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Frail and Elderly Hospital Patients

– The Challenge of Participation in Medical Decision Making

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*With love to my husband Steen,
and my late parents Mary and Viggo*

What you see depends on what you're looking for!

Niels Bohr

Danish atom physicist, Nobel price winner in physics 1922.

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ABSTRACT

In research, patient participation in medical decision-making has been shown to be associated with higher patient satisfaction and improvement of treatment outcomes. But when it comes to patient participation when being old and frail there are pitfalls and the research in this area is sparse.

The aim of this thesis is to explore participation in medical decision making of the frail elderly patient in hospital from the perspectives of patients themselves and the health care staff. In this thesis frail, elderly patients is defined as individuals 75 years old or older, who during the past 12 months have received inpatient hospital care three or more times and who have three or more diagnoses in three or more diagnostic groups according to the classification system ICD-10.

The participants were frail patients' in hospital or newly discharged and it was health care personnel working with frail elderly patients. In three of the studies the method was mainly qualitative (Paper I, III, IV) and in one (Paper II) quantitative. The qualitative methods were one-to-one tape-recorded interviews of 25 patients (Paper I and IV), 18 personnel (III and IV), 5 focus group interviews of physicians (Paper III) and 26 days of observations in hospital wards (IV). Chosen methodologies of analysis were content analysis and Grounded Theory. The quantitative study (II) was a cross-sectional survey using telephone interviews with patients (n= 156). This material was descriptively analysed and examined using weighted kappa statistics.

The results reported in Paper II show that elderly patients generally want to participate more in medical decision making than they do, though preferences for degree of participation are highly individualized – both findings important to consider in clinical practice.

According to the patients important key concepts of patient participation in medical decision making are to be listened to and to be informed (Paper I). The main reasons for not being able to participate was an overall bad medical condition (Paper II). Also, cited as a problem was difficulty in understanding medical information, for example when given by a foreign-speaking physician (Paper I, II and IV). Frail, elderly patients complained that they were less informed than was their preference (Paper I, II and IV).

Moderate agreement was obtained between patient's preferred and actual roles in medical decision making. Patients often expressed gratitude and confidence in their health care (Paper I and IV), but also, sympathy for stressed health care personnel who had so much to do.

The frail elderly patients do sometimes feel like a burden to the health care (Paper I and IV). The professionals gave expressions of trying to avoid taking care of frail elderly patients and at the same time expressions of frustration and bad conscience not being able to take good care of them due to lack of time and lack of beds (Paper III, IV). Especially the physicians felt they were trapped between the needs of the patients' and the remunerations system rewarding time-constricted health care production (number of investigations, operations, easy accessibility) – not a time-consuming holistic view on all illnesses and medications including communication with the patients and all caregivers involved (Paper III).

Both patients and the professionals perceive the hospital as some kind of "institution of power", difficult to challenge, and the decisions of which one has to accept.

In this thesis there are shown a number of challenges to participation in medical decision making by frail, elderly patients, which thus limits quality of care for this patient group. A model is presented that explains how the organisation of health care, and the reimbursement system, does not facilitate a holistic view. The health care professionals appear to adapt to the organisation and the remuneration system, which leads to practices, such as, rapid discharges and a tendency to examine the patient for only one or a few problems. Finally a suggestion for a model to improve care of frail elderly patients is presented. This model includes the need of more hospital wards being able to work with a holistic view, better skills in gerontology and geriatrics and a more adapted remuneration system for the frail, elderly patients.

LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by Roman numerals.

- I Ekdahl AW, Andersson L, Friedrichsen M. "They do what they think is the best for me." Frail elderly patients' preferences for participation in their care during hospitalization. *Patient Education and Counseling* 2010(80):233–240.
- II Ekdahl A, Andersson L, Wirehn A-B, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. *BMC Geriatrics* 2011;11(1):46.
- III Ekdahl AW, Hellström I, Andersson L, Friedrichsen M. Too complex and time-consuming to fit in! Physicians' experiences of elderly patients and their participation in medical decision making: a grounded theory study. *BMJ Open* 2012;2(3).
- IV Ekdahl AW, Linderholm M, Hellström I, Andersson L, Friedrichsen M. **"Focusing on acquiring available beds!"**- The process of discharging elderly patients: A qualitative observational study (**submitted**).

ABBREVIATIONS

ADL Activities of daily living

CPS The Control Preferences Scale

CGA Comprehensive Geriatric Assessment

GT Grounded Theory

SNCE-definition of elderly with multimorbidity:

Swedish National Centre of Epidemiology in 2001:

“Individuals 75 years old or older, who during the past 12 months have received inpatient hospital care three or more times and who have three or more diagnoses in three or more diagnostic groups according to the classification system ICD-10”

SBC Situation-based care: A care based on a holistic view on the patient’s accumulated situation of life – (physical, psychological, social and functional) in balance with accessible resources of care. ¹

²

DBC Diagnosis-based care: A care based on one diagnose at a time.^{1,2}

FOREWORD

I have been a geriatrician for 20 years, and, for more than half that time, head of two different geriatric departments.

