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From the Department of Health Sciences, Medical Faculty,
Lund University, Sweden 2006

OLDER PEOPLE'S VIEWS OF PRIORITISATION AND RESOURCE ALLOCATION IN HEALTH CARE

av

Elisabet Werntoft
Leg sjuksköterska

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<p>Abstract</p> <p>The aim of this thesis was to investigate older people's views and experience of prioritisation and resource allocation in health care, which is important because older people are the group that use public health care and service most. The aim was also to investigate differences in the view of prioritisation and resource allocation in relation to age, gender, housing, health-related quality of life, financial situation and degree of dependency between the participants receiving and those not receiving care and service. A further aim was to describe older people's reasoning about prioritisation in health care. The sample was identified in a longitudinal cohort study in southern Sweden called Good Ageing in Skane (GAS), 902 participants not receiving care and service, aged 60–93 years, and 146 participants receiving care and service, aged 66–100 years. Data were collected in personal interviews based on a questionnaire. The total sample was divided into the age groups young-old (60–75 years), old-old (76–84 years) and oldest old (85–100 years). Quantitative descriptive statistics, comparative statistics and multinomial and multiple logistic regression analyses as well as qualitative analyses were used when analysing the data.</p> <p>Eighty-one percent of the participants not receiving care and service and 85 % of the participants receiving care and service did not want age to be a criterion for prioritisation (Papers I and III) but their reasoning revealed that they experienced that <i>being old meant low priority</i> (Paper IV). In their reasoning the participants saw <i>prioritisation as a necessity</i> but also emphasised that all people are of equal value and that everyone should have the same rights to health care regardless of age (Paper IV). It was clearly stated that the participants wanted physicians to decide who should be prioritised (Papers I and III). The findings also showed that the oldest-old and men prioritised younger people to a higher extent than the other two age groups, while women prioritised older patients to a higher extent (Paper I). The participants not receiving care and service were furthermore reluctant to give priority to treatment for lifestyle-related diseases than participants receiving care and service (Framework). The participants' reasoning in relation to the willingness to pay for treatment revealed that they experienced that <i>buying treatment requires wealth</i> (Paper IV). Most of the participants not receiving care and service (63 %) but only 48 % of participants receiving care and service wanted to pay €1100 to get cataract surgery at once instead of being on a waiting list for 18 months, but significantly fewer participants receiving care and service actually had access to €1500 ($p < 0.001$) (Framework). Women were also less willing to pay for treatment than men, which also seemed to be associated with a worse economic situation (Paper II).</p> <p>The results showed that older people did not emphasise age as a criterion for prioritisation, which is in contrast to earlier studies including younger people. This thesis further showed that age, gender, financial situation and receiving care and service or not, influenced the way the respondents viewed prioritisation and resource allocation, while housing, grade of dependency and HRQoL seemed to have limited influence.</p>		
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Date 28th of July 2006

Department of Health Sciences, Faculty of Medicine, Lund University, Sweden,
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OLDER PEOPLE'S VIEWS OF PRIORITISATION AND RESOURCE ALLOCATION IN HEALTH CARE

Elisabet Werntoft



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*Muskelmassan krymper
när man blir äldre.
Modet sjunker.
Förmågan att uthärda
är på topp.*

Kristina Lugn
Ur: Hej då, ha det så bra (2003)

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ABSTRACT

The aim of this thesis was to investigate older people's views and experience of prioritisation and resource allocation in health care, which is important because older people are the group that use public health care and service most. The aim was also to investigate differences in the view of prioritisation and resource allocation in relation to age, gender, housing, health-related quality of life, financial situation and degree of dependency between the participants receiving and those not receiving care and service. A further aim was to describe older people's reasoning about prioritisation in health care. The sample was identified in a longitudinal cohort study in southern Sweden called Good Ageing in Skane (GAS), 902 participants not receiving care and service, aged 60–93 years, and 146 participants receiving care and service, aged 66–100 years. Data were collected in personal interviews based on a questionnaire. The total sample was divided into the age groups young-old (60–75 years), old-old (76–84 years) and oldest old (85–100 years). Quantitative descriptive statistics, comparative statistics and multinomial and multiple logistic regression analyses as well as qualitative analyses were used when analysing the data.

Eighty-one percent of the participants not receiving care and service and 85 % of the participants receiving care and service did not want age to be a criterion for prioritisation (Papers I and III) but their reasoning revealed that they experienced that *being old meant low priority* (Paper IV). In their reasoning the participants saw *prioritisation as a necessity* but also emphasised that all people are of equal value and that everyone should have the same rights to health care regardless of age (Paper IV). It was clearly stated that the participants wanted physicians to decide who should be prioritised (Papers I and III). The findings also showed that the oldest-old and men prioritised younger people to a higher extent than the other two age groups, while women prioritised older patients to a higher extent (Paper I). The participants not receiving care and service were furthermore reluctant to give priority to treatment for lifestyle-related diseases than participants receiving care and service (Framework). The participants' reasoning in relation to the willingness to pay for treatment revealed that they experienced that *buying treatment requires wealth* (Paper IV). Most of the participants not receiving care and service (63 %) but only 48 % of participants receiving care and service wanted to pay €1100 to get cataract surgery at once instead of being on a waiting list for 18 months, but significantly fewer participants receiving care and service actually had access to €1500 ($p < 0.001$) (Framework). Women were also less willing to pay for treatment than men, which also seemed to be associated with a worse economic situation (Paper II).

The results showed that older people did not emphasise age as a criterion for prioritisation, which is in contrast to earlier studies including younger people. This thesis further showed that age, gender, financial situation and receiving care and service or not, influenced the way the respondents viewed prioritisation and resource allocation, while housing, grade of dependency and HRQoL seemed to have limited influence.

ABBREVIATIONS

Add an	Additional analyses
ADL	Activities of daily living
CVM	Contingent valuation methods
EYLS	Equity-adjusted years of life saved
GAS	Good Ageing in Skåne
HRQoL	Health-related quality of life
I-ADL	Instrumental activities of daily living
OECD	Organisation for Economic Co-operation and Development
P-ADL	Personal activities of daily living
QALY	Quality-adjusted life year
RPS	Random Paired Scenario
SALA	The Swedish Association of Local Authorities
SF-12	Short Form Health Survey (12-item)
SNAC	Swedish National study on Ageing and Care
THR	Total hip replacement
TKR	Total knee replacement
VHI	Voluntary health insurance
WTA	Willingness to accept
WTP	Willingness to pay

DEFINITIONS

According to Crowther (1993), one definition of *view* is “personal opinion or attitude”; thought or observation on a subject. The same reference defines *attitude* as: way of thinking or behaving. Another definition, used by Eagly and Chaiken (1993), is: attitude is a psychological tendency that is expressed by evaluating a particular entity with some degree of favour or disfavour. “Preference” could be used in the sense of “attitudes”, but for the sake of clarity they should be reserved for use in circumstances where whole clusters of idea structures are not necessarily at hand. In some situations “preferences” are expressions of “valuations” or “attitudes”, but are generally more sporadic and spontaneous (Rosén, 2002). In this thesis *view* is used to mean personal thoughts or observations.

ORIGINAL PAPERS

This thesis is based on the following papers, referred to in the text by their Roman numerals:

- I Werntoft E., Hallberg I. R., Elmståhl S., Edberg A.-K. (2005) Older people's views of priorities in health care. *Aging Clinical and Experimental Research*, 17, 402–411
- II Werntoft E., Hallberg I. R., Elmståhl S., Edberg A.-K. (2006) Older people's views of how to finance increasing health care costs. *Ageing & Society*, 26, 497–514.
- III Werntoft E., Hallberg I. R., Edberg, A.-K. Prioritisation and resource allocation in health care, The view from older people receiving continuous public care and service. Submitted for publication
- IV Werntoft E., Hallberg I R., Edberg A-K. (2007) Older people's reasoning about age related prioritisation in health care. Accepted for publication in *Nursing Ethics*.

The papers have been reprinted with the kind permission of the respective journals.

INTRODUCTION

As older people are the group that use public health care and service most, it is important to explore their view and experience of prioritisation and of resource allocation in regional as well as municipal health care and service. To Swedish people in general, public health care and services represent confidence and security in life (SOU, 2001a). This is where people, when at their most vulnerable, can turn, and it is an institution available day and night. As long as people can trust and rely on this knowledge there is a readiness among the citizens to accept prioritisation in health care and service (SOU, 2001a). Prioritisation means “putting first” – opting for one thing and thereby discarding another. Prioritisation has always existed and will always be necessary in the health care sector on various levels and in various ways. However, for democracy people want, and have the right, to know and have a chance to influence the grounds on which priorities are decided (SOU, 1995) and one way to do this is to reveal the citizens’ view of prioritisation. This has been done in several studies (Johannesson and Johansson, 1996, Myllykangas et al., 1996, Rosén and Karlberg, 2002, Ryyanen et al., 1999) that have addressed younger persons or a mixed population with rather low representation of older persons. The results of these studies have shown that old age was a criteria for not being prioritised by young and middle aged people (Johannesson and Johansson, 1996) as well as by physicians (Ryyanen et al., 1997). Further, ration theories (Daniels, 1985, Callahan, 1995) suggest limited resources to older people in times of scarce resources. Since older people may be the target in prioritisation, it seems important to investigate their views of prioritisation and resource allocation, with and without experience of health care, not only from a democratic point of view but also to illuminate a field that appears to be sparsely investigated.

BACKGROUND

People in the developed countries are living longer, and in combination with fewer births this results in a significantly changing age profile of populations in many parts of the world (Williams, 1997a). In Sweden, the average life expectancy is 77 years for men and 82 years for women. The number of people over 65 in Sweden is 1.6 million, which is almost one fifth of the total population, while the number of people aged 80 years and above is 480,000, which is about 5 % of the total population (Statistics, 2005). Furthermore, the older population (65 years and over) cannot be considered as homogeneous since there is too much that distinguishes the oldest old from younger old people, i.e. they are members of different cohorts that have lived through different historical times and they have grown up under different conditions and in different contexts (Field and Gueldner, 2001). In several studies (Mariotto et al., 2003, Zweibel et al., 1993) older people have been presented as one large group but in reality the group of older people represents a span between the youngest old and the oldest old that corresponds to up to 40 years, and as health status and life experiences differ within this group, the view of health care and prioritisation also may do so. There is

thus a need to consider differences between age groups within this wide group of older people.

As older people are affected more than younger people by diseases, they will further be the ones mostly affected by prioritisation in health care. Most studies concerning people's views of prioritisation are based on participants from the general population, i.e. with little or no representation of older people. It is essential that older people are included in clinical studies, yet Bugeja et al. (1997) found that a third of the original research papers in major medical journals excluded older people without justification. Williams (2000) also stated that older people are often excluded from research trials, have their surgical operations cancelled more often and are less often accepted for cardiological investigation and intervention than younger people. One study on views of prioritisation, performed in a Swedish context, reported old age as a factor that the population wanted to use in prioritisation (Johannesson and Johansson, 1996). The Swedish study, and most other studies, had samples in which older people are sparsely or not represented at all. For instance, among 1000 randomly selected adults who were asked about life saving with regard to age in the study by Johannesson and Johansson, the youngest persons were 15 years old and the mean age was 46.6 (SD 18.5). The majority of the sample was thus under 65 years of age and thereby had little experience of health care and difficulties imagining life when old and unhealthy.

Prioritisation in health care

Prioritisation in health care is an issue of growing importance. In publicly financed health care systems, the combination of increasing demands and constrained resources has led policymakers to address this issue more directly than in the past, with the result that prioritisation has become more explicit (Ham, 1997). The Swedish health care system is financed by taxes and is governed democratically by political decisions in democratically chosen conventions, at both local and national levels (Socialstyrelsen, 1998). Horizontal or macro prioritisation is done on the political level and concerns different fields, for example allocation of resources between non-institutional care and hospital treatment or between different disease groups. The ambition of the politicians is to reach the goals set up for health care concurrent with the need to keep the costs down (SOU, 2001a). Among citizens, vertical or micro prioritisation is discussed most. Vertical prioritisation concerns how care should be performed and how much effort should be made for individual persons. These types of prioritisation are carried out by the working staff that are also responsible for their decisions. If the working staff, because of limited resources, is unable to achieve the goals that have been set up for health care, they could jeopardise their own well-being (SOU, 2001a). The administrators in health care often have an intermediate position between the other two groups and are at risk of being placed in situations where vague decisions from the politicians could be contrary to the staff's need for more resources (SOU, 2001a). Both vertical and horizontal prioritisations should emanate from knowledge about and views of the needs of health care among citizens (Waldau, 2001). From the citizens' point of view, the most important thing in prioritisation is to have the possibility to receive

health care and to have their needs fulfilled. From the professional point of view, the ambition is to give the best health care possible with the aid of existing knowledge and resources. From the politicians' point of view it seems most important to achieve the goals that have been set up for health care with the available money (SOU, 2001a). Prioritisation between different types of health services has not as yet been a common research topic internationally (Kinnunen et al., 1998) and needs to be further explored since the struggle about the available money will probably increase in health care sectors.

Prioritisation policy from an international perspective

Several efforts to handle the issues of prioritisation have been made in different countries. The emergence of explicit prioritisation is exemplified by experience in Oregon, New Zealand, the Netherlands, the UK, Norway, Finland and Sweden. In all of these countries, prioritisation is high on the health policy agenda as publicly financed health care has come under review (Ham, 1997). The state of Oregon has developed a unique method to set priorities for health services (Dixon and Welch, 1991); a Health Services Commission was appointed in 1989 to make recommendations on how Medicaid coverage could be expanded to groups in the population who had previously been excluded and how priorities could be set within the Medicaid programme (Ham, 1997). The Commission drew up a list of conditions and treatments to be given priority for funding. This was based on the result of public consultation, research evidence, professional judgements by its members and tested through economic analyses. The Oregon health plan was implemented in 1994 with 565 out of 696 treatments on the final priority list being funded. Since, then the Commission has kept the list under review and moving treatments up and down the list in the light of experience (Ham, 1997).

In the Netherlands the Dunning Committee, 1991, offered advice to the Dutch government on the determination of priorities in the reformed social insurance system. The Committee set out framework of values and principles intended to assist decision makers to decide which services should be in the basic health care package. The Dunning Committee believed that explicit prioritisation, including the exclusion of certain services, was necessary if essential care was to be guaranteed for all (Ham, 1997).

The first Norwegian model presented examples of diseases and caring measures in various groups but did not contain a complete list of diagnoses and treatments for prioritisation (NOU, 1987). The model made a constructive contribution to the debate on principles of resource management and has been made law by the Norwegian Parliament. The Norwegian model has been unfavourably reviewed as the prioritisation decisions it lead to were seen to be more or less self-evident in the clinical context. The purpose of the model was, however, to control the allocation of resources, and in this respect it has made an important difference (SOU, 1995). The Norwegian government revised its model ten years later to evaluate and further develop it (NOU, 1997). The revised guiding principles were made clearer and expert

groups were supported to find a system for national prioritisation within their respective areas (SOU, 2001a). From an international standpoint, Norway set up the first national priority commission. The Norwegian priority setting report (NOU, 1987), in turn, influenced the work of the Swedish Parliamentary Priorities Commission (Calltorp, 1999).

The Swedish Parliamentary Priorities Commission

After several waves of public and media discussions, the Swedish Parliament took the initiative and organised a public hearing focused on the issue of choices in health care. This resulted in a request to the Government to set up a parliamentary commission 1992 (Calltorp, 1999). The work of the Swedish Parliamentary Priorities Commission progressed in two stages. The work started in 1992 with an inquiry conducted through questionnaires and deliberations with experts and representatives of organisations and authorities. The Commission also studied prioritisation inquiries in other countries. On the basis of this material and with the support of its own expert advisers, the Commission pursued the discussion that led to the report “No Easy Choices” (SOU, 1993). A large number of replies were given to the Commission at the beginning of 1994, and during that year the Commission held meetings for discussion with politicians, health service employees and representatives of the general public. The unanimous final report was based on the replies received in the circulation process, viewpoints from the regional meetings, new questionnaire surveys, several conferences and hearings, and discussion within the Commission itself (SOU, 1995). A distinctive feature of the Swedish approach was the membership drawn from all political parties, an emphasis on an ethical platform for setting priorities, and the elucidation of protestation for use at both policy and clinical levels of decision making. This resulted in recommendations for a way of thinking about prioritisation to assist those responsible for decision making (Ham, 1997). In 1997 the Swedish Parliament established the suggestions from the Swedish Parliamentary Priority Commission on guiding principles for prioritisation, which resulted in an Act concerning Priorities in Social Service (SFS 1997:142). The Commission’s new purpose was now to inform the health care system about its mission. For example, in 2000 the commission arranged a seminar in ethic and prioritisation to inform those responsible for the education of physicians and nurses how to deal with these questions. The commission had also initiated the idea of asking older people about prioritisation in the Good Ageing in Skåne study (SOU, 2001a), thus resulting in this thesis.

The implementation of the guidelines has varied among the Swedish county councils. For example, the county council of Östergötland uses the same ethical principles as the Swedish Parliamentary Priority Commission as a basis for their prioritisation and has worked with the implementation in health care for several years (LiO, 2004). The commitments that are prioritised by the county council have been elucidated and so too have the forms of treatment that have to be dispensed due to scarce resources, which implies that, for example, older people can get a hearing aid for one ear but not for two ears subsidised by the council. Further, seven municipalities in Skåne were subjects of research aiming to get a basis for prioritisation in elder care, managed by

the Swedish Association of Local Authorities (SALA) and the National Centre for Priority Setting in Health Care. The project involved politicians as well as citizens and health care professionals and was based on the idea that prioritisation in elder care has to include not only ethical principles but also the Health and Medical Services Act (SFS, 1982:763) and the Social Services Act (SFS, 2001:453). The results of this research showed that common rules of procedures for politicians and professionals to perform their different parts in the process were needed. The result is meant to be generalised to and used for prioritisation in elder care in other Swedish municipalities (Rosén, 2005). There are thus several efforts on local levels in progress to make prioritisation as easy and transparent as possible.

