Clinical fairness - Improving bedside rationing

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Abstract

Difficulties in medical ethics are traditionally discussed in relation to problems arising in clinical care between individuals: disagreements between patients and health care providers as to the best course of action, confidentiality, end-of-life choices, how to make ethically justifiable decisions for patients who are incapable of decision-making, and the like. Difficulties related to fairness, to sharing what resources we have equitably in caring for the sick, pose a special challenge. They are situations where thinking in terms of individuals tends to be less helpful. To address these issues, we need to think in terms of groups. In terms of weighing conflicting claims in a way that can be justified as fair overall, as well as to the individuals involved. This thesis explores the practice of clinical rationing, and the ethical issues associated with it, with a particular focus on fairness. We conducted studies showing that doctors ration care and realize that they do so, that they attempt to include various concerns for fairness in their allocation decisions, and use various strategies for doing so. Some of these [...]
Prevalence and Determinants of Physician Bedside Rationing
Data from Europe

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BACKGROUND: Bedside rationing by physicians is controversial. The debate, however, is clouded by lack of information regarding the extent and character of bedside rationing.

DESIGN, SETTING, AND PARTICIPANTS: We developed a survey instrument to examine the frequency, criteria, and strategies used for bedside rationing. Content validity was assessed through expert assessment and scales were tested for internal consistency. The questionnaire was translated and administered to General Internists in Norway, Switzerland, Italy, and the United Kingdom. Logistic regression was used to identify the variables associated with reported rationing.

RESULTS: Survey respondents (N=656, response rate 43%) ranged in age from 28 to 82, and averaged 25 years in practice. Most respondents (82.3%) showed some degree of agreement with rationing, and 56.3% reported that they did ration interventions. The most frequently mentioned criteria for rationing were a small expected benefit (82.3%), low chances of success (79.8%), an intervention intended to prolong life when quality of life is low (70.6%), and a patient over 85 years of age (70%). The frequency of rationing by clinicians was positively correlated when quality of life is low (70.6%), and a patient over 85 years of age from 28 to 82, and averaged 25 years in practice. Most respondents (82.3%) showed some degree of agreement with rationing, and 56.3% reported that they did ration interventions. The most frequently mentioned criteria for rationing were a small expected benefit (82.3%), low chances of success (79.8%), an intervention intended to prolong life when quality of life is low (70.6%), and a patient over 85 years of age (70%). The frequency of rationing by clinicians was positively correlated when quality of life is low (70.6%), and a patient over 85 years of age (70%).

CONCLUSION: Bedside rationing is prevalent in all surveyed European countries and varies with physician attitudes and resource availability. The prevalence of physician bedside rationing, which presents physicians with difficult moral dilemmas, highlights the importance of discussions regarding how to ration care in the most ethically justifiable manner.

KEY WORDS: health care rationing; health resources; attitude of health personnel; ethics; clinical; Europe.

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PARTICIPANTS AND METHODS

Participants

General physicians were identified through the 2002 official list of the Norwegian Medical Association, the Swiss Medical Association, published listings of UK general practitioners and general physicians, and regional listings of Italian general practitioners and members of the Italian Society of Internal Medicine. A random sample of 400 individuals was drawn in each country in proportions of general practitioners and General Internists reflecting that of each national physician pop-

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ulation. This sample was chosen to capture similar physician populations, who do the same kind of work in general internal medicine, in both in patient and outpatient care.

Survey Methods

Because of the controversial nature of rationing and the lack of clarity about its definition, we did not use the word “rationing” in the questionnaire. Although some regard rationing restrictively as dependent on following set rules and criteria, our definition of rationing was based on the more comprehensive definition proposed by Ubel and Goold,29 who define rationing as “any implicit or explicit mechanisms that allow people to go without beneficial services.” Based on this definition, we asked respondents exclusively about those decisions they had made that led to patients going “without beneficial services.” We specified that we meant decisions based on costs, in order to avoid confusion with situations where beneficial services were withheld because patients did not want them.

