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# Preferences for disclosure: the case of bedside rationing David L.B. Schwappach\*, Christian M. Koeck

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### Abstract

While rationing is present in many health care systems, little empirical research has been undertaken to investigate the public's preferences and information needs towards the rationing of their care. This paper reports the results of an interactive survey administered via an internet survey panel to investigate preferences for the provision of information about explicit rationing decisions. We presented a series of vignettes to respondents, describing hypothetical patients and explicit rationing decisions. In two different survey versions, patients were either characterized as matching or mismatching respondents' age and gender.

We observed strong preferences for the disclosure of rationing information to patients. Seventy one percent of responders expressed a general attitude in favor of explicitly informing patients about the rationing of their care. In the presented scenarios, the fraction supporting disclosure to patients ranged from 63% to 89%. The clinical situation described in the vignettes, a positive, general attitude towards the disclosure of rationing decisions, age, and gender of respondents were main predictors for participants' votes. Preferences were relatively unaffected and insensitive to the matching of hypothetical patients and respondents' characteristics. This study suggests that if doctors are to play an active role in health care rationing, patients expect them to honestly discuss the decisions made, the economics behind these and finally, to deal with those patients that do not accept the final decision.

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#### Introduction

Rationing, the withholding of beneficial medical care due to economic constraints, is present in Germany as it is in many other health care systems, either implicit or explicit, at the bedside or by administrative mechanisms (Brockmann, 2002; Nadolski, 2002). During the last decades, there has been a broad debate on the role of the medical profession in rationing care and communicating and revealing rationing decisions to individual patients. Opponents of explicit rationing argue that withholding of care *expressis verbis* counteracts trust in the doctorpatient relationship, and causes 'disutility of ignorance' in doctors and 'disutility of deprivation' in patients

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(Askin, 2002; Coast, 1997). Contrary, rationing decisions that are not disclosed, or are concealed behind clinical reasoning may impose an even greater burden for any trustful relationship. Patients are left to question the reasons underlying the care they receive and whether it is affected by economic considerations. If a deception is revealed, patients' 'sense of betrayal will probably far outweight any distress from being told the truth' (Doyal, 1997). Also, some authors have argued that the limitation of appropriate, effective care has to be disclosed to enable patients to seek evading strategies, such as appeals against the health insurance or out-ofpocket payments (Lee & Miller, 1990; Levinsky, 1998; Menzel, 1990). Unfortunately, little empirical research has been undertaken to investigate the public's preferences and information needs towards rationing. Using in-depth interviews, Coast explored the views of citizens about whether they want to know about the rationing of

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their own care (Coast, 2001). Citizens revealed overwhelming preferences for being informed about rationing decisions. These findings are supported by Edwards et al., who surveyed members of the general public about their preferences for the explicit prioritization of elective waiting lists (Edwards, Boland, Wilkinson, Cohen, & Williams, 2003). 80% of survey respondents stated, 'they would like to know how their waiting time was determined relative to other patients on the waiting list'. In conclusion, the available data suggest that citizens want to be informed about the rationing of their own care. But preferences for disclosure may not be as uniformly strong as reported in survey or interview studies.

We consider factors of two dimensions that may influence these preferences. First, they may be affected by the type of care being rationed or the severity of the underlying condition. As Coast reports, one of the main reasons for citizens' views and anticipated reactions to being informed about rationing was to be enabled to evaluate the adequacy of the decision and potentially change it either by payments or protest. Consequently, preferences for explicitness may be particularly strong if patients perceive the chance of a successful evading strategy as high, or if the care rationed is regarded essential. We therefore hypothesize that preferences for disclosure would be strongest for the rationing of chronic condition care. Here, the loss encountered by the withholding of care, and the incentive for revising the rationing decision, are permanently present and the 'technical' circumstances for the evaluation of the decision by patients are better compared to single treatment situations. Second, we assume that attitudes towards the communication of rationing decisions may in part be an artefact that origins from the hypothetical nature of the question, i.e., from surveyed individuals' imagination of rationing situations, their anticipated reactions and uncertainty regarding the disutility associated with being informed about the withholding of care. We argue that general attitudes towards disclosure are vulnerable to social desirability bias towards an active, autonomous, and self-confident patient and may not adequately reflect true values. Attitudes may be rendered if survey participants are stimulated to identify with and put themselves in the position of the rationing 'victim'. We conducted a survey to further investigate preferences for the provision of information about explicit rationing decisions. We presented a series of vignettes, describing hypothetical patients and explicit rationing decisions that may be communicated to patients. Our main interest was to assess whether preferences for disclosure depend on the type of care being rationed and whether they are affected by the identification of respondents with patients presented in the vignettes. We hypothesized a priori, that support for informing patients about rationing would be stronger for chronic conditions and would differ if participants identify themselves with the hypothetical patient subject to the decision.