Prioritisation in relation to ethical principles

The main result of the work of the Swedish Parliamentary Priority Commission is based on three fundamental ethical principles: the principle of human dignity, the principle of need and solidarity and the cost-efficiency principle. Consideration was also given to the principles of doing good, not evil, being just and respecting autonomy and integrity (SOU, 1995). Philosophers have proposed several theories to determine how to distribute social burdens and health care. Beauchamp and Childress (1989) stated that moral justification is appropriate when there is a need to defend moral convictions or/and when judgements express a decision about a particular action. These judgements are justified by moral rules. Moral rules in their turn are justified by principles which are ultimately defended by an ethical theory. The precise distinction between rules and principles is controversial because both of them aim to justify actions that ought, or ought not, to be performed. Rules are more specific to the context and more restricted in scope, while principles serve to justify rules and are more general and fundamental (Beauchamp and Childress, 1989). Principles are general norms that leave room for judgement and do not function as precise action guides that inform us how to act, as rules and judgements do (Beauchamp and Childress, 2001). Prioritisation in health care involves people in need and is therefore strongly correlated to ethical values and raises several questions, for example about human dignity, need and solidarity and economy.

The principle of human dignity

The principle of human dignity means that all human beings have equal dignity and the same rights, regardless of their personal characteristics and their functions in the community (SOU, 1995). The principle could be connected to utilitarian theories that focus on how benefits and burdens are distributed independently of aggregate welfare. For utilitarians it seems unjust for a society to maximise utility by denying access to health care for some of its sickest and most vulnerable populations (Beauchamp and Childress, 2001) such as older people. In reality the principle of human dignity does not establish prioritisation, as it is not a guide for allocating resources. Its function is instead to prevent prioritisation based on personal characteristics or qualities, which means that the principle of human dignity functions as a framework for prioritisation since the Commission maintains that the principle is in conflict with establishing prioritisation based on e.g. old age, low birth weight or lifestyle-related diseases

(Collste, 1999). According to this principle, no account of the patients' age should thus be taken in prioritisation.

The principle of need and solidarity

With the principle of need and solidarity, the Swedish Parliamentary Priority Commission meant that resources should be committed to those fields where the needs are greatest. Solidarity also means paying special attention to the needs of those groups which are unaware of their human dignity, for example, children, patients who have dementia or are unconscious and others who have difficulty in communicating or stating their view (SOU, 1995). Beauchamp and Childress (2001) emphasise that the principle of need is a valid material principle of justice to fulfil fundamental needs. The principle of need and solidarity also signifies the responsibility to find and explore unsatisfied requirements (SOU, 2001a). However, the concept of need may be defined in several ways according to Liss (1993): teleological need or a state of lack or scarcity, as a motivating force for a certain behaviour. The concept of health care need is defined as a difference between an actual state and a goal. The goal is the justifying component in the need concept. Knowing the goal is necessary to be able to tell whether someone has a need or not (Liss, 1993). However, it is not obvious what should constitute the goal of a need-based distributed health care (Bernfort, 2003). Von Wright (1982) defined needs as follows: "a person needs whatever is bad for that person to be without" and suggested that it is objectively true or false that something is bad for a person even though it is often difficult to determine how things really are. One of the members of the National Centre for Priority Setting in Health Care in Sweden, Liss (2006), preliminarily suggested that the principle of need and solidarity should be expanded so that the degree of pain or other suffering not caused by disease or injury will also be assessed when determining the needs. He also suggested that the duration of pain and suffering should be considered when judging who is in need of care. Further, a principle of responsibility could aim to give people some kind of accountability in care, i.e. that certain costs should be paid by the patient herself. The concept of needs is thus multifaceted and can be interpreted in different ways, thereby leaving decisions concerning prioritisation to individual judgement.

The two principles, the principle of human dignity and the principle of need and solidarity, are further reflected in two major Swedish laws; the Health and Medical Services Act (SFS, 1982:763) and the Social Services Act (SFS, 2001:453). The goal of the Health and Medical Services Act is good health, and care and service on equal terms for all citizens. According to the Social Services Act older people have the right to receive public service and help at all stages of life. All who need help to support themselves in their day-to-day existence have the right to claim assistance if their needs cannot be met in any other way, which must be kept in mind in the debate concerning prioritisation in health care.

The cost-efficiency principle

When choosing between different fields of activity or different measures, one should aim for a reasonable relation between cost and effect measured in terms of improved health and quality of life. Costs could be defended by communitarian theories which

emphasise the responsibility of the community to the individual but also the responsibility of the individual to the community (Beauchamp and Childress, 2001). The cost-efficiency principle should only be applied in comparisons of methods for treating the same disease. Where different diseases are involved, fair comparison of the effect is regarded as impossible. Bernfort (2003) stated that decisions on prioritisations are almost solely based on the principles of need. This implies that the principle of cost-efficiency is given very little space, which is a problem as this means an obvious risk of inefficient resource use.

According to the Swedish Parliamentary Priority Commission (SOU, 2001a), the rank order given to these three principles is such that the principle of human dignity comes before that of need and solidarity, which in turn comes before the principle of cost-efficiency, and all three principles form the basis of a prioritisation ranking list with four groups according to their state of ill-health and patients in different need (Table 1).

Table 1. Prioritisation groups I, II, III and IV according to the Swedish Parliamentary Priority Commission (SOU, 2001a)

Prioritisation group	Content of care
I	Treatment of life-threatening acute diseases. Diseases which, if left untreated, will lead to permanent disability or premature death. Treatment of severe chronic disease. Palliative terminal care. Care of persons with reduced autonomy
II	Prevention. Habilitation/rehabilitation
III	Treatment of less severe acute and chronic disease
IV	Care for reasons other than disease or injury

The idea was that the list should be used as guidelines, giving moral support for all caregivers and decision makers, although the county councils have the ultimate responsibility. The guidelines for prioritisation are to be used as a supplement to the Swedish Health and Medical Services Act (SFS, 1982:763) and the Social Services Act (SFS, 2001:453). In addition, on the basis of these principles, the ethical framework identifies client groups that should be accorded priority based on the administrative as well as clinical level of care (Ridderstolpe et al., 2003). However, Ridderstolpe et al. (2003) asked 208 physicians if they were aware of the meaning of the three principles for priority setting. About 55 % acknowledged knowing the meaning of the principle of human dignity, the principle of need and solidarity was known to 47 % and the meaning of cost efficiency was known to 45 %. These results could indicate that the recommendations from the Swedish Parliamentary Priority Commission are not well established among those responsible for vertical prioritisation.

Resource allocation

Methods for economic evaluations

Although the cost-efficiency principle should not be guiding prioritisation in health care, one should aim for a reasonable relation between cost and effect measured in terms of improved health and quality of life. Economic evaluations can be used as tool to assess the benefits and the costs of different uses of resources and are distinguished primarily by the way in which an outcome is treated (Kobelt, 2002). Kobelt stated that the economic question is whether a treatment is a good use of resources within the disease area, the comparison is with similar treatment and the outcome measure can be disease-specific. If there is only one single outcome the evaluation will be *cost-effectiveness analysis*. With multiple outcomes an index is needed; for example, when the disease is hypertension the outcome can be either stroke or chronic heart disease or with a cancer diagnosis the outcome can be measured in terms of survival, remissions, side effects, quality of life etc. Other forms of economic evaluations are *cost consequences analysis*, used as description of costs and outcomes; *cost minimisation analysis* compares treatments within the same disease; *cost benefit analysis* compares investments in the health care sector with investments in other sectors expressed as monetary benefit, e.g. willingness to pay (Kobelt, 2002). When the economic question is whether a treatment represents a good investment considering the entire spectrum of diseases, the comparison will be with treatment in other diseases and the outcome measure will be, for instance, the Quality-Adjusted Life Year (QALY), giving a *cost-utility analysis*, a specific type of cost-effectiveness analysis. Thus there are several methods to be used for evaluating and measuring the benefits and the costs for treatment related to the outcome that is desired.

Quality-adjusted life year (QALY)

In cost-utility calculations or analysis, cost-effectiveness analysis incorporates both quantity and quality of life by assessing the cost per quality-adjusted life year (QALY) (Kobelt, 2002). Since health is a function of both length of life and quality of life, the QALY has been developed to combine the value of these attributes into a single index number (Dolan, 2001). The quantity component of the QALY is the number of life years under consideration and can be the number of life years saved due to a particular course of treatment. Time free from disease is assigned the utility value 1, while time with disease is assigned a utility value between 1 and 0 (Figure 1). To save one person from death and thereby gain 10 QALYs is equal in value to giving 10 persons 1 QALY each. The summed up QALY values gained are in line with the utilitarian health maximisation concept (Drummond, 1990). An analysis using QALY for a hip replacement is often considered cost-effective (SOU, 2001c). Several researchers and philosophers (Harris, 1987, Williams, 1993) have argued about the equality of QALYs and most notably Harris (1987) have criticised QALYs for discriminating against older people. This is because any calculation of the life-years generated for a particular patient with a special treatment must be based on the life expectancy of the patient. The older a patient is when treated, the fewer the life years that can be achieved by the therapy (Harris, 1987). Also Tsuchiya (2000) suggested that a full recovery from a given acute life-threatening condition for older people will always be smaller in terms

of QALYs gained than a full recovery from the same condition for the young; he calls this utilitarian ageism. Hence it seems that using QALY as outcome measurement for treatment of older people not is a method that, with regard to economy, gives priority to older people.

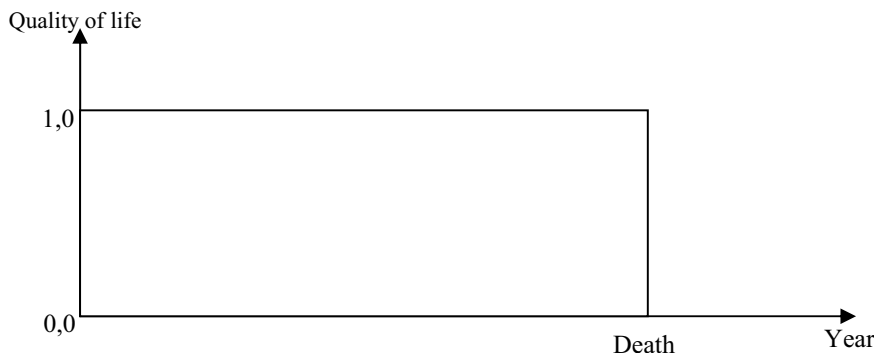


Figure 1. Life span for a person living without diseases to sudden death, in high age.

Willingness to pay (WTP)

One aspect of prioritisation is allocation of resources, which includes the discussion about which disciplines should be financed with taxes versus private funding. For example, the contingent valuation method (CVM) is intended to elicit people's valuation of different actions in health care and also to enable comparisons between the costs and benefits for a special treatment (Olsen, 1997). Two forms of CVM are willingness to pay (WTP) and willingness to accept (WTA). WTA is the amount of compensation an individual is willing to take in exchange for giving up some good or service. This may be elicited from stated or revealed preference approaches. Olsen (1997) implied that WTP corresponds to the maximum willingness to pay for a given specific good and WTA a minimum given reduction of the good. The WTP method is the more frequently used of the two in studies concerning prioritisation. One example of a study using WTP was carried out in Canada, Spain and Denmark, where patients aged 50 years and above were asked "Would you be willing to pay x sum of money to reduce your waiting time for cataract surgery to less than one month?" (Bishai and Lang, 2000). The result showed that an average patient suffering from cataracts was willing to pay for a reduction in waiting time. Several researchers have criticised the methods and emphasised problems with, for example, how best to ask the questions, how to provide the participants with indispensable information to be able to make a rational decision, and the effect of their different socio-economic background (Johannesson, 1996, Olsen, 1997, Miller et al., 2002, Cookson, 2003). The researchers also stated that WTP includes elements of purchase of moral satisfaction or "warm glows". Although CVM and WTP have been questioned, Johannesson et al. (1998) emphasised that one can have at least some confidence in the methods and that the risk of overvaluation could be reduced with a careful study design (Olsen, 1997). One of the criticisms of measuring WTP is that people would not actually behave in the same way in which they respond to the questions. In a study by Anderson (1997) 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. In another study (Cross et al., 2000)

patients who had undergone primary total hip replacement (THR) or total knee replacement (TKR) were asked if they would be willing to pay “something” or “nothing” for the treatment. The results showed that age was significantly associated with willingness to pay (WTP) (OR 1.14, $p=0.009$) for the patients who had undergone TKR and that income was significantly associated with WTP (OR 19.87, $p=0.008$) for those who had undergone THR. Thus, it seems as if age as well as income influence the willingness to pay for treatment. It has been shown that older people with disabilities have lower income than older people without disabilities. There are also other differences between the two groups, as older people with disabilities have more economic problems than older people without disabilities (SOU, 2001b). Firstly, because older people with disability, if they have suffered long enough, have had less opportunity to earn pension points. Secondly, it could be that different types of disabilities arise from social classes with lower income from pension and capital (SOU, 2001b). Also, according to Persson et al. (2001), income differs between men and women. Of all pensioners in 1997, 17 % received only the basic retirement pension. Of these 90 % were women. However, although there are several problems connected to the WTP there appears to be a consensus in the literature that WTP is a preferable method.

Growing older

Even if most people remain healthy in high age, growing older is often accompanied by a decrease in self-care capacity and increased frailty due to physiological and psychological changes. The age at which a person is considered older varies in literature, and approaches to old age are described as chronological, biological, psychological as well as social (Arber and Evandrou, 1997). Chronological age is measured for describing a person’s age as a distance from birth but reveals nothing about functional ability. Biological ageing is described as a process of decline and deterioration of the person’s body organs, while psychologically and socially oriented definitions distinguish it as a developmental process and stress change rather than deterioration (Persson et al., 2001). However, to use other means than chronological age might raise methodological problems since chronological age allows comparisons between studies and sub-groups in, for example, age cohorts of older people. The group of older people (65 years and over) is however not a homogeneous group as they represent a large span of life years. Field and Gueldner (2001) have shown differences within the group of older people and emphasised the importance of distinguishing the youngest-old from the oldest-old since they are members of different cohorts and lived through different historical time and have grown up with different experiences. Several researchers (Field and Gueldner, 2001, Given and Given, 1989) have suggested a division of chronological age: young-old age group (65–74 years), old-old age group (75–84 years) and oldest-old age group (85 and over). Biological ageing becomes more apparent the older a person becomes, and research has found that the oldest-old in comparison with the young-old show significant decrease in physical and mental health (Baltes and Smith, 2003). These authors also argued that living in the oldest-old age appears to be a risk factor for

human dignity since psychological control and self-identity may be increasingly violated. It therefore seems important to involve especially the oldest-old in research concerning health care as they probably have the greatest experience of the subject.

The ageing process shows great individual variation. For example, women grow older than men, and they also have more functional limitations than men. Guralnik et al. (1997) stated that older women have consistently been found to have higher prevalence rates of disability than men of the same age, above all due to longer surviving with their disabilities. For example, a Swedish study (al-Windi et al., 1999) showed that women aged 65 years and over had significantly higher prevalence of depression than men of the same age. According to Samuelsson et al. (2005) the strongest risk factors for the development of depression were perceived economical problems. Women are overrepresented in single households, whether ordinary housing or special accommodation. The older the women become, the higher the likeliness is that they are widows, live alone and report a poorer economic situation than men (Lagergren, 2002). Furthermore, socio-economic status and education among older women are lower than among older men (Statistics Sweden, 2005). As women have a longer life expectancy than men, prioritisation based on age can thereby be seen as discriminating against women (Bell, 1989). Women are moreover nearly three times more likely than men to be informal care providers for older relatives (Johansson et al., 2003). The conditions concerning health, care and socio-economy in old age thus differ, not only between individuals but also in relation to gender.

Since the risk of diseases grows with age, this in turn influences a person's health-related quality of life (HRQoL) (Persson et al., 2001). For example, health-related complaints such as pain, fatigue and mobility impairment have been found to predict low overall and health-related quality of life (Borglin et al., 2005). Most of the existing definitions of HRQoL are in line with WHO's definition of health; a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (Bowling, 1998). There is also a consensus that relevant aspects of HRQoL should include general health, physical function, emotional function, role function, social well-being and functional and existential issues (Anderson et al., 1993). Also dependency on help from others influences HRQoL. For example, Stenzelius et al. (2005) found that people who were dependent on help reported significantly lower HRQoL than those who were independent. This was also seen in a study by Thomé et al. (2004) where receiving help with activities in daily life from others and high number of complaints were associated with low HRQoL. Thus, health, dependency and how people experience their HRQoL seem to be interrelated. The concept of dependency can however be viewed at different levels, at the behavioural, personal situational or interpersonal level, depending on the theoretical and methodological approach (Baltes, 1996). Baltes stated that dependency is a characteristic of individual behaviour, such as being passive, accepting help, asking for help and labelled it behavioural dependency. Older people's behavioural dependency could be a product of environmental circumstances and seen as an instrument of personal, although passive control, either as "learned helplessness", as "learned dependency" or a dependency that results from coping with the unavoidable shrinking of reserves and

capacities in old age. Other types of dependencies in old age are structured and physical dependency. Structured dependency, according to Baltes (1996), is created by the social structure in our society. Physical dependency is caused by disease in old age and has found wide clinical relevance in the construction of Activities of Daily Living (ADL) scales that are used to make decisions about the ability to live independently at home. Dependency is, however, one of the most pressing problems in old age as a product of decline and deterioration and a loss in both physical and mental function (Baltes, 1996).

The situation for older people also differs in relation to place of living. Those living in special accommodation (7 % of people aged 65+) are older, more functionally dependent and have a higher number of health complaints than those living at home (National Board of Health and Welfare, 2005, Hellström et al., 2004). It has also been shown that people living at home, receiving continuous public care and service, have significantly more stays in hospital than people living in special accommodation during their last year in life (Andersson et al., 2006). People receiving continuous care and service are further admitted to hospital more frequently if they are living at home than if they are living in special accommodation (Karlsson et al., submitted). Older people are thus a heterogeneous group with different prerequisites and living under different circumstances.