Getting more and more experienced as a geriatrician it has sometimes troubled me to think about the way I were as a younger physician – trying to fit in the patients to the care in hospital, not always the opposite. I have always wanted to share my experiences to younger physicians to help them not doing the same mistakes.

My interest in patient participation as a geriatrician is focused on the elderly patient. This group has special challenges because of their many illnesses and because of their growing incidence of cognitive decline.

The care of elderly – including care of elderly in hospital – is one of the main tasks of health care in the Western Countries, and due to the demographic changes this will continue and grow in the next decades. It is therefore important to adapt the hospital care to these patients' needs. One might wonder how I started with a focus on patient participation but ended up with a focus on the whole Swedish health-care system. One influential knowledge domain is systems thinking, in particular, a philosophical approach, called "lean".

Besides being a geriatrician for many years I have been president of the Swedish Association of Geriatric Medicine; a board member of the European Geriatric Organisations, EUGMS (European Union Geriatric Medicine Society) and UEMS-GMS (European Union of medical Specialities – Geriatric Medicine Section). Since 2007, I have been Scientific Counsellor to the National Board of Health and Welfare, where I have been involved in the planning of the future care of frail and elderly people in Sweden.

I enjoyed the personal relationships I made while visiting the old folks in their homes. At first, I was a bit nervous, leaving my comfortable role as a physician. But, I found that afterwards I would feel happy and, indeed, a bit proud upon seeing that the patients soon seemed to forget that I was a physician. They would open up and share their thoughts and considerations about the hospital, and their own bodies, prescriptions and experiences of the many meetings with the health care staff. I became very impressed by the elderly. They often kept up good spirits and coped magnificently, despite

illness and, often, loneliness as the nearest and dearest had passed away. I was surprised to see all time and effort the elderly patients spent trying to sort out all medications that had been hastily prescribed by different physicians (myself often being one of them). This gave the word, compliance, new meaning to me.

This thesis is, above all, dedicated to all of these brave, old people.

1 AIMS OF THE STUDY

The overall aim of this thesis is:

– To explore participation in medical decision making of the frail and elderly patient in the hospital setting, from the perspectives of the patients and the health care staff.

The specific aims of the thesis are as follows:

PAPER I: To deepen the knowledge of frail elderly patients' preferences for participation in medical decision making during hospitalization.

PAPER II: To investigate the preferred and the actual degree of control, i.e. the role elderly people with multimorbidities wish to assume and actually had with regard to information and participation in medical decision making during their last stay in hospital.

PAPER III: To explore physicians' thoughts and considerations of participation in medical decision making by elderly patients with multimorbidity who are admitted to hospital.

PAPER IV: To explore the interactions around the frail elderly patient around discharge from acute hospital wards and their participation in medical decision making. The views of the patients and the medical staff were also investigated.

OUTLINE

Here, background is described to contextualize important concepts that relate to the frail and elderly patients' participation in medical decision making, such as:

- Demographics and care utilization by frail and elderly patients;
- The hospitals: remuneration system, organisation structure and process, management, structure of many disciplines. (acute, non-geriatric care versus geriatric care);
- The concept of frailty; and the special conditions this leaves to the frail and elderly patients in order for them to participate in medical decision making;
- Definitions, importance and conceptual frameworks of patient participation in medical decision making;

After describing these concepts the methods will be presented. The results of the four papers are integrated to build the basis for a model to understand different conditions that influence frail elderly patients' participation in medical decision making in Chapter Four. After the discussion in Chapter Five, a suggestion will be presented for a model to improve the conditions for participation, and, by this, the quality of care of frail and elderly patients in hospital settings.

2 BACKGROUND

2.1 Background factors

2.1.1 Demographics and care utilization by the elderly in hospital settings

In the coming half-century the population of elderly age will increase with the “greying of the baby boomers”,³ especially the oldest age groups. Prevalence of multiple chronic conditions increases for all age groups, from 10% in the 0-19-year-old age group up to 78% of people aged 80 and over.⁴ As you can see from the figure below the number of inhabitants in Sweden 80 years and older will have doubled, from around 500,000 in 2012 to over a million in the year 2052.

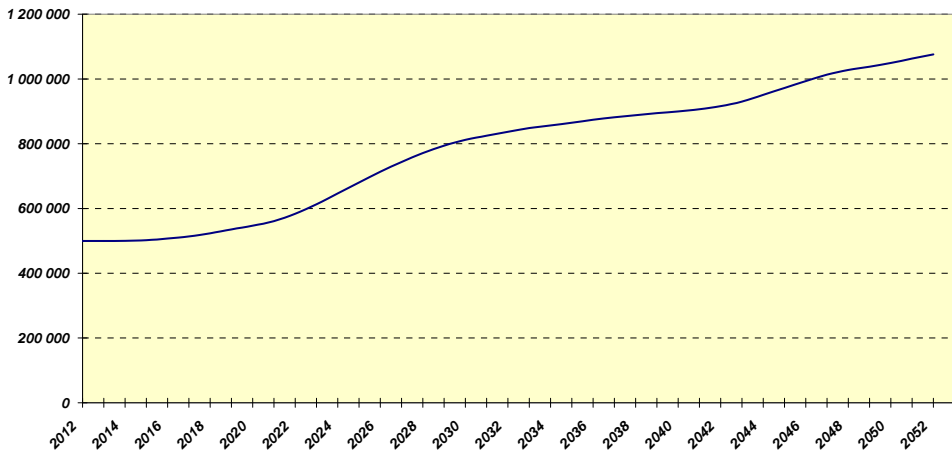


Figure 1: Population increase in the number of people in Sweden 80 years and older, years 2012-2052.

