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Citation for the published paper:
Werntoft, Elisabet and Hallberg, Ingalill R and Edberg,
Anna-Karin.

"Older People's Reasoning About Age-Related Prioritization in Health Care" Nurs Ethics, 2007, Vol. 14, Issue: 3, pp. 399-412.

http://dx.doi.org/10.1177/0969733007075887

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OLDER PEOPLE'S REASONING ABOUT AGE-RELATED PRIORITISATION IN HEALTH CARE

| Werntoft, | Elisabet ¹ , | RNT, | PhD, | Hallberg, | Ingalill | $R^{1,2}$, | RNT, | PhD, | Professor, | & | Edberg, |
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| Anna-Kar | in ^{1,2} , RN, F | PhD, As | ssoc P | rof | | | | | | | |

¹Department of Health Sciences, Division of Nursing, Lund University, Sweden

Corresponding author:

Elisabet Werntoft

Department of Health Sciences

Lund University

P-O-Box 157

Se-221 00 Lund, Sweden

Tel: +46-46-2221840

 $\pmb{Email: \underline{elisabet.werntoft@med.lu.se}}\\$

Fax: +46-46-2221934

²The Vardal Institute, Lund University, Sweden

ABSTRACT

The number of older people has increased and so also the use of expensive treatments and medicine. Some sectors and patients have been prioritised while others have been set aside, deliberately or not. Knowing that there are different views on the subject it is important to find out how older people reason about age-related prioritisation in health care. The aim of this study was to describe the reasoning of people, 60 years and over, about prioritisation in health care with regard to age and willingness to pay. Healthy people (n=300) and people receiving continuous care and service (n=146), between 60 and 101 years old, were interviewed about their view of prioritisation in health care. The transcribed interviews were analysed using qualitative manifest and latent content analysis. The participants' reasoning on prioritisation embraced eight categories: *Feeling secure and confident in the health care system, Being old means low priority, Prioritisation causes worries, Using underhand means in order to be prioritised, Prioritisation as a necessity, Being averse to anyone taking precedence over others, Having doubts about the distribution of resources*, and Buying treatment requires wealth.

Key words: experience, health care, older people, prioritisation, qualitative study, resource allocation, view

INTRODUCTION

Older people are a heterogeneous group regarding age, socio-economy, health and experience of health care. Their views on age-related prioritisation are likely to vary. The number of older people has increased and so also the use of expensive treatments and medicine. According to the Swedish National Board of Health and Welfare (1), health care costs for people aged 85 and over have decreased in recent years. It has also been shown that total spending on older people in Sweden has stagnated (2). The 1982 Health Care Act stipulates equal access to services on the basis of needs and emphasises a vision of equal health for all regardless of age (3). Prioritisation has always occurred in health care, but in times of scarce resources and in response to growing demand for health care, prioritisation between patients and between different treatments will increase and be more demanding. By referring to ethical principles the Swedish Parliamentary Priority Commission did not recommend age as a criterion in health care prioritisation and emphasised that health care should be given to those who are most in need (4). This is in line with the results from earlier studies involving people aged 60 and over, based on a structured questionnaire concerning prioritisation and resource allocation. The participants did not want age to be a criterion in prioritisation, and if they could afford it, they were willing to pay to get treatment at once instead of being on a waiting list (5, 6). In order to increase the understanding of their standpoints it seems important to investigate how older people reason about prioritisation in health care.

The main result of the work of the Swedish Parliamentary Priority Commission was based on three ethical principles. (a) *The principle of human dignity*, meaning that human dignity is not geared 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 of the resources of care should be given to those who are most in

need, with special consideration for the needs of the weakest, for example, children, people with dementia, and others who have difficulty in communicating with others. (c) *The cost-efficiency principle*, meaning that one should aim for a reasonable relation between cost and effect, measured in terms of improved health and enhanced quality of life (7). Thus the Swedish Parliamentary Priority Commission suggested that no account should be taken of age when allocating resources within the health care system. Also the Swedish Health Care Act incorporates equal access to services on the basis of need and emphasises a vision of equal health for all (3). In an international perspective, several authors (8-10) have campaigned against denying older people treatment and defended the individual's basic right to health care. Thus, there seems to be consensus about not using age as a criterion in health care in Sweden according to health care regulations.

