates they were willing to attend. Each respondent was told that they would be paid £30 (at the end of the second meeting) for attending. Potential respondents were asked to indicate their gender and which of three age groups they belonged to (18–34, 35–55, or 55–70 years).

There were 207 (21%) positive replies from which 72 people were invited to participate (eight groups of seven and two groups of eight). Twelve people from each gender–age category were chosen and it was possible to invite at least one person from each category to attend each group. Of the 72 people invited to the meetings after indicating willingness to take part, 60 (83%) attended. Table 1 gives a breakdown of the characteristics of respondents and shows that, on average, the sample was better educated and had higher incomes than would have been expected if the sample were truly representative of the general population.

2.2. The discussion groups

Each discussion group was moderated by one of the authors of this paper, both academics specialising in health policy, with the other one in attendance. In the first meeting, respondents were initially asked to discuss the question, 'How would you set priorities in health care?'. They were then asked to fill in a questionnaire about which factors should be taken into account in priority-setting, and to discuss their responses once they had finished. For the remainder of the first meeting, respondents were asked to arrive at group decisions, following discussion, on a series of hypothetical questions about how to set priorities between groups of patients on the basis of differing quality and/or length of life. The results of the questionnaires and discussions in the first meetings are published elsewhere [9,10].

The health care rationing exercise which is relevant to this paper, and reproduced in Appendix A, was administered during the first part of the second meeting. On an individual basis, each respondent was asked to rank the four individual patients in order of priority, allowing ties. Then, on a group basis, respondents discussed the questions and gave reasons for their responses. Following the rationing exercise,

Table 1
Respondent characteristics ($n = 60$)

Characteristic	Category	n
Gender	Male	32
	Female	28
Age	18–34	16
	35–54	21
	55–70	23
Annual household income	<£15,000	25
	>£15,000	35
Smoking status	Smoker	15
	Non-smoker	45
School-leaving age	Minimum	26
	Stayed on	34
Private health insurance	Insured	10
	Uninsured	50
Visits to doctor in last year	Two or less	29
	More than two	31

respondents were asked some further questions about choices between groups of patients, and finally to give repeat answers to three of the questions they were faced with in the first meeting.

This particular rationing exercise was selected as a life-like example which would (1) encourage lively debate about a range of health care rationing issues, (2) focus discussion on general principles rather than particular details of the case, and (3) not be overly biased by recent selective media coverage of particular cases. It was felt that a concrete and highly visual 'micro-level' choice between individual patients might engage respondents and encourage lively debate better than a more abstract 'macro-level' choice between groups of patients. It may be that the public support different principles at these two different decision-making levels, which is an interesting question that needs to be addressed by future research.

Respondents were told that the exercise departs from any real situation facing health service managers and doctors in at least three important respects: (1) the stated budget of £4000 is assumed to be rigidly fixed, (2) information is presented in a dramatic way using actors photographs to represent the patients, and (3) relatively little information is presented about the four patients.

It was carefully explained to respondents that the purpose of the exercise was to find out what general ethical principles they support. Given the purpose of the study, it was felt that a presentation of detailed information might lead discussions too far away from general ethical principles and towards particular details of this case. Furthermore, it was felt that a minimalist presentation of information would encourage respondents to consider what extra information they would require to make a decision, thus encouraging deliberation about what aspects of the situation are most important to them.

Another important aspect of the methodology was that the discussion moderator adopted a pro-active role in encouraging discussion and debate about general ethical principles, although without taking sides in the debate. Moderators were careful not to put across any particular point of view, or to raise ethical points not previously made by group members. However, they did encourage deliberation and discussion by chairing the discussion and, where appropriate, by questioning respondents to further articulate or clarify their views. This more proactive role was felt appropriate given that the purpose of this study was to elicit considered public opinions, rather than existing public opinions.

2.3. The qualitative analysis

An innovative method of qualitative analysis was developed for the purpose of this study, with the aim of translating what people said into the principles of rationing that have been proposed in the theoretical literature. We took the whole sample as our unit of analysis, rather than each individual respondent. Our general approach was to code word groups within the text using a classification scheme built up through an iterative process, and then to count the number of times each idea was mentioned.