Source: Statistics Sweden 2012.

Elderly people account for a large percentage of hospital care.⁵⁻⁸ In Sweden 30% of all in-care periods in hospital consists of patients 75 years and above.⁹ Frail and elderly patients (using the SNCE-definition described more in detail later on page 17) comprise 19% of all in-care costs in hospital. Overall, there is a mortality risk of about 30% in the first 6 months after an acute hospital admission when the patient is 75 years-old and older.¹⁰ Of course, mortality

risk for a given individual is not easy to foresee.¹¹ However, taking this high mortality rate into account, it is not surprising that frail-elderly patients are often in hospital since they are so often ill.

The number of hospital beds has diminished in recent years. In part, this development is a natural consequence of having a better range of treatment options; and more conditions that are medically treated outside the hospital, with or without invasive surgery (such as the treatment of rheumatoid arthritis, gastric ulcers, gallstones etc.)¹² In Sweden, less than four hospital beds are available per 1000 people, the lowest number in Europe according to an OECD rapport 2010.¹³

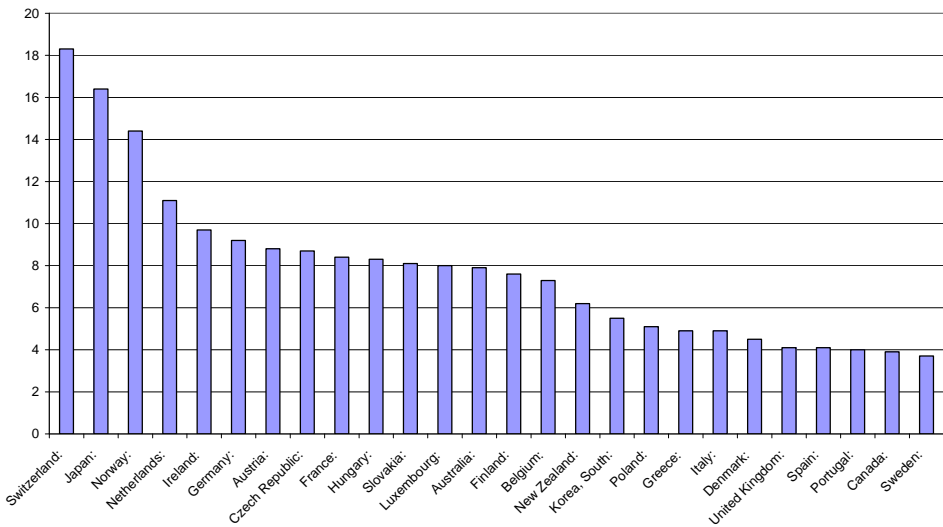


Figure 2: Number of hospital beds per 1000 people.
 Source: OECD. Number of hospital beds. Nation Master 2010.

This shortage of beds makes it important to deliver hospital care quickly and perform rapid discharges leaving little time to look over all medications and illnesses and giving little time for expectation and recovery.

2.2 *The elderly patient*

2.2.1 The concept of “frailty” – our object of study

In the title of this thesis the target patient population is described as “frail” – but what does it mean? It is a condition that has been defined in several ways and is related to one’s level of activity, strength, social activity/network^{6 7 14 15} and it implies high risk for falls, disability, hospitalization, low quality of life and mortality.^{7 14} No general international consensus has been agreed to on how to define and measure frailty^{8 16-19} but different domains are considered, such as, physical activity, mobility, strength, cognition and mood.^{7 8 14 20-22} As a consequence of its multiple facets and due to lack of consensus in the area, definition and measurement of frailty is difficult to achieve.

Below are presented two common international “definitions”, as well as a third commonly used in Sweden. Fried defined frailty as “...a clinical syndrome in which three or more of the following criteria were present: unintentional weight loss, self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity”.¹⁴ This definition demonstrates good predictability concerning further decline in medical status (incident falls, worsening mobility or ADL disability, hospitalization, and death); but it is not easy to measure outside the frame of scientific work and has not gained acceptance among practising clinicians.^{7 8 19}

A second definition, or perhaps more a description of frailty, offers a measure that relies on clinical judgment.⁷ The CSHA-scale conceived by Rockwood et al. is based and developed on the number of impairments that can be measured and matched against a list of 70 clinical deficits. Although much easier to apply and lately translated to Swedish²³, it is not in common use and lacks international acceptance or consensus.⁸

In Sweden there have been several attempts to identify frail elderly patients through extensive care and treatment population registries found in the Swedish County Councils and the National Board of Health and Welfare, including the Swedish National Centre of Epidemiology (SNCE).