Age as a criterion for prioritisation can be viewed from several perspectives. The fair innings argument (FIA), according to Williams (11), takes the view that there is a span of years that are considered a reasonable life or a fair innings and required that everyone should be given an equal chance to have a fair innings to reach the appropriate portion, but having reached it, they have received their entitlement. Callahan (12) argued for the necessity of setting limits to health care and one strong candidate criterion was old age. In "Just Health Care" Daniels (13) argued that older people might feel "left out in the cold" as their opportunities might seem to be in the past, and instead of biasing the allocation in favour of one stage of life, they should consider the age-relative opportunity range. He suggested that everyone is entitled to a certain amount of health care during a life span, and that saving resources from one stage of life for use at another does not produce inequalities across persons in the way that differential treatment by race or gender does. People age but do not change gender or race. Daniels (2001) thus emphasised that fairness between age groups is retained by the idea of allocation over a

life span. Although philosophers explained their thoughts differently, through fair innings or Just Health Care, they all considered rationing by age acceptable under conditions of scarcity. In the USA and the UK there is thus an active debate about age as a criterion in rationing. In Sweden, however, the debate about rationing by age is not explicit, probably due to the recommendations from the Swedish Parliamentary Priority Commission and the Swedish Health Care Act not to use age as a criterion, which makes it important to involve older people themselves in discussions about prioritisation.

In times of scarce resources the debate about the possibility to pay for treatment increases. Studies have shown that people aged 60 and over are willing to pay for treatment to avoid waiting lists if they are in a financial situation that allows them to do so (6, 14). The results of Werntoft et al. (6) nevertheless showed that the oldest-old, 85 years and over, were more likely to chose staying on waiting lists than people under 85, although their financial situation was considered equal to that of the others. Anderson et al (15) interviewed patients who were originally scheduled for cataract surgery in publicly funded settings and who had an anticipated waiting time of at least one month. The result showed greater willingness to pay as the length of an anticipated wait increased and the willingness to pay was also greater for persons with more education, lower visual acuity, and more bother associated with their vision. One of the criticisms of measuring willingness to pay is that people would not actually behave in the same way in which they respond to the questions. In the study by Anderson (15) 17 % of the participants expressed a willingness to pay the market price to reduce the queue to less than one month, but only 1.7 % actually did. It might be that when people aged 60 and over reason about such questions of concern they will give a more realistic response. Thus, a valuable contribution to the discussion about prioritisation and resource allocation in health care would be to describe the reasoning of older people concerning their views on the subject.

The aim of this study was to describe the reasoning of people aged 60 and over about prioritisation in health care with regard to age and willingness to pay. Including people receiving continuous care and service as well as healthy people was designed to provide a broader picture of the reasoning concerning prioritisation.

METHODS

The study involved interviews with participants identified in a larger prospective longitudinal cohort study, the GAS project (Good Ageing in Skane), which is currently in progress in five municipalities in southern Sweden (16). The study consists of two parts: (a) one population part where a large representative panel of people aged 60–93 years, randomly selected from the Total Population Register, Statistics Sweden, is followed over time to record and describe the ageing process from different aspects. The other part (b), the care and service part, concerns participants receiving continuous care and service in the public sector who are aged 65 years old and over.

Sample and procedure

The sample consisted of 446 persons between 60 and 101 years old (Table 1). The participants were identified in connection with the population part (a, n=300) as well as in the care and service part (b, n=146) of the GAS study. In the population part (a), structured interviews concerning prioritisation were held with 902 persons in connection with the examinations for the main study, during the years 2001–2003. In all, six interviewers were involved in the data collection, having received training in how to perform the interviews. Participants with cognitive decline and/or exhaustion after the examinations were excluded. The quantitative results of that study have been presented previously (5, 6). The first 500 interviews were tape-recorded and 300 were selected for this study. The selection was based

on the quality of the interviews. Structured interviews were also performed with 146 patients receiving continuous public care and service, from the care and service part (b), during two months in 2003 and 3 months in 2005. The inclusion criteria for the care and service part were being 65 years and over and receiving continuous public care and service. Continuing public care and service implied that people should have decision about public home help, a place in special accommodation or at least four visits per month from home nursing care or rehabilitation. Individuals with only a body-carried alarm, meals on wheels or transport service were not included. For the interviews, contacts with the participants were conveyed by nurses working in the municipalities. The nurses received information about the study and then asked persons, whose care and service they were responsible for and who were able to participate in an interview about permission for an interview in their home. Thereafter the first author (EW) contacted them to arrange an appointment. The quantitative results from that study have been presented earlier (17).