#### Method

Survey instrument

The survey was administered through the internet as part of a larger questionnaire study about citizens' experiences with the health care system and current debates on health policy in Germany. The part of survey we report about included seven questions:

- whether participants had experienced the rationing of their own care;
- whether such experiences had been reported to them by relatives or friends:
- where they had experienced rationing, how the rationing decision was communicated to them, and
- their general attitude about whether physicians should inform patients about rationing decisions.

Throughout the questionnaire, "rationing" was defined as 'the withholding of beneficial, reasonable medical care due to economic reasons'. Three vignettes describing situations in which physicians have to decide whether to communicate rationing decisions to their patients (Appendix) followed the four questions mentioned above. The vignettes presented rationing decisions affecting a patient in a nonrecurring treatment situation (A), a patient with a chronic condition (B), and a patient suffering terminal illness (C). After each vignette, responders were asked to indicate whether they thought the physician should inform the patient about rationing.

# Interactivity of the survey instrument

We aimed to assess the influence of participants' identification with patients presented in the vignettes on their attitudes about communicating rationing. Besides respondents' experiences with rationing, we expected hypothetical patients' age and gender to be important identification triggers. Therefore, we included interactive, invisible elements in the survey that would invite respondents to put themselves in the position of the hypothetical patient by matching—or mismatching—the age and gender between hypothetical patient and respondent on an individual level. Participants were randomized to either of two questionnaire versions: While in version 1 ('match'), age and gender of the patients matched those of the respondent, in version 2 ('mismatch') these variables were set so as to reflect large differences to participants. For the gender variable, matching and mismatching patient and respondent characteristic is obvious.

For the 'matching' age variable, we aimed to prepare three values as close as possible to participants' true age while not matching this age exactly more than once to avoid the task being too obvious. There were also technological constraints in the way the age values were determined. For example, the generation of the age value and its assignment to the vignettes should not be affected by participants' hard- and software settings or their response behavior, e.g., in case respondents jumped back and forth in the survey, or suspended and later returned. Therefore, respondents were first virtually grouped in predefined age groups, each covering 5 years. For each age group, three variables were generated (each to be used in one vignette) taking the inner three age values in steps of two. For the age group 35–41 years, as an example, the variables take the values 36, 38, 40. In survey version 1, the value of patients' age was determined by allocating the respondent to the matching virtual age group and transferring the prepared variable values as patients' ages in the three vignettes. Thus, age of presented patients differ with a maximum of  $\pm 5$  years from respondent's age. In version 2, respondents were 'falsely' allocated to the virtual age group 4 groups above or below their true age. Younger respondents (≤48 years) were allocated to higher age groups (beginning with the group 42-48 years), and older participants (≥49 years) to lower age groups (beginning with the group ≤20 years), respectively. For example, a female participant aged 42 would receive vignettes involving female patients aged 43, 45, and 47 years if she had been randomized to version 1 and male patients aged 71, 75, and 83 years in version 2, respectively. After participants were allocated to either version, the ordering of vignettes was randomly rotated to avoid ordering effects.

# Survey administration

The survey was administered through the 'GesundheitsPanel' (available at www.gesundheitspanel.de), an internet survey panel which was initiated in 2003. Details about the panel are described elsewhere (Schwappach & Koeck, 2003). The GesundheitsPanel provides an environment under which surveys can be processed, fielded, and administered to samples of members. To become a panelist, interested citizens participate in a master survey to collect demographic and health-related data. Members agree to be regularly surveyed and consent to membership and data protection rules. Samples of panelists are drawn, invited by email to participate, and specific survey projects are then administered to these subjects on personalized, protected internet pages. Finally, responses are linked to the master data available for each respondent.

#### Sample

Since we had no reasonable estimate of preferences, we decided to estimate a sample size valid to detect differences in the votings of respondents in groups 1 and 2 for a single vignette. We assumed the proportions voting in favor of disclosing rationing in the vignettes would be 0.8 in group 1 and 0.65 in group 2, respectively. We calculated a sample size of 198 subjects for each survey version (power=0.9, type I error probability=0.05), conservatively expected a response rate of 70-75% and thus invited 550 panelists, selected by simple random sampling.

