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**Lack of support structures in prioritisation decision making concerning patients and resources.  
Interviews with Swedish physicians.**

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## **ABSTRACT**

*Aim:* To investigate physicians' experiences in relation to prioritisation and financing in healthcare in order to gain a deeper understanding of the reasons behind their standpoints.

*Methods:* Eighteen physicians, seven women and eleven men, aged 30 to 69 years were interviewed and the text was analysed using an inductive approach, also described as conventional qualitative content analysis.

*Results:* Experience of setting healthcare priorities and difficult decision making differed widely among the physicians and seemed to be related to number of years in professional practice. Their view of how resources should be allocated between disciplines/patients showed that they wanted politicians to make the decisions, with support from medical professions. The overwhelming impression of their reasoning showed that they lacked support structures for their decision making and could be understood under the following categories; Prioritisation, easier in theory than in practice and Increasing costs threaten the Swedish welfare model.

*Conclusions:* The findings of this study highlight the importance of practical national guidelines concerning vertical prioritisation, also as an important measure to make prioritisation more distinct and transparent. The physicians further had a need for tools to increase patients' awareness of their health. The findings of this study also showed that an awareness of the actual costs involved might increase the responsibility among both physicians and patients.

The physicians' lack of support structures implies an urgent need for practical national guidelines, especially concerning vertical prioritisation. This will also make prioritisation appear clear and transparent for the citizens.

*Keywords;* decision maker, economy, healthcare priority, physician, recourse allocation, Sweden

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## BACKGROUND

In times of scarce resources setting priorities in healthcare is a necessity. It is important that such prioritisation is made transparently and equally, on the same grounds regardless of who is behind the decision. Healthcare priorities are made at different levels, partly by healthcare politicians and partly by physicians. Several studies [1, 2] have shown that politicians and physicians do not share the same view about how priorities should be made and how healthcare costs should be financed. The citizens however have the right to know the grounds and the arguments on which these decisions are based.

The Swedish Parliamentary Priority Commission [3] has provided national guidelines for healthcare priorities based on three ethical principles. (a) *The principle of human dignity*, meaning that human dignity is not linked to people's personal qualities or functions in the community, such as ability, social status, income etc., but to their very existence. (b) *The principle of need and solidarity*, according to which most resources for care should be given to those who are in most need, with special consideration for the needs of the weakest, such as, children, people with dementia, and others who have difficulty in communicating and (c) *The cost-efficiency principle*, meaning that one should aim to achieve a reasonable relation between cost and effect, measured in terms of improved health and enhanced quality of life [3]. These guidelines should be considered irrespective of health care field or organisation. The Swedish National Centre for Priority Setting in Healthcare has also suggested a controversial fourth ethical principle recommending personal responsibility for one's own health implying both personal prevention of ill health and the personal responsibility to choose a healthy lifestyle [4]. However, this fourth principle has given rise to debate and the Swedish National Board of Health and Welfare has not reached agreement about accepting the recommendation proposed by the National Centre for Priority Setting in Healthcare. This highlights some of the difficulties concerning this issue.

Studies have shown that people have great confidence in physicians as professionals [5] It has also been shown that older people (aged 60 to 100 years) have great confidence in physicians but little confidence in politicians as decision makers regarding healthcare priorities [6]. Arvidsson [7] found that 55 per cent, of the patients from Swedish primary healthcare, did not want the

politicians to be the responsible for priority setting and rationing, not even in collaboration with medical staff. This is interesting since a study with 700 politicians and physicians [8] indicated that politicians were more orientated to national guidelines than the physicians seemed to be. Politicians were also more willing to give priority to older people. We, however, have limited knowledge concerning physicians' knowledge about the bases for ethical principles for setting healthcare priorities.