INSERT TABLE 1

Data collection

During the interviews, a questionnaire was used as an interview guide comprising questions about prioritisation and resource allocation. The questions had been developed in relation to diseases in old age within the scope of feasible treatments, diseases related to lifestyle and in the light of three ethical principles: the principle of human dignity, the principle of need and solidarity and the cost-efficiency principle (5). In this study the answers to two open-ended questions about prioritisation were selected for qualitative analysis: In television and newspapers we can see and read about prioritisation in health care, 1) what are your thoughts about prioritisation? and 2) what experiences do you have of prioritisation yourself? The comments and reflections on the structured questions regarding prioritisation in general, age

as a criterion in prioritisation and the comments on a question regarding willingness to pay (WTP) for treatment were also included in the qualitative analysis. Structured questions regarding age that were selected were; whom do you think should be prioritised in health care — younger patients, older patients or all age groups? What alternative do you think is most fair among people with life-threatening illness? with the response alternatives younger patients should have some priority over older people, people should have the same priority with respect to life-saving treatment, unless they are very old, or people should have the same priority with respect to life-saving treatment no matter what their age is. Who should be the one to have a new kidney, a 60-year-old woman, a 70-year-old or an 80-year-old woman? The question selected concerning WTP was: if you need cataract surgery to be able to see, what alternative would you choose? Be on a waiting list for 18 months or pay €100 out of your own pocket and have the surgery at once?

Analysis

The tape-recorded interviews were transcribed verbatim by the first author and two secretaries. The text was analysed using qualitative manifest and latent content analysis. The manifest content is comparable to the surface structure presented in the message while the latent content is the deep structural meaning conveyed in the message (18). Berg (18) suggested that the best solution is to use both manifest and latent content analysis when it is possible. The intent of content analysis is to describe the phenomena of interest for a particular purpose (19). A particular framework or perspective can also be used to analyse the data: "what you see in the dark depends on where you choose to focus the light" (19).

The analysis of the data proceeded in several steps. At first the text was read and reread in order to get a general impression of the content. The first and the third author (EW, AKE)

read the text independently and thereafter compared and discussed their impression of the text. Units of meaning related to the aim of the study were then identified. This text was read again and codes embracing the content of the meaning units were identified. Codes with similar content were grouped and labelled as categories. In the last step the categories were compared with the text and with each other, as a constant movement between the whole and the parts and between the text and the categories. The second author (IRH) read the transcripts and confirmed the interpretation of the text.

Ethical considerations

The tape recordings were obtained in connection with a structured interview where the participants were supported to narrate their thoughts in relation to the questions asked. There was a risk that the participants' willingness to participate in the study would be influenced by the fact that some of the participants were in a state of dependence on the nurses asking them to participate. The participants had however previously agreed to participate in the GAS study, and the advantage of having information from a well-known person was judged to be more ethical, as this group was vulnerable. The inclusion of not only healthy people, but also people in rather poor health, could further be criticised. The value of including people who probably have experienced prioritisation, however, made the advantages outweigh the disadvantages. Before inclusion in the study, written informed consent for participation in the GAS study was obtained from the participants. Permission for the study was obtained from the research ethics committee of Lund University (LU 744-00 and LU 650-00).

RESULTS

The participants' experience of prioritisation varied, from not having any experience at all to having positive as well as negative experiences. The participants who said that they did not

have any experience related this to the fact that they had not been in contact with health care services or had always received the help they needed, meaning that they interpreted prioritisation as a negative act rather than taking precedence. The participants' reasoning emphasised the difficulty of setting priorities and having a standpoint on these issues. The participants also highlighted the necessity of all people having what they need, young as well as old. The text, however, revealed two opposite standpoints, the first view being that everyone should be treated in order of succession while the other view acknowledged the need for prioritisation for the most severely ill. Signs of dissatisfaction with how resources were allocated were shown in the text, as were positive and negative thoughts about willingness to pay for treatment. The participants' reasoning about prioritisation in health care was based on their own experiences as well as on their perception of how prioritisation ought to be done. Their reasoning could be understood in the categories: Feeling secure and confident in the health care system, Being old means low priority, Prioritisation causes worries, Using underhand means in order to be prioritised, Prioritisation as a necessity, Being averse to anyone taking precedence over others, Having doubts about the distribution of resources, and Buying treatment requires wealth.

INSERT TABLE 2

Feeling secure and confident in the health care system

The text revealed that the participants felt confidence in the health care system and that they were secure with the way their needs had been fulfilled. Being prioritised meant having one's needs fulfilled. Their experience concerned hospital-based health care as well as municipal elder care. Participants who had been in contact with the health care system in cases of emergency felt that they had been taken well care of. This was also shown when they had

diseases requiring repeated care, where they and their relatives had positive experiences. For those persons, prioritisation was not seen as a problem or an impediment.

> "I have been prioritised several times and I think it works. Once when I had my coronary bypass and now when I've got my cancer. I passed several in the queue when I was treated. I am positive." (M 66)¹

"There is so much in the newspaper about the scarcity of special accommodations for older people, so I am glad that I got a place here. If it was today I might have been without one. I was prioritised." (W 81)

Being old means low priority

The text conveyed that being old implied having low priority. There were stories about long periods spent in waiting rooms as well as on waiting lists. This in turn aroused feelings of anger and frustration as the reason for waiting was interpreted as a consequence of their age. The participants also feared that treatments and examinations were granted to a lower degree to older people. The feeling of anger and frustration increased when they felt they encountered bad manners and disrespect, for example when not being listened to and when symptoms were disregarded or neglected.