The iterative process of building up the classification scheme started with a preliminary framework developed by the two authors of this paper who were present at all group meetings. This framework classified ideas into five main categories corresponding to the five main rationing principles identified in the literature (described below). Respondents' reasons for decisions were then further subcategorised according to various aspects or variants of each main principle. As the analysis proceeded, these subcategories were modified to incorporate new ideas. Thus the final classification scheme, while firmly based on principles identified in the theoretical literature, was also sensitive to particular concepts and distinctions raised by respondents. One of the researchers coded all the transcripts, the other then checked all the codings, and any disagreements were resolved through discussion.

Respondents' reasons were coded into 'principles' and 'factors'. Principles are general rules for distributing health care (such as giving priority to those in most urgent need), whereas factors are specific aspects of the decision (such as the age of a patient), which are not further articulated into a general rule by the respondent. To give an indication of whether or not particular principles and factors had widespread support, we counted how many times they were mentioned. As well as the total number of mentions by individuals across all ten groups, we also present the number of groups (out of ten) in which the reason was mentioned. This is because the total number of mentions presented on its own may be a somewhat misleading indicator of popularity, since one individual may repeat the same idea several times.

For the purpose of counting, a conservative view was taken about what does and does not count as a 'mention' of a reason. For example, a word group was never given more than one coding; if the same person repeated the same idea this only counted as a second mention if someone else had interjected in the mean time; and mentioning both general and specific versions of the same idea counted as a single mention of the specific idea. A check was made for whether mentions were 'positive' or 'negative'; as we shall see, however, 'negative' mentions only occurred in relation to the principle of giving lower priority to those with self-inflicted illnesses.

2.4. The five rationing principles

The five main classes of rationing principle we identified in the theoretical literature were: (1) lottery principles or 'not playing God' [11], (2) distribution according to immediate need or 'rule of rescue' [12], (3) health maximisation [3], (4) equalising lifetime health or 'fair innings' [4] and (5) equalising opportunity for health or 'choicism' [13]. This list was based on a review of the literature on equity in health care from economics, political philosophy and medical ethics, which is published elsewhere [14]. This review involved consultation with a wide range of experts. Unfortunately, however, attempts at performing a systematic electronic literature search on key equity and health care terms did not prove fruitful, because general social science and humanities databases are not designed for specialist searches of this kind.

Table 2
Rankings of the four patients given by members of the public (sample size 60)

	Rank 1	Rank 2	Rank 3	Rank 4	Mean rank
Daniel	48	8	1	3	1.3
Marinder	23	19	13	5	2.0
Steve	15	13	25	7	2.4
Joanne	7	5	17	31	3.2

A brief description of each class of principle is given below. Lottery principles refer to the idea that explicit rationing is unethical and that no-one should be put into the invidious position of choosing who will live and who will die. Instead, according to this principle, scarce health care resources should be allocated using a lottery mechanism of some kind, such as first-come first-served. Distribution according to immediate need, or 'rule of rescue', refers to the idea that explicit priority should be given to those in greatest need of health care. However, the principle of distribution according to 'need' can give very different recommendations depending on what one means by 'need' [15]. As we shall see, the public's interpretation of 'need' focused on immediate threat to life and/or immediate pain and immobility, and this is the interpretation we shall adopt from now on.

Health maximisation refers to the idea that health care should be distributed so as to increase the aggregate health of the whole community. Equalising lifetime health, or the 'fair innings' argument, refers to the idea that everyone is entitled to a similarly decent lifetime experience of health, and hence that health care should be distributed so as to reduce health inequalities. Finally, equalising opportunity for health, or 'choicism', refers to the idea that people should be free to choose their own level of health through their lifestyle choices, and that the state should give priority to those who suffer ill-health through no fault of their own.