In the late 1990s, two Swedish researchers, Ingegerd Nydevik and Ulla Gurner, offered a third definition, referred to as the SNCE definition, “Individuals 75 years old or older, who during the past 12 months have received inpatient hospital care three or more times, and who have three or more diagnoses in three or more diagnostic groups according to the classification system ICD-10.”²⁴ This definition was first used in a scientific

paper in 2001²⁴ and later used in several reports and papers.²⁵⁻²⁷ This definition has proved to identify elderly patients on a group level with high consumption of care and complex needs²⁶ All information needed to identify the patients is available in the care registers so clinical and costly assessments are unnecessary.

The SNCE definition has limitations. You can be frail according to these more internationally accepted definitions, and yet not have been hospitalised in the past 12 months. For example, one may be diagnosed having Parkinson disease, or suffer from dementia, and, yet, not seek care. One can be non-frail yet be identified by the SNCE-definition. For instance, one may have several in-care periods following traumatic injury and surgical repair or treatment, after which you fully recover.

Nevertheless, there is a high overlap between the more international accepted definitions of frailty and the SNCE-definition as there is an overlap between multimorbidity and chronological age and frailty^{6 7 14} and in this thesis the SNCE-definition is used to identify frail elderly patient's on a group level and as a support to identify individual patients to interview.

Regardless of definition the frail elderly patient's it is characterised as a patient with vulnerability, high costs of care and often with many diseases and medications. Their main symptoms are fatigue, and they suffer from a high degree of disabilities, low quality of life and have a high mortality.⁵

2.2.2 The remuneration system of health care and diagnosis-based care (DBC) versus situation-based care (SBC).

The health care system in Sweden is mainly funded by income taxes.²⁸ Earlier, for many years, the remuneration system was based on provider competition.²⁹ It was important for heads of medical departments to negotiate funding provisions with politicians and health care leaders.

Because of steadily growing medical knowledge, and the growing list of treatable and manageable medical conditions a gap began to grow between what treatment and care could be accomplished and what society could actually afford.³⁰ Together with the hardened economical situation such developments in the 1990s compelled the Swedish government to change from the remuneration system to a more market-oriented competitive system.^{29 31} County Councils contracted with health care providers with scheme emphasizing cost reduction and high healthcare production volume, using

indicators, such as: number of patients seen in ambulatory services, length of in-care time, measures of accessibility, and number of treatments.²⁹

Over many years hospital wards and departments have been subdivided into different entities, mainly based on medical specialty.³² Instead of addressing multimorbidity, the focus lies on one or a few illnesses to treat, which are related to the physician's specialty, and not the patient as a whole. The newer, competitive remuneration system of healthcare has further compartmentalized medical departments into economically separate entities due to competition, not only between County Council health care providers, but with private provider alternatives also.

When it comes to frail and elderly patients, broader, more holistic healthcare is needed more than the acute, non-geriatric health care. This focus is found in the departments of geriatric medicine where the fundament of the specialty is awareness to all the patients' problems, a team approach care, prevention of exacerbations of chronic illnesses and rehabilitation.³³⁻³⁶

These differences in focus from the acute, non-geriatric care and the geriatric care when taking care of elderly with co-morbidities was discussed in a policy-document produced by the professional unions for geriatric medicine, primary care and internal medicine in Sweden in 2009. The concepts of "Diagnosis-based care" (DBC) versus "situation-based care" (SBC) was described as two approaches to care.^{1 37} Health care contacts and hospital care episodes evaluated on the basis of diagnosis are termed, DBC; while, SBC refers to a holistic approach, attempting to capture the patient's full and accumulated situation of life (physical, psychological, social and functional), and then to seek a balance with accessible resources of care.¹

Essential to SBC is comprehensive geriatric assessment (CGA), a interdisciplinary thorough assessment to determine medical, psychological, social and functional factors important to form the basis for diagnosis in older adults, and to enhance coordinated and integrated plans for treatment and long term follow up.³⁶

No international consensus, nor Swedish, exists for how to perform a CGA,³⁸ but here are some example tasks to obtain data. Everyday, routine functioning is most often addressed using the activities of daily life scale (ADL/IADL)³⁹, which may indicate a level of dependency. Physical strength assessment is defined as the time, in seconds; it takes for a patient to rise from a chair and walk three meters, for example. Cognitive assessment may be performed using the Mini Mental Status Examination.⁴⁰ Depending on the

patient and situation, this basic testing may be supplemented by assessments of nutrition, psychological well-being and social activities/network. This complex (and time-consuming) assessment of the elder person's health condition is then used to plan care and arrange follow-up cooperatively with the patient, family and other caregivers, such as primary care, with healthcare and allied care staff in the municipalities, and other specialist carers.