"I got a brochure sent home saying that we older people should visit the health centre and not the emergency unit, because the emergency unit was not for us, it said clearly and plainly. Yes, it is true, they just want to give us painkillers and then immediately send us back home to home service. We have no place in hospital, that is my experience." (W 78)

"A while ago, I got lot of blood on the paper when I went to the toilet. Although I asked for help, nobody cared. If I had been younger, I am sure they would have helped me. I don't think you always know when you are not prioritised." (W 66)

"When my mother became ill last July and my daughter and I went with her to hospital there was an awful row. The doctor came and said that relatives keep coming here with their family members when they are going on vacation. Then my daughter got really upset and that doctor was not spared the truth. It ended up with a crying doctor and my mother hospitalised for two months." (W 78)

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¹ The codes refer to the gender (man/woman) and age of the participant

Prioritisation causes worries

The text revealed a worry about what the future might bring about when becoming in need of care and service. Especially future needs of moving to special accommodation were highlighted as such an option was felt to be decreasing in the near future. Becoming older and in need of health care was thus a scaring thought. The view that older people were not wanted as patients, and thereby not prioritised, created feelings of being abandoned and losing security, which in turn led to anxiety. The participants also highlighted that today one has to have extensive needs to be allowed to enter special accommodation, and that this service ought to be available also for single people, to avoid loneliness and feelings of helplessness.

"When I consider that I am an older, single woman, I can't help wondering how I will be prioritised." (W 78)

"When I was in rehabilitation after aorta surgery I told my daughter to get rid of my apartment because I was not going to live alone any more, absolutely not. If I didn't get a place in special accommodation, the care and service unit would have to put me in the market square. That's it. But, at last, I ended up here. I mean, you really have to speak up and explain otherwise nothing happens." (W 80)

"Prioritisations make me afraid of getting old. What will happen to me if I have to live alone?" (W 72)

Using underhand means in order to be prioritised

The text revealed that others, or the participants themselves, had used underhand means to take precedence, and they were convinced that money and power influenced prioritisation.

This was experienced as a common problem and considered unfair. The participants also highlighted that people with injuries due to sports and physical activity seemed to be prioritised before older people. When in need of health care, having useful contacts was seen as an advantage, for example close relations with physicians or other persons in powerful positions. The participants also had experiences of using contacts to take precedence, but mostly expressed a fear of others using this means, thereby getting low priority for

themselves. Another way to use underhand means was to persistently ask and nag about the possibility of getting priority, and they said that it was no use to sit down and stay quiet.

Another way was to use threats about going to another doctor or another clinic or to take precedence on the waiting list due to a physician's guilty conscience related to previous mistreatment.

"I am prepared to pay to get help but I have always got what I want. However, I must admit that it has been of great use to have the right contacts." (W 66)

"I have never waited because I nag until I get help. You can't pity yourself, you have to act." (W 66)

Prioritisation as a necessity

In their reasoning the participants were open to the idea that prioritisation was necessary.

They said that it was because resources were limited and public costs were increasing.

However, the participants stated that there should be no doubt about how and why a specific prioritisation was made and it had to be done in the open, even if it was difficult for ordinary people to have an opinion about who should be prioritised. Prioritisation was also seen as a method to distribute health care equally and to provide it to the most seriously ill.

"It is tremendously difficult to sit at your kitchen table and have insight into how prioritisations are made. How should we know who should be prioritised?" (W 72)

"We have to give the resources to the most important things, I've got the feeling that the same persons come here at all times, occupying expensive time." (W 66)

"You have to prioritise so that a person who is losing his life comes first, others have to wait." (M 81)

When discussing prioritisation the participants identified both youth and old age as reasonable criteria. The arguments for using youth as a criterion were that older people were finished with life and the young ones have their life ahead of them. Younger people were further seen

as more productive and more economically profitable than older people. Although the participants thought that everyone should get help, the younger should be prioritised in case of scarce resources.

"People of young age are needed in the production and the older ones have to wait. I can't force myself before a boy who is driving the bus in this town. As a pensioner, I can wait and if we don't keep society going it will go wrong." (M 81)

"Statistically an 80-year-old person will live only three years more and society will save a lot of money by treating a 60-year-old instead. It would be a different thing if we had unlimited resources." (W 78)

Other participants argued that *older* people should be prioritised. The reasons expressed were that older people have less time left and were often suffering from several diseases. Older people were further considered more fragile and should therefore not spend their last time waiting for health care. Other arguments for prioritising older people were that they have paid taxes all their life and contributed to today's welfare. It was also seen as a human right that older people should get a place in special accommodations when they are no longer able to live a tolerable life at home.