To develop the survey instrument, we started with a literature review using PubMed’s database of Medical Subjects Headings and combining the following search terms: “resource allocation,” “health care rationing,” “attitudes of health personnel,” “professional practice,” and “physician’s practice patterns.” Where existing survey items were found in the literature, they were included in our survey tool. Validated items were degree of agreement with the following statement: “Physicians should adhere to clinical guidelines that discourage the use of interventions that have a small proven advantage over standard interventions but cost much more,” and the following question: “On balance do the financial incentives in your main practice: favour reducing services to patients, favor expanding services to patients, favour neither?,”30 as well as a number of listed criteria for rationing.

Two new items were developed based on a previously published questionnaire.27 These items were “cost to society is important in my decision to use or not to use an intervention,” and “I should sometimes deny beneficial but costly services to certain patients because resources should go to other patients that need them more.” Other new items grew out of a prior study in which we performed qualitative analysis of ethical dilemmas related to justice and scarcity reported by Internists in the U.S.22,33 In this prior study, we categorized comments made by physicians regarding their response to scarcity-related ethical difficulties. New items were independently rated for content validity by 2 ethicists with expertise in the ethics of rationing. The questionnaire was refined following these comments, and piloted on a convenience sample of 96 physicians in the United States, United Kingdom, and Switzerland. A cognitive questionnaire was appended to the pilot, asking respondents whether they had found any of the questions unclear, or awkward, and whether any questions had made them uncomfortable. Each scale was tested for internal consistency following the pilot, again on the entire sample, and for each national sample. Scale consistency was similar among the national samples. The questionnaire was translated into Norwegian, French, German, and Italian, back translated for accuracy, and checked by bilingual physicians for equivalence. The survey instrument is available online.

The Rationing scale, developed to explore physician reported rationing, was worded as follows: “During the last 6 months, how often did you personally refrain, because of cost to the health care system, from using the following interventions when they would have been the best intervention for your patient?” Ten listed interventions were chosen to represent the range of interventions across the spectrum of care from prevention to life-sustaining treatment (see Fig. 1). A separate item asked respondents about rationing of time in the prior 6 months. Response options were as follows: never or not applicable (0), less than once a month (1), monthly (2), weekly (3), and daily (4). The summed scale scores range was 0 to 40.

An Agreement with Rationing scale was composed of the following items “Cost to society is important in my decisions to use or not to use an intervention,” “Physicians should adhere to clinical guidelines that discourage the use of interventions that have a small proven advantage over standard interventions but cost much more,” and “I should sometimes deny beneficial but costly services to certain patients because resources should go to other patients that need them more.” Responses were on a 5-point Likert scale ranging from “strongly agree” (5) to “strongly disagree” (1). The summed scale scores range was 3 to 15.

A Perceived Scarcity scale was based on items worded as follows: “During the last 6 months, how often were you unable to obtain the following services for your patients when you thought they were necessary (this includes unacceptable waiting times)?” Listed items included surgery, referral to a specialist, admission to a hospital, access to mental health services, admission to a nursing home, endoscopy for colon cancer screening, rehabilitation for stroke, prescription drugs, referral to ICU, referral to dialysis, and services for patients at the end of life. These items used the same response options as the rationing scale. Scale range was 0 to 44.

Perceived pressure to ration was assessed using the following item: “In the last 6 months, how often have you felt under pressure to deny an expensive intervention that you thought was indicated?” These items used the same response options as the Rationing scale.

FIGURE 1. Percentage of physicians reporting rationing in the prior 6 months. Percentages shown exclusive of missing data.
Participants were contacted by mail, and told about the aims of the study in a cover letter. Questionnaires were self-administered by the respondents. To maximize response rate, cover letters were addressed by local researchers and a repeat mailing was sent, including an incentive of €10, or the closest equivalent in local currency. Questionnaires were mailed to 1,600 physicians. Data collection was open from February 2003 to June 2004.

Human Subjects Protection

Participation was voluntary and responses were made anonymous before analysis to ensure confidentiality. Approval was given by the IRB of the National Institute of Child Health and Development at the U.S. National Institutes of Health, and by the Trent Multi-Centre Research Ethics Committee in the United Kingdom. This study was designated exempt from ethics committee review by IRBs in Norway, Italy, and Switzerland.