In non-geriatric care comprehensive assessments are sporadically used, nevertheless, the team-care approach is valued. However, typically then, the focus is more on an isolated illness, such as stroke or hip-fracture.

The competence and possibility to perform a full CGA is sparsely found outside the clinics of geriatric medicine as there are a lack of geriatric competence and the broad multiprofessional teams needed. The educational level in geriatrics is low both in the preclinical and clinical training of physicians and other health care providers both in- and out-side Sweden.⁴¹⁻⁴⁴

So despite what should be a demand for more CGAs, due to the growing number of frail elderly patients, and in the face of reductions in number of geriatric hospital beds CGAs are actually not increasing at a rate consistent with the increased geriatric patient population (see Figure 3).

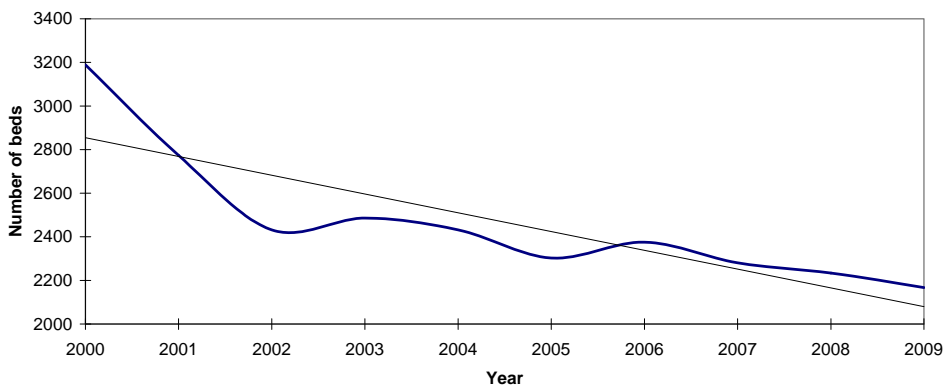


Figure 3: Development in number of beds in Sweden 2000 – 2009.
Source: Swedish Association of local Authorities and Regions (SKL) 2010.

2.3 Patient participation in medical decision making

2.3.1 Definitions and importance

Patient participation is a complex concept.⁴⁵ When searching the literature it is not easy to come up with one distinct definition of patient participation. This definition from Brownlea, in 1987, has been widely used, "Participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or even simply to become one of a number of people consulted on an issue or a matter."⁴⁶

The National Libraries of Medicine database, Pubmed (MeSH-terms, Medical subject headings) describes "patient participation" as "...patient involvement in the decision-making process in matters pertaining to health."⁴⁷ and "shared decision making" as "...the process of making a selective intellectual judgment when presented with several complex alternatives consisting of several variables, and usually defining a course of action or an idea".⁴⁸ Both definitions imply active choices or actions from the patient, reflected by the word "involvement" in the first definition, and, in the latter, by the words "selective intellectual judgment". However, these concepts are used interchangeably in the literature.⁴⁹

Patient preference is more coupled to patients' satisfaction, which, according to MeSH, is defined as, "(the) individual's expression of desirability or value of one course of action, outcome, or selection in contrast to others".⁵⁰ Considering this definition, there is an opening for not making active choices between different treatment alternatives if you do not want to and to have more focus on the patients' perspective.

But, why is this concept important? For many years evidence has accumulated showing that patient participation in medical decision making is associated with both better treatment outcomes and higher patient satisfaction.⁵¹⁻⁵⁶ However, not all patients want to participate in medical decision making,⁵⁷⁻⁵⁸ especially among the older and the less educated⁵⁸⁻⁵⁹ But at the same time there have been little research on patient participation in medical decision making among the oldest old.⁶⁰

Patient participation in medical decision making is the ethically approved way of working. Consequently, ethical findings have been implemented in policy and are now part of health care legislation in many countries.⁶¹⁻⁶³ It is,

indeed, required that the physician fully enable patient participation in medical decision making.

2.3.2 Models and taxonomies on patient participation

For many years the popular concept of patient participation from the professionals was paternalism.^{64 65} This concept refers to the physician's accepting the role as a "parent" who knows what is best for the patient, as if a "child". Later, society shifted focus to a more shared or collaborative role in medical decision making.

In the beginning of the 1960s and onwards, the focus was brought to human rights. At the same time the numbers of available treatments to many new diseases broadened alternatives. This new focus in society made the issue of patient participation in medical decision making more important and relevant. What control over medical diagnosis and treatment do patients want?⁶⁶ From this central concept the Control Preferences Scale was developed.⁶⁷ Other terms of patient participation beside the paternalistic approach was introduced such as a) shared medical decision making and b) informed decision making:

- a) Shared medical decision making is characterised as a dynamic process, which includes that: 1) Both the physician and patient are involved in treatment decision-making; 2) information is exchanged between the two; 3) both patient and physician take steps to express treatment preferences; and, 4) treatment decisions are made by both the physician and the patient, who come to agreement on how to proceed.^{68 69}

- b) Informed decision making is when the physician provides the patient with all medical information needed in order for the patient to choose among different treatments alternatives (for characteristics of the different decision-models please see Table 1.