A further important aspect concerning prioritisation is increasing healthcare costs. The study by Werntoft and Edberg [8] showed that twice as many politicians as physicians thought that "if a disease has an effective treatment, the patient should be treated regardless of cost". The results also showed that 44 per cent of the politicians but only 12 per cent of the physicians wanted higher general taxation to finance increasing healthcare costs. Most of politicians (95 %) as well as physicians (82 %) did not think that age should influence prioritisation, however, among physicians 16 per cent thought that younger patients should be prioritised compared to only 4 per cent of the politicians. Accordingly views on how to make healthcare priorities differed among decision makers and it seems essential to explore the ground on which the physicians based their standpoints.

## **AIM**

To investigate physicians' experiences concerning prioritisation and financing in healthcare in order to gain a deeper understanding of the reasons behind their standpoints.

## **METHODS**

### *Participants and data collection*

The participants were recruited using snowball sampling and comprised eighteen physicians, seven women and eleven men, aged 30 to 69 years. The advantages of snowball sampling is that an introduction from the referring person may make it easier for researchers to establish a trusting relationship with new participants and to ask for referrals to people who would add other dimensions to the subject. To capture as much variation of experiences as possible, four different threads were used for sampling: recently certificated physicians (n=5); physicians with about ten

years experience (n=4); physicians with long experience in executive positions (n=5, all men); and physicians with experience of aid work in developing countries (n=4). The physicians represented primary care, hospital care (oncologists, surgeons, medics, radiologists and gynaecologists) and psychiatry. After each interview the participant was asked to recommend a colleague in the same position, but in another workplace/hospital. The recommended physician was then sent a letter presenting the study and asking for their participation. The letter also presented a guide to the four themes that the interview would concern: Experience of setting healthcare priorities and difficult decisions; Grounds or evidence concerning decisions; The patients' own responsibility; and resource allocation among disciplines/patients. These themes were based on the work of the The Swedish Parliamentary Priority Commission. One recommended participant, a recently certificated physician, declined to participate due to heavy workload and the referring physicians recommended another colleague instead. The tape-recorded interviews lasted between 45 minutes and one and a half hour and for the most took place at the physicians' workplace, three interviews were performed in the physicians' home. As a guide for the interview, the four themes described in the letter were used. The first author made all interviews, the second author was present during the two first interviews. When 16 interviews (four in each thread) were performed, no new perspectives on the subject were expressed. To secure that saturation was reach, two more interviews were performed. The tapes were transcribed verbatim by a secretary and checked by the first author for correctness.

### *Analysis*

The text was analysed using a conventional qualitative content analysis [9]. The purpose of the method is to gain information from study participants, without imposing preconceived categories or theoretical perspectives but based on participants' unique perspectives and grounded in the actual data [9]. At first the transcribed text was read and reread independently by the two authors to achieve immersion and obtain a sense of the whole. The two authors then discussed their impression of the text and decided on a structure for the analysis. Meaning units related to the aim of the study were then identified and collated. The meaning units were read again and coded according to the content of the text. Codes of similar content were then grouped and labelled as categories. The statements in each category were analysed critically and questioned, read and compared. In the last step the categories were compared with the original text and with each

other, in a constant movement between the whole and the parts and between the text and the categories, and a theme embracing the physicians' experiences of prioritisation was decided on [10].

## **RESULTS**

Experience of setting healthcare priorities and difficult decision making differed widely among the physicians and seemed to be related to the number of years in professional practice. Their view of how resources should be allocated between disciplines/patients showed that they wanted politicians to make the decisions, with support from medical professions. The physicians' reasoning about prioritisation and the financing of healthcare was based on their own experience as well as on their perception of how prioritisation and financing ought to be carried out. The overwhelming impression of their reasoning showed that they lacked support structures for their decision making and could be understood under the following categories; *Prioritisation, easier in theory than in practice* and *Increasing costs threaten the Swedish welfare model*.