"Old people should not have to wait, they should be cared for at once. But I believe we are left waiting because we don't cost any sickness benefit." (W 66)

"When the day comes when I can't go to the toilet myself or I can't go for a glass of water then I want a place in a home. There should be a place for me then." (W 78)

Other arguments for taking precedence were based on the principle of need and solidarity, as the participants suggested that the most seriously ill patients should be treated first, regardless of age, and this was also seen as the intention of prioritisation on the whole. Not only serious illness was an indicator for prioritisation, the participants also emphasised pain, suffering and increased quality of life as important indicators in prioritisation.

"The most seriously ill patients should come first, a friend of

mine waited 102 days for radiotherapy, should have been two days, these things have to go fast." (M 66)

"If my surgery is postponed because of someone who is more seriously ill, needs to go first, I have to accept that. It could be me next time that needs to take precedence." (M 66)

Being averse to anyone taking precedence over others

The text revealed the aversion to anyone taking precedence over others, meaning that the first to come should be served first. One reason for this was that if someone took precedence it would create worries and envy for others. The participants based their reasoning on the belief that it was unfair that anyone should be considered more important than another and that everyone should get what they need as a human right. Their arguments also revealed that money or "VIP lanes" were not supposed to influence prioritisation.

"Health care is important in society to everybody, we are treated in order of succession, aren't we?" (M 90)

"Everyone should be treated equally. If there aren't enough resources for that, more tax revenue has to be allocated." (W 66)

Having doubts about the distribution of resources

The text revealed a disappointment and dissatisfaction with politicians and the way they allocated and administrated health care resources and tax revenue. The politicians' knowledge of how to handle health care and the work of the regional board was questioned. The participants thought that there ought to be less queues in health care and compared the present situation with the past, saying that everything had turned out worse. The prevailing opinion was that care and service for older people and access to special accommodations had decreased.

"I don't understand what they do with the money. Perhaps it goes to unjustified high salaries instead of more nurses." (M 66)

"When reaching my age one should not have to cook and clean, you should be treated like a princess. Four billion was earmark

for health care, where has it gone?" (W 87)

Buying treatment requires wealth

The text reflected both pros and cons concerning the willingness to pay, and the participants also used different principles when reasoning about wanting to wait or to pay for treatment. The participants used health and wealth factors as well as ethical considerations when arguing about paying for treatment. One reason to pay to be treated earlier was to minimise the risk of complications due to long waiting time or to increase quality. It all depended on how seriously ill a person was and what he or she would gain if it were worth paying for. The text also gave the impression that willingness to pay depended on the quantity of time remaining in life.

"€1100 is nothing when it comes to health. When it comes to winning in a lottery people pay anything, I have seen that in the stores." (M 93)

"When I went fishing once there was an older man at my side and he told me that he hadn't been fishing for a while because he had not been able to see but now he had gone through surgery and could see again. It was worth every penny." (M 60)

"If you are as old I am there is no time to stay on a waiting list, I have to pay although it would hurt my wallet." (W 90)

The participants' way of reasoning showed that their willingness to pay was also related to their ability to pay. Without this ability the participants stated that there was no choice to consider and it became more tempting to wait and get surgery for free.

"I don't have €1100 so that's it. I will stay on the waiting list." (W 78)

The participants further emphasised that all people are of equal value and everyone has the same rights to health care regardless of age, thus referring to the principal of human dignity and the principal of justice. Paying to take precedence was seen as morally wrong and unfair to other persons waiting for treatment.

"I should be in the queue, incidentally I already am. I think it is selfish to pay to pass the others." (W 78)

"I can pay €1100 without problem but the question is if I should. I think I would stay on the waiting list, course I have said before that it should not be permitted to pay to take precedence but if you can't see, God knows, I think I would have paid. It is terrible." (M 81)

DISCUSSION

The aim of this study was to investigate the reasoning of people aged 60 years and over about prioritisation in health care with regard to age and willingness to pay. Their reasoning could be understood in the categories: Feeling secure and confident in the health care system, Being old means low priority, Prioritisation causes worries, Using underhand means in order to be prioritised, Prioritisation as a necessity, Being averse to anyone taking precedence over others, Having doubts about the distribution of resources, and Buying treatment requires wealth.