3. Results

Table 2 shows the rankings that respondents gave to the four patients. Five of the 60 respondents (8%) argued that it is unethical to make explicit rationing choices and hence gave all four patients the same priority. However, the vast majority (92%) were prepared to give priority to at least one of the patients. Daniel was the top or joint-top priority for 80% of respondents, followed by Marinder and then Steve, with Joanne receiving lowest priority on average. Although Daniel emerged as the clear top priority for the group of respondents as a whole, it is worth noting that there was considerable variation in the rankings given by individual respondents. Only seven respondents gave precisely the 'average' ranking of Daniel, then Marinder, then Steve, then Joanne.

Turning to the qualitative analysis of the reasons for these decisions, the final classification scheme for principles and factors mentioned by respondents is shown

in Tables 3 and 4, respectively. A wide range of principles and factors were mentioned, covering all the major ethical principles proposed in the literature, although lottery principles and choicism principles received much less widespread support than the other principles. It seems that the most common justifications for the decisions were that: (1) Daniel, Marinder and Steve gain more health from treatment than Joanne; (2) Daniel is a child; (3) Daniel is in urgent need of life-saving treatment; (4) Marinder's hip replacement would save money on nursing care, and (5) Joanne's illness is self-inflicted. There was near universal agreement

Table 3
Principles[a] mentioned by members of the public

Principles	Total number of mentions across all ten discussion groups	Number of groups that mentioned this principle
1. Lottery or 'not playing God'		
a. A life is a life and everyone is equal	4	4
b. Priority to patients waiting a long time	3	3
2. Health maximisation		
a. Priority for larger gains in length of life	17	5
b. Priority for larger gains in quality of life	1	1
c. Priority for larger health gains in general	7	4
3. 'Rule of rescue'		
a. Priority for life-threatening conditions	24	7
b. Priority for patients with more urgent needs	5	5
4. Equality of lifetime health or 'fair innings'		
a. Priority to patients with lower lifetime health	2	2
b. Priority to patients with disability in general	1	1
c. Priority to the young in general	10	5
d. Priority to children in particular	6	4
5. Equality of opportunity for health or 'choicism'		
a. Same priority for self-inflicted illnesses	8	6
b. Lower priority for self-inflicted illnesses	35	9

[a] Principles are general rules for rationing health care.

Table 4
Factors mentioned by members of the public[a]

Factors	Total number of mentions across all ten discussion groups	Number of groups that mentioned this factor
1. Factors associated with health maximisation		
1.1. Internal health gains to this patient		
a. Length of life gains	3	3
b. Quality of life gains	22	9
c. Health in general	2	2
d. Uncertainty about health gains	12	7
e. Psychological suffering can be real	19	9
1.2. External health gains to other patients:		
a. Costs of ongoing treatment	3	3
b. Savings from less future treatment	19	7
c. Tax revenue from earnings	4	2
d. Long-term gains from research	11	4
1.3. Non-health gains		
a. People with children	2	1
b. Contribution to society	3	3
2. Factors associated with 'rule of rescue'		
a. Life-threatening conditions	11	7
b. Pain and suffering	1	1
c. Urgent needs in general	1	1
d. Cosmetic surgery	7	4
3. Factors associated with 'fair innings'		
a. Children	18	8
b. The elderly	1	1
c. Age in general	8	4
d. Young people in general	8	3
e. Special status given to a full life	4	2
4. Factors associated with 'choicism'		
a. People who smoke	4	1
b. People who use illegal drugs	7	3
c. People who drink heavily	4	1

[a] Factors are aspects of the situation not articulated by the respondent into a general rule.

that the first four of these considerations should be taken into account, but there was considerable debate and disagreement about the fifth. It was clear that no single consideration had over-riding weight, but rather that respondents weighed these sometimes conflicting considerations against one another.

In terms of our general principles for rationing, the public seem to adopt a pluralistic position which combines three of the main five rationing principles identified in the literature. Public concern for saving Daniel's life suggests that the public support the principle that priority should be given to those facing an immediate to life or health [16]. Public concerns for Mirander and Steve's pain and suffering suggests the public support a broad version of the 'rule of rescue' principle, which gives priority to those in immediate pain and suffering as well as to those facing an immediate threat to life.

