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To accept, or not to accept, that is the question: citizen reactions to rationing

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Abstract

Background The publicly financed health service in Sweden has come under increasing pressure, forcing policy makers to consider restrictions.

Objective To describe different perceptions of rationing, in particular, what citizens themselves believe influences their acceptance of having to stand aside for others in a public health service.

Design Qualitative interviews, analyzed by phenomenography, describing perceptions by different categories.

Setting and participants Purposeful sample of 14 Swedish citizens, based on demographic criteria and attitudes toward allocation in health care.

Results Participants expressed high awareness of limitations in public resources and the necessity of rationing. Acceptance of rationing could increase or decrease, depending on one's (a) awareness that healthcare resources are limited, (b) endorsement of universal health care, (c) knowledge and acceptance of the principles guiding rationing, and (d) knowledge about alternatives to public health services.

Conclusions This study suggests that decision makers should be more explicit in describing the dilemma of resource limitations in a publicly funded healthcare system. Openness enables citizens to gain the insight to make informed decisions, i.e. to use public services or to "opt out" of the public sector solution if they consider rationing decisions unacceptable.

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Introduction

In the decades following World War II, healthcare coverage was extended to Europeans, and by the 1970s universal health care had become firmly rooted in the Nordic countries, the UK, the Netherlands, Italy, and other nations. Publicly funded programs received strong political backing and became highly popular among citizens. But the conditions for generously providing health care have changed over the years in most countries, visible at least to governments through an increasing gap between demands and diminishing resources.¹ Consequently, debates on restrictions in access to health care and actual changes in the provision of services often tend to evoke strong public sentiment.^{2,3}

In an international context, Sweden stands out as a country that has made a major commitment to the development of universal health care.⁴ The *solidarity* principle served as a cornerstone as the healthcare system expanded from 1950 to 1980. Every Swedish citizen became entitled to comprehensive health services on the basis of need in a regionalized public system. Starting in the late 1980s, health care came under increasing economic pressure, forcing policy makers to consider restrictions.⁵

In 1997, the Swedish Parliament established the ethical principles for priority setting in health care, resulting in the explicit inclusion of the *principle of need* in the Health and Medical Services Act.⁶ (“The person with the greatest need for health care shall be given priority by the health service.”). On one hand, the Swedish public has indicated strong support for universal welfare provisions.⁷ On the other hand, one survey clearly indicated that people with minor medical needs are not prepared to stand aside for fellow citizens with more severe needs.⁸

It was left to local government providers – the county councils – to interpret the ethical principles and decide how to distribute services at the local level. An inquiry in 2007 revealed that there has been little transparency in Sweden on the mechanisms used to handle resource constraints in health care.⁹ A few county councils have experimented with explicit priority setting in recent years,¹⁰ but little is known about citizen awareness of health care actually being rationed. In 2009, the Population and Patient Survey, an annual telephone survey including approximately 40 000 randomly selected interviewees in 20 county councils, revealed wide variations in views among people living in different parts of the country – from 70% to 86% believed they had access to all the health care they needed.¹¹ Whether or not this should be considered an indication of awareness about rationing, at least in some part of the population, is far from evident.

In a publicly funded system where services are heavily subsidized, rationing (limiting the possibilities to fully meet needs for health care) in some form is inevitable, e.g. through waiting lists (delay), by lowering quality (dilution), or excluding certain services from the public menu (denial). The inevitability of rationing in publicly funded healthcare systems, where services are distributed according to need, is usually not explained to the public and thus little understood and discussed.^{12,13} Evidence from the UK indicates, however, that ordinary people could be aware of rationing, but nevertheless question its inevitability. Since the media often report on contrasting experiences of personal encounters with health care, people’s understanding of how the health service operates easily becomes blurred.¹⁴