Methodological considerations

Each study should be evaluated in relation to the procedures used to generate the findings, and the findings must be as trustworthy as possible (20). In qualitative research, the concepts of credibility, dependability, confirmability and transferability are used to describe various aspects of trustworthiness (21). To increase credibility most of the interviews were conducted after spending one to two hours with medical examinations and tests with the participants, giving opportunities for the participants and the interviewer to get to know each other. The interviews with the participants in the care and service part of the GAS study took place in their homes, and a sufficient amount of time was allowed for the interviewers to understand the participants' life situation and to give opportunities for the participants and the

interviewers to get to know each other and thereby increase the participants' feelings of confidence.

To strengthen dependability and confirmability (21), two of the authors (AKE, EW) initially analysed the text independently. The interpretations were then compared and discussed against the pre-understanding of the two authors. In the next phase, the third author (IRH) discussed the analysis and interpretation with the first two authors. All three authors had continuous discussions about the findings during the process of analysis process. To further strengthen the trustworthiness and make the findings open to confirmation, quotations were used to reflect the interpretation of the text. Since the participants were selected partly from a group of healthy older people and partly from older people receiving continuous care and service, the findings most likely reflect the characteristics of the group of older people in general and the findings may thus be transferable to the group of people aged 60 years and over. Thus, several steps were taken to increase the trustworthiness in relation to data collection and the process of analysis as well as in relation to the findings.

Discussion of the findings

The findings revealed contradictory opinions and experiences of prioritisation in health care. The participants, on the one hand, felt secure and confident in the health care system and did not view prioritisation as an option. On the other hand, they felt that being old means low priority and that prioritisation causes worries. The participants who felt secure and confident have seemingly got what they need in terms of care and service in the public sector and did not feel that they hade been subject to prioritisation. It seemed as if they equated prioritisation with not being prioritised and as something negative that they have then been spared. The reason for this could be either that the respondents have not been exposed to prioritisation or

that prioritisation has not been made explicit. Another reason could be that the participants were not aware of the possibility of being prioritised or the risk of someone else taking precedence. According to the Swedish Parliamentary Priority Commission, prioritisation has not always been made explicit and has sometimes been conducted covertly (7). Several researchers (22-25) have emphasised the importance of transparency in prioritisation. For example Litva et al. (25) interviewed 57 informants in UK about involvement in particular types of ration decisions. Over two third of the informants highlighted the importance of public involvement and emphasised that lay knowledge could make an important contribution to health-care decision making. The informants further pointed at the need for accessible information to enable the public to contribute rationally and reasonably to the decision making process. It thus seems to be of importance to increase the transparency in priority setting in health care as well as to enlarge the public debate in this area.

Despite the findings that prioritisation is a necessity and that being old means low priority, the participants' reasoning revealed different views on the basis on which prioritisation should be undertaken. There were participants who argued that *young* people should be prioritised in health care, thereby supporting Williams (11), Callahan (12) and Daniels (13), as they considered rationing by age acceptable. The opposite view was also expressed, however, thereby supporting the ideas of Cohen-Almagor (8), Bell (9) and Rivlin (10), who did not favour rationing due to old age. The argument that younger people should be prioritised was based on the view that they were productively and economically more profitable than older people, while the argument that older people should be prioritised was based on the shorter life span they were likely have left and the fact that they often suffered from several diseases. In addition they had also paid taxes all their lives in order to get treatment whenever needed. This is in line with the findings by Lindblad et al. (26), who interviewed 22 patients (30–82

years) with rheumatoid arthritis about priority settings for new medicines. Some participants stated that younger persons should be prioritised because it might be necessary to favour them in terms of allocation of medication to avoid losses in productivity, while others pointed out that age should not influence prioritisation and apprehension that society would favour people in the workforce over older people. They instead highlighted people's equal value whether fit for work or not (26). This is also in line with earlier quantitative research concerning older people's views about prioritisation, showing that a majority, 81 %, did not want prioritisation in health care to be based on age, neither in terms of youth nor old age. Instead, factors such as quality of life, pain and health had higher impact on how they wanted people to be prioritised for treatment (5). This is also in line with Dicker and Armstrong (27) who showed in interview study from UK (n=16, aged 20-73) that the single most important attribution that interviewees identified as a determinant of their opinions concerning prioritisation was visible unmet need. The informants further showed a lack of acceptance that prioritisation should be necessary and pointed to a variety of ideological positions (27). It could be argued that the participants in our study have experienced being in a low priority group, so it is reasonable to assume that the wish to prioritise older people was a reflection of this awareness. Older people's reasoning about being judged as having low priority might be based on their encounter with professionals in health care. This indicates the variable adherence to the ethical principles and the recommendations of the Swedish Parliamentary Priority Commission, in terms of its opposition to the use of age as a criterion for prioritisation in health care.