Support for the principle of health maximisation is shown by various concerns for long-run savings to the National Health Service (NHS); for instance, from Mirander's hip replacement, meaning that she would no longer require costly nursing care. The money saved could thereby be used to fund extra health care and hence ultimately to increase population health. Support for reducing lifetime inequalities in health is demonstrated by public concern to give priority to the two younger patients, and especially to Daniel. However, the lottery principle did not gain much support at all. And although 'choicism' was broadly acceptable to a small majority of respondents, the significant minority of respondents who did not accept it were strongly opposed to discriminating against self-inflicted conditions.

So, if we were to translate the public's view into a philosophical position, we might say that it is a pluralistic position which gives some weight to three principles: (1) a broad 'rule of rescue' principle (requiring rescue of those in immediate pain and suffering as well as those facing an immediate threat to life), (2) health maximisation and (3) reducing inequalities in people's lifetime experience of health. It is remarkable that, although all of these principles have been discussed in the literature in isolation, to our knowledge this combination of principles which seems to be favoured by the public has never been developed into a coherent philosophical position nor into a quantifiable model that can give guidance to health care managers.

4. Discussion

On the basis of the study of considered public opinion reported in this paper, it would seem that the public accept three main principles of justice: (1) a broad 'rule of rescue', (2) maximising the health of the whole community and (3) reducing inequalities in people's lifetime experience of health. The public do not appear to accept the view that improving population health is the primary goal of the health care system [3]. Nor does the public appear to accept the official view of the medical profession, which is that distribution according to 'clinical need' is the only relevant principle of justice.

Of course, the methodology used in this study is at an early developmental stage, and the sample size was small, so results should be approached with caution. More confidence in the generalisability of the results could be obtained by replicating the study using different samples of people and using different hypothetical rationing exercises. In particular, it would be important to test the hypothesis, suggested to us at seminars, that the public would be less supportive of the rule of rescue principle at a 'macro-level' of choice between health care programmes as opposed to a 'micro-level' of choice between individual patients. It would also be important to compare the results of this small group discussion approach with those of other opinion polling techniques, and in particular the 'citizen's jury' approach of using real-life decisions and presenting respondents with more detailed information.

An inevitable drawback of all 'deliberative' methods of obtaining public opinion, as compared to ordinary questionnaire methods, is the high cost per respondent. Deliberative methods are more demanding of both respondent and researcher; and the process of transcribing and analysing qualitative data is more labour-intensive than the corresponding process for quantitative data. A second general drawback is that a group discussion is a more complex and dynamic stimulus to respondents than a questionnaire, which makes replication more difficult and potential bias less easy to assess. However, it is our contention that these drawbacks are a price worth paying in order to better understand the reasons that lie behind people's quantitative responses to questionnaires, and to obtain more 'considered' opinions about difficult and unfamiliar issues.

A particular drawback of the methodology used in this study is that it only investigates what the public said as a whole, and gives little indication of either (1) what proportions of respondents accept each principle or (2) the strength of preference. Future research needs to address both of these problems, perhaps by combining individual interviews with group discussions. Finally, the methodology could be further developed by giving respondents even more intensive opportunities for deliberation, for example using more in-depth questioning of respondents and feeding back to respondents the policy implications of their views and the results of past discussion groups.