# Data analysis

We performed a logistic regression analysis with responses to vignettes as dependent variable. The unit of analysis is the judgment provided to vignettes, and not the individual respondent. Because each participant responded to three vignettes, responses provided by each individual cannot be regarded as independent. All regression models were therefore specified with Huber-White sandwich variance estimators for clustered data with survey responders as unit of clustering. The robust cluster variance estimator is robust to misspecification and within-cluster correlation (Williams, 2000). Survey version, vignette (dummies for vignette A, B, or C), participants' personal characteristics, their attitudes and reported experiences with rationing were included as explanatory variables. A p-value of 0.05 was considered significant. Confidence intervals are reported at the 95% level. Data were analyzed using the statistical package STATA (StataCorp. 2003).

# Results

Of the 550 persons invited, 518 participated (response rate 94%) and 517 (94%) completed the questionnaire. Fifty percent of participants were female, and responders' age ranged from 18-76 years (mean: 42 years). Including primary school, 6% of responders had less than 10 years of education, 31% had 10-15 years, 55% had 16-21 years and 8% had more than 21 years of education. Self-perceived health was rated 'very good' by 20%, 'good' by 43%, 'fair' by 24%, 'bad' by 10% and 'very bad' by 3% of responders. Two hundred and nine participants (40%) responded that they had experienced the rationing of their own care and 338 (65%) answered that such experiences had been reported by relatives or friends. A vast majority (71%) stated that physicians should explicitly disclose rationing decisions. Hundred and twenty nine participants (25%) responded that this should depend on the situation and the persons involved and 1.7% did not want the physician to inform patients. Participants that had experienced rationing themselves previously were more likely to respond that physicians should reveal rationing decisions (OR 1.8, CI 1.2–2.8, p = 0.004). Also, responders to whom a rationing decision had been explicitly communicated (45% of those that experienced rationing) were more likely to share a general attitude in favor of disclosure of rationing decisions compared to respondents that intuitively understood their care had been rationed (37%) or had to ask for this information (16%) (OR 2.5. CI 1.2–5.6, p = 0.01). Responses to the three vignettes are presented in Table 1. Calculated over both survey versions, there were considerable differences in the votes between the three vignettes. Fifty two percent of participants voted in favor of, and 5% against informing patients in all three vignettes. Forty one percent discriminated according to the situation presented and 2% refused to opt for either alternative in all three choices.

Results of the logistic regression analysis (Table 2) show that judgments can be explained by responders' general attitude towards disclosure of rationing, the type of vignette under consideration, age, and gender of respondents. Notably, having been reported rationing by relatives increases the likelihood of opting for disclosure, while own experiences with rationing has no effect. No other personal characteristics (income, education, marital status, employment, occupation, perceived health, health insurance, characteristics of internet utilization) were significant predictors. There were no systematic differences in votes between survey versions. Only for vignette A, the fraction of responders

Table 1 Responses to three vignettes by survey version. Numbers are values (%) of responses

Should the physician inform the patient on the rationing decision?

Response (survey version) <sup>a</sup>	Vignette		
	$A^b$	B <sup>b</sup>	Cb
Yes (total)	400 (77)	458 (89)	325 (63)
Survey ver.1 ('match')	210 (82) <sup>c</sup>	226 (88)	160 (62)
Survey ver.2 ('mismatch')	190 (73)	232 (89)	165 (63)
No (total)	78 (15)	35 (7)	128 (25)
Survey ver.1 ('match')	29 (11)	17 (7)	62 (24)
Survey ver.2 ('mismatch')	49 (19)	18 (7)	66 (25)
Don't know (total)	39 (8)	24 (5)	64 (12)
Survey ver.1 ('match')	18 (7)	14 (5)	35 (14)
Survey ver.2 ('mismatch')	21 (8)	10 (4)	29 (11)

 $<sup>^{</sup>a}$  n1 = 257; n2 = 260

that voted in favor of communicating rationing decisions to patients was significantly higher in the survey version that matched respondents' age and gender (Table 1: 82% vs. 73%, p = 0.0095). This effect of survey version in vignette A can be mainly attributed to males that were much more likely to opt for informing patients in the 'matching' (88.4%) vs. the 'mismatching' version (76%).