Statistical Analysis

Data were analyzed using descriptive statistics, and bivariate correlations were analyzed using Pearson’s χ² or Kruskal-Wallis tests as appropriate. We selected a significance level of .01 (2-tailed). Logistic regression was used to identify variables independently associated with reported rationing on the Rationing scale, and with rationing of time. The models were built using the variables that were found to be associated with reported rationing in bivariate analysis.

RESULTS

Respondents

Respondents (N=656, 43% of eligible sample) ranged in age from 28 to 82, they had been in practice for an average of 25 years, and 38.4% were at least partly hospital based (Table 1). Respondents were predominantly male (85%), with the proportion of women ranging from 42.1% under the age of 30 to 7.8% from 61 to 70 years of age.

Reported Rationing

Rationing of interventions was reported by 56.3% of respondents for the prior 6 months (Fig. 1). The most frequently rationed interventions were MRI (40.9%) and screening tests (28.6%), and the least frequently rationed referral to ICU (13.7%) and dialysis (15.4%). The mean score on the Rationing scale was 3.4 out of a maximum of 40 for the total sample, with a mean score of 6.4 for those physicians who reported rationing (Cronbach’s α=0.90). A score of 6 could signify rationing each of 6 interventions but cost much more. Two-thirds (68.7%) agreed that physicians should adhere to clinical guidelines that discourage the use of interventions but cost much more.

Determinants of Reported Rationing

In bivariate analysis, physicians’ age, gender, specialty, site of practice (in patient or outpatient, public or private admitting hospital, teaching admitting hospital), appointment with a university department, and years in practice since graduation were not associated with the degree of reported rationing, The most frequently reported criteria for rationing decisions were a small expected benefit (82.3%), low chances of success (79.8%), intention to prolong life when quality of life is low (70.6%), and age over 85 years (70%) (Table 2).

Personal Attitudes Toward Rationing

On the Agreement with Rationing scale (Cronbach’s α=0.60), 82.3% of respondents showed some degree of agreement, with a median score of 10 (range =3 to 15). Over a third of respondents (36.6%) agreed that they should sometimes deny benefits to their patients at least sometimes when avoiding an expensive alternative (Fig. 2).

The most frequently reported criteria for rationing decisions were a small expected benefit (82.3%), low chances of success (79.8%), intention to prolong life when quality of life is low (70.6%), and age over 85 years (70%) (Table 2).

Perceptions of System-wide Rationing

Perceived Scarcity (Cronbach’s α=0.84) was reported by 87.6% of respondents. Perceived pressure to ration was reported to have occurred in the prior 6 months by 46.2% of respondents. In addition, 44% agreed that their job or financial situation was threatened by current pressures to contain costs in health care. Despite this, 73.3% felt free to utilize resources in their patients’ best interest.

Determinants of Reported Rationing

In bivariate analysis, physicians’ age, gender, specialty, site of practice (in patient or outpatient, public or private admitting hospital, teaching admitting hospital), appointment with a university department, and years in practice since graduation were not associated with the degree of reported rationing.
based on the Rationing scale. Degree of rationing was positively associated with number of hours a week in patient care, perceived scarcity, perceived pressure to ration, and agreement with rationing. There was a negative association between the degree of rationing and length of waiting time for an appointment, perceived freedom, and working in Norway or the United Kingdom.

A logistic regression model of factors associated with reported rationing included both personal attitudes toward rationing as well as perceptions of rationing at the system-wide level. Physicians were more likely to report rationing if they perceived more scarcity (odds ratio [OR]=1.11, 95% confidence interval [CI] 1.06 to 1.16), or more pressure to ration (OR =2.14, 95% CI 1.52 to 3.01), and if they agreed more strongly with rationing (OR=1.13, 95% CI 1.05 to 1.23). Physicians from Norway (OR=2.61, 95% CI 1.34 to 5.06), Italy (OR =3.62, 95% CI 1.65 to 7.91), and Switzerland (OR=5.1, 95% CI 2.28 to 11.68) were more likely to report rationing than those in the United Kingdom.