Age as a criterion for prioritisation

The debate about old age as a criterion for prioritisation has been going on for a long time (Zweibel et al., 1993). Callahan (1995) stated that age is a legitimate basis for allocation of resources because it is a universal category and can be understood at the level of common sense. He also stated that there should be an opportunity for every young person to become old, and it is only fair to limit assistance to those already old to make that possible. In the struggle between young and old for resources, the young should, according to Callahan (1991), be given the advantage. This view was, in a way, supported by Daniels (1988), who stated that we don't change gender or race but we all age, and fairness between age groups in health care is created by the idea of prudent allocation over a life span. Daniels (2001) suggested that rationing by age is permissible under some conditions of scarcity. Williams (1997a, 1997b) required greater discrimination against the older and asserted that everyone is entitled to some normal span of health and anyone failing to achieve this has been cheated, whilst those getting more than this are living on borrowed time. Veatch (1988) suggested guidelines to limit care for people who are terminally ill and old and saw younger people as worse off than older people because they have lived less of their lives. Several researchers (Bell, 1989, Cohen-Almagor, 2002, Purviance, 1993, Williams, 2000) have argued against these theorists on the ground of discrimination and ageism. However, responses have been offered to the criticisms; "for one thing because we will not be able to evade the problem as easily as some critics have proposed, and that an age-limit proposal should be compared with other unpleasant choices, not with an ideal world" (Callahan, 1994). According to the theory of gerotranscendence, older

people experience an increased feeling of affinity with past generations and a decrease in interest in superfluous social interaction (Tornstam, 1996), which ought to be viewed in the debate on prioritisation. Tornstam supposed that development into old age might lead to a stage with its own specific quality of life, such as a transformation characterised by new ways of understanding life, oneself and others. There is thus an ongoing debate about ageing and on age as a criterion for prioritisation, in which older people themselves are rarely included.

Ageism was first defined by Robert Butler (1969) as discrimination against older persons on the basis of age. Butler cited many examples of prejudiced, dismissive, and harmful acts and attitudes directed towards old people by both individuals and institutions for example when the middle-class and middle-aged citizens protested on a variety of grounds against a proposal for a new public building for older people. Minichiello et al. (2000) have investigated older people's experiences of ageism. The informants were aged between 65 and 89 years and the result showed that they had not had many such experiences in normal life. However, the informants identified a number of negative experiences with health professionals, such as that they were expected to tolerate and accept physical discomfort and pain or that they had minimal access to preventive health initiatives. The authors stated that older people adopt their own strategies for dealing with ageism as they experience it. Minichiello et al. (2000) identified two forms; accommodating ageism and negotiating new images of ageing. Accommodating ageism involves accepting situations as they are, trying to "get on with life", "make the most of things" and ignore unpleasant interactions. Negotiating new images of ageing was when older people use strategies to prevent people from seeing them and treating them as old. This could, for example, be trying to educate people about positive ageing and believing that older people can work collectively to achieve change at policy level. Minichiello et al. (2000) emphasised the importance for researchers to understand and articulate the experiences of older people so they will be aware of understanding ageism as depending on their developing an awareness of being treated as old. It is therefore important to include older people in research, especially concerning subjects that involve themselves.

A Finnish research team has conducted several studies (Kinnunen et al., 1998, Ryyanen et al., 1999, Myllykangas et al., 1996) examining the attitudes towards prioritisation in health care among the general public, politicians, and physicians and nurses. The sample of about 3800 subjects representing the general public had a median age of 43 years (range 18 to 71 years), the physicians and nurses were 21–63 years old (median age 40 years) and the politicians 27–77 years old (median age 52 years). The study showed that old age among the participants in the general public (46–71 years) was associated with non-acceptance of statements like "the patient is an older person" as a prioritisation criterion. Older persons further accepted "self-inflicted diseases" and "patient's wealth" as prioritisation criteria to a higher extent than the younger participants did (Ryyanen et al., 1999). In all groups, a majority agreed that children should be treated before older people (Myllykangas et al., 1996). Bowling (1996) reported results resembling those surveys, in which the lowest priority was given to "treatment for infertility" and "treatment for people aged 75 and over with

life-threatening illness". Mariotto et al. (2003), though, asked 504 participants 65 years and over (mean age 75 years), if a citizen had the right to any form of health care, even in old age. Ninety-six percent of the older participants agreed, 2 % did not agree and 2 % were unsure. Dicker and Armstrong (1995) found that participants in their study were reluctant to use their own personal needs as a basis for resource allocation; instead they argued for what they thought were the needs of others. Lindblad et al. (2002) 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 allocate medication to avoid losses in productivity while others pointed out that age should not influence prioritisation and showed apprehension that society would favour people in the workforce. They instead highlighted people's equal value, whether fit for work or not. (Lindblad et al., 2002). Thus, several studies have indicated that age is a criterion that professionals as well as the general public want to use in prioritisation, which makes it important to find out what criteria the ageing population wants to use in prioritisation.

The knowledge about the citizens' standpoints concerning prioritisation in health care is, so far, mainly based on the views of the younger or middle-aged population. The few studies that have included older people indicated that their views differ from those of younger people. One reason for this may be that it is difficult for younger people to imagine life as old, while older people have a life-span perspective to relate to. As older people are a group that use health care most, they will further be the main target of prioritisation in this sector. People receiving continuous care and service are further probably the most experienced citizens concerning prioritisation. Accordingly, the fact that women grow older than men and that women are poorer in both health and economy than men, means that research involving this group should take factors such as age, gender, degree of dependency in activities of daily living (ADL), health-related quality of life (HRQoL), housing and financial situation into consideration.

AIMS

The overall aim of this thesis was to investigate older people's views of prioritisation and resource allocation in health care.

The specific aims were:

- to investigate the view of older people, persons not receiving continuous care and service as well as persons receiving continuous care and service, on prioritisation in health care and how to finance health care costs (Papers I, II and III).
- to investigate differences in their view of prioritisation and resource allocation in relation to age, gender, housing, health-related QoL, financial situation and degree of dependency in ADL (Papers I, II and III).
- to compare the views of prioritisation and resource allocation between people not receiving continuous care and service and people receiving continuous care and service (Additional analyses presented in this framework).
- to describe the reasoning of people, 60 years and over, about prioritisation in health care with regard to age and willingness to pay (Paper IV).

METHOD

The context of the study

This thesis should be viewed against the background of the Swedish model of publicly financed and provided health care and services for all citizens. Responsibilities with regard to health care and medical services are defined in the Health and Medical Services Act (SFS, 1982:763, National Board of Health and Welfare, 2004). By this law, the municipalities (290 in all) are responsible for providing long-term social services and care. Help from the municipality includes home service care, home nursing care and rehabilitation, while the 21 county councils are responsible for medical health care, hospital care and outpatient care. The county council has the responsibility for home nursing care and rehabilitation instead of the municipalities. Both the county councils and the municipalities have elected assemblies and have the right to levy taxes (National Board of Health and Welfare, 2004).

The total expenditure on health care differs between European countries and the USA, where the expenditure on health care is almost twice the European countries' (Table 2). The major part of US health care system is financed by voluntary health insurance (VHI) (Mossialos and Thomson, 2002). In Sweden, however, VHI is rare.

The share of the total VHI market in health care in Sweden is 0.1 %, in Finland 0.6 % while in UK the share is 8.7 (Mossialos and Thomson, 2002). There are two kinds of VHI, one covering treatments that are not available in the national health system and the other covering treatments that are available but for which the insurance gives better accessibility or service. Mossialos and Thomson (2002) described inconveniences that can result from VHI, such as the possibility for the insurance company to exclude older people or people at risk of disease.

Table 2. Total expenditure on health in four countries (OECD, 2004)

Country	% Gross Domestic Product	Per capita US\$
Finland	7.3	1943
United Kingdom	7.7	2160
Sweden	9.2	2517
United States	14.6	5267

Design and overview

In this thesis a descriptive and explorative design was used including both quantitative and qualitative methods. When a study integrates both qualitative and quantitative data, researchers may be in a stronger position to derive meaning from the statistical findings through the analysis of qualitative material (Polit and Beck, 2004) as well as to expand the scope and improve the analytic power of the study (Sandelowski, 2000). Data were collected in personal interviews based on a questionnaire. All participants (Papers I–IV, framework) were invited from a larger prospective longitudinal cohort study, the GAS study (Good Ageing in Skåne) that is carried out in southern Sweden and consists of two parts, the population part (a) and the care and service part (b). The population part (a) involved a representative panel of about 2900 persons and the care and service part involved 2500 older people receiving continuous care and service in year 2001 (Figure 2) (Jakobsson and Hallberg, 2006). The GAS study is, in turn, a part of the Swedish National study on Ageing and Care (SNAC) a large, national, longitudinal study, initiated by the Swedish Ministry of Health and Social Affairs (Lagergren et al., 2004). The data collection for both the population part and the care and services part, is ongoing in five municipalities in Skåne, representing urban areas as well as rural areas and areas with mixed structure.

In Papers I and II the sample derives from the population part (a), from which a panel of older people is followed over time to record and describe the ageing process from different aspects by including a variety of domains considered to influence the ageing process: health and disease, social network and support, lifestyle, material conditions and personal resources (Figure 2). The data collection involves questionnaires concerning living conditions, education, socio-economic conditions, social network and support, a medical examination and cognitive tests. The aim of the population part of the GAS study is to increase the understanding of the ageing process and to identify possible preventive strategies to improve health and care in older people (Lagergren et

al., 2004). A random sample was chosen from 9 age cohorts between 60 and 93 using the Total Population Register, Statistics Sweden. The cohorts begin at the age of 60 up to the age of 93 years with a six-year interval between the younger cohorts (up to age 78) and three-year intervals thereafter.

In Paper III, the sample derives from the care and services part (b) (Figure 2). In the care and service part, a longitudinal, individually based collection of data is performed (Jakobsson and Hallberg, 2006). Registered nurses and home help officers, and in some cases occupational therapists and physiotherapists, perform the registrations in the municipalities using a form. The form contains items about demographic data, functional ability, health complaints, adaptation and standard in housing, public and informal care. Demographic data include age, gender, civil status and living condition. The aim of the care services system part is to develop a method for individual-based monitoring of the long-term care services that can be used by any municipality in Sweden. The participants are aged 65 years and over (Jakobsson and Hallberg, 2006).

Paper IV is based partly on the sample in Papers I and II and the sample in Paper III and analysed with a qualitative content analysis (Figure 2). Additional analyses for this thesis were made comparing the sample not receiving care and service (Papers I and II) and the sample receiving care and service (Paper III). The results from these analyses are presented in table 5-8, in figure 3-5 and as additional analyses (Add an) in the findings. (Figure 2).

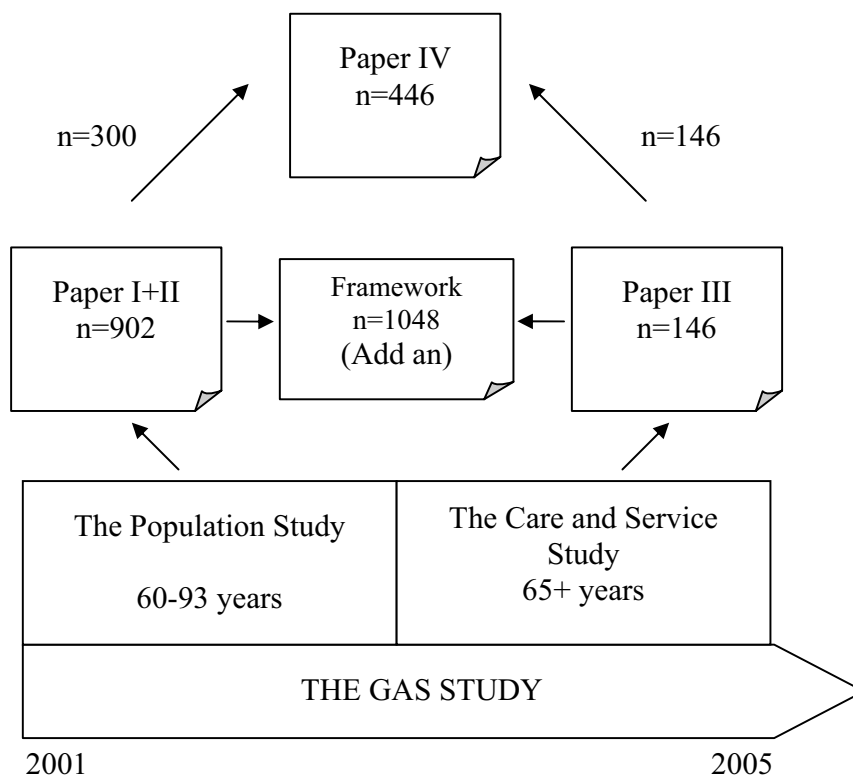


Figure 2. Description of origin of the samples in the papers.

Sample

In Papers I and II, 930 persons (n=902) were selected from the population study (a) and were asked to participate in a structured interview about prioritisation, consecutively during 17 months (year 2001 and 2002). The exclusion criteria for the GAS study were language difficulties and for the additional interview, cognitive decline and/or exhaustion. Twenty persons had to be excluded from participation due to cognitive decline and/or exhaustion after the medical examination and cognitive tests, and eight persons declined participation. In all 902 persons, 424 men and 478 women aged between 60 and 93 years (mean age, 73 years (SD 10), participated in the structured interview (Table 3). Even if the age 65+ is normally used as a borderline for being older, people aged 60 years were also included in the studies to increase the possibility of identifying age differences. The distribution of men and women in this sample corresponds to the gender distribution in the same age groups in the total Swedish population, with the exception of the oldest-old group (87, 90 and 93 years old) where an under-representation of women (51 %) compared to the total Swedish population (62 %) was seen (Statistics Sweden, 2005). The invitation to the GAS study was made by letter and there was an initial dropout, 47 %, in connection with the invitation. The response rate in the second step, participation in the interview concerning prioritisation, was 97 %. There were additionally a small but unknown number of participants in the GAS project that some days were not asked to take part in the interview study due to heavy workload on the part of the nurses who performed the interviews.

In Paper III the sample consisted of 146 persons receiving care and service, 34 men (23 %) and 112 women (77 %), aged from 66 to 100 years with a mean age of 86 years (SD 7). The mean age for men was 84 years (SD 7) and for women 86 years (SD 7) (Table 3). The inclusion criteria for Paper III were that the participants should be 65 years and over, receiving continuous public care and service, not have any cognitive impairment, and be able to understand and speak Swedish. Continuous public care and service meant that people should have been granted public home help, a place in special accommodation or at least four visits per month from home nursing care or rehabilitation. Individuals having only body-carried alarm, meals on wheels or transport service were not included. Fifty-five percent of the participants were living in special accommodation and 45 % at home. Nurses working in the municipalities received information about the inclusion criteria and then asked persons whose care and service they were responsible for and who met the inclusion criteria if they would permit an interview in their home. Then the author contacted them to arrange an appointment. The data were collected during two months (2003) in two of the municipalities and during 3 months (2005) in the other three municipalities.

Additional analyses for this thesis were performed with the merged samples of participants who were not receiving care and service and participants who were receiving care and service (Framework). The mean age in this sample (n=1048) was 74 years (SD 10), for men 73 years (SD 10) and for women 76 years (SD 10) (Table 3).

The sample in Paper IV consisted of 446 participants, 300 persons not receiving care and service (from Papers I and II) and 146 persons receiving care and service (from Paper III). When data were collected among the participants not receiving care and service (n=902), they were asked to give comments and explanations about the structured questions and to answer two open-ended questions. The first 500 interviews were tape-recorded and 300 were selected for Paper IV. The selection was based on the quality of the interviews, i.e. interviews not adding anything to the answers to the structured questions were excluded (about 200). The mean age of the 500 participants was 72 years. All 146 participants receiving care and service also gave their comments and explanations on the structured questions and answered two open-ended questions.

Table 3. Characteristics of the participants

	Total Framework %	No public care Papers I, II, IV and Framework %	Public care Papers III, IV and Framework %	
	n=1048	n=902	n=146	<i>p</i> -value ¹
Gender				<0.001
Men	44	47	23	
Women	56	53	77	
Age				<0.001
Mean (SD)	74 (10)	73 (10)	85 (7)	
Marital status				
Married	55	60	13	
Widowed	29	24	70	
Unmarried/Never married	6	5	12	
Divorced	8	9	5	
Live apart	2	2		
SF-12 mean (SD)				
PCS ²	44 (11)	45 (10)	34 (11)	<0.001
MCS ³	51 (8)	50 (7)	56 (10)	<0.001
Financial situation				
Access to €1500	85	87	64	<0.001

¹ between people not receiving care and service and people receiving care and service

²Physical component summary ³Mental component summary

Data collection

Development of a questionnaire

Data for Papers I–IV and the framework were collected in the form of a personal structured interview based on a questionnaire. The questionnaire was developed based on a review of the literature and on the ethical principles: the principle of human dignity, the principle of need and solidarity and the cost-efficiency principle. Four questions were replicated from previous studies, one from Nord et al. (1996) concerning priorities in relation to age, and three questions from Mossialos and King (1999), one concerning who should decide on priorities, one concerning how the increasing health care costs should be financed, and one asking about methods for selecting between patients. The latter question was modified from the original by changing the alternative “the decision is made by following the rules of the hospital,

whatever they may be” to the alternative “whatever the patient’s age” since the age criterion was one of the main focuses of this study. To test the applicability of the questionnaire concerning the view of prioritisation in health care, 54 older persons were asked to participate in a pilot study where the participants’ reflections in relation to the questions were tape-recorded. (Werntoft et al., 2005). The results from the pilot study showed that both the construction and content of the questionnaire were well suited for the study group, but revealed a need for questions distinguishing between horizontal and vertical prioritisation and about how to finance health care (Werntoft et al., 2005). Questions from previous studies illuminating these aspects were therefore added to the questionnaire, for example questions from Mossialos and King (1999) about how to finance the increasing health care cost. Statements concerning financial questions were replicated from a Finnish study (Myllykangas et al., 1996), as were questions about resource allocation in health care (Kinnunen et al., 1998). One question about how to finance cataract surgery and one question with treatment alternatives that could be paid by the patient were further developed by the authors and added to the questionnaire. The final questionnaire used for the papers in this thesis had 26 questions, two of which were open-ended, the rest having from two to seven response alternatives. Three questions were not used for analysis in this thesis. Question number 8 and 9 was excluded from analysis because they did not provide any additional knowledge and question number 24 because the participants had difficulties to understand the question (Appendix). For paper III demographic questions, questions about the participants’ health-related quality of life (SF-12) and financial situation were added to the interview.

Interview

The questionnaire was distributed in form of a personal interview. For Paper I and II the interviews were carried out in connection with the medical examination in the population study. Registered nurses (including the author) carried out the interviews, lasting from 20 to 60 minutes at the end of their examination. In all nine nurses participated in the data collection and the first interviews by each nurse were supervised by the author, thus all nurses involved in the data collection received the same repeated information on how, when and where to present and carry out the interview. For Paper III the interviews were carried out in participants’ homes and lasted for 30–90 minutes, carried out by two researchers (including the author). The presence of the nurse made it possible for the participants to get help with potentially unclear points in the questionnaire. All interviews proceeded from one open-ended question “In newspapers, radio and TV we often read and hear about prioritisation in health care. What do you think about that?” followed by the structured questions. The interviews were completed with another open-ended question “What are your own experiences of prioritisation in health care?” The 500 first interviews among the participants not receiving care and service and all 146 interviews among the participants receiving care and service were tape-recorded and transcribed verbatim by the author and two secretaries.