### **Lack of support structures for decision-making**

The physicians said that it was a lack, a great need, of national guidelines for prioritisation in practice. Their narratives showed that prioritisations are made every day but not always transparently. The grounds for decisions varied among physicians, the oldest physicians emphasised the ethical framework that prioritisation in Sweden should be based on, while the younger physicians did not refer at all to the guidelines from the Swedish Parliamentary Priority Commission. The younger physicians said they turned instead to older colleges and asked for advice in the faced prioritisation dilemmas. The younger physicians recalled working with ethical questions during medical studies, but they did not concern dilemmas in relation to prioritisation and they thus had limited knowledge concerning the work from the Swedish Parliamentary Priority Commission. The older physicians described the national guidelines as not applicable to vertical prioritisation, for example when the physician finds a patient too fragile to have coronary by-pass surgery. The physicians highlighted the need for an advisory board or more practically applicable national guidelines that could be used in difficult situations. The physicians also concluded that laws and regulations exist that are sometimes in conflict and constitute a threat instead of a help.



*“I remember once when there was only one bed available and three patients needed hospital care. If I did not prioritise all three patients I could be reported to HSAN (Medical Responsibility Board), and if I put two more beds in a room I would be reported to the Working environment inspectorates which lays down that there has to be 80 cm between the beds. It is madness with these contradictory laws ....., it is also remarkable that we did not get any formal ethical education until two or three years before retirement.*

Man, aged 66 years.

*“Nowadays it is only in ethical dilemmas that I call on my “senior colleague on-call”, only then, because these aspects are the most difficult to deal with.”*

Man, aged 40 years.

#### *Prioritisation, easier in theory than in practice*

The text conveyed the views that physicians found it easier to prioritise medical referrals on paper than to meet patients directly, for example patients who ask for treatment that has only a limited effect. The physicians also pointed to the imbalance in that guidelines for when and how to start are available while those for how and when to end treatment are missing. So-called “breakpoint conversations” with patients for whom no treatment will help are difficult to carry out and only a few doctors are trained to do this. The physicians said that it was sometimes easier to allow one more treatment period, than to have the discussion with the patient, even the treatment would affect the patient negatively for example through a reduced health-related quality of life caused by nausea and vomiting. Some of these drugs, for example chemotherapy, are also extremely expensive. The text reflected different views and values concerning treatment according to the specialty the physician represented. The physicians stated that physicians in some specialties were more focused on medical treatment than they thought was in the best interest of the patient. It was also said that surgical treatment, for example, for prostate cancer was used less than chemical treatment, although chemical treatment is more expensive and both methods are considered equally good. The physicians also emphasised that the influence of patient associations and media has greatly impacted on the use of various treatment methods.

*“Concerning breast cancer, we have guidelines for how we should treat it but not when to end treatment. When progressive treatment is to be discontinued there is always an oncologist who will be brave and want to try a new medicine. Oncologists are born optimists, and they have their tools, their toxins to work with and they've always had a patient who has become so amazingly much better.”*

Woman, aged 58 years.

*“I don't think we listen to our patients. Patients are often relieved after a breakpoint conversation. The patients might not want more treatment but will not say no because it seems impolite. There are so many things that influence the choice that you become irrational.”*

Woman, aged 58 years.

The text also revealed that the patient's own responsibility was theoretically of great importance for the physicians, but in practice most of them found it difficult to insist on the patient's personal responsibility. The physicians described their lack of tools, for example to give the patient lower priority for treatment, to force a patient to stop smoking, lose weight or in other ways change their lifestyle although it would save both lives and healthcare resources. Sometimes this caused them to feel frustrated as they saw what such actions could make, both for the individual patient and for the healthcare system.

The physicians clearly expressed the views that high age per se was not a criterion for not being prioritised, on the contrary, it was sometimes a reason for being prioritised. However, the patient's condition or biological age sometimes made it difficult or even dangerous to treat an older person. This was described as a situation that was not always easy to explain to the patient or relatives. The physicians thought that relatives were sometimes more resistant to treatment than patients themselves and that could put both the patient and the physician in a difficult position. It was also seen as a dilemma that older, fragile patients were admitted to hospital from nursing homes as nursing home staff have limited training in palliative care. This caused frustration for both the patient and the physicians who felt that resources were being diverted from the seriously ill patients. Another dilemma when treating older people was described as the uncertainty about how new drugs and treatments affect older people.