Reported rationing of time was not associated with physicians’ age, gender, years in practice since graduation, type of admitting hospital, number of patients cared for, or hours a week in inpatient care in bivariate analysis. It was positively associated with working in a rural area, in an outpatient setting, number of hours in outpatient care, being under pressure to ration interventions, reporting less freedom to utilize resources in patients’ best interest, and reporting scarcity, rationing of interventions, and agreement with rationing. There was a negative association between the degree of reported rationing of time and working in Italy, being specialized in internal medicine, and fearing that denying care could jeopardize the doctor-patient relationship.

In a logistic regression model of factors associated with rationing of time, physicians were more likely to report rationing if they reported more scarcity (OR=1.1, 95% CI 1.02 to 1.18), and less likely to do so if they practiced in Italy (OR=0.13, 95% CI 0.04 to 0.43).

**DISCUSSION**

Bedside rationing is reported by physicians in all European countries studied. Physicians who personally agree with rationing, perceive more pressure to ration, and perceive more scarcity are more likely to report rationing. The interventions reported as being rationed the most frequently are personal time spent with patients, MRI, screening tests, lab tests, and prescription drugs. Although the most frequently mentioned criteria were a small expected benefit, and low chances of success, a majority of respondents also reported being more likely to refrain from using an intervention if the patient was over age 85.

Our study has several limitations. Using self-reports may have led to an underestimation of actual bedside rationing given its controversial nature. Additionally, self-reports will

### Table 2. Criteria Influencing the Use of Expensive Interventions

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less Likely</td>
</tr>
<tr>
<td><strong>Intent</strong></td>
<td></td>
</tr>
<tr>
<td>The aim is to prolong the life of a patient whose quality of life you judge to be low</td>
<td>71</td>
</tr>
<tr>
<td>The aim is to improve quality of life in a patient whose life expectancy is short</td>
<td>35</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td></td>
</tr>
<tr>
<td>The benefit to the patient is small</td>
<td>82</td>
</tr>
<tr>
<td>Chances of success for the intervention are low</td>
<td>80</td>
</tr>
<tr>
<td>While you think the patient would benefit, the evidence base for the intervention is lacking</td>
<td>58</td>
</tr>
<tr>
<td>The intervention is primary prevention</td>
<td>26</td>
</tr>
<tr>
<td><strong>Condition</strong></td>
<td></td>
</tr>
<tr>
<td>The condition is attributable to smoking</td>
<td>18</td>
</tr>
<tr>
<td>The condition is attributable to a dangerous sport</td>
<td>15</td>
</tr>
<tr>
<td>The condition is attributable to pregnancy</td>
<td>7</td>
</tr>
<tr>
<td>The condition requires chronic care</td>
<td>30</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td></td>
</tr>
<tr>
<td>The patient is over 85</td>
<td>70</td>
</tr>
<tr>
<td>The patient is frail</td>
<td>63</td>
</tr>
<tr>
<td>The patient is cognitively impaired</td>
<td>50</td>
</tr>
<tr>
<td>The patient holds an important position in society</td>
<td>7</td>
</tr>
<tr>
<td>The patient asks for the intervention</td>
<td>12</td>
</tr>
<tr>
<td>The patient is poor</td>
<td>8</td>
</tr>
<tr>
<td>The patient will not work again</td>
<td>15</td>
</tr>
</tbody>
</table>

*A patient you are treating would benefit from an intervention. This intervention is very expensive. It is paid for by public money, or by a private insurer, or both. Under these circumstances, do the following factors make you more or less likely to use this intervention? Percentages shown exclusive of missing data, and rounded to the nearest whole number.
only capture instances of rationing of which practitioners are aware. Moreover, information gathered in the survey about withheld services did not include details regarding the particular circumstances. Cases where physicians may have reassessed medical indications so they are better aligned to match available resources are thus excluded. As we only surveyed general physicians, generalizations to other medical specialties, or to other health care systems should be cautious. Finally, the response rate was modest, as is often the case for physicians and questionnaires addressing sensitive topics. Nonrespondent bias is most likely to be associated either with lack of time, which we would expect yields an underestimation of the rationing of time, or with lack of interest in the topic, which we would expect to yield an overestimation of reported rationing of interventions. Reluctance to report a controversial practice could also have led to underreporting of bedside rationing. However, extrapolating our results to a response rate of 100%, and considering all nonrespondents to report no rationing results in a percentage of physicians reporting rationing of interventions of 23%. One concern could be that the associations between variables could be affected by nonresponse bias. Variables independently associated with reported rationing were perceived scarcity, pressure to ration, agreement with rationing, and country of practice. If nonresponse were due primarily to lack of interest in the topic, then we could expect overestimation of pressure to ration. As this would also likely be associated with overestimation of reported rationing, however, the association between these 2 variables may not be affected.