Still, decision makers appear to hold increasingly stronger beliefs that openness is to be preferred in situations of priority setting and rationing. The hope is to contribute to sustained legitimacy for universal health care, and guidelines such as “accountability for reasonableness” have been influential in this thinking.¹⁵ Unconditional openness is contested, however, and some critics prefer implicit strategies to the dilemma of rationing.¹⁶ In a democracy, decision makers cannot easily evade public opinion on difficult topics. According to a qualitative study of citizens’ attitudes to rationing, people want to know if care is being denied so they can judge if the decisions were correct and, if not, either protest or seek private solutions.¹⁷ But people also tend to question if the reasons for rationing are well grounded, and if the decisions to restrict services actually ought to be altered.¹⁴ In situations where your own care is being rationed, there appears to be a problematic trade-off between wanting to be told about resource limitations and actually trying to cope with this fact.^{18,19} Hence, the evidence to date suggests that explicitness about rationing is a far more complicated matter than previously anticipated, and further studies need to clarify how people react when faced with resource constraints in a less generous welfare state.

How citizens¹⁷ and patients¹⁸ react to resource constraints in health care is an under-researched area. This paper reports selected findings from a qualitative study of Swedish citizens’ views on justice in health care, resource allocation, and rationing. It describes different perceptions of rationing and, in particular, what citizens themselves believe influences the acceptance of having to stand aside for others in a public health service.

Material and methods

To examine how people understand and react to resource constraints in health care we used a phenomenographic approach. The epistemological assumption of phenomenography is that humans differ in how they experience the world. Hence, by using this method we could capture *variations* in how people experience a phenomenon (foremost the acceptance of having to stand aside for others in health care). We then categorized these variations and analyzed the relationship between them.²⁰ Explaining *why* the informants hold their various views was not part of the study design.

Recruitment of informants

We used purposeful sampling, in several steps, with the intent to include a diversity of people in terms of age, gender, education, and ethnicity, but also to make room for a wide range of opinions and views. First, we used non-proportional quota sampling when potential participants were approached through work sites that would mirror the bulk of the Swedish work force. Five sites were approached; two requiring university education (high technology and culture) and three requiring upper secondary education (trade, agriculture, and mechanical engineering). To secure participation by additional strata of the population (retired people, unemployed, students, and immigrants) we also approached a pensioners’ club, a project for young unemployed arranged by the Swedish Public Employment Service, a university, and an immigrant organization.

As no solid evidence shows the relationship between perceptions of justice in health care and standard variables such as age, gender, and education, we rejected the idea of relying only on such criteria to establish the final sample.²¹ To secure a variety of opinions among participants, we used a brief questionnaire to elucidate views on legitimate decision makers in

health care, openness in priority setting, and fairness in allocating health services (thus reflecting the aim of the broader project).

The questionnaire was distributed to 124 citizens drawn from the nine quota groups referred to earlier (work sites, etc). Seventy-two questionnaires were returned, resulting in nine different combinations of answers (of 24 possible). Finally, we selected one representative for each of the nine available combinations for the study. However, to secure variations in age, gender, and ethnic background we decided to expand the sample to 14 participants, drawn from within the nine types (combinations) we had identified.

Data collection

In 2006, one of the authors (MB) conducted semi-structured, open-ended interviews with questions designed to capture each informant's attitudes on a broad range of topics related to justice and priority setting in health care. Questions relevant for this paper focused on the informants' perceptions of acceptance for standing aside in three situations; having to wait in favor of others (delay), not having the best available treatment (dilution), and exclusion from public health (denial). The interviewer asked follow-up questions based on the subject's own narrative. Also, projective questions about other people's thoughts on rationing were used to capture the subject's perceptions that were not directly expressed. The interviews lasted 30 to 70 minutes and were carried out at sites chosen by the subjects.