#### Discussion

To the authors' knowledge, this is the first quantitative study that investigated citizens' preferences towards the communication of explicit rationing decisions. Consistent with the available qualitative research, our results indicate that there is a strong preference towards disclosing the rationing of care to patients. This preference became apparent in the general attitude question and in three vignettes. While gender- and agespecific differences in views on disclosing rationing existed, contrary to our expectations participants were relatively unaffected and insensitive to identification with the patient subject to the rationing of care. We had expected that preferences for disclosure would be vulnerable if they concern the care of others and vary depending on the perspective respondents adopt to. We assumed that participants would either make 'easy choices' for others without considering the positive and negative consequences for affected patients or would lure themselves into paternalistic choices that would protect others from being told the truth. We did not observe such differences though, which, under the assumption, that our approach effectively triggered identification, indicates the strength and fundamental nature of these preferences.

As expected, the description of the type of care being rationed had a significant effect on judgments with the vignette that illustrated a chronic condition (C) obtaining the highest support for disclosure. Here, the strong motivation to be enabled to change rationing decisions either by payments or by protest (Coast, 2001) appears to be most feasible and worthwhile. This in turn supports the hypothesis that the major rationale for requesting disclosure of the decision may indeed be to seek evading strategies. This is of particular importance for health care systems in which individual providers decide on the rationing of individual patient care by implicit, subjective mechanisms. Patients to whom such decisions have been disclosed may actively fight rationing or simply try to obtain the limited ressources from other providers. As a consequence, honest professionals that communicate these decisions with best intentions would be at disadvantage. Though a considerable number of opt-outs was observed, indicating a higher degree of uncertainty, and the fraction was significantly

 $<sup>^{\</sup>rm b}$ Differences in votes between all vignettes significant (p<0.0001).

<sup>&</sup>lt;sup>c</sup> Difference between survey versions significant (p = 0.0095).

Table 2
Factors associated with preferences towards disclosure of rationing decisions. Results of robust multiple logistic regression analysis

Variable	Odds ratio	95% CI	p
Survey version ('match'/'mismatch')	0.95	0.70-1.27	0.720
Vignette (base category: 'A—nonrecurring treatment')			
B—chronic condition	2.45	1.79-3.35	0.000
C—terminal illness	0.45	0.35-0.60	0.000
Age (years)	1.02	1.00-1.03	0.009
Female gender	0.56	0.41 - 0.76	0.000
Having experienced rationing (no/yes)	0.87	0.63 - 1.22	0.427
Having been reported rationing by relatives or friends (no/yes)	1.47	1.05-2.06	0.025
General attitude in favor of disclosure (no/yes)	3.73	2.74-5.07	0.000

n=1551 (vignette votes) N=518 clusters (individuals) Wald  $chi^2=173$ , p<0.0001; McKelvey and Zavonia's  $R^2=0.24$ .

smaller, still, a majority preferred to inform dying patients about rationing. However, the underlying rationale may be different. Terminally ill patients have probably been perceived as having fewer options for changing rationing decisions. Rather than enabling patients to revise the decision ('value of potential action'), respondents may have preferred to inform terminally ill patients due to a 'value of truth' per sé. This seems to mirror the literature on information needs of terminally ill patients which reports that most patients prefer to be told the truth, 'even if truth hurts' (Fallowfield, Jenkins, & Beveridge, 2002; Jenkins, Fallowfield, & Saul, 2001). One has to take into account though that all rationing decisions presented had only moderate effects on the care delivered. It is unclear whether participants' views would also apply to the disclosure of rationing of care with major impact on quality of life or even life-saving treatments.

This study has some limitations and results should be interpreted cautiously. The first constraint regards the sample, which is biased towards the young and well educated and those using the internet (self-selectivity bias). However, the strength of preferences paired with the diversity of participants' backgrounds and experiences, and the equal distribution of gender, which remains a problem in online research, suggest that most important aspects and views are covered. Also, compared to stand-alone internet surveys, the problem of self-selectivity is alleviated within the panel design, since members selected themselves for panel membership, but not for participation in the particular survey (Theobald, Dreyer, & Starsetzki, 2001). A second limitation relates to the situations described in the vignettes. These were designed to be, above all, realistic and to stimulate participants' attitudes by presenting a variety of situations. However, to allow observed differences in votes to be attributed to differences in single, well-separated factors, more complex designed vignettes would be needed that differ only in one factor at a time. Third, we

used 'age' and 'gender', which are rather facile characteristics, as variables to trigger identification. Other social attributes, such as education or occupational group may have introduced larger variability in the views expressed. Finally, this study relies on selfreports and models stated preferences in hypothetical situations. There is no objective evidence that participants that reported rationing had in fact experienced rationing of their care and vice versa. For the purpose of this study, however, the subjective interpretation that one's own care has been rationed may be even more important. Though one's own experience with explicit rationing did not alter respondents' views towards a policy of disclosure or raise concerns to prevent others from making the same experience, we also cannot transfer participants' hypothetical judgments to actual information needs of patients at the time of treatment.