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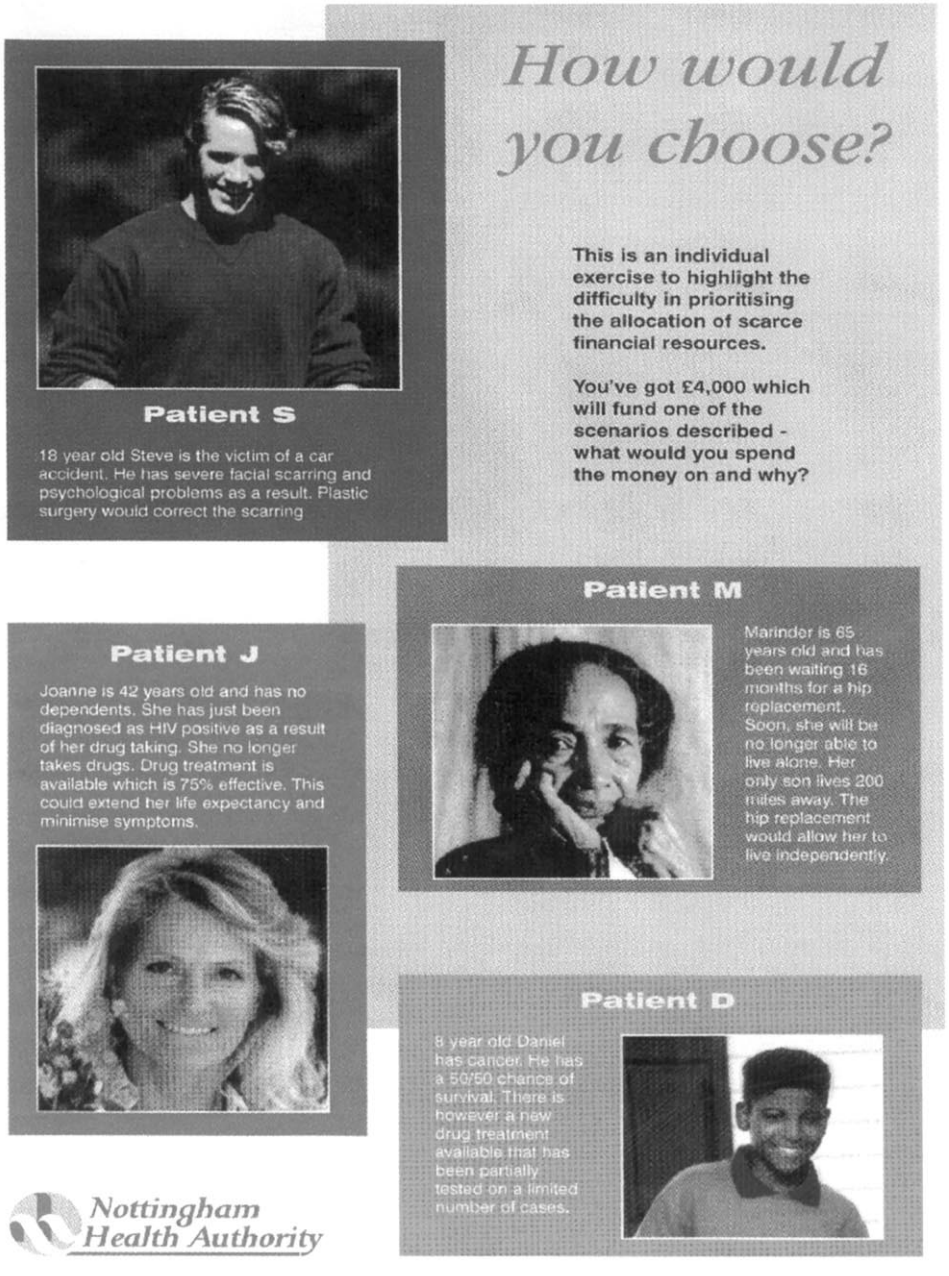
Appendix A. The rationing exercise



(Please see overleaf).

Text of the rationing exercise

Unfortunately the text of the rationing exercise is hard to read from the illustration reproduced above, so this text is printed below:

How would you choose? This is an individual exercise to highlight the difficulty of prioritising the allocation of scarce resources. You've got £4000 which will fund one of the scenarios described — which would you spend the money on and why?

Patient S "18-year-old Steve is the victim of a car accident. He has severe facial scarring and psychological problems as a result. Plastic surgey would correct the scarring."

Patient M "Marinder is 65 years old and has been waiting 16 months for a hip replacement. Soon, she will no longer be able to live alone. Her son lives 200 miles away. The hip replacement would allow her to live independently."

Patient J "Joanne is 42-years-old and has no dependants. She has just been dignosed HIV positive as a result of her drug taking. She no longer takes drugs. Drug treatment is available which is 75% effective. This could extend her life expectancy and minimise symptoms."

Patient D "8-year-old Daniel has cancer. He has a 50/50 chance of survival. There is however a new drug treatment available that has been partially tested on a limited number of cases."

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