Data analysis

All interviews were digitally recorded, fully transcribed verbatim, and analyzed according to the principles of phenomenography with the aim to describe the perceptions by category.²⁰

Transcriptions were re-read repeatedly to capture a general impression of different perceptions of rationing that the informants believed would influence acceptance of having to stand aside for others in a public health service. Respondents' answers referring to rationing and having to stand aside were then compiled and central issues condensed. The next step involved initial classification of similar answers. Categories were named according to theme and preliminarily compared. In the final step the categories were contrasted and compared, their unique characteristics were captured and described, and similarities between categories were noted.

Verbatim quotes were used to validate the perceptions forming the categories. The research team also used triangulation, i.e. the first steps in the analysis were performed separately, but prior to establishing the categories we discussed the analysis until consensus was reached. Central to achieving credibility in qualitative research is the ability of the subjects to identify themselves in the findings.^{20,22} For this purpose, all 14 participants were invited by mail to read and comment on the results. Seven responded, confirming that their perceptions were represented in the material, and a comment was included in the results.

Given the aim of this study and the small sample, we did not analyze the linkages between the different characteristics of the informants and the categories identified. This study has focused on finding and describing variations in perceptions, not on generalizing the findings. Hence, the results will not be reported in quantitative terms.

Each participant gave their informed consent before answering the questionnaire and being interviewed. Participating informants were assured of confidentiality and anonymity. All raw data were protected as confidential and available only to the research team.

Results

Participant characteristics

The 14 participants that were eventually interviewed were recruited as citizen informants and not as patients. Experience of being a patient was not used as a criterion for exclusion. Table 1 presents the sociodemographic characteristics of the informants.

Table 1 Characteristics of participants in the interviews

Occupational group	Total no.	Men	Women	Age						
				18-29-	30-39-	40-49-	50-59-	60-69-	70-79-	>80
Non-manual employment	4	2	2	0	2	1	1	0	0	0
Manual employment	3	1	2	0	0	3	0	0	0	0
Student	1	0	1	1	0	0	0	0	0	0
Retired	3	2	1	0	0	0	0	2	1	0
Unemployed*	3	0	3	3	0	0	0	0	0	0

* Including 2 participants from an immigrant organization

Main findings

When analyzing the participants' line of reasoning about what aspects are important to accept standing aside for others in the health service, we were able to identify a pattern starting with the importance of having an understanding of limitations in health care. From this basis, further reasoning followed, where participants were split into those who emphasized solidarity and those who emphasized self-interest. Within the two categories, people took their way of thinking in new directions, e.g. the importance of insights into the principles applied to rationing, or knowledge of the alternatives available in the health service. Interconnections between the different categories (an understanding of limitations in health care, feelings about self-interest or solidarity, insights into the principles, and knowledge of the alternatives available in the health services) were not explicitly stated, but are the result of our analysis. Within these categories, the participants' highlighted aspects that pointed toward increasing or decreasing acceptance, respectively.

1. Limitations in health care

Awareness of resource limitations in health care was an important factor that was perceived to increase acceptance for standing aside for others. This category is formed by

perceptions held by all informants. The other categories emanate from this condition, forming the basis for further reflections upon rationing.

Some participants' comments indicated a high level of awareness about resource limitations.

"You can't expect magic. If there are just limited numbers of doctors or specialists you have to stand in line." (I13)

"All of our public resources cannot be spent on health care...there are other meaningful things in life that cost." (I1)

Regardless of this awareness, some participants also expressed unawareness of the options facing decision makers when having to impose rationing in the health service. Strikingly, the options for dealing with resource limitations on regional and local levels were virtually unknown. Concepts concerning the necessity to set priorities between different groups of patients appeared to come as a complete surprise.

"It has never occurred to me that someone has to decide how much money should go toward treating cancer versus geriatric care...strange really." (I3)

The explanations offered for the growing deficit in Swedish health services were tied exclusively to the growing expectations in the general public of what the health service can deliver. The public was perceived as constantly asking for increasingly more medical care, motivated only to a limited extent by deterioration in health status.