SF-12

In Papers I and III health-related quality of life was investigated using the Short Form (SF-12) Health Survey. SF-12 is a 12-item questionnaire based on the Short Form (SF-36) Health Survey that has 36 questions. Although the SF-36 has proved to be useful for a variety of purposes it has been found to be too long for inclusion in large-scale studies (Ware et al., 1996). The original 36-item scale has therefore been reduced to 12 items in the short form and has been translated into Swedish by Sullivan (1997). The use of the SF-12 as a health status instrument in large community-based studies of older people has been supported by, among others, Petit et al. (2001). The correspondence between means for SF-36 and SF-12 has been considered good (Ware et al., 1996, Gandek et al., 1998). SF-12 consists of two components: Physical Component Summary (PCS) and Mental Component Summary (MCS). PCS in turn consists of Physical Functioning, Role-Physical, Bodily Pain and General Health, while MCS consists of Vitality, Social Functioning, Role-Emotional and Mental Health. The score in each component summary is standardised to range from 0 (poorest well-being) to 100 (highest well-being) (Ware et al., 1996). Jakobsson (2006) showed, in a Swedish sample of 4278 older people living at home as well as in special accommodation (response rate 51 % of 8500), that the mean value for PCS/MCS in the age group 75–105 years was 37.5/50.3. When divided into specific age groups, the mean value in age group 75–79 was 41.6/52.1, in age group 80–84: 38.6/50.6, in age group 85–89: 35.0/49.2 and in the group aged 90 years and over: 31.1/47.8. Cronbach's alpha for PCS was 0.85 and for MCS 0.76 in the total sample in the study by Jakobsson (2006).

ADL

To assess dependency in Paper III, information about P-ADL and I-ADL was collected, six P-ADL items from Katz's ADL Index (Katz et al., 1963), bathing, dressing, going to the toilet, transfer, continence and feeding, and four I-ADL items from Hulter Åsberg and Sonn (1989): cleaning, shopping, transportation and cooking. Each item is graded 0–1, where 0 indicates no dependency and 1 indicates dependency on help from someone to perform the activity. One additional I-ADL item, laundry, was also added in accordance with Karlsson et al. (2003). The summarised score for P-ADL ranges between 0–6 and for I-ADL between 0–5 (Hulter Åsberg and Sonn, 1989). The hierarchic structure of the ADL staircase has been confirmed by Hulter Åsberg and Sonn (1989).

Data available from the GAS study

For Papers I and II demographic data concerning educational level, marital status, health-related quality of life (HRQoL), and financial situation were obtained from the data collection in the population part in order to minimise the number of questions in the questionnaire about prioritisation. The questions concerning financial situation was explored by asking if they had access to €1500 (SEK 14,000, 15 December 2001) and if they had any problems with their finances in the last few months.

ANALYSES

The results of the questionnaire were analysed using quantitative methods and the tape-recorded transcribed answers to the open-ended questions and the comments and reflections in relation to the structured questions were analysed using qualitative methods. The quantitative analysis aimed to describe phenomena and assess relationships among them through statistical procedures. Qualitative analysis is aimed at organising and interpreting non-numeric data to discover important underlying dimensions and patterns (Berg 2001).

Statistical analyses

In Papers I–III, Chi-square test was used to analyse differences between men and women and between age groups for categorical data and in the framework to analyse differences between people not receiving continuous care and service and people receiving continuous care and service. Mann-Whitney U-test and Kruskal-Wallis test were used for comparisons between two and three groups respectively where ordinal data were compared.

In Papers I, III and in the framework multinomial logistic regression analysis was performed with the independent variables sex, age group and HRQoL (MCS and PCS) as covariates. In the multinomial logistic regression analysis presented in the framework (Add an) access to €1500 and receiving continuous care and service or not were also added as independent variables. Different prioritisation criteria were used as dependent variables.

In Papers II and III and in the framework a multiple stepwise logistic regression analysis was used to detect factors associated with the willingness to pay, i.e. responses to the question, “if you need cataract surgery to be able to see, would you choose either to be on a waiting list for 18 months (‘0’) or to pay €1100 out of your own pocket to have the surgery at once (‘1’)?” The independent variables used in Paper II were sex, age and financial resources (having access to €1500 or not), in Paper III HRQoL (PCS and MCS), PADL, IADL, housing, sex and age and in the framework sex, age, PCS, MCS (HRQoL) and having access to €1100. Before being entered in the model PADL was divided into no/minimal dependency (0–2) and slight to total dependency (>3) while IADL was divided into no/minimal/moderate (0–3) and much/total dependency (>4). (Hosmer and Lemeshow, 2000) while the median value was used to divide HRQoL into high and low PCS and MCS. Cronbach’s alpha (Cronbach, 1951) was used in Papers I and III to calculate internal consistency for SF-12, showing $\alpha=0.85$ for PCS and $\alpha=0.79$ for MCS in Paper I, $\alpha=0.71$ for PCS and $\alpha=0.69$ for MCS in Paper III.

Confidence intervals (CI) of 95 % were calculated for the odds ratio (OR) in the logistic regression analyses. For comparisons a p -value <0.05 was considered significant. When analysing differences between more than two groups Bonferroni’s post-hoc test was applied with a reduced p -value to avoid the risk of finding a large

number of significant differences by chance (Altman, 1991). Statistical data analysis was performed using SPSS, 11.5.

In this thesis different definitions of age groups were used. In Papers I and II the sample was divided into three groups: “young-old” (60, 66 and 72 years old), “old-old” (78, 81 and 84 years old) and “oldest-old” (87, 90 and 93 years old) in accordance with the suggestion by Field and Gueldner (2001). In Paper III the sample was divided into: “young-old”, 66–84 years, and “oldest”, 85–100 years. For analyses in the framework the sample was divided into three age groups, “young-old” 60–75 years, “old-old” 76–84 years and “oldest-old” 85–100 years (Table 4).

Table 4. The division of age in age groups in the Thesis.

		Age groups		
Paper I, II	n=902	Young-old (60, 66 and 72 years) n=528 (58 %)	Old-old (78, 81 and 84 years) n=277 (31 %)	Oldest-old (87, 90 and 93 years) n=97 (11 %)
Paper III	n=146	Young-old (66–84 years) n=67 (46 %)		Oldest (85–100 years) n=79 (54 %)
Framework (Add an)	n=1048	Young-old (60–75 years) n=545 (52 %)	Old-old (76–84 years) n=327 (31 %)	Oldest old (85–100 years) n=176 (17 %)

Content analysis

Qualitative research means exploring the depth, richness and complexity inherent in a phenomenon (Burns and Grove, 2001) and can be used to discover important underlying dimensions and patterns of relationships (Polit and Beck, 2004). In Paper IV a qualitative approach was used when analysing data from the two open-ended questions in the questionnaire and the tape-recorded comments and explanations on the answers to the structured questions. Comments and reflections on 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 selected for the analysis. The participants’ reasoning in relation to the answers 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 illnesses 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 participants’ reasoning in relation to the answers 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 €1100 (SEK 10,000 SEK, 19 July 2002) out of your own pocket and have the operation at once.*

In Paper IV a combination of manifest and latent qualitative content analysis was used, proceeding in several steps. First the transcribed text was read and reread to get a general impression of the content and to apprehend essential features in the texts. Two researchers read the text, independently of each other, and compared and discussed the utterances in relation to each question. Meaning units 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. The statements in each category were analysed critically and questioned, read and compared to arrive a reasonable interpretation. 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 (cf. Graneheim and Lundman, 2004). In this step a third researcher read the transcripts and confirmed the categorisation. All the researchers, who had a pre-understanding of older people through research, lastly reflected on and discussed the findings, taking the research question and their pre-understanding into account (Paper IV).

ETHICAL CONSIDERATIONS

In a research project there are certain rights of the participants that must be considered (Nilstun, 1994). The participants should not be harmed, informed consent must be obtained, participation must be voluntary, participants must be assured confidentiality and they should be treated with dignity and respect. These rights are explained in four principles: the principle of non-maleficence and the principle of beneficence (both deriving from the principle of utility), the principle of autonomy and the principle of justice. The principle of non-maleficence means that the good derived from the research must be weighed against the potential harm. The principle of beneficence means that researcher ought to prevent or remove suffering and promote well-being. The principle of autonomy means respecting a participant's decision-making capacity while the principle of justice concerns whether the research strategies and procedures are fair and just (Nilstun, 1994). The principle of autonomy also entails a person's right to hold views, to make choices and to take actions based on personal values and beliefs (Beauchamp and Childress, 2001). These ethical principles guided the ethical considerations in this thesis.

To show respect for the participants' autonomy the participants were asked if they were willing to take part in the study and if we were allowed to tape-record the interview and they were told that the result should be presented in a way that no one could be identified. There is a risk that the respondents from the population study (a) participated in the interviews for this study, as they were already "in place" and might have felt gratitude to the researcher, having a free medical examination (Papers I and II). In Paper III there was a risk that the participants' willingness to participate in the study was influenced by the fact that they were in a state of dependence on the nurses asking them to participate. The participants in Papers I, II and III had however previously agreed to participate in the GAS study, and the advantage of having information from a well-known person in Paper III was judged to be more ethical as

this group were vulnerable. The inclusion of people in a rather poor health condition could further be criticised (Paper III). The value of including people who probably have experienced prioritisation, however, made the advantages outweigh the disadvantages. The questionnaire was used in a structured interview and the participants were supported to narrate their thoughts in relation to the questions asked, in line with the principle of non-maleficence that asserts an obligation to not inflict harm on others (Beauchamp and Childress, 2001). The reason for this procedure was previous reports from the literature (Ryynanen et al., 1999) and experiences from the pilot study (Werntoft et al., 2005) indicating a need for the participants to explain their standpoints in relation to each question to avoid discomfort on the part of the participants. For all studies permission was obtained from the research ethics committee of Lund University (LU 744-00 and LU 650-00).

FINDINGS

The findings are presented in relation to the following headings: experiences of prioritisation, the view of prioritisation in general, the view of prioritisation in relation to the participants' age, the view of prioritisation in relation to the participants' gender, the view of prioritisation in relation to the participants' HRQoL, the view of prioritisation concerning lifestyle-related diseases, the views on resource allocation, the views on resource allocation in relation to the participants' age, the views on resource allocation in relation to the participants' gender, willingness to pay in relation to the participants' financial situation, and lastly the willingness to pay and financial situation in relation to the participants' age and gender.

Experiences of prioritisation

The analysis of the answers from the two open-ended questions and the comments from the participants revealed that the experience of prioritisation varied among the participants, from not having any experience at all to having positive as well as negative experiences (Paper IV). 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 that they always had received the help they needed, meaning that they interpreted prioritisation as a negative act rather than taking precedence. Several participants felt secure with the way their needs had been fulfilled in the health service as embraced in the category *Feeling secure and confident in the health care system*. Their experience concerned hospital-based health care as well as experiences of municipal elder care. Participants who had been in contact with the health care system in case of emergency felt that they had been taken well care of. This was also shown when they had diseases requiring repeated care, of which they and their relatives had positive experiences. For those persons, prioritisation was not seen as a problem or an impediment (Paper IV).

“My husband has been seriously ill and we have always been helped. I don't see the problem.” (W 84)¹

The participants also had experiences of having to use *underhand means to be prioritised*. When in need of health care, having useful contacts was seen as an advantage, for example personal relations with physicians or others in powerful positions. The participants also had experiences of using contacts to take precedence, but also expressed a fear of others using this means, thereby being given low priority themselves (Paper IV).

“If you are in need of health care and are placed in a queue, it is a matter of hard work. You have to call, call and call again and tire them out. That was what my husband did.” (W 84)

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

The participants' reasoning also revealed the experience that *being old meant low priority*. This was related to feelings of anger and frustration since they interpreted their age to be a reason for having to wait when being in contact with the health care sector. The participants also feared that treatments and examinations were performed to a lower degree for older people. The feeling of anger and frustration increased when being met with bad manners and disrespect, for example when not being listened to and when symptoms were disregarded or neglected. 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 and created *worries about what prioritisation might bring about* for themselves in the future (Paper IV).

"I have pain in one of my hips but they don't do much when you are old, or maybe they believe you don't want to be treated when you are this old. They rather help people who are of working age. I hope it won't get worse." (W 90)

The view of prioritisation in general

In the participants' reasoning about prioritisation being *averse to anyone taking precedence over others* was present. The participants said that they thought that it was unfair that anyone should be considered more important than another and that it was a human right to everyone to get what they need. Their arguments also revealed that money or "VIP lanes" were not supposed to influence prioritisation (Paper IV). Eighty-one per cent of the participants considered that all age groups should be prioritised, with no significant differences between the participants not receiving care and service and those receiving care and service (Table 5). There were significant differences between the groups concerning life-saving treatment, as 66 % of the participants not receiving care and service and 80 % of participants receiving care and service thought that life-saving treatment should be given to everyone, no matter what age they were ($p < 0.001$). When deciding between patients of different age waiting for a new kidney, the youngest patient was prioritised by 93 % of the participants. When other criteria were added, such as health and pain an 80-year-old healthy patient was prioritised before both a 60-year-old patient with dementia and a 70-year-old patient with coronary disease for cataract surgery by 57 % of the participants. A 70-year-old was prioritised for a new hip joint before a 60-year-old and an 80-year-old when he suffered from more pain by 71 % of the participants (Table 5).

Table 5. Older people's view of priority setting, and comparisons between people not receiving care and service and people receiving care and service

Questions	Total			No public care (Paper I)	Public care (Paper III)	Chi ² <i>p</i> -value
	n=1048 %	men /women	Chi ² <i>p</i> -value	n=902 %	n=146 %	
Who do you think should be prioritised in health care?			0.001			0.100
Younger patients	13	18/10		14	8	
Older patients	6	7/5		5	8	
All age groups	81	75/85		81	84	
What alternative do you think is fairest?			0.115			<0.001
Among people with life-threatening illness younger patients should have some priority over older people	18	20/17		19	15	
People should have the same priority with respect to life-saving treatment unless they are very old	14	16/12		15	5	
People should have the same priority with respect to life-saving treatment no matter what their age is	68	64/71		66	80	
Who should be the one to have a new kidney?			0.830			0.588
A 60-year-old woman	93	93/94		94	92	
A 70-year-old woman	4	4/4		3	5	
An 80-year-old woman	3	3/2		3	3	
Who should be the one to have a new hip joint?			<0.001			0.139
A 60-year-old man with walking difficulties	21	26/16		20	24	
A 70-year-old man with bad pain	71	67/74		72	65	
An 80-year-old man using a wheelchair because of his bad hip	8	7/10		8	11	
Who should be the one to have cataract surgery to improve the eyesight?			0.001			0.153
A 60-year-old with dementia	15	21/10		15	13	
A 70-year-old with coronary disease	28	30/27		30	23	
An 80-year-old healthy person	57	49/63		55	64	
Who should make the decisions in vertical priority settings?			0.220			0.076
The doctors	94	93/95		95	91	
The nurses	2	2/2		2	3	
Local politicians	1	1/1		1	0	
National politicians	0	1/0		0	1	
The National Board of Health and Welfare	1	2/0		1	1	
The public	2	1/2		1	4	
Who should make the decisions in priority settings on resource allocation?			0.028			0.082
The doctors	73	69/75		73	72	
The nurses	4	5/3		3	5	
Local politicians	6	6/6		6	7	
National politicians	5	4/6		5	2	
The National Board of Health and Welfare	9	12/7		10	7	
The public	3	4/3		3	7	

Both study groups thought that the most important criterion that should affect prioritisation was the severity of the disease and only few 2 respectively 3 % thought that prioritisation should be done by lottery (Papers I and III). Significant differences

between the groups were found in the view of other criteria for prioritisation. The fact that the patient was a child was an important criterion for 48 % of the participants not receiving care and service and for 26 % of the participants receiving care and service ($p<0.001$) (Figure 3). Also the multinomial regression analysis showed that the view that younger people should have priority over older people (with “people should have the same priority no matter what their age” as reference) was associated with not receiving continuous care and service (OR 2.51; 95 % CI 1.03–6.06, $p=0.041$) (Add an).

People who were not receiving continuous care and service further tended to let the fact of being a child (OR 2.47; 95 % CI 1.28–4.77, $p=0.007$), being older (OR 3.84; 95 % CI 1.64–9.04, $p=0.002$) and still be working (OR 2.32; 95 % CI 1.14–4.74, $p=0.020$) affect prioritisation much. Belonging to the group not receiving care and service was also associated with agreement with the statement “Expensive procedures for older people should not be subsidised by public money” (OR 3.15; 95 % CI 1.14–8.76, $p=0.028$) and “No more expenditure cuts can be made in health care” (OR 2.94; 95 % CI 1.32–6.52, $p=0.008$), with disagreement as reference (Add an). The criteria that the patient was old or middle-aged was used less as criteria by the participants receiving care and service than by the participants not receiving care and service ($p<0.001$) and so was also the fact that the disease was self-inflicted ($p<0.001$) (Figure 3).