Table 1. Models of treatment decision making.

	Paternalistic	Shared decision-making	Informed
Information transfer	One way: from doctor to patient, minimum necessary for informed consent	Two way: doctor provides all medical information needed for decision-making, patient provides information about her preferences	One way: from doctor to patient, all medical information needed for decision-making
Deliberation	Physician alone, or with other physicians	Physician and Patient (plus potential others)	Patient (plus potential others)
Decision about implementing treatment	Physician	Physician and Patient	Patient

Reprinted from Charles C, Gafni A, Whelan T.: Decision-making in the physicians patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine* 1999;49(5):651 with permission from Elsevier.

What does patient participation mean from the perspective of the patients? From the patient's point of view, "to get informed", "to have knowledge of them as persons", "to be listened to" or "to be respected" are important examples of its meaning.^{70 71}

Patients often describe that they think less about choosing between treatment alternatives, and more on good communication.^{70 72} In 2007, a large qualitative study was conducted to describe the meaning of the phenomenon of patient participation portrayed by the patients. In it, five levels of increasing patient-determined involvement were described, including: 0) Non-involvement (patient passive recipient of care); 1) Being given information; 2) Dialogue (where exchange of information takes place); 3) Shared decision making (cooperation between physician and patient to find the best solution); and, 4) Autonomous decision-making (the patient makes her own decisions basing these on information given) (for the five levels please see Table 2).⁷¹

Table 2: Levels of involvement. ⁷¹

Patient-desired Level	Patient determined	Co-determined	Professional-Determined
4	Autonomous decision-making		Informed decision-making
3		Shared decision-making	Professional-as-agent
2	Information giving	Dialogue	Consultation
1	Information-seeking/receptive		Information-giving
0	Non-involved		Exclusion

Reprinted from Thompson AGH.: The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine* 2007;64(6):1297-1310 with permission from Elsevier.

In that report it was also described how patient demand for participation in medical decision making is not a static but a dynamic condition, one which is dependent on factors like the need of health care, the personality of the patients and the level of confidence between the patient and the health care providers. Being seriously ill was associated with less preference for participation (for the different dynamic dimensions and their influences on the preferred level of participation please see Table 3).

The presented models ^{68 69 71} have been used when discussing results in relation to earlier findings in this area of patient participation in medical decision making. In this thesis, the focus is on patient participation from the perspective of the patients' preferences and not participation in terms of choosing between available treatments alternatives.

What is noticeable is that research in the area seems to be more in focus among nurses than physicians. Until now publications have been done mainly in nursing science and published in nursing papers with some exceptions from general practice. ^{59 60} Nevertheless, it is crucial that physicians encourage participation in medical decision making in order to enhance the patient's feeling of participation, especially in medical decision making.

Table 3. Dynamic dimensions of involvement.

	Reduced demand	Increased demand
Need for health care		
Type of illness	Acute	Chronic
Seriousness	High	Low
Personal characteristics		
Knowledge/experience	(Variable)	(Variable)
Personality	Passive	Active
Professional relationship		
Trust	High	Low

Reprinted from Thompson AGH: The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science and Medicine*, 2007; 64(6):1297-1310, with permission from Elsevier.

2.3.3 Obstacles to frail-elderly patient participation in medical decision making

To enable participation in making medical decisions relevant information must be communicated to the patient, affording them the opportunity to choose among treatment alternatives.^{73 74 75} This may be difficult to achieve with the elderly patient, for whom there is a higher incidence of chronic problems, such as, hearing^{72 76 77} and cognitive deficits,⁷⁸ making communication more difficult. The prevalence of hearing loss in adults aged 70-years and older is nearly two-thirds⁷⁷ and, therefore, constitutes a substantial hindrance to effective exchange of verbal information and communication with elderly patients.⁷²

Cognitive functions generally slow with increasing age,⁷⁹ which may make communication more difficult and time consuming. An underlying process of dementia would contribute to cognitive slowing. The incidence of dementia increases with age, from about 10% at age 70 to 45% those over the age of 95. In its nature dementia makes it difficult to understand and remember information and if a patient has a more serious degree of dementia, patient participation in medical decision making is relying on the relatives and their knowledge of the patients' former preferences.

Age gaps between caregivers and patients reflect cultural gaps. The elderly patient had not grown up in a world with internet, cell phones and Facebook.

To sum up, there are several conditions related to the frail, elderly patient that make patient participation in medical decisions difficult.

2.4 Rationale

The Western World populations are growing old, especially in the highest age groups, and with aging come increasing frailty.

The concept of patient participation in medical decision making has been in focus for decades.^{51 80} In many countries it is a part of health care laws; and the subject has also been, since the 1970s, a key topic at supranational levels, for instance at the WHO.^{61 81 82} Notwithstanding its ethical importance, patient participation has been shown to be associated with higher patient satisfaction and improved treatment outcomes;^{53 54 83} but is this also the case with the frail elderly?