"It's sad that the demands on health care are constantly increasing. Are we getting sicker and sicker, or what's the problem?"(I1)

Some informants expressed serious reservations that changes in health status could actually explain the strain on the health service. Instead they put forward a view that a change in attitude toward the use of the public system might explain the increasing gap between available resources and new demands.

"Things will be completely different when the generation born in the 1940s begins making demands [on public authorities] and starts looking around and wondering [where the services are]." (I11)

Also, some perceptions represent a more passive approach; *resignation* (a view that it is impossible to influence decisions and therefore not worth thinking about), *trusting* (a view of not having to reflect on this matter), and *uninformed* (a view that it is impossible to form an opinion on restrictions in health care due to a lack of information about limitations in public resources).

"I have no frame of reference. I don't know if other [healthcare] resources are available...I don't know if I have a margin for sharing with others." (I1)

2. *Self-interest or solidarity*

Although they were aware of limitations in health care, the participants expressed a variety of reactions to rationing. These *reactions* comprise the next step in the informants' reasoning about having to stand aside.

An active approach manifested itself in terms of comparing one's own need for treatment with the other person's need. In the active approach, an aspect emerged that affected one's acceptance of standing aside. This can be labeled *self-interest*, i.e. to prefer the best treatment for oneself or one's next-of-kin and never accept standing aside for others under any circumstances.

"People always want the best care for themselves. Everyone does. People are selfish, that's my belief." (I14)

"No, I wouldn't accept it...why should I have pain in my kidneys caused by [complications of] my medication when others do not." (I1)

The self-interest perspective was particularly pronounced when people associated it with having to contribute to the welfare system while others do not.

"If you're one of the people paying taxes then you want to have the best." (I2)

Among informants reasoning from a perspective of self-interest, we found a strong desire to counteract what they perceived to be signs of unfair allocation and, in extreme cases, to seek options for medical treatment outside of the public sector.

Another line of argument from the active approach involves thinking in terms of *solidarity*. This could manifest itself as a reciprocal argument; as a patient I should be prepared to stand aside for the benefit of others (e.g. to accept waiting lists), but I also expect others to be prepared to stand aside for me when I have greater needs. According to the participants using this line of argument, solidarity could also be expressed in terms of deliberate actions to avoid unnecessary claims on healthcare resources, e.g. by making an effort to stay healthy.

"You have a responsibility for how you live...so you don't neglect your health...so you don't have to take healthcare resources from someone else who is sick [for reasons outside of their control]." (I4)

The informants indicated that acceptance of standing aside for others might increase if norms promote solidarity. Although participants acknowledged that justice linked to rationing is often a highly individual perception, the view of justice was also put forward as a collective perception, formed by the prevailing societal norms.

"In Sweden our perception of justice, as regards public funding, has been shaped by a long period of social democratic government." (I1)

Some participants expressed concern about current social norms, which they thought promoted a more individualistic perspective on health care (*What's in it for me?*) rather than

solidarity. Solidarity in health care was described as more of an ideal than a reality in Sweden today, but nevertheless an element they would like to see more of.

3a. Principles applied to rationing

The third and final category of perceptions is represented by the *strategies* used to deal with the previous reactions, either by referring to *principles applied to rationing* or *alternatives to publicly funded health care*. Here, two different lines of reasoning could be observed: Informants representing the solidarity approach indicated that both principles and private alternatives influence the acceptance of rationing. Informants representing self-interest, on the other hand, referred only to private alternatives and could not find any principles acceptable for rationing.

Participants mentioned one factor in particular that could potentially jeopardize the acceptance of letting others have priority, noting that insufficient knowledge about the reasons why other patients were given higher priority would negatively affect the willingness to stand aside. Another factor, which could have an impact, would be if the reasons were known, but considered unacceptable.