The participants had doubts about the distribution of resources. The present situation was compared with the past, and the participants felt that everything had turned out worse. It has been verified by Sundstrom et al. (2) and the National Board of Health and Welfare (1) that,

despite the increased number of older people, the total spending on this group in Sweden has stagnated. This may worry older people. According to Nunes (28) citizens have the right to know how policy makers spend their taxes in health care. Although health is a major individual right, it has to compete for resource with other social goods such as education, job training and environmental protection, and seemingly any allocation decision affects other important social rights (28). The participants further argued that if enough resources were allocated to health care, people should not have to pay for treatment. The findings showed that buying treatment requires wealth but also that respondents were averse to anyone taking precedence over others because of financial advantage. As the willingness to pay for treatment corresponded to the ability to pay, questions about the willingness to pay made people uncomfortable and uncertain about what is morally right or wrong, showing comprehension of the difficulty in addressing these issues. Dicker and Armstrong (27) conclude that people in general argue from what they perceived to be the needs of others. The findings in this study indicate that the principle of justice and the principle of need and solidarity were in conflict with that of self-interest when deciding to pay in order to take precedence over others. Paying to take precedence was further seen as morally wrong and unfair to other persons waiting for treatment. Further, although the participants had doubts about distribution of resources, they were aware of the inconveniences and problems the decision-makers have to deal with. These problems have to be solved in the open, on a political and professional level, in a scientific as well as ethical way, to maintain patients' trust in the public health care system.

A lot of the participants' arguing and reasoning could be translated into the ethical principles. For example the principle of need and solidarity could be referred to when the participants suggested that the most seriously ill patients should be treated first. The health maximisation

principle could also be referred to when the participants expressed that everyone should have what they need. This is in line with research by Cookson and Doland (29) who investigated ethical principles of health care rationing in an interview study with 60 respondents (aged 18-70 years) in UK. The results showed that the informants used a combination of three main rational principles; priority to those in immediate need, health maximisation and equalisation of life time health. (29). Thus there is reason to believe that older people support the same ethical principles as the general population do, although it is on their behalf ration decision often are being made.

CONCLUSIONS

The expressed views of people aged 60 years and over about prioritisation in health care indicated contradictory opinions and experiences. The participants felt secure and confident in the health care system but also stated that being old means being in a low priority category and that prioritisation causes worries. This could be explained by the fact that prioritisation has not been done transparently, which makes it important to highlight this requirement for the general public. Prioritisation was considered a necessity but different opinions were revealed concerning the basis for age-related prioritisation; the priority of younger people was based on economic reasons while humanitarian reasons were cited in favour of prioritising older people. The text revealed doubts about the distribution of resources in health care, which could be due to awareness that total spending on aged people in Sweden had stagnated. The findings also showed that participants were averse to anyone taking precedence over others and were aware that buying treatment requires wealth, which made them express discomfort and uncertainty about what was morally right or wrong in regard to willingness to pay for health care.

ACKNOWLEDGEMENT

We are most grateful to the older persons for their participation in this study, and to the nurses involved for their support and co-operation with data collection. We are also grateful to Alan Crozier for revising the language, and to the Vardal Foundation for Health Care Sciences and Allergy Research no E2003 022/ E2005 003, the Vårdal institute, Lund University and the Swedish Council for Working Life and Social Research, for financial support.

The GAS study is a part of Swedish National Study on Ageing and Care, SNAC,

(www.snac.org) financially supported by the Ministry of Health and Social Affairs, Sweden,
the participating county councils, municipalities and university departments.

REFERENCES

- 1. The National Board of Health and Welfare. Care and service of the older (In Swedish: Socialstyrelsen, Vård och omsorg om äldre. Lägesrapport 2005), 2006.
- 2. Sundstrom G, Johansson L, Hassing LB. The shifting balance of long-term care in Sweden. *Gerontologist*. 2002 Jun;42(3):350-5.
- 3. The Swedish Health and Medical Services Act (In Swedish: Hälso- och Sjukvårdslagen). Stockholm: Socialdepartementet; 1982:763.
- 4. Priorities in health care. Perspectives for politicians, profession and citizens. Final report by The Swedish Parliamentary Priorities Commission. (In Swedish: Prioriteringar i vården). Stockholm: Socialdepartementet; 2001.
- 5. Werntoft E, Hallberg IR, Elmståhl S, Edberg A-K. Older people's views of priorities in health care. *Aging Clinical and Experimental Research*. 2005;17 402-11.
- 6. Werntoft E, Hallberg IR, Elmståhl S, Edberg A-K. Older people's views of how to finance increasing health care costs. *Ageing & Society*. 2006;26:497-514.
- 7. SOU. Priorities in health care. Ethics, economy, implementation. Final report by The Swedish Parliamentary Priorities Commission. (In Swedish: Vårdens svåra val). Stockholm: Socialdepartementet; 1995.
- 8. Cohen-Almagor R. A critique of Callahan's utilitarian approach to resource allocation in health care. *Issues Law Med.* 2002 Spring;17(3):247-61.
- 9. Bell NK. What setting limits may mean: a feminist critique of Daniel Callahan's Setting Limits. *Hypatia*. 1989 Summer;4(2):169-78.
- 10. Rivlin MM. Why the fair innings argument is not persuasive. *BMC Med Ethics*. 2000;1:E1.
- 11. Williams, A. (1997) Intergenerational equity: an exploration of the 'fair innings' argument. *Health Econ*, 6, 117-32.
- 12. Callahan D. Health care struggle between young and old. *Society*. 1991 Sep-Oct;28(6):29-31.
- 13. Daniels N. Just health care. Cambridge: Cambridge Univ. Press; 1985.
- 14. Bishai DM, Lang HC. The willingness to pay for wait reduction: the disutility of queues for cataract surgery in Canada, Denmark, and Spain. *J Health Econ*. 2000 Mar;19(2):219-30.
- 15. Anderson G, Black C, Dunn E, Alonso J, Christian-Norregard J, Folmer-Anderson T, et al. Willingness to pay to shorten waiting time for cataract surgery. *Health Aff* (Millwood). 1997 Sep-Oct;16(5):181-90.