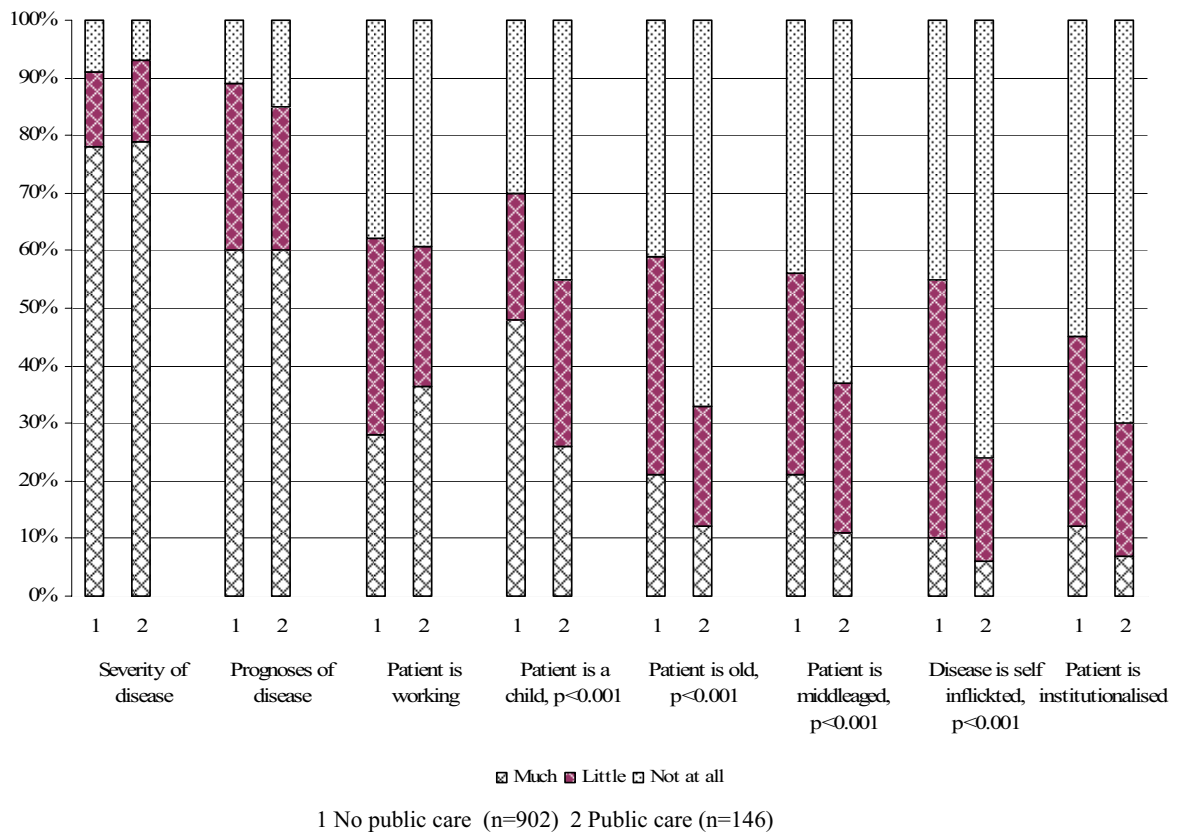


Figure 3. The participants’ view of how different indicators should affect prioritisation, and comparisons between people not receiving care and service and participants receiving care and service.

The results showed that the participants saw prioritisation as a necessity (Paper IV) and wanted physicians to make the decisions concerning prioritisation: 95 % of the participants not receiving care and service and 91 % of the participants receiving care and service on vertical level and 73 % and 72 % respectively on horizontal level (Paper I and III). Significant differences were seen within the group receiving care and service since participants living at home, to a higher degree than participants living in special accommodation, thought that the National Board of Health and Welfare and the public should make decisions about prioritisation on horizontal level ($p<0.001$) (Paper III). Neither local nor national politicians were regarded as being the ones being able to make priorities in health care. No significant differences were seen between the two study groups in their view of who should decide on prioritisation (Table 5).

Even if the participants emphasised that all people are of equal value and everyone has the same rights to health care regardless of age, the view of prioritisation as a necessity was present in their reasoning (Paper IV). The participants highlighted both young and old age as reasonable criteria. When emphasising *young* age as a criterion for prioritisation this view was based on the idea 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. When emphasising *old age* as criterion for prioritisation, this view was based on the idea that older people have less time left and are often suffering from several diseases. Older people were further considered more fragile and should therefore not spend their last time waiting for health care. Also, the view that older people had paid taxes all their life and contributed to the welfare of today was expressed (Paper IV).

The views of prioritisation in relation to the participants' age

Comparison between the age groups showed that the oldest-old prioritised younger people to a higher extent than younger age groups, especially among the participants not receiving care and service. The oldest-old prioritised a 60-year-old in need of a new hip joint before a 70-year-old with worse pain to a higher extent than the young-old and old-old participants ($p=0.004$). Also the oldest-old, more than the young-old and old-old participants, thought that being middle-aged is an indicator that should affect prioritisation a great deal ($p<0.001$) (Paper I). Among the younger participants receiving care and service, 20 % thought that old age was an indicator that should affect prioritisation a great deal while 5 % of the oldest participants thought so ($p=0.023$) (Paper III). The multinomial logistic regression analysis, including both study groups, showed that belonging to the young-old age group was associated with not wanting the fact that the patient was middle-aged (OR 0.38; 95 % CI 0.21–0.68, $p=0.001$) to affect prioritisation (Add an).

The view of prioritisation in relation to the participants' gender

Comparisons between men and women showed that men prioritised younger people to a higher extent than women, who prioritised older people to a higher extent. The results showed that male sex was significantly associated with prioritisation of younger age groups (Paper I and add an) while women asserted old age to be a stronger indicator for prioritisation than men did ($p<0.001$) (Paper I). Male sex was also associated with prioritisation of younger people when the patient was suffering from dementia (OR 2.99; 95 % CI 1.90–4.73, $p<0.001$)(Add an). When men and women were compared, both study groups included, men prioritised younger persons more often than women did, as regards who should have a new hip joint (26 % versus 17 %, $p=0.001$), cataract surgery (21 % versus 10 %, $p<0.001$) as well as the “overall” question about “who should be prioritised in health care” (17 %/10 %, $p=0.001$) (Table 5).

The view of prioritisation in relation to the participants' HRQoL

Among the participants not receiving care and service, a high Physical Component Summary (PCS) was associated with giving high priority to “a 70-year-old man with pain (with an 80-year-old man in a wheelchair as reference) (OR 1.04; 95 % CI 1.01–1.06) to get a new hip joint and with giving low priority to a 60-year-old with dementia (with an 80-year-old healthy person as reference) (OR 0.98; 95 % CI 0.95–0.99) for receiving cataract surgery (Paper I). Among the participants receiving care and service, those having high Mental Component Summary (MCS), more than those having low MCS, thought that the prognosis of the disease should affect prioritisation ($p=0.026$). Differences in HRQoL were also seen in relation to who the participants wanted to be the one to make priorities in health care, as participants with high PCS to a higher extent wanted the physicians to make decision concerning resource allocation (82 %) compared to 58 % of the participants with low PCS ($p<0.001$) (Paper III).

The view of prioritisation concerning lifestyle-related diseases

In the total sample 43 % wanted to prioritise a patient who was infertile because of several abortions and needed an operation to be able to get pregnant, while a patient who was a football player, injured during training and needing a new knee to be able to continue his sport activity, was prioritised by 40 %. An alcoholic in need of a liver transplant was prioritised lowest by both groups (5 %). The view of how to prioritise people with lifestyle-related disease differed significantly between the group receiving care and service and the group not receiving any ($p<0.001$). The group receiving care and service prioritised a smoker to a higher degree, while they gave the woman wanting to be pregnant lower priority than did the group not receiving care and service (Table 6). The multinomial logistic regression analysis showed that male sex was associated with not prioritising a smoker (OR 0.55; 95 % CI 0.32–0.92, $p=0.023$), having access to €1500 was associated to not wanting to prioritise an alcoholic

(OR 0.41; 95 % CI 0.18–0.96, $p=0.039$) and young-old age group was associated with not wanting to prioritise a football player (OR 0.49; 95 % CI 0.29–0.83, $p=0.008$), all with women wanting an operation to be able to get pregnant as reference (Add an).

Table 6. The participants’ view of prioritisation for treatment of lifestyle-related diseases, and comparisons between people not receiving care and service and participants receiving care and service

Question	Total n=1048 %	No public care Paper I n=902 %	Public care Paper III n=146 %	Chi ² p-value
Which of the following patients should be first ranked for treatment?				<0.001
A patient who smokes, refuses to stop and needs a coronary by-pass operation	12	10	21	
A patient who is an alcoholic and needs a liver transplant	5	5	6	
A patient who is a football player, injured during training and needs a new knee to be able to continue his sport activity	40	40	43	
A patient who because of several abortions is infertile and needs an operation to be able to get pregnant	43	45	30	

The view of resource allocation

In the participants’ reasoning *having doubts about the distribution of resources* was present and a disappointment over the politicians and the way they allocated and administered health care resources and tax revenue was clearly stated. 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 fewer queues in health care and compared the present situation with the past and thought that everything had become worse. The prevailing opinion was that care and service for older people and access to special accommodations had decreased. The participants expressed the view that more money was needed and that it should be earmarked for health care and not be wasted on, for example, cosmetic surgery, which was viewed by the participants as unnecessary (Paper IV).

“I think that all people in need should be prioritised and I am willing to pay more taxes if the money is spent rationally on health care.” (M 60)

The participants thought that the services that received too little resources were elder care and health education (Paper II and III). There were significant differences between the two groups, as more of the participants not receiving care and service (75 %) than participants receiving care and service (57 %) thought that elder care got too little resources ($p<0.001$) (Figure 4). There were also significant differences concerning health education, as 77 % of the participants not receiving care and service and 60 % the participants receiving care and service thought that it received too little ($p=0.003$) (Figure 4). The service that was considered to receive too much resource was health care administration and drug addict care (Paper II and III). Here too,

significant differences between the groups were seen, as 42 % of the participants not receiving care and service and 31 % of the participants receiving care and service thought that health care administration received too much resources ($p<0.005$) (Figure 4).

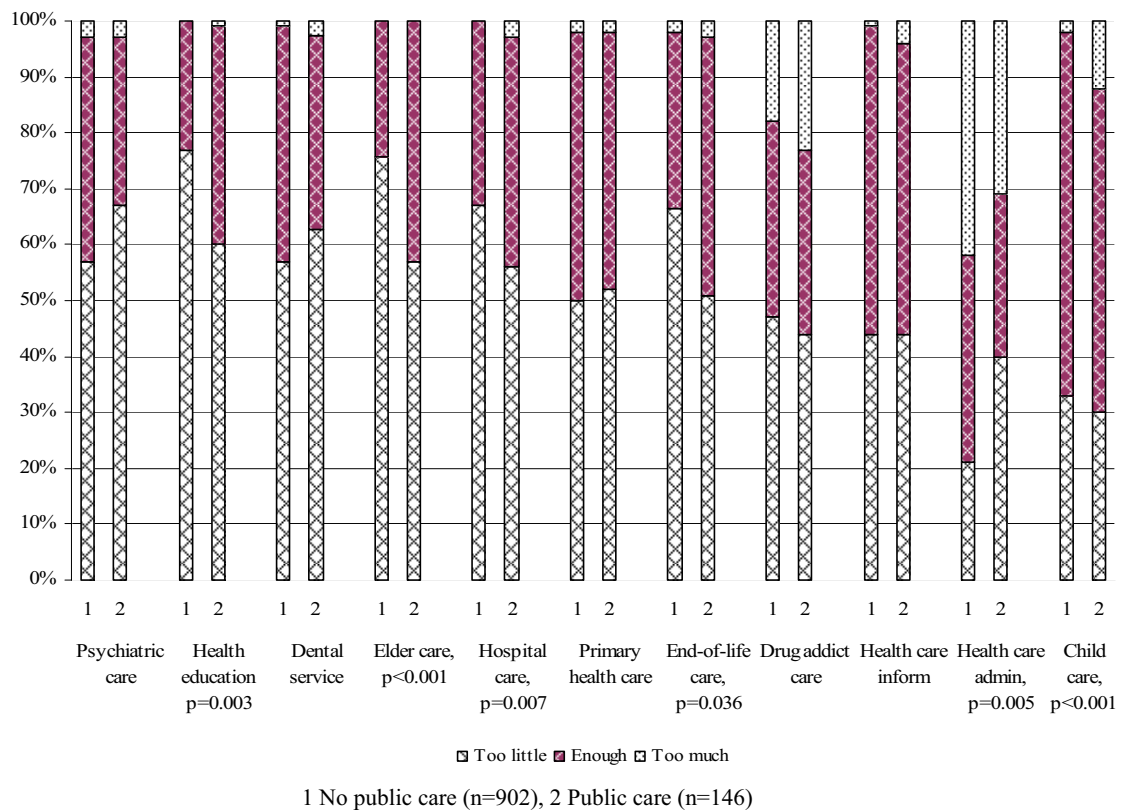


Figure 4. The view of how resources are allocated, from participants not receiving care and service versus participants receiving care and service. The participants were asked “How do you view resource allocation to these disciplines? Which gets too much, enough and too little?”

The views of resource allocation in relation to the participants’ age

In Paper II the oldest-old (44 %) significantly more than the young-old (18 %) and old-old (30 %) participants, not receiving care and service, thought that elder care was allocated enough resources ($p<0.001$). The multinomial logistic regression analysis showed young-old age group (OR 0.11; 95 % CI 0.06–0.23, $p<0.001$) and old-old age group (OR 0.23; 95 % CI 0.12–0.46, $p<0.001$) was associated with not agreeing with the statement “expensive procedures for older people should not be subsidised by public money”, meaning that the younger the participants’ were, the more likely they wanted to subsidise expensive procedures for older people (Add an).

The view of resource allocation related to the participants' gender

When men and women were compared, it appeared as if women more than men thought that too little resource were allocated to health care in general. In Paper II the participants not receiving care and service thought that psychiatric care and drug addict care got too little resources allocated, 68 % and 57 % respectively of the women and 46 % and 39 % respectively of the men ($p<0.001/p<0.001$). Elder care was considered to receive too little resource allocated by 66 % of the women and by 57 % of the men ($p=0.002$). Among the participants receiving care and service significant differences were seen between men and women, as where 76 % of the women considered psychiatry to get too little resources compared to 41 % of the men ($p=0.030$) (Paper III). When both study groups were included, significant differences were seen between men and women concerning resource allocation to elder care ($p=0.004$), psychiatric care ($p<0.001$), end-of-life care ($p=0.004$), drug addict care ($p=0.001$) as well as health care administration ($p=0.002$) (Figure 5). A multinomial regression analysis showed that agreement with the statement “If two types of treatment exist, the cheaper one should be chosen even if it is less effective” was associated with male sex (OR 6.78; 95 % CI 3.24–14.20, $p<0.001$) and male sex was further negatively associated with the statement “No more expenditure cuts can be made in health care” (OR 0.43; 95 % CI 0.0.28–0.67, $p<0.001$) (Add an).

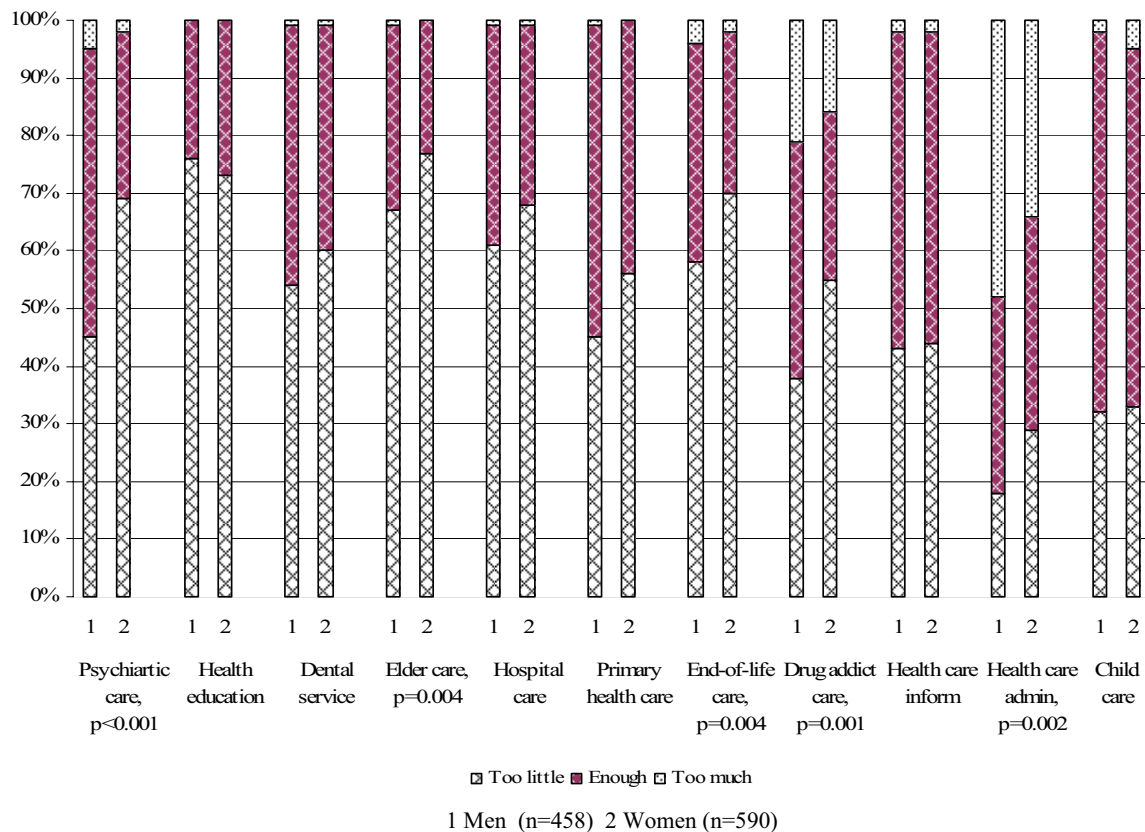


Figure 5. The view of resources allocation, comparison between men and women. The participants were asked “How do you view resource allocation to these disciplines? Which gets too little, enough and too much?”

Willingness to pay in relation to the participants' financial situation

The participants' reasoning in relation to willingness to pay for treatment revealed that they experienced that *buying treatment required wealth*. When not having the ability to pay the participants stated that there was no choice to consider and that it thereby became more tempting to be on a waiting list and get surgery for free. The participants further emphasised that all people are of equal value and everyone has the same rights to healthcare referring, to the principle of human dignity and the principle of justice. Paying to precede in rank was further experienced as morally wrong and unfair to other persons waiting for treatment. The participants argued that a person who pays his taxes should not need to pay to get treatment despite having the possibility (Paper IV).

“Not many pensioners can come up with €1100, it will be those with money who take precedence and lengthen the waiting lists for the rest.” (W 84)

In Papers II and III 74 % and 79 % respectively of the two groups, not receiving and receiving care and service, wanted to finance the increasing health care costs either through higher taxes in general or higher taxes on alcohol and tobacco. Thirteen and 8 % respectively wanted to reduce the social expenses; 7 % and 4 % respectively thought that higher patient fees were the best alternative and 6 % and 7 % respectively wanted private health insurance to finance the increasing health care costs (Papers II and III).