“Receiving an explanation can help you accept things that you initially reject. I think that’s the way [people react] in a lot of situations.” (I5)

Some participants expressed total unawareness of the criteria used for priority setting in the Swedish health service. This knowledge gap was said to be an important reason why they could not accept letting other people have priority to health services. One example mentioned – to prevent people from suspecting age discrimination – involved the personal experience of one interviewee and concerned the importance of explaining to older patients why they could not receive a particular treatment.

“If it was impossible to operate [e.g. due to medical risk] then they should have told me that it’s better to try something else, rather than letting me think I was rejected because of my age.” (I6)

However, participants held diverse opinions on what should be considered a fair principle for rationing. Age was but one example, where some expressed readiness to stand aside for children, while others were prepared to give priority to older people.

“I don’t think anyone would think of pediatrics as an unnecessary priority. Children are our future.” (I13)

“I could wait so the elderly would receive their care first.” (I9)

Although some expressed willingness to stand aside for people with important functions in society, others considered this to be totally unacceptable and felt that all patients should be treated equally.

“Suppose that a doctor gets priority. Then he or she could help more patients who would’ve otherwise had to wait longer.” (I6)

“It’s a human right that all people have the same value.” (I8)

The number of people concerned and the severity of disease were mentioned as factors that could affect the willingness to stand aside for other patients. Disease severity appeared to be the most important factor.

“If there are 100 000 who have a mild disorder that doesn’t affect them so much, and maybe 1000 people who have something causing terrible suffering, then perhaps you should let the 1000 people receive treatment instead.” (I10)

What was perceived as a fairness principle could vary depending on the rationing mechanism used – exclusion from treatment (denial), having to wait for treatment (delay), or lowering the quality of care by delivering a treatment with less effect or higher complication rates than necessary (dilution). (Table 2)

Table 2 Association between rationing methods and perceptions of the fairness principle

	Denial	Delay	Dilution
Fairness principle	Minor needs Non-medical illness Self-infected Private care options Knowledge of self-care	Minor needs Age Function in society	(Number of sick treated)

Denial would be accepted more readily if treatments were being denied for problems not regarded as ‘real illness’, but reduced well-being. Variations in physical appearance perceived as normal among humans (e.g. natural aging), or pressure to live up to contemporary physical ‘ideals’ (e.g. breast enlargement), were considered unacceptable reasons for access to publicly funded health care (although we noted that the threshold between what is perceived as acceptable or not was not easy to identify explicitly).

“We should not accept pure luxury [vanity]...for example, if someone doesn’t want to accept aging.” (I4)

“Some people regret getting a tattoo on their face or neck...and they want to remove it. I think that public health services should cover that. But if it’s a butterfly tattooed on their shoulder, I think they have to live with it instead of pushing out someone else who needs surgery for something more important.” (I13)

Other reasons mentioned for denying publicly funded health care included minor care needs (described as low severity of illness or poor effectiveness of treatment), having possible options to public health care, or self-inflicted injury/illness. However, the principle of denying care in cases of self-inflicted problems was regarded as controversial. Our findings indicate that people could consider this principle to be fair or unfair depending on the circumstances. For example, one could argue that in situations where someone consciously takes unnecessary

risks, this person must be willing to stand aside for others if such risk-taking results in injury or illness.

“If she’s drunk and goes out boating...and crashes into another boat where they’re sitting still and fishing, and wearing life vests...and we see the same [severity of] injures...well, I don’t want the drunk person to receive care first.” (I4)

Participants also expressed counterarguments that favored being able to take risks without losing access to public health care.

“Many accidents you end up having are those you cause yourself. Had you done something different, the accident might not have happened.” (I4)

Age, severity of need, and/or what is best for the community were said to be acceptable motives for rationing by delay (e.g. waiting lists). No principles were said to justify rationing by dilution if that would mean not having the best available treatment in situations where you are aware of the best alternative.