Hearing difficulties and cognitive decline in this group are bound to give problems with participation in medical decision making. The hospitals with their organisation in medical department in silos are not organised to meet the complex needs of the frail elderly patients.³²

Older patients, and those less educated, have shown less preference to participate,⁵⁹ though these findings are not consistent.^{58 84 85} Little research has been reported on the oldest age groups.⁶⁰ Furthermore, limited research was found in the literature that examines healthcare staff viewpoints on frail, elderly patient participation in medical decision making in the context of hospitals. This will be enlightened in this thesis.

3 MATERIAL AND METHODS

Methods were used to describe the phenomenon of patient participation in hospital settings, with different strategic approaches that matched the needs of specific research questions (see Table 4). In three of the studies the method was mainly qualitative and in one (Paper II) quantitative.

Table 4: Overview and general description of Papers.

Paper	I	II	III	IV
Design and data collection	Qualitative, descriptive design with individual interviews	Cross sectional survey with a questionnaire. (Telephone-interviews)	Qualitative grounded theory (GT) design using focus-group interviews	Qualitative GT design using participant observations, interviews and a questionnaire
Inclusion criteria	≥ 75 years ≥ 3 diagnoses and ≥ 3 inpatient hospital care periods during the last year		Physicians working in hospital wards with elderly patients	Patient ≥ 75 years; soon to be discharged. Health care staff working on the wards where observations took place
Sampling and Participants	Purposeful sampling. 15 patients, 5 males and 10 females, mean-age 84.0 yr	Consecutive sampling 156 patients, 77 males and 79 females, mean-age 83,1 yr	Purposeful sampling. 30 doctors, 20 males and 10 females working in departments of geriatrics, general and orthopaedic surgery, and internal medicine	Theoretical sampling. 180 hours of observations on medical wards in departments of general surgery, acute and internal medicine. Interviews with 9 patients and 9 doctors/nurses
Settings	One county in the southeast of Sweden		Five different wards in three hospitals in Sweden	Four different wards in three hospitals in Sweden
Data collection period	June 2008 to March 2009	April and May 2009	April 2010 to May 2011	October 2011 to February 2012
Data analysis	Content analysis	Descriptive and kappa statistics	Constant comparative method	

3.1 Sampling

Overall the material of the thesis consisted of 24 individual patient interviews (Paper I and IV), five focus group interviews (Paper III) and 9 individual interviews of physicians and nurses (Paper IV), all audio-taped and transcribed, verbatim. In Paper II the material came from 156 telephone interviews using a questionnaire and in Paper IV (in addition to the interviews) material came from observations on hospital wards.

The mean age of the patients in all Papers was 83.1, highest in Paper IV, where it was 85.7 years. The sampling in paper I was purposeful where a dispersion in age, gender and place of living were to be attained. The interviewed patients in Paper I included 15 recently discharged patients from acute hospital-care. They fulfilled the SNCE criteria of being frail.²⁴ The mean age was 84 years. Patients in the sample had been in the hospital 3-9 times during the last year, on average, 5.5 times. Most of them carried a main diagnosis of cardiovascular disease, and most of them were interviewed in their homes. The interviewed patients in Paper IV were demographically similar to the patients in Paper I, except for the difference that the patients were all still in the hospital.

For the study reported in Paper II, the patients were consecutively sampled during a two-month period. The patients were identified by the Data Care Warehouse of Östergötland, which is a population-based, administrative database run by the County Council of Östergötland. Of the 297 elderly patients identified, 52.5% responded (n=156, 46.5% male) (For sample description see Figure 4).

Inclusion criteria: all met SNCE-criteria; all lived in the selected county; all discharged from one of three acute hospitals in the county, and only during the period from the beginning of April to end of May 2009. Elderly were excluded if they lived in a special accommodation for the elderly.

In paper III and IV the first two interviews/observations were selections of convenience, but as the data sampling went on, new sites were selected based on data already collected, and to further develop an emerging interpretation of the first results - theoretical sampling. In the third paper 30 physicians were interviewed in five focus group interviews in departments of geriatrics, internal medicine, general and orthopaedic surgery. Almost half of the participants had more than 20 years of experience.

In Paper IV the data consisted of participant observations and interviews, as well as a questionnaire administered in acute wards in hospital.

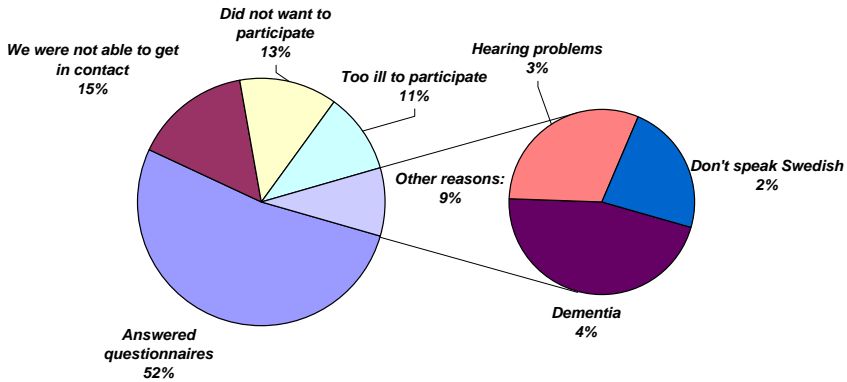


Figure 4: Description of the 297 patients identified in Paper II and reason for not participating

Observational data were obtained from three different types of wards: Two in internal medicine, one acute care and one general surgery. Nine elderly patients above 75 years on their way home after an in-care period in hospital and nine physicians or nurses serving on the wards observed were interviewed.