Our results complement studies that have examined clinical rationing such as nonreferral to dialysis. While it has been suggested that physicians often deny scarcity, our findings indicate that physicians are aware of personally denying some modicum of benefit to their patients. These findings will need to be supplemented with additional data gathered from sources such as medical records and administrative data sets. However, despite the exploratory nature of this study, our results raise a number of intriguing points.

We found significant differences between countries regarding the frequency of reported rationing. While one might expect that physicians in countries that spend more money per capita would report rationing less, this does not appear to be the case. Physicians in Switzerland, where the most is spent, report the most rationing. One plausible explanation is that, when more leeway is left to physicians by the structure of their health care system, a larger share of the responsibility for rationing falls to them. Thus, they may indeed more often “personally refrain from using interventions,” which a more rule-bound system would simply not have given them the discretion to use. Whether more leeway for clinical decisions regarding rationing is a favorable arrangement depends upon judgments about where rationing decisions ought to take place and upon clinical outcomes that we did not measure here. Moreover, we cannot know precisely all the factors that dictate the reported frequency of rationing. In addition to scarcity, or to agreement with rationing, it could also be a function of how often the clinical need arises.

This study has several implications. First, our results suggest an interaction between resource allocation at the levels of health care systems and individual providers. This interaction may occur at various levels of health care organization including national and more local levels. The literature on practice variation shows that the availability of resources such as hospital and ICU beds varies geographically within a country and that utilization rates parallel this availability. Our finding that physicians’s self-reports of rationing correlate with their perception of scarcity helps to provide an insight into this relationship. At a national level, we found that Italy, the country with the highest number of physicians per 1,000 population, is also where our respondents reported the least rationing of time. This suggests that manpower allocation decisions at the system level, whether intentionally or otherwise, impact reported bedside rationing.

Second, it seems that both health care systems that are more centralized, as exemplified by the United Kingdom, and those that are more market based, as exemplified by Switzerland, include clinical rationing behavior, as judged by physician self-reports. Of what interest might the findings in this study be to practitioners and patients in the United States where rationing is often thought to be driven by inability to pay due to uninsurance or by insurance coverage rules? While expansion of insurance may reduce inequities in access to care, it will not eliminate rationing. One can only hope that the pattern of rationing might be fairer. In this regard, this study is aimed at providing initial insights that may yield fair rationing strategies.

Overall, our study indicates that bedside rationing is ubiquitous but its extent and patterns vary with system-wide factors. Those who consider bedside rationing by physicians to be ethically unacceptable can glean from our findings that it would be prudent to promote aspects of any health care delivery systems that reduce pressure for physicians to take responsibility personally for the cost of care. But they might also be reassured by the finding that those interventions that are reportedly rationed involve nonvital benefits and interventions for which there are clinical alternatives.

While it is reassuring to see so few physicians report rationing based on poverty, criteria such as a patient’s work status may suggest worrisome practices. While rationing criteria such as cognitive impairment may be viewed as discriminatory, they may, alternatively, reflect concerns for quality of life that are shared by patients and their families. In sum, physicians report a range of criteria for forgoing medical interventions that appear to be more and less equitable. These findings highlight the need for a more detailed attention both to the factors that do and to those that should influence rationing decisions. Given the prevalence of rationing, the public may be well served by more explicit discussion of how best to ration care at the bedside in an ethically justifiable manner. The concepts and skills required for fair rationing would also need to be included in medical curricula, which typically do not currently include such training.

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S.A.H. had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

REFERENCES


Supplementary Material

The following supplementary material is available for this article online at www.blackwell-synergy.com