“If you know that this treatment is effective, that it’s the best, then of course you want to have the best alternative.” (I8)

However, some participants were prepared to discuss dilution if it meant that more people could be treated for an illness by lowering the quality level, but they remained reluctant to fully apply this principle.

3b. Alternatives to publicly funded health care

Another factor affecting one’s acceptance of having to stand aside for others was the availability of alternatives to public health care; either through private market options or self-care, if appropriate and known. However, participants’ views on the private market as an option varied considerably. Some viewed this as a suitable alternative.

“If there were two people and just two possible options for treatment, but it would cost you 300 000 Swedish kronor – then I would take that offer. You would have to sacrifice something else instead, sell your car or whatever.”(I10)

Other participants regarded private options as unfair, asserting that everyone should have access to comprehensive health care through public funding. But even participants who accepted the private option held the view that it carried a major risk, since this option might be known to only a few – hence, it would not be available on an equal and fair basis. One of the informants referred to a personal experience of having to wait for an operation:

“So there I am in a queue ...and have been informed to wait in that queue. Then later I’m told that someone bought a place [ahead] in the queue, but no one informed me of the possibility to buy such a place. Things have to be fair; you have to be informed that such options exist so you can choose. Everyone should have an equal chance.” (I10)

Although self-care was mentioned as an alternative, some participants admitted that they lacked knowledge about this option. Knowledge about self-care was perceived to be limited in

today's society, in contrast to the situation some decades ago. This also contributed to diminishing acceptance of standing aside for others.

“I have a feeling that a lot of acute care is unnecessary. If people would just stay home a couple of days...the problem would solve itself.” (I2)

Discussion

The intention behind this study was to gain knowledge about perceptions of public acceptance of rationing; especially what makes people willing to stand aside for others in a universal healthcare system. Our findings suggest that factors affecting people's willingness to stand aside for others include: (a) awareness that healthcare resources are limited, (b) endorsement of universal health care, (c) knowledge and acceptance of the principles guiding rationing, and (d) knowledge about alternatives to public health services. However, the study is unable to reveal any interdependence between identified factors and the participants' characteristics, the relative weight carried by the different factors in rationing situations, or the extent to which different perceptions are represented in the Swedish population.

Studies examining citizen awareness of limitations in public health care point in different directions. Some studies show that people have unrealistic expectations and believe resources are endless, as in one study among older persons,²³ while other studies confirm our findings that people have a high level of awareness about resource limitations in health care.^{14,17} In our study, participants were aware of resource limitations in health care, but they could still react with non-acceptance to rationing. Although the participants were not unaware of limitations in health care, their frame of reference seemed to be restricted mainly to the macro and micro levels of rationing.²⁴ This is understandable since it is from these levels that media information (resource allocation at the national level) and personal experience (resource allocation at the clinical level) are drawn. However, this evidence is not always easy to consolidate to form a consistent view.¹⁴ On the important meso level, however – where in Sweden the county councils decide on the allocation of resources among patient groups – our study confirms that the public receives little information about the mechanisms in use.

A universal healthcare system materializes social solidarity, but can be appreciated by the individual for highly selfish motives (*I expect to gain from it*). Nevertheless, publicly funded systems will easily evoke sentiments associated with issues of distributive justice. For instance, some of the interview participants held views that diligent taxpayers should have priority over those who have not contributed funding, which is contrary to the principle of need. We conclude that such views largely result from a lack of understanding about the basic elements of a universal system. We noted that participant knowledge appeared to be limited regarding the need principle and the other priority setting and rationing principles explicitly spelled out by the Swedish Parliament.