Among the participants not receiving care and service, 63 % wanted to pay to have cataract surgery at once instead of being on a waiting list for 18 months. In Paper III 48 % of the participants receiving care and service wanted to pay for cataract surgery. When the two groups were compared, significant differences were found concerning willingness to pay ($p < 0.001$) (Table 7).

Table 7. The participants' willingness to pay and financial situation

Questions	Total	No public care	Public care	p-value
	n=1048 %	Paper II n=902 %	Paper III n=146 %	
If you need cataract surgery to be able to see, what alternative would you choose?				<0.001
Be on a waiting list for 18 months	39	37	52	
Pay €1100 out of your own pocket and have the operation at once	61	63	48	

Willingness to pay in relation to the participants' age and gender

Among the participants not receiving care and service the alternative to pay to have cataract surgery at once instead of being on the waiting list was more often chosen by the young-old participants (68 %) than by the old-old (53 %) ($p<0.001$) No significant differences were seen between the age groups regarding financial situation (Paper II). Also, more men (72 %) than women (55 %) wanted to pay to have cataract surgery at once ($p<0.001$) and more women (45 %) than men (28 %) wanted to be on a waiting list for 18 months ($p<0.001$). The opinion that an effective treatment should be performed regardless of the expense was lower among the oldest-old (64 %) than the young-old (79 %) ($p=0.002$) among participants not receiving care and service (Paper II).

Differences related to age was also found among the participants receiving care and service, as 59 % of the youngest age group were willing to pay compared to 39 % of the oldest ($p=0.019$) (Paper III).

Significantly fewer women (78 %) than men (92 %) among all the participants wanted to pay €1100 out of their own pocket to have cataract surgery at once instead of being on a waiting list for 18 months ($p<0.001$) (Add an). This was further verified in the multiple logistic regression, since factors significantly associated with willingness to pay €1100 were male sex (OR 1.74) and having access to €1500 (OR 4.08). Old age was significantly associated with less willingness to pay €1100 to have cataract surgery at once (OR 0.97) (Table 8).

Table 8. Logistic regression analysis of variables associated with willingness to pay €1100 for cataract surgery (n=1048).

Final model	OR	95 % CI for OR	<i>p</i> -value
Having access to €1500	4.082	2.70–6.17	<0.001
Male sex	1.740	1.29–2.25	<0.001
Old age	0.968	0.954–0.983	<0.001

Variables entered in the regression analysis: age, PCS, MCS (HRQoL), having access to €1500 and sex. Hosmer-Lemeshow test for goodness-of-fit: 0.939 and Nagelkerke R^2 : 0.134.

DISCUSSION

Methodological considerations

The aim of this thesis was to investigate older people's views of prioritisation and resource allocation in health care. The research questions were approached by both quantitative (Papers I–III and framework) and qualitative (Paper IV) methods. The different methods were seen as complementary and increasing the validity of the findings (Mitchell, 1986), giving a more complete picture of older people's views of prioritisation and resource allocation. The methodological approach in this thesis will be discussed on the basis of trustworthiness as described by Lincoln and Guba (1985), including four major concerns: *Truth value*, *Consistency*, *Neutrality* and *Applicability*. According to Lincoln and Guba (1985), *truth value* concerns confidence in the “truth” of the findings in relation to both participants and the context of the study. A quantitative study's truth value may be judged by its internal validity and a qualitative one by its credibility. *Consistency* concerns questions such as whether the study result could be repeated with the same participants in the same context. Consistency in a quantitative study may be judged by its reliability and in a qualitative one by dependability. *Neutrality* refers to whether the findings are determined by the participants and not biased by the motivations, interests and perspective of the researcher. In a quantitative study neutrality is judged by its objectivity and in a qualitative one by its confirmability. Finally, *applicability* refers to external validity in quantitative studies and transferability in qualitative studies and concerns how the findings are applicable in other context or with other subjects (Lincoln and Guba, 1985).

Considerations with regard to quantitative methodology

Internal validity

Internal validity refers to the extent to which the independent variables truly influence the dependent variables, and the relationship between the two should not be the effect of an extraneous variable. According to Kazdin (2003), loss of respondents may be a threat to internal validity. Several efforts were made to achieve as high a response rate as possible in the GAS project, for example by increasing the population's knowledge about and interest in the study, by advertising in the press and on television (Lagergren et al., 2004). There was an initial dropout in connection with the invitation to the GAS population study, and there is a risk that the respondents in the study group were healthier than those who declined participation. However, by including participants from the care and service part of the GAS study, the views of less healthy persons were considered. The response rate in the second step of the population study, when people were asked to participate in the semi-structured study about prioritisation, was high, 97 %.

There is a risk that the respondents from the population study participated in the interviews for this study, as they were already “in place” and might have felt gratitude to the researcher, having a free medical examination (Papers I, II). In Paper III there

was also a risk that the participants' willingness to participate in the study would be influenced by the fact that they were in a state of dependence on the nurses asking them to participate, referring to the principle of autonomy. This is an important ethical question but most likely not something that influenced their honesty in the interview situation.

Another threat to internal validity is selection bias, referring to systematic differences between groups based on the selection of participants. According to Kazdin (2003), randomly selected participants are commonly used as informants to minimise the risk of selection bias. The participants in the two study groups (Papers I, II and Paper III) were chosen using two different procedures. The participants in Papers I and II were randomly chosen within age cohorts, and participants in Paper III receiving care and service were chosen by nurses working in the municipalities. This was not only a practical solution but also had the methodological advantage that the author had no influence on which persons were asked to participate in the study. Selection bias could still occur as the municipal nurses chose suitable participants for Paper III. It was not possible, however, to randomly select this sample in realistic time due to the difficulty of finding participants matching the inclusion criteria. It is reasonable to believe that the participants in Paper III were more concerned and experienced in prioritisation and resource allocation in health care than the participants in Papers I and II. However, although the two study groups were selected differently and had different experience of the subject in focus, the study provides useful information about how older people, with and without experience of the subject, view prioritisation. Several steps to increase the internal validity have thus been taken.

Construct validity

Construct validity involves logical analysis and tests predicted by theoretical considerations (Polit and Beck, 2004). The questionnaire was developed mainly based on questions used in earlier studies, but some questions were constructed by the research group (Papers I, II and III). Lewis and Cuevas (1996) stated that a researcher may use a self-constructed test if there are no acceptable instruments available. The theoretical rationale upon which item selection was based could be one attempt to support validity, i.e. based on ethical principles. *Instrument clarity* emphasises the importance of an instrument in plain terms, sometimes described in terms of face validity (Polit and Beck, 2004). The questions were discussed with a panel representing different professions, such as nurses, physicians and teachers. The main purpose of these discussions was to improve face validity, referring to the extent to which the meaning of the questions is reasonable or obvious (Kazdin, 2003). The questionnaire was further tested and thereafter adjusted in concordance with the results of the pilot study (Werntoft et al., 2005). Questions in an instrument may further be interpreted differently by different respondents, leading to distorted measuring of the variable (Polit and Beck, 2004). The presence of the nurse made it possible for the respondents to obtain help with potentially unclear points in the questionnaire. This opportunity was used occasionally. As the questions were carefully tested in the pilot study, the risk of misinterpretation was however reduced.

Instrument format refers to the way data from an instrument are formatted as text. Oral responses to a question may be at odds with written responses to the same questions (Polit and Beck, 2004). The results of the qualitative analysis of the tape-recorded interviews (Paper IV) corresponded to and confirmed the results of the quantitative analyses of the structured interviews (Papers I, II and III). Several steps have thus been taken to reduce the risk of measurement failure, which has strengthened the validity of the findings.

Reliability

Reliability concerns the extent to which the measures assess the characteristic of interest in a consistent fashion. Reliability refers to random variability associated with measurements (Kazdin, 2003). The reliability of an instrument can be assessed in various ways. The method chosen depends on the nature of the instrument, and one key aspect is stability (Polit and Beck, 2004). Assessments of an instrument's stability involve procedures that evaluate test-retest or stability reliability, for example, when the same instrument is administered to a sample on two occasions and the results are compared. However, many traits do change over time, irrespective of instrument, i.e. attitudes, behaviours and knowledge (ibid.). In this study the respondents were presented with the questionnaire unprepared. As the questions forced them to reflect on prioritisation in health care, their standpoints would most likely have been different if they had been exposed to the same questions again. According to Dolan et al. (1999), the public's view of prioritisation in health care could differ when they have been given the opportunity to discuss the issues. All the respondents in this study answered the questionnaire under the same circumstances. However, debates in society are continuously ongoing and the effect these debates had on the answers from the participants is not possible to measure, but at that point the answers reflected the view of the participants. The reliability of an instrument is also related to the heterogeneity of the sample. The more heterogeneous the sample, the higher the reliability will be concerning the ability to detect differences among those being measured (ibid.). The heterogeneity of the sample was characterised by age, gender, HRQoL, degree of dependency and financial situation.

Statistical conclusion validity

Statistical conclusion validity refers to the extent to which a statistical relation can affect the conclusions drawn from the results (Kazdin, 2003). The conclusions in a study depend on hypothesis testing and statistical evaluation, and the null hypothesis specifies that there are no differences between different groups. The null hypothesis is rejected if there is a statistically significant difference or is accepted if there is not. In this thesis a level of significance was set at 0.05. When using multiple comparisons (Papers I and II), a reduced significance level of 0.017 was used to avoid the risk of finding a larger number of significant differences by chance, which is possible when large numbers of significance tests are included. In those cases, according to Bland and Altman (1995), there will inevitably be something that is "significant". This was

done to avoid Type I error (α) which occurs when the null hypothesis is rejected falsely or the conclusion is that there is a difference when in fact there is not. When choosing a significance level of 0.05 or 0.01 α errors are best avoided. Type II or β errors occur when the null hypothesis is accepted falsely or the conclusion is that there is no difference when in fact there is. One way of reducing β errors is to increase sample size (Brink and Wood, 1998), and with a sample of 902 persons the risk of β errors in Papers I and II could be considered low. In Paper III, though, the sample size (146 persons) ought to be considered and comparisons between gender and age groups discussed. Calculation showed low power (between 0.20 and 0.40) in study III, with the possible implication that true differences could not be detected by the statistical analysis. However, p -values for non-significant results were high ($> .20$), thereby diminishing the risk of β errors.

Objectivity

Objectivity concerns whether two independent researchers would arrive at similar judgements or conclusions, judgements not biased by personal values or beliefs (Polit and Beck, 2004). The use of standardised instruments, SF-12 in Paper I and SF-12 and activities of daily living (I-ADL and P-ADL) in Paper III strengthens the objectivity. Objectivity in quantitative research is assured by using preset levels of significance and by using predetermined aims and hypotheses. According to Altman (1991), it is preferable to decide in advance of the analysis which outcome measure are of interest and when analysing the data, to focus on this variable in order to avoid too many analyses with unavoidable significant values, which was done in this thesis.

External validity

External validity refers to how far the results can be generalised to other settings or samples. A study is externally valid to the extent that the sample is representative of the broader population and the study setting are representative of other environments (Polit and Beck, 2004). The sample in Paper I and II was randomly selected from the population register, which strengthens the external validity and minimises the influence of systematic biases. In Paper III the participants were identified by nurses working in the municipalities. They received information about the inclusion criteria and then asked persons whose care and service they were responsible for and who met the inclusion criteria if they would permit an interview in their home. The findings could not, however, be generalised to groups with more severely impaired function since they were not included due to impaired speech or cognitive decline, which is a limitation to the study.

Questions about generalisability also concern whether the sample represented a very special sample in terms of demographic characteristics (Kazdin, 2003). The sample represented older people, aged 60 to 100 years, living in ordinary dwellings as well as in special accommodation. The data collection for both the population part and the care and services part is ongoing in five municipalities in the south of Sweden, representing urban areas as well as rural areas and areas with mixed structure aiming

to replicate the whole of Sweden. However, the results can mainly be generalised to countries with the same health care context as in Sweden, i.e. publicly financed and provided health services and care for all citizens. The sample also represented differences in gender, HRQoL and financial situation. Thus, since the participants furthermore were selected partly from a group of older people not receiving care and service and partly from a group of older people receiving care and service, the findings most likely reflect the group of older people in general and the findings may thus be generalised to the group of people aged 60 years and over.

Considerations with regard to qualitative methodology

Credibility

Credibility in qualitative studies refers to the believability of the data (Polit and Beck, 2004). Credibility is when the results present a faithful description of the participants' experiences and produce results that are plausible (Lincoln and Guba, 1985). Credibility also depends on the quality of interviews and on whether the researcher has managed to remain open to alternative interpretations (Hamberg et al., 1994). To increase credibility, several efforts were made to create good conditions for the participants to feel secure and comfortable with the interview situation. Most of the interviews with the participants not receiving care and service were made 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. A relationship was achieved that made the participants feel safe and secure although they sometimes were tired. The interviews with the participants in the care and service part of the GAS study took place in their home and a sufficient amount of time was allowed for the interviewers to understand the participants' context and to give opportunities for the participants and the interviewers to get to know each other and thereby increase the participants' feelings of confidence.

Alterations in the methods of collecting data from one person to the next can result in score variations unrelated to variations in the target attribute (Polit and Beck, 2004). All eight nurses involved in the data collection received the same repeated information on how, when and where to present and carry out the interview. The first interviews by each nurse were supervised by the author. There is, however, always a risk that the interviewer develops new models for the procedure over time. This risk was most likely reduced as the interview performance was continuously discussed among the nurses during the period of data collection. As the interviews were structured, the risks of interview effects were further reduced.

The interviews varied greatly in length and depth and some participants made several comments and utterances concerning and in connection with the structured questions while others did not make any comments at all apart from answering the questions. Of the 500 tape-recorded interviews with the participants not receiving care and service, only 300 were considered usable. The remaining 200 did not add anything as the respondents did not make any comments on the structured questions and did not give any answer to the two open-ended questions. All participants receiving care and

service made some comments and/or answered the open-ended question(s). This different outcome is probably due to the increased time spent on the interview with the participants receiving care and service. The interview also affected the participants differently. Some participants became enthusiastic and emphasised the importance of these kinds of questions while others felt discomfort and wanted to hurry through the questionnaire.

An inadequate sample size can undermine the credibility of research findings. According to Sandelowski (1995), an adequate sample size in qualitative research is a matter of judgement in evaluating the quality of the information collected against the research method, the sampling strategy employed and the aim of the study. Sandelowski further suggests that an adequate sample size in qualitative research is one that permits the deep, case-oriented analysis and that results in a new and richly textured understanding of experiences. This cannot be the case if the sample size is too large or too small (Sandelowski, 1995). The large number of participants in this qualitative study could be discussed, as also the depth in many of the interviews, which could interfere with the case-oriented trust of the findings. However, the rich variation in the findings might still contribute to knowledge of how older people reason about prioritisation and resource allocation.

Dependability

Dependability refers to the replicability of the study and to the stability of data over time. Since, according to Lincoln and Guba (1985), it is difficult to establish dependability and there is no credibility without dependability, a careful description of credibility is needed to establish dependability. There is a risk of inconsistency when dealing with a large amount of data and a long-drawn-out data collection period with the participants subject to different influences in society. During the years of data collection there have been incidents that might have influenced the findings. For example, a few both local and national politicians have caused discussions and public debate that could have influenced participants' views of them as decision makers in questions of prioritisation. This occurrence is however inevitable, and Guba (1981) suggested that dependability could be enhanced when an auditor examines the process of the analysis and confirms that the interpretations are representative and represented in the data. In this thesis the dependability was strengthened by having two researchers analyse the text and the interpretations of the text were discussed between all three researchers.

Confirmability

Confirmability means that the findings are grounded in the data and not in the subjective or objective view of the researcher. The interviews were analysed by manifest and latent content analysis and the findings illuminating the reasoning about prioritisation were validated by the quantitative results. The credibility was also strengthened by having several researchers involved in the analysis process in an attempt to limit the risk of subjective influence. According to Sandelowski (1998), the

findings in a qualitative paper intertwine data and interpretations of those findings. It is important that sufficient emphasis is given to the voices, actions and experiences of participants themselves so the readers can gain an apprehension of their lives and worlds. Most often this occurs through inclusion of quotes. Sandelowski (1994) also discussed whether quotations should preserve every element of the participant's expression or be cleaned of grammatical errors or non-standard speech patterns. The confirmability was enhanced by the inclusion of quotations from the original text and they were chosen in order to allow the reader to judge the categorisation and interpretation of the text, thus presented in the original version.

Transferability

Transferability refers to the idea of fittingness, i.e. the extent to which the findings can be generalised or transformed to other groups or settings (Lincoln and Guba, 1985). The researcher has to provide sufficient data and descriptions to ensure that the sample is as heterogeneous as possible (Polit and Beck, 2004). The samples in qualitative studies are seldom randomly selected. Morse and Field (1995) argued that drawing participants randomly could bring participants who know nothing or very little about the topic of concern. However, one reason for the sampling procedure was to obtain variation in responses. 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 group of older people in general and may thus be transferable to the group of people 60 years and over, also considering the large variance in gender, age, physical condition, financial situation and experience in health care.

General discussion

The prevailing view among older people was that age should not be a criterion for prioritisation in health care. This was seen in the quantitative results as well as in the participants' reasoning in connection with age-related questions. Eighty-one percent of the participants not receiving care and service gave priority in health care to all age groups (Paper I). In Paper III, 80 % of the participants receiving care and service thought that people should have the same priority with respect to life-saving treatment, no matter what their age is. In the participants' reasoning about prioritisation they were *averse to anyone taking precedence over others* (Paper IV). Exceptions to this view were based on partly human and partly economic reasons, but pain, health and quality of life were criteria that the participants rated higher in their priorities. This is in line with the recommendation from the Swedish Parliamentary Priority Commission, to the effect that all human beings have equal dignity and the same rights, regardless of their personal characteristics and their functions in the community, and that resources should be committed to those fields where the needs are greatest (SOU, 1995). In the work of the Parliamentary Priority Commission, however, the meaning of need is not specified, which has been highlighted by Liss (2006). Liss (2006) suggests that the principle of need and solidarity should be expanded so that the degree or duration of

pain or other suffering will also be assessed when determining needs. The findings in this thesis thus support the idea of expanding the principle, thereby making the principle of need and solidarity more applicable and explicit in work with prioritisation in health care.