- 16. Jakobsson U, Hallberg IR. Mortality among elderly receiving long-term care: A longitudinal cohort study. *Aging Clinical and Experimental Research*. 2006; 18: 503-511.
- 17. Werntoft E, Hallberg IR, Edberg A-K. Prioritisation and resource allocation in health care. The views of older people receiving continuous public care and service. Submitted for publication.
- 18. Berg BL. Qualitative research methods for social sciences. 5th ed: Boston; 2004.
- 19. Downe-Wamboldt B. Content analysis: method, applications, and issues. *Health Care Women Int*. 1992 Jul-Sep;13(3):313-21.
- 20. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004 Feb;24(2):105-12.
- 21. Lincoln YS, Guba EG. Naturalistic inquiry. Beverly Hills, Calif.: Sage; 1985.
- 22. Ham C, Coulter A. Explicit and implicit rationing: taking responsibility and avoiding blame for health care choices. *J Health Serv Res Policy*. 2001 Jul;6(3):163-9.
- 23. Mullen PM. Quantifying priorities in healthcare: transparency or illusion? *Health Serv Manage Res.* 2004 Feb;17(1):47-58.
- 24. Daniels N. Accountability for reasonableness. BMJ. 2000 Nov 25;321(7272):1300-1.
- 25. Litva A, Coast J, Donovan J, Eyles J, Shepherd M, Tacchi J, Abelson J, Morgan K. "The public is too subjective": public involvement at different levels of health-care decision making. *Social Science & Med*icine. 2002, 1825-1837.
- 26. Lindblad AK, Hartzema AG, Jansson L, Feltelius N. Patients' views of priority setting for new medicines. A qualitative study of patients with rheumatoid arthritis. *Scand J Rheumatol*. 2002;31(6):324-9.
- 27. Dicker A, Armstrong D. Patients' views of priority setting in health care: an interview survey in one practice. *BMJ*. 1995 Oct 28;311(7013):1137-9.
- 28. Nunes R. Evidence-Based Medicine: Anew tool for resource allocation. *Medicine, Health Care and Philosophy.* 2003; 6, 297-301.
- 29. Cookson R, Dolan P. Public views on health care rationing: a group discussion study. *Health Policy*. 1999; 49, 63-74.

Table 1. Demographics of the participants

| Characteristics | 5 | n=446 | % | | | | |
|--------------------------------|--------------------|------------------------------------|-------|--|--|--|--|
| Age mean (SD) | | 60 – 101 years 76 years (10.57) | | | | | |
| Sex | | | | | | | |
| Men/women | | 178/268 | 40/60 | | | | |
| Living | | | | | | | |
| Large city | (>200 000) | 170 | 38 | | | | |
| Small city | , | 205 | 46 | | | | |
| Village | (<50 000) | 71 | 16 | | | | |
| Receiving continuous municipal | | | | | | | |
| care and service | ce | | | | | | |
| Yes/no | | 146/300 | 33/67 | | | | |
| Housing | | | | | | | |
| 0 | cial accommodation | 392/54 | 88/12 | | | | |
| Access to €1500 | 0 | | | | | | |
| yes/no | | 370/76 | 83/17 | | | | |

Table 2. Older people's reasoning about prioritisation in the health care system

CATEGORIES

Feeling secure and confident in the health care system

Being old means low priority

Prioritisation causes worries

Using underhand means in order to be prioritised

Prioritisation as a necessity

Being averse to anyone taking precedence over others

Having doubts about the distribution of resources

Buying treatment requires wealth