A number of concerns have been discussed relating to the involvement of doctors in rationing (Ubel & Goold, 1997). Qualitative studies indicate that it is not the explicit communication of rationing decisions per sé, e.g., determined through administrative processes, but rather the individualized attribution of blame that is feared by physicians (Berney et al., 2003; Coast et al., 2002). Doctors see the open communication of rationing decisions often as a threat to their relationship with the patient undermining their role as patient advocate (Berney et al., 2003). Contrary, Levinsky and others argue that it is the revealing of deception that erodes patients' trust in their doctors (Levinsky, 1998).

This study cannot provide evidence on the impact of disclosing rationing decisions 'at the bedside' on factual changes in the doctor—patient-relationship. However, the results show that citizens have a strong preference towards being informed on the rationing of their care, even if —or in particular if—they have a history of such communication with their doctors. One may then hypothesize that, in the population studied, if and only if doctors reveal rationing decisions to their patients can

these maintain their trust that treatment decisions actually have an underlying clinical, and not a hidden economic, rationale. This study indicates that if doctors are to play an active role in health care rationing, patients expect them to honestly discuss the decisions made, the economics behind these and, at the end of the day, to deal with those patients that do not accept the final decision.

# **Appendix**

Italic letters represent variable content, determined by the questionnaire version the respondent was randomized to (see methods).

Vignette A

Mr. Wenzel, an 18-year-old male, had an accident. He had been admitted to the hospital. There, Doctor Tanner undertakes complex surgery on the knee joint. The operation was successful and Mr. Wenzel has already recovered. Doctor Tanner now wants to refer Mr. Wenzel to a rehabilitation clinic to train and exercise the injured knee joint. Though there is a clinic with a very good reputation which is specialized in rehabilitative care and such injuries and operations, Doctor Tanner refers her patient Mr. Wenzel to another clinic. This institution is not specialized and Doctor Tanner has made the experience that patients are not as satisfied, and need longer until complete recovery and until they may move around painlessly. However, it is much less costly. Since Mr. Wenzel has made good progress already in hospital, Doctor Tanner regards it as appropriate to refer him to the less expensive clinic. What do you think: Should Doctor Tanner inform her patient Mr. Wenzel that she refers him to the less costly rehabilitation clinic though she expects quality of care to be better at the other institution?

Vignette B

Mr. Osterfeld is 19 years old and suffers from a chronic-inflammatory skin disease. Large parts of his skin are affected, e.g. back, forearms, and his neck. The skin is extremely reddened, is often itching, and burning and then fissures occur. Besides the application of ointments, his dermatologist, Doctor Arnold, prescribes medicated therapeutic baths to his patient. As specific equipments and qualified staff are necessary, Mr. Osterfeld is referred to a balneo clinic. Doctor Arnold prescribes bi-weekly treatment though he knows that a more frequent application would be reasonable and beneficially for Mr. Osterfeld. However, Doctor Arnold does not want to burden the budget of the statutory health insurance too much. What do you think: Should Doctor Arnold inform his patient Mr. Osterfeld that he prescribes only bi-weekly treatment due to economic reasons though a more frequent treatment would increase relief of symptoms?

Vignette C

Mr. Bergmann is a 20-year-old male and has fatal malignant cancer. Mr. Bergmann often suffers severe pain and he knows that he will die within the next days or few weeks. He receives home care by his physician, Doctor Michaels. Doctor Michaels prescribes a very effective analgesic that relieves Mr. Bergmann's pain nearly completely. However, the drug frequently causes nausea and sometimes vomiting. Doctor Michaels knows that there is a new drug that would be optimal for Mr. Bergmann's needs. This new drug is equally effective but has no side effects. It is extremely expensive and Doctor Michaels cannot prescribe it to Mr. Bergmann due to this reason. Otherwise, his budget would not suffice for other patients in similar situations. When Doctor Michaels asks for his well-being at the home visit, Mr. Bergmann complains about the side effects of the analgesic. It is a difficult situation: Do you think that Doctor Michaels should inform his patient Mr. Bergmann that he does not order the costly drug without side effects due to financial constraints?

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