The finding that older people did not want age to be a criterion in prioritisation differs from earlier studies involving younger age groups. Previous studies with low participation of older people have shown that the general public, (Johannesson and Johansson, 1996) as well as physicians (Ryynanen et al., 1997) gave priority to younger people, in line with the reasoning of Daniels (1985), Callahan (1995) and Williams (2000), meaning that rationing by age is permissible under conditions of scarcity. Kobelt (2002) further argued that both quality and quantity of life should be considered when deciding priorities for treatment by calculating costs by quality-adjusted life years (QALY). The quantity component of the QALY is the number of life years under consideration and can be the number of life years saved due to a particular course of treatment. Williams (1993) suggested that a beneficial health care activity is one that generates a positive amount of QALYs and that an efficient health care activity is one where the cost-per-QALY is as low as it can be. Another method, called equity-adjusted QALYs or equity-adjusted years of life saved (EYLS) has been proposed by Lindholm and Rosen (1998) and Lindholm et al. (1999). EYLS includes a balance between health maximisation and justice, i.e. if a programme both maximises health and increase equity the relative efficiency of the programme will increase further when the concept of EYLS is applied. Jacobsson (2001) argued that the distribution principle underlying EYLS's health gains are more valuable the more severe the disease from which the patient suffers, in line with the principle of need and solidarity. Thus when using calculations based on the balance between health maximisation and justice, the treatment of, for example, malignant glioma appeared more cost-effective than hip replacement although the treatment of the malignant glioma increased the length of life by only one year (SOU, 2001a). The more QALYs a person can expect to reach during her life, the less is the marginal effect or value of additional QALYs measured in EYLSs (SOU, 2001a). Lindholm (SOU, 2001a) discusses this model with regard to severe illness (lung cancer and brain tumour) but when it comes to people with a shorter lifetime perspective, the model might also be applicable in the discussion of prioritisation of older people and thus support the treatment of older people in financial terms as well.

The principle of need stood out as an important criterion in prioritisation except concerning lifestyle-related diseases. When choosing between four different lifestyle-related diseases to receive treatment, the most life-threatening disease were given the lowest priority. A football player was placed first by the participants receiving care and service (Paper III) and an infertile woman by the group not receiving care and service (Paper I). A patient who is an alcoholic needing a liver transplant was given lowest priority by both groups although he suffered from a life-threatening disease. Among the participants receiving care and service, however, a majority of the participants – to a significantly higher degree than those not receiving care and service – thought that, although the disease was self-inflicted, it should not affect prioritisation

(Add an). This is in contrast to the view of, for example, health care professionals. In one study among 208 physicians, 53 % considered patients' age and lifestyle-related diseases to be important factors in priority decisions (Ridderstolpe et al., 2003). In a Finnish study with nurses, physicians, politicians and the general public (n= 5700) all groups considered that self-inflicted diseases should not be subsidised by the community (Myllykangas et al., 2003). The authors argue that there are several reasons why lifestyle cannot be accepted as a rule on which to base prioritisation as it is usually impossible on an individual level to determine to what extent genetic, rather than lifestyle factors, have contributed to a disease (Myllykangas et al., 2003). Many lifestyles are further closely associated with low education and low socio-economic status. If low priority is given to people with unhealthy lifestyles, there is a risk that inequality in health care will increase. This would further be in contradiction to the principle of need and solidarity (Asplund, 1995) and also to the Swedish Health and Medical Services Act (SFS, 1982:763), which enshrines equal access to services on the basis of need and emphasises a vision of equal health for all.

The results showed that the participants wanted physicians to decide who should be prioritised. The participants wanted the physicians to make decisions about prioritisation on a vertical level as well as a horizontal level. Only small differences were seen between the two study groups in their view of who should decide on prioritisation (Add an). Similar results have been demonstrated in several studies (Bowling, 1996, Mossialos and King, 1999, Myllykangas et al., 1996, Worth, 1999). This standpoint, however, entails the risk that older people are given lower priority. For example, Myllykanga (2003) found that physicians were less willing to prioritise older people than nurses, politicians and the general public were. This research team also found that physicians were less willing to refer elderly patients for elective surgery (Ryynanen et al., 1997). Rosén (2002) suggested that since decision makers in general and physicians in particular are more positive towards the age criterion than the public, the utilitarian arguments weigh more heavily among both decision makers and physicians. The general public, according to Rosén, are more inclined to support egalitarian reasons against using age as a rationing criterion. Maybe this explains why, among the participants receiving care and service, significantly fewer with a low physical component summary (PCS), who are probably the ones in most frequent contact with physicians, wanted the physicians to make decisions on a horizontal level, compared to participants with a high PCS (Paper III). It might be that they have found that their needs are not met in contact with physicians. However, Sabin (2000) argued that vertical prioritisation cannot be legitimate without the support and participation of clinicians. The clinicians' experiences in health care institutions, which are the context of conflicts between the needs of patients and the good of society, can give them a unique perspective important to institutional priority setting. Hurst et al. (2005) identified strategies used by physicians in dealing with ethical difficulties. The findings showed that, when faced with ethical difficulties, the physicians avoided conflict and looked for assistance, which contributed to protecting, or attempting to protect, the integrity of their conscience and reputation, as well as the integrity of the group of people who participated in the decisions. In another study (McGuire et al., 2005) it was shown that physicians expressed consistently positive attitudes towards

patient participation in medical decision-making. Many physicians saw their role as an expert who educates the patient but retains control over the decision-making process; others took a more collaborative approach, encouraging patients to assume decisional priority. Thus, it appears as if physicians in general manage and deserve the confidence that they are given from older people, although several of them, according to Ridderstolpe et al., (2003) are not aware of the established principles for priority setting.

Neither local nor national politicians were regarded as being the ones to make priorities in health care (Papers I and III). Also the reasoning of the participants (Paper IV) sometimes expressed contempt for politicians' work. A study by Holmberg and Weibull (2006) showed that the general public's confidence in how politicians do their work has decreased from 29 % in 2002 until 16 % in 2005. There thus seems to be decreasing confidence in the work of politicians not only among older people but also among the general public. Confidence in the work of health care staff was however high, in line with the results from this thesis, even though decreasing from 85 % in 2002 to 81 % in 2005 (Holmberg and Weibull 2006). Rosén and Karlberg (2002) further asked politicians and physicians who should have the greatest influence on resource allocation in public health care. Most politicians (61 %) but only 28 % of the physicians thought that regional health care politicians should have the greatest influence. According to a Swedish study (Hermansson, 2006) 86 % of politicians considered medical research important but only 16 % used research findings as a basis for proposing motions in a political context. The fact that decisions made on political levels do not seem to be based on scientific grounds might explain the physicians' resistance towards politicians as decision makers in resource allocation. The lack of confidence in politicians' work among older people, the general public and the health care professionals is, however, a serious threat to democracy, and it is urgent for politicians to restore confidence in the work they do.

The view of prioritisation among older people differed in relation to age. The oldest-old, to a higher degree than young-old and old-old, prioritised young age as criterion. Differences in relation to age were also seen when asking about other criteria for prioritisation. The older the respondents were, the more they seemed to emphasise "working" and "being middle-aged" as criteria for prioritisation (Paper I). The oldest-old further seemed to prioritise more in favour of others than themselves compared to the young-old and old-old (Paper I and II). This can be seen in the light of gerotranscendence as described by Tornstam (1997). Gerotranscendence implies a shift in meta-perspective from a materialistic and pragmatic view of the world to a more cosmic and transcendent one. Gerotranscendence is regarded as the final stage in a natural progression towards maturation and wisdom, where the individual becomes less self-occupied and at the same time more selective in the choice of social and other activities. In this stage there is also an increased feeling of affinity with past generations and an interest in superfluous social interactions. This process is individual and dependent on experiences in life that could either curb or accelerate the progress, and the degree of gerotranscendence therefore varies (Tornstam, 1998). Erikson and Erikson (1997) have also described this age as the eighth and last stage of life. During

this stage there is time for reflecting upon one's own life and upon its role in the big scheme of things, and seeing it filled with either pleasure and satisfaction or disappointments and failures, depending on earlier experiences in life. A difference between Erikson's eighth stage and gerotranscendence is that in Erikson's theory the individual is looking back at the life lived, while the gerotranscendence implies looking forward with a new view of one's self and the world (Thomas and Eisenhandler, 1994). In a review concerning older people's views of death and dying, Hallberg (2004) emphasised that older people feel comfortable about meeting death when completing their life span perspective mainly positively, as well as through connecting generations as a higher meaning of their lives. The findings in our study indicate that people in the eighth stage of life to a higher degree than the younger age groups gave priority to other generations, implying a new and different view of values in later life, and by giving priority to younger generations feeling comfortable about the approaching death.

The view of prioritisations was further related to the participants' gender. The results showed that men prioritised younger persons more often than women did, while women asserted old age to be a stronger indicator for prioritisation than men did (Paper I, add an). Women also, significantly more than men, thought that too little resources were allocated to elder care. Further, significantly more women than men thought that psychiatric care, drug addict care and end-of-life care received too little resources (Add an). Differences related to gender can be seen in the light of theories concerning moral judgement. According to Gilligan (1996, 1977), women's concerns are centred on care and responsibilities to others and they characterise their failure to care as not being a "good woman". Gilligan et al. (1996) also hypothesised that there are two distinct differences between men and women in moral judgement, as men mainly turn to justice and women mainly turn to care in their thinking. As women are nearly three times more likely than men to be care providers for older people (Johansson et al., 2003), these results may further be a sign of women's fear that, if resources are not provided by the health care system, they will be the ones taking care of this group. Bell (1989) discussed this phenomenon from another angle, and suggested that discriminating against old age also means discriminating against women. It is the older woman who will have most need of support and she will be society's greatest burden, and it is for her that limits will be set when people in old age are not prioritised. Perhaps this difference in the view of prioritisation between men and women is a way for older women to avoid discrimination in the future.

Differences were seen in the view of prioritisation in relation to depending on help from others or not. In the results several differences were seen between the participants not receiving care and service and the participants receiving care and service. For example, the participants receiving care and service, to a significantly lower degree than the others, thought that criteria such as being a child, middle-aged or old should affect prioritisation (Add an), indicating that the participants who have probably experienced health care most were more resolved to consider age as a criterion in prioritisation than the group with less experience of health care. Within the group receiving care and service (Paper III), though, there were fewer differences than within

the group not receiving care and service related to age as well as to gender (Papers I and II). The homogeneity in the view of those having care and service could be seen in the light of the reasoning by Baltes (1996) meaning that the focus may become thoroughly limited when having concerns about daily functioning and just getting through a day intact. Baltes and Reichert (1992) suggested that some older people choose a dependent behaviour as a coping strategy and not as a sign of passive acceptance. Erikson and Erikson (1997) further stated that loss of capacities and disintegration may demand almost all of one's attention. Being dependent on care and service could thus give an overwhelming experience that decreases the influence of gender as well of age, which might influence the view of prioritisation.

The participants said that being old meant low priority, and these statements were illuminated with several examples of experience being neglected and not listened to (Paper IV). When investigating older people's experience of ageism, Minichiello et al. (2000) identified a number of negative experiences that the participants had experienced in the encounter with health professionals, such as being neglected or treated as unimportant patients. The participants further felt that their autonomy was removed when they were not consulted about major decisions regarding their health and lives (Minichiello et al., 2000). This is thus in line with experiences of the participants in this thesis, who described being met with bad manners and disrespect. The participants also feared that treatments and examinations were granted to a lower degree to older people. Minichiello et al. (2000) further argue that some older people may believe that it is best just to accept what happens and try to get on with their lives. They may believe that they do not have the social power to change their situation and make things worse for themselves by protesting. Older people thus feel that they are given low priority in health care and have only limited ability to change the situation. In this way ageism will be accepted not only by health care professionals, but by older people themselves.

The willingness to pay (WTP) for treatment was primarily related to the financial situation. In the results, people not receiving care and service and men were more willing to pay for treatment, while women and people receiving care and service were more willing to be on a waiting list for cataract surgery (Paper II and add an). There were significant socio-economic differences between the groups, as men and people not receiving care and service to a higher degree had access to €1500. Access to €1500 also proved to be the strongest predictor for the willingness to pay for treatment (Add an). In the participants' reasoning about willingness to pay, the view that buying treatment requires wealth further confirms these findings (Paper IV). These findings are not surprising, however, as it is well known that socio-economic status influence the willingness to pay for treatment (Johannesson, 1996). On the one hand the participants wanted to pay for treatment but on the other hand only few participants wanted private health insurance to finance the increasing health care costs. Instead the participants wanted the increasing health care costs to be financed through higher taxes (Papers II and III). These contradictory findings could be emphasised by the arguments of Olsen et al. (2004) saying that there is a difference in views of conventional private insurance and insurance through taxation. In Denmark, 214

respondents (18 years and over) were asked if they were willing to pay *extra tax* to the county for a reduction in the waiting time for cataract surgery from 12 months to 1 month. Another group (n=215) was asked if they were willing to pay an *insurance premium* for the same reason. The study indicated that the respondents interpret the community and the insurance-based WTP question differently. The proportion of respondents willing to pay was higher in the insurance through taxation ($p=0.045$), and the arguments for that were altruistic, such as “other people will benefit”, while the arguments for the private insurance were more selfish, such as “I might benefit” (Olsen et al., 2004). Olsen (1997) argued that most people behave “inconsistently” or more likely people think differently and apply other norms when responding to individual WTP exercises than they do when asked to make social choices. Thus it seemed as if participants did not view the use of private health insurance in the same way as they viewed paying for treatment. Paying for treatment seemed to be more acceptable, although it requires wealth and preferably male sex. However, the possibility to buy treatment could result in different kind of services depending on people’s ability to pay, which would be an entirely new situation in the Swedish health care system (Thorslund, Bergmark and Parker, 1997) and ought to be discussed in the light of the principle of justice. It should also be questioned whether buying treatment gives equal health for all.

The participants’ reasoning about prioritisation (Paper IV) could be translated into three fundamental ethical principles: the principle of human dignity, the principle of need and solidarity and the cost-efficiency principle. For example when the participants view that being old means low priority, that it is not right for anyone to take precedence over others or that buying treatment requires wealth, these findings could be referred to the principle of human dignity, as this principle seeks to prevent prioritisation based on personal characteristic or qualities (SOU, 1995). The principle of need and solidarity could be referred to when the participants’ reasoning revealed that they felt secure and confident in the health care system, i.e. they have had their needs fulfilled. However, the participants also expressed a fear for that the principle of need and solidarity should not be acknowledged in prioritisation, which caused worries. The cost-efficiency principle aims to create a reasonable relation between cost and effect measured in terms of improved health and quality of life (SOU, 1995). This could be applied to the participants’ view of prioritisation as a necessity due to scarce resources. However, there are other principles that are not used in the ethical platform of the Parliamentary Priority Commission. For example, the lottery principle, meaning that everyone should have the same chance of a share in medical resources. If there are not enough resources, chance should decide (SOU, 1995). When the participants were asked about which criterion ought to be used when choosing between patients for treatment, lottery was mentioned by only a few participants (Papers I and III). Alwin et al. (1996) and Mossialos and King (1999) reported that 22.3 % of the 16,121 persons of general public in 12 countries, mainly in Europe, put “choice made by lottery” in first place. It thus seemed as if the principles that are chosen as a basis for prioritisation in Sweden constitute a stable platform in line with older people’s views.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings of this thesis indicated that older people in general do not want to use chronologic age as a criterion for prioritisation in health care, which is in line with the principle of need and solidarity, a principle that might need reinforcement. The findings showed that the participants not receiving care and service were more positive towards using lifestyle-related diseases as a criterion in prioritisation than the participants who received continuous care and service. If lifestyle as a rule for prioritisation is accepted, there is a risk that inequality in health care will increase. Older people were further willing to pay to have treatment at once and avoid waiting lists if they could afford it. The young-old and men were more willing pay to get treatment without waiting than the other old age groups and women. Regarding women this seems to be associated with their worse economical situation. An increased possibility to buy treatment could result in different kinds of services depending on people's ability to pay, which would be an entirely new situation within the Swedish care services. This situation would also affect women and people already receiving care and service more drastically as they are in a worse economic situation.

Older people showed a firm trust in physicians as decision makers, although physicians are more positive towards using age as criterion for prioritisation than the general public. Perhaps the utilitarian arguments weight more heavily among them than among the general public, who are more inclined to support egalitarian reasons against using age as a rationing criterion. Further, the findings in our studies indicate that people in the last stage of life, to a higher degree than the younger age groups, gave priority to younger generations, implying a new and different view of values in later life, in line with the theory of gerotranscendence. The findings showed that gender also influenced the view of prioritisation. Men prioritised younger persons more often than women did, while women asserted old age to be a stronger indicator for prioritisation than men did. The differences in the views of men and women concerning prioritisation and reasoning in terms of justice and care should be considered when planning and performing care for the older population. For example, the older population should be more involved in the planning of elder care in order to incorporate and utilise their perspective. This also emphasises the importance of equality in decision making process, i.e. that the decision makers are represented by both men and women.

Neither local nor national politicians were regarded as being the ones to make priorities in health care. Also the reasoning of the participants sometimes arrived at contempt for politicians' work. The lack of confidence in the work of politicians among older people, the general public and the health care professionals is a serious threat to democracy, and it seems urgent for politicians to restore the confidence in their work.

The participants' experienced that being old meant low priority aroused feelings of anger and frustration, which increased when they were treated with bad manners and disrespect, for example when not being listened to and when symptoms were

disregarded or neglected. This can be regarded as ageism, and older people may believe that they do not have social power to change their situation. In this way ageism will be accepted not only by health care professionals, but by older people themselves.

The findings also revealed that not all participants were aware of what prioritisation implies or even of its existence. This emphasises the importance of transparency in prioritisation and also the objectivity in the public debate so that the exact grounds on which a decision on prioritisation has been taken are known to patients and the public. Lastly, the model of equity-adjusted years of life saved (EYLS) might be applied in the discussion of prioritisation of older people and thus support the treatment of older people also in economic terms as well and thereby strengthen the feeling of security and confidence in the health care system.

FURTHER RESEARCH

The findings of this thesis reveal new research questions about views of prioritisation.

- The findings show that the participants seldom felt that they were prioritised in health care but still thought that they had had their needs fulfilled. However, other studies have indicated that age is sometimes used as criterion by physicians. A deeper knowledge about how prioritisation is done in reality is needed.
- The findings showed that older people wanted physicians as decision makers in prioritisation in health care on a vertical level as well as a horizontal level. Further research about views, of prioritisation in general and of prioritisation related to age in particular, among physicians as well as other decision makers in health care is needed to give a more comprehensive picture of the views of prioritisation.
- As people with more severely impaired function were not included in the studies in this thesis due to impaired speech or cognitive decline, further research concerning this group is needed. One way to reach this group is through narratives from family care givers to persons with cognitive and/or speech impairment focusing on how their relatives have been prioritised in health care and how they view prioritisation in general.
- As immigrants were represented only in a low number in these studies and as the number of older immigrants will increase it could be valuable to find out how older immigrants view prioritisation to be able to prepare for their expectations in the future.