*“One patient, about 98 years old, had angina and was anxious to have a by-pass surgery. They calculated his risk ratio and found it to be 99 %, meaning 99 % risk of dying. The doctor told him; I could just as well drop you from the balcony here on the fifth floor, which would have the same risk as the surgery. Then the patient understood.”*

Woman, aged 40 years.

*“To be honest, we have no idea about how our treatments affect patients who are over 80 years old. All drug research is done on patients younger than 75 and we know that older people, for example, are more fragile and bleed more easily. Therefore, we often don’t know if we doing harm or good.”*

Man, aged 42 years.

#### *Increasing costs threaten the Swedish welfare model*

The physicians showed that they wanted to preserve the publicly funded Swedish healthcare system, although the increasing costs created concerns. The rising cost of pharmaceuticals and equipment was described as a threat to equality and other developments in healthcare since these costs arose undermine healthcare finance. The physicians said that most hospitals today struggle with budget deficits and it was seen as a dilemma that politicians cut the budgets without paying any attention to the effects on patients or staff. There also seems to be a difference between younger and older physicians concerning economic responsibility. Older physicians, especially those with experiences in executive positions such as hospital managers, reasoned in economical terms while the younger physicians seemed less concerned about the economical effects of their acts.

Even if most of the physicians wanted publicly financed healthcare the view concerning private health insurances was not uniform; some physicians saw them as a VIP lane for wealthy people and a phenomenon that might demolish the Swedish healthcare model while some participants saw private health insurances as a matter of freedom of choice.

*“I am proud of that in Sweden we treat people equally, wealthy or not wealthy and I don’t want*

*it to be possible to pay to be prioritised. We must reduce our queues without being bought.”*

Man, aged 40 years.

*“If you had asked me five years ago I would have said that private health insurance was the devil’s invention but unfortunately I think we are heading towards a model where our taxes only pay for the most basic healthcare. If you want anything more, you will need private health insurance.”*

Man, aged 63 years.

*“Concerning private health insurances, they are here to stay. People have to be able to do what they want with their money; for example to buy healthcare or go on a holiday trip.”*

Man, aged 31 years.

In general the physicians’ confidence in healthcare politicians appeared to be low although it was obvious that the politicians were accountable for the taxpayers’ money. The physicians expressed a belief that politicians were worried about their reputation, which could result in politicians deciding in favour of people or groups who would improve their chances of being re-elected. For example the physicians thought that the maximum per capita cost for healthcare was too low and that the politicians did not have the courage to increase the cost ceiling for free healthcare. This has resulted in healthcare easily becoming free of charge and people are not aware of the heavy expenses involved.

*“The patients ought to be aware of the costs in healthcare, not least the costs when patients fail to come or fail to appear in time for an appointment, meaning that staff and expensive equipment stand idle.”*

Man, aged 55 years.

## **DISCUSSION**

This study aimed to investigate physicians’ experiences concerning prioritisation and financing in healthcare in order to gain a deeper understanding of the reasons behind their standpoints.

The findings showed that the lack of support structures for decision-making lead to a development of hesitation among the physicians. Not knowing whether or not a decision is correct, for example in the treatment of older patients or patients in palliative care, turned the situation into an ethical dilemma. Bærøe [11] argued that clinical guidelines are generally specific about what physicians should do in pre-defined situations but they still have to judge whether the patients in front of them fall within the scope of the guidelines or if a different course of action is justified. We thus need both to develop legitimate guidelines and to rely on clinical discretion in judging the suitability of applying the guidelines in each individual case to secure just distribution of healthcare. The younger physicians recalled working with ethical questions during medical studies, but they did not concern dilemmas in relation to prioritisation and they had limited knowledge concerning the guidelines from the Swedish Parliamentary Priority Commission. Omar et al. [12] who showed that knowledge about the priority principles is thoroughly disseminated among Swedish medical students although it's contextualisation within an open process is clearly lacking it is however important to remember that study took place among students in the same University where the Swedish Parliamentary Priority Commission is established and the result could perhaps not be generalised to other medical students.