Our study illustrates that views on what constitutes a fairness principle can vary depending on the method of rationing. Moreover, the findings confirm that people can react to rationing measures with acceptance or non-acceptance, depending on the situation. Contrary to one study on patients' reactions to rationing,¹⁸ we found that dilution (rationing by not offering the very best treatment) received little acceptance among the citizen informants, while denial (of treatments) was considered more acceptable.¹⁷ Most principles considered to be *fair* were associated with exclusion (denial), indicating that each of these principles could be used to justify this method of rationing. Conversely – in contrast to other forms of

rationing – it could mean that to accept exclusions, multiple principles must be fulfilled concurrently. However, more research is needed to shed light on the interplay between principles regarded as fair and the various methods of rationing.

Based on the observations presented above, we hold the opinion that the democratic institutions in charge of public health care in Sweden have failed to describe (1) the dilemmas associated with limited resources and (2) the need to set priorities and employ rationing mechanisms. The dynamic elements in health care (e.g. the unending influx of new, expensive drugs and other technologies) and the implications for making decisions about resource use are seldom debated in Sweden. Hence, the public reflects little on these issues. To underpin legitimacy, a universal healthcare system must be able to explicitly demonstrate the mechanisms that support *impartiality* while concurrently conforming to the principle of need.²⁵ Healthcare staff²⁶ and democratic institutions¹⁵ alike have the ability to influence the public's understanding of conditions under which public healthcare systems operate.

Being more explicit in this respect is one way to make the public aware of the necessity of trade-offs in publicly funded systems and how this might be achieved. Another way that has been tried is to directly involve people through various consultative arrangements, e.g. to provide opportunities for citizens to deliberate on difficult topics related to resource allocation in health care. Knowledge about such exercises, and especially their linkage to the decision making process, still seems patchy and needs to be further developed to be useful in reinforcing the legitimacy of rationing mechanisms.²⁷

We are not saying that openness about the principles and mechanisms for rationing would lead to unequivocal acceptance of the results. In a democratic society, however, openness is essential for giving citizens opportunities to voice their opinions. Openness enables citizens to gain the insight to make informed decisions, e.g. to "opt out" of the public sector solution if they consider it less advantageous. Protests against perceived injustices and a search for exit options to public health care are well-known reactions also found in our study.^{14,15} The post-war welfare system in Sweden established strict boundaries between public and private alternatives, where the former have dominated. Hence, it seems fairly logical if people want high-quality public services in return for paying high taxes. Likewise, if medical care and prescription drugs are subsidized, the patient's search for alternatives such as self-care may seem less imperative. If citizens are to take full responsibility for their own health it is important to empower them to make informed decisions on alternatives to public health care. Telephone help lines and self-care manuals are examples of interventions to better equip people for self-care.

Some limitations in this study, aside from the small number of participants, need to be acknowledged. We used a mix of sampling methods with the intention to include participants representing a range of attitudes on resource allocation and rationing in health care. Despite this effort, we have been unable to capture all possible perceptions of rationing in Sweden. Is our result a true account of how Swedish people think the strain on healthcare resources should be eased? Are people really prepared to stand aside for others? Universal health care in Sweden is, to use the words of Bergmark, a "*manifestation of institutionalized solidarity*" (p.408)²⁸ and thus an impersonal system of redistribution between the rich and the poor, the healthy and the sick, and less an expression of altruism. In Sweden today, measures like extended private funding or rationing are debated mainly in local government circles,²⁹ by various think tanks,³⁰ and among university researchers.³¹ This study indicates how people might react when confronted with a situation where they must reflect on something they

normally would not contemplate. It tells us less about what particular policy solutions citizens would prefer in a democratic context. When selecting participants we could not control for their previous experiences of utilizing health services. The difference between a patient's and a citizen's perspective is not indisputable. In the interviews, participants referred to their opinions about an ideal healthcare system (normative perspective), but also to their own experiences of being a patient (empirical perspective). Although other studies indicate that citizens' and patients' perspectives on rationing in health care differ, this topic has not been sufficiently explored.^{14,19} Hence, continued study of rationing from both a patient perspective and a citizen perspective is important to better understand the mechanisms that would support the legitimacy of publicly funded health care when having to enforce restrictions.

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