POPULÄRVETENSKAPLIG SAMMANFATTNING

”Äldre personers syn på prioriteringar och fördelning av resurser inom hälso- och sjukvård”

Prioriteringar av olika slag har alltid genomförts inom hälso- och sjukvård, vilket har inneburit att vissa verksamheter och patienter har prioriterats och andra har valts bort. Tidigare studier som har varit fokuserade på allmänhetens syn på vem eller vilka som ska prioriteras, har framförallt varit riktade till yngre och medelålders personer. I dessa studier framkommer ålder som ett viktigt kriterium och att hög ålder är ett kriterium för att inte bli prioriterad. Representationen av äldre personer i dessa studier har dock varit låg och det är rimligt att anta att äldre personers syn på prioriteringar inom hälso- och sjukvården skiljer sig från yngre grupper. Det övergripande syftet med studierna var att undersöka äldres syn på prioriteringar och resursfördelning inom hälso- och sjukvård samt att undersöka skillnader i relation till ålder, kön, boende, behov av vård och finansiell situation. Ett ytterligare syfte vara att beskriva äldre personers resonemang kring frågor som rör prioriteringar och resursfördelning inom hälso- och sjukvård.

Avhandlingen omfattar fyra delarbeten som är baserade på strukturerade intervjuer med äldre personer. Intervjuerna utgick från ett frågeformulär som först testades i en pilotstudie och därefter utvecklades. Studierna utgår från två olika urval inom ramen för studien Gott Åldrande i Skåne (GÅS); (a) äldre friska personer mellan 60-93 år (n=902) som intervjuades i samband med en hälsoundersökning i den s.k. befolkningsstudien samt (b) 146 personer i åldern 66-100 år som hade varaktig kommunal vård och omsorg som rekryterades via den s.k. vårdsystemstudien och därefter intervjuades i hemmet. De första delarbetena omfattar äldre friska personers syn på prioriteringar inom hälso- och sjukvård (delarbete I) samt synen på hur de ökande sjukvårdskostnaderna ska finansieras (delarbete II). Delarbete III belyser samma frågeställningar som delarbete I och II (prioriteringar och resursfördelning) men baserar sig på äldre vård- och omsorgstagares syn. Delarbete I-III har en kvantitativ ansats där jämförelser bl.a. avseende kön, ålder, hälsorelaterad livskvalitet och ekonomisk situation har genomförts. I delarbete IV presenteras de äldres erfarenheter av prioriteringar samt deras resonemang kring ålder som grund för prioritering. Detta delarbete har en kvalitativ ansats. Urvalet i den studien består av 300 personer från deltagarna i delstudie I och II samt samtliga 146 deltagare i delstudie III (n= 446).

I det första delarbetet genomfördes strukturerade intervjuer med 424 män och 478 kvinnor (n=902) med ett frågeformulär som grund i samband med en hälsoundersökning inom ramen för GÅS-studiens befolkningsdel. Urvalet skedde konsekutivt (dvs. alla som kom till hälsoundersökningen blev tillfrågade) under en 20 månaders period och de 500 första intervjuerna spelades in på band. I delarbete I presenteras dock endast kvantitativa data. Data som rörde socioekonomiska aspekter och hälsorelaterad livskvalitet inhämtades från GÅS-studien. Resultatet visade att majoriteten av de äldre inte ansåg att ålder skulle vara ett kriterium för prioritering

utan lyfte istället fram andra aspekter, som livskvalitet, smärta, välbefinnande och kostnadseffektivitet. Skillnader i relation till deltagarnas ålder och kön kunde identifieras. De allra äldsta och män ville i högre utsträckning än övriga åldersgrupper och kvinnor, prioritera yngre, medan kvinnor i högre utsträckning ville prioritera äldre personer. Resultaten visar att äldre personers syn på prioriteringar inom hälso- och sjukvård skiljer sig från tidigare studier som har involverat yngre personer. De visar även att det inom gruppen äldre förekommer skillnader i relation till kön och ålder.

Delarbete II är baserad på samma datainsamling som delarbete I, men fokuserad mot finansiella aspekter på prioriteringar. Resultatet visade att äldre personer var villiga att betala för vård och omsorg, om de hade råd. Det vill säga att den egna finansiella situationen hade betydelse för vilka ställningstaganden man gjorde. De äldre personerna ansåg att samhället inte skulle bekosta vissa insatser, som t.ex. kosmetisk kirurgi och läkemedel vid impotens och övervikt. Kvinnor ville i större utsträckning att de ökande sjukvårdskostnaderna skulle bekostas via högre skatter på alkohol och tobak, medan männen i större utsträckning ville öka skatten generellt. Endast ett fåtal personer ansåg att högre patientavgifter eller privata sjukförsäkringar var godtagbara alternativ. Män ville även i större utsträckning än kvinnor betala för att slippa stå på väntelista för operation, vilket kan ha samband med att betydligt färre kvinnor än män angav att de hade tillgång till 14.000 SEK. Resultaten visar att synen på prioriteringar hade samband med den egna ekonomiska situationen, där skillnader mellan män och kvinnors syn till stor del kan förklaras av deras olika ekonomiska förutsättningar.

Även i delarbete III användes samma frågeformulär, men med ett nytt urval. I denna studie tillfrågades personer som ingick i GÅS-studiens vårdssystemdel, där personer 65 år och äldre med varaktig kommunal vård och omsorg ingick. Sammanlagt 146 personer, 34 män och 112 kvinnor, mellan 66 och 100 år intervjuades i hemmet (ordinärt såväl som särskilt boende). Samtliga intervjuer bandinspelades, men resultatet i detta delarbete omfattade enbart kvantitativa data. Resultatet visade att de äldre vård- och omsorgstagarna hade liknande syn på prioriteringar som de äldre i delstudie I och II (vilka inte hade kommunal vård och omsorg) i det att de inte ansåg att patientens ålder skulle vara ett kriterium för prioritering utan att aspekter som livskvalitet och välbefinnande, men även familjesituation, istället skulle påverka prioriteringar. Trots att de äldre föredrog att hälso- och sjukvården skulle finansieras med skattemedel var relativt många (48 %) villiga att själva betala för exempelvis en starroperation istället för att stå på väntelista. Resultatet visade även att de skillnader i relation till ålder och kön som sågs i delarbete I och II inte återfanns i gruppen vård och omsorgstagare vilket indikerar att erfarenheten av att vara beroende av vård och omsorg är en överväldigande upplevelse som kan bidra till att denna grupp blir mer homogen i sin syn på prioriteringar.

Delarbete IV har en kvalitativ ansats och baserar sig på transkriberade bandinspelningar av de strukturerade intervjuerna som tidigare har presenterats i delarbete I-III. Materialet bestod av 300 av de 500 intervjuerna som bandinspelades till delstudie I och II och selektionen baserades på kvaliteten i de utskrivna intervjuerna. Materialet bestod även av samtliga 146 intervjuer i delstudie III. Urvalet var således 446 personer, 176 män och 268 kvinnor, i åldern 60-100 år. Resultatet visade att de

äldre kände sig trygga i kontakten med hälso- och sjukvården och att få personer gav uttryck för att de hade erfarenhet av prioriteringar, men att de samtidigt kände sig lågt prioriterade på grund av sin ålder. Resultatet visade även att prioriteringar inom vård och omsorg skapade oro och att de ibland var tvungna att använda påtryckningar för att bli prioriterade. I intervjuerna fanns uttryck för att de äldre ansåg att prioriteringar var nödvändiga, samtidigt som de var emot att någon skulle gå före i kön. I deras resonemang kring att prioriteringar var en nödvändighet, fanns argument både för att yngre såväl som äldre personer borde bli prioriterade. Resultatet visade även att de var kritiska till hur resurserna hälso- och sjukvården användes och var fördelade. Deras resonemang gav också uttryck för att de var villiga att själva betala för behandling men att det förutsatte välstånd, samtidigt som det skapade etiska och moraliska konflikter genom att de därigenom skulle gå före andra i kön. De äldres resonemang visar att prioriteringsfrågor medför svåra etiska och moraliska ställningstagande. Det faktum att relativt få personer uppgav att de hade erfarenhet av prioriteringar kan innebära att prioriteringar inom hälso- och sjukvården genomförs utan insyn och därmed ej är möjliga för allmänheten att diskutera och påverka.

I ramberättelsen presenteras även kvantitativa analyser avseende skillnader mellan de två olika grupperna (a) äldre friska och (b) äldre vård- och omsorgstagare. Resultatet visade att äldre vård- och omsorgstagare tyckte att till exempel ålder skulle påverka prioriteringar i lägre utsträckning än vad de friska äldre tyckte. Färre av deltagarna med vård- och omsorg än deltagarna utan vård- och omsorg tyckte att äldrevården fick för lite resurser tilldelat. När det gällde prioriteringar till personer med livsstilsrelaterade sjukdomar visade sig vård- och omsorgstagarna vara mer benägna att ge en patient som söker behandling medan båda grupperna var restriktiva med att prioritera en patient med alkoholberoende. Kvinnor och deltagare med vård- och omsorg ville i lägre utsträckning betala för en starroperation vilket visade sig ha samband med att de hade sämre ekonomi än män och deltagarna utan vård och omsorg.

Sammanfattningsvis visar studierna att äldre personers syn på prioriteringar skiljer sig från tidigare studier som har omfattat företrädesvis yngre personer. De äldre tycker inte att ålder ska vara ett kriterium för prioriteringar utan lyfter fram andra aspekter som ex. smärta och livskvalitet. Studierna visar också att det inom gruppen friska äldre finns skillnader i synen på prioriteringar relaterat till deltagarnas ålder, kön och finansiell situation, medan dessa skillnader inte är lika påtagliga inom gruppen som har varaktig vård och omsorg. Synen på prioriteringar skiljer sig också mellan grupperna, dvs gruppen friska äldre och gruppen som får vård- och omsorg. I deltagarnas resonemang om prioriteringar framkommer att de känner trygghet i den svenska sjukvården men samtidigt upplever sig vara lågt prioriterade i kontakterna med hälso- och sjukvård. Avhandlingens resultat är betydelsefulla i det avseende att kunskapen om de äldres syn på prioriteringar tidigare har varit mycket begränsad, trots att de är den grupp i samhället som använder hälso- och sjukvård mest och därmed i större utsträckning riskerar att utsättas för prioriteringar. Studierna kan utgöra ett viktigt kunskapsunderlag om befolkningens syn på prioriteringar som kan ligga till grund för det fortsatta arbetet med prioriteringar inom hälso- och sjukvård.

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Intervjuprotokoll för Prioriteringar inom hälso- och sjukvård

Datum.....tid start.....tid slut.....

Plats mottagning hemmet annan.....

Intervjuare.....

I tidningar, radio och TV läser och hör vi ofta talas om prioritering (förtur) i hälso- och sjukvården.

1. Vilka tankar har Du om detta?

.....
.....
.....

2. Vilka tycker Du skall prioriteras i hälso- och sjukvård?

- personer med låg ålder
- personer med hög ålder
- alla åldersgrupper
- vet ej

Kommentar:.....

3. Vilket av nedanstående alternativ anser Du vara rimligast?

- bland personer med livshotande sjukdomar bör yngre prioriteras före äldre
- alla skall ha samma rätt till livräddande åtgärder med undantag för de mycket gamla
- alla skall ha samma rätt till livräddande åtgärder oavsett ålder
- vet ej

3b. Begreppet "äldre" och begreppet "mycket gammal" används ofta. Vad betyder begreppen för Dig?

Kommentar:.....

.....

3c. När anser Du att man är "äldre" respektive "mycket gammal"?

"Äldre" vid.....års ålder.

"Mycket gammal" vid.....års ålder.

Kommentar:.....

4. Nedanstående personer har alla en utslagen njurfunktion och får dialysbehandling i hemmet, nattetid, tre gånger i veckan. En av dem kan få en ny njure inopererad inom en vecka. Vem skall få njuren?

- en 60-årig kvinna
- en 70-årig kvinna
- en 80-årig kvinna

Kommentarer:.....

5. Vilken av nedanstående patienter skall i första hand få en ny höftled inopererad?

- en 60-årig man med gångsvårigheter
- en 70-årig man med svåra smärtor
- en 80-årig man som är rullstolsburen på grund av sin dåliga höft

Kommentarer:.....

6. Vilken av följande patienter skall i första hand få en starroperation, som förbättrar synen?

- en 60-åring med demenssjukdom
- en 70-åring med hjärtsjukdom
- en för övrigt fullt frisk 80-åring

Kommentarer:.....

7. Vem tycker Du skall göra besluten angående patienterna i de tre ovanstående frågorna (nr 4, 5 och 6)?

- läkare
- sjuksköterskor
- lokala sjukvårdspolitiker
- nationella sjukvårdspolitiker
- socialstyrelsen
- allmänheten

8. Nedanstående behandlingsalternativ medför ungefär lika stora kostnader. Vilket alternativ bör i första hand prioriteras?

- en höftledsoperation
- fem operationer för att behandla inkontinens
- tio starroperationer

9. På vilket av nedanstående alternativ bör i första hand mer pengar satsas?

- hjärttransplantationer
- respiratorvård av mycket för tidigt födda barn
- hospiceverksamhet för vård i livets slutskede
- ökad hälsouppllysning ute i samhället

Kommentarer:.....

10. Vem tycker Du skall göra beslutet i ovanstående fråga (nr 9)?

- läkare
- sjuksköterskor
- lokala sjukvårdspolitiker
- nationella sjukvårdspolitiker
- socialstyrelsen
- allmänheten

Tre patienter med operationskrävande hjärtåkomma inkommer samtidigt till sjukhuset. Alla patienterna är i lika stort behov av behandling. Den patient som behandlas först har störst möjlighet att överleva.

11. Vilken metod eller vilket kriterium bör användas för att välja ut den patient som skall få adekvat behandling?

- lotteri
- patientens betydelse för samhället
- ålder
- patientens möjlighet att betala
- patientens betydelse som familjeförsörjare
- vet ej

12. Vilka av nedanstående behandlingsalternativ (flera alternativ kan väljas) bör helt eller delvis betalas med privata medel?

- kosmetisk kirurgi t ex näsförminskning, bröstreducering eller ärrborttagning
- s k provrörsbefruktning
- läkemedelsbehandling av impotens med t ex Viagra® eller fetma med t ex Xenical®
- tandvård
- företagshälsovård
- höftledsoperation
- hörapparat
- annat.....

Utgifterna för hälso- och sjukvård stiger i takt med den ökande andelen äldre i befolkningen, nya behandlingstekniker och växande krav. De ökade kostnaderna kräver ytterligare resurser.

13. Vilket av följande alternativ, tycker Du, skall täcka de nya utgifterna?

- högre skatter
- högre skatt på alkohol och tobak
- högre patientavgifter
- privata sjukförsäkringar
- lägre sociala utgifter för övrigt
- vet ej
- annat:.....

14. Om Du skulle behöva en starroperation för att återfå synen, vilket alternativ skulle Du välja?

- stå på väntelista i 18 månader före operation
- betala 10 000 kr av sparade medel för att opereras utan väntelista

14b. Skulle Du kunna tänka Dig att ta ett banklån för att betala ögonoperationen?

- ja
- nej

Kommentar.....

15. I vilken ordningsföljd tycker Du att dessa patienter skall behandlas? Rangordna från ett till fyra.

- patienten som röker, vägrar sluta och behöver en kranskärlsoperation
- patienten som missbrukar alkohol och behöver en levertransplantation
- patienten som är fotbollsspelare, skadat sig på träningen och behöver ett nytt knä inopererat för att kunna fortsätta med sin idrottsutövning
- patienten som pga flera aborter blivit steril och behöver opereras för att kunna bli gravid

Kommentar.....

16. Hur ser Du på tillgängliga resurser inom hälso- och sjukvård. Vilka tycker Du får för lite, lagom respektive för mycket resurser sig tilldelat?

	för lite	lagom	för mycket	vet ej
a) äldre vården	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) barnhälsovården	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) vård i livets slutskede	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) upplysande hälsovård	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) tandvård	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) psykiatrisk vård	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) missbrukarvård	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) öppen hälso- och sjukvård (vårdcentraler)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) sluten sjukvård (medicin och kirurgavdelningar)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) sjukvårdsadministrationen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) vårdutbildningar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Hur tycker Du att följande faktorer bör påverka patienters plats i kön till behandling?

Kryssa i de rutor som bäst motsvarar din åsikt.

	mycket	lite	inte alls
a) att patienten är minderårig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) att patienten är medelålders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) att patienten är äldre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) sjukdomens svårighetsgrad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) sjukdomens prognos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) att sjukdomen är självförvållad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) patientens förmåga att betala	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) att patienten är yrkesverksam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) att patienten vårdas på institution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) annat,.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Nedanstående frågor innehåller ett antal påståenden, som beskriver olika prioriteringsåtgärder. Kryssa i det alternativ som bäst motsvarar Din åsikt.

18. Man skall inte genomföra dyra undersökningar eller behandlingar av äldre på samhällets bekostnad.

- Instämmer
- Tveksam
- Instämmer inte

19. Om sjukdomen är självförvållad skall patienten själv bekosta vården.

- Instämmer
- Tveksam
- Instämmer inte

20. Patienter med egna tillgångar skall själva betala för sin vård.

- Instämmer
- Tveksam
- Instämmer inte

21. Om det finns en behandling mot en sjukdom skall den alltid användas oberoende av kostnaden.

- Instämmer
- Tveksam
- Instämmer inte

22. Inom hälso- och sjukvård kan man inte spara mer.

- Instämmer
- Tveksam
- Instämmer inte

23. Av två behandlingsmetoder skall man välja den billigaste även om den är mindre effektiv.

- Instämmer
- Tveksam
- Instämmer inte

24. Vid sjukdom, som med största sannolikhet, leder till döden skall man nöja sig med standardvård.

- Instämmer
- Tveksam
- Instämmer inte

25. Inom hälso- och sjukvård används mycket pengar till onödiga saker.

- Instämmer
- Tveksam
- Instämmer inte

26. Vilka är Dina erfarenheter av prioriteringar i hälso- och sjukvård?

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