Another finding of interest was that physicians became frustrated with the lack of tools for dealing with issues of patients themselves risking their health, leading to additional costs for society. Although the Swedish National Centre for Priority Setting in Healthcare has suggested a fourth ethical principle recommending responsibility for one's own health, implying personal responsibility for prevention of ill-health as well as personal responsibility for choosing a healthy lifestyle [4] the Swedish National Board of Health and Welfare has not agreed to adopt this recommendation. Hasman et al. [13] interviewed members of committees responsible for making resource allocation decisions in the UK and concluded that such responsibility was an unimportant reason in priority decision making. There may be both genetic and social reasons for a person's behaviour and increased risk meaning that people do not have a genuinely free choice in the avoidance of risk behaviour. The consequences of risk behaviour are not always clear before a patient becomes ill or in need of healthcare. Also, as everyone indulges in unnecessary

risky behaviour sometimes, giving lower priority in healthcare to certain people would be both unfair and present practical difficulties [13]. However, even though the principle of human dignity is emphasised by the Swedish National Board of Health and Welfare, saying that all human beings have equal dignity and the same rights, regardless of their personal characteristics and their functions in the community [14], studies such as that by McIvor et al. [15] have shown that only a few questions from the physicians about risk behaviour make a patient reconsider their way of living. This is one tool that can be used to make patients change their bad habits and save both lives and healthcare resources.

A noteworthy finding in this study was that younger physicians did not seem concerned about the economic effects of their actions. This is in line with the findings of Schilling [16] who studied cost awareness among Swedish physicians working at an emergency department and found that younger doctors generally tended to underestimate the costs of investigation but also that the level of cost awareness was considered low among all participating doctors. The author suggested further education to raise the level of cost awareness among hospital doctors. Bærøe [11] also emphasises that physicians have a double responsibility; the duty to secure treatment of high quality according to individual needs but also to see that resources are distributed justly and effectively. Perhaps health economy should be part of medical training, especially considering that physicians to a great extent hold leading positions in both hospital and non-institutional care. Schilling [17] also found that the distribution and promotion of price lists at the emergency department as a tool for highlighting cost awareness resulted in a major reduction in investigation costs among physicians. The Swedish maximum per capita cost for healthcare results in healthcare rapidly becoming free of charge and in patients being unaware of the heavy expenses involved in healthcare. Perhaps a presentation of the total costs of a patient's visit will make them more aware of the real cost and induce a feeling of responsibility, for example, to cancel an appointment in time. In Sweden, after visiting the dentist, the patient gets a receipt with an exact description of the costs together with the amount of money the patient has to pay and the amount of money the public dental insurance pays. It ought to be possible to also implement this procedure in other healthcare facilities.

The findings of this study have to be valued in the light of methodological aspects

One crucial aspect in qualitative research is the quality of the data collected. The interviews contained comprehensive narratives based on the participants experience. A snowball sampling method was used meaning using initial contacts to identify other potential participants. A weakness of this approach is that the sample might be restricted to a rather small network of friends [18]. However, this was carefully monitored so that the physicians should represent a wide span of age, specialities and workplace/hospitals and have varying experiences of prioritisation. The analysis was further made by two independent researchers, thus strengthening the trustworthiness of the findings. The transferability of the findings is however limited in contexts not having a public financed health care system.

## **CONCLUSIONS**

There is need for more practical national guidelines especially concerning vertical prioritisation. This is also an important measure for the citizens, as prioritisation will then appear as more distinct and transparent. There is also need for tools to deal with patients who take risks with their health, leading to additional costs for society. Simply showing an interest in a patient's risk behaviour can, however, lead a patient to reconsider her/his lifestyle. It also seems as if health economy should be a part of medical training and that an awareness of the actual costs might increase the responsibility among both physicians and patients.

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