3.2 Setting and data collection

The studies were conducted in three different counties in the southeast in Sweden. These counties comprise mostly rural and agricultural areas and number one million inhabitants.⁸⁶

In Paper I and III an interview guide was used and in Paper IV an observational protocol was constructed as a memorandum to the interviewer of what to focus on and not forget important areas to discuss.⁸⁷

In Paper I, data was collected using individual, semi-structured interviews. The patients were identified by nurses working as unit coordinators. After written and verbal consent was obtained, the patients were phoned to decide place and time for the interviews. Most of the interviews took place in the patient's home. Interviews began with a short introduction of the aim of the interview. The patients' were encouraged to talk freely. Probing

questions were employed to encourage deeper explanation. All interviews were tape-recorded and transcribed, verbatim (three by me and twelve by the study secretary).

In paper II the method of data collection was a cross-sectional survey with a questionnaire. To describe the *preferred* versus *actual* role in decision making The Control Preference Scale (CPS) ⁶⁷ were used. The construct is defined as “the degree of control an individual wants to assume when decisions are being made about medical treatment” ⁶⁷. Patients are provided five alternative selections, from the most passive alternative, “physician makes all decisions”, through, “shared decision making”, to the most active alternative, autonomous patient decision. The CPS has been used in various populations, from the general public to people with mental disorders, and has been shown clinically relevant, easy to administer, and has been determined a valid and reliable measure of preferred roles in health care decision making. ^{88 89} The CPS has been used in several telephone interview studies. ⁹⁰⁻⁹³

As reported in Paper I, since some patients had not been invited to participate⁹⁴ the CPS was modified by including an additional question about what the patient’s actual role was in decision making: “I was not asked for my opinion” (see Table 2).

Additional questionnaire items were included in the study reported in Paper II in order to quantify barriers to participation in medical decision making based on the results from paper I. These barriers were: illness severity, number of physicians involved in the decision making, difficulty understanding informational content, or difficulty understanding a physician speaking Swedish with an accent. To estimate the importance of these barriers, all the patients who answered “Yes” or “Don’t know” to any single question were further asked to what degree this affected them, “a little”, “somewhat”, or “a lot”. Other questions were designed to quantify preferred and actual information seeking roles. The questions and CPS scale are shown in Appendix , Tables 3 and 4.

The CPS is comprised of 5 preferred-role and 6 actual-role items. Due to its length, the CPS was mailed home in advance of the telephone interview to give the patients’ time to read it and begin to come up with answers, beforehand.

The data collection for our study reported in Paper III utilized focus group interviews (six participants). Interviews with physicians were conducted in various department conference rooms at a time chosen by the physicians. All interviews were approximately an hour in length. At the beginning of each interview, the aim of the study was introduced and physician informants were asked to share their thoughts about frail and elderly patients, asked to describe perceived barriers, as well as what factors facilitated patient participation in medical decision making.

For the study reported in Paper IV, “participant observation” was employed. This method is defined as, “...a process of learning through exposure to, or involvement with, the day-to-day routine activities of participants in the research setting.”⁹⁵⁻⁹⁷ The role used of the observers during the observations was primarily observation with limited participation. Observers followed an observational protocol that guided them to note certain features.⁹⁸ The protocol included the following questions:

- 1) How are decisions made concerning the discharge of the frail, elderly patient?
- 2) What influences these decisions?
- 3) Who participates in the medical decision making around discharge the frail, elderly patient?
- 4) How is this decision communicated – and by whom?
- 5) How does the frail, elderly patient want to participate?
- 6) How does this patient experience the decision making regarding her own discharge?

Most observations and note taking was performed by the second author of Paper IV, a district nurse of master’s degree level Märit Linderholm.

The recording of detailed field notes is a key component of observation in the qualitative method of grounded theory (GT).⁹⁹ For focus groups interviews and observations reported in Papers III and IV, field notes, integrative diagrams and memos were written down, serving as a continuous guide to develop understanding of the material and guide further data collection.

3.3 Data analysis

Qualitative methods are recommended when there are no previous studies dealing with the phenomenon or when knowledge is fragmented.¹⁰⁰⁻¹⁰² Interpreting qualitative analysis depends on the investigator insights, analytic abilities and style.

3.3.1 Qualitative methods

Qualitative methods were the primary approach to data in this thesis because it enables exploration of patient and health care staff attitudes, beliefs and preferences, which may lead to more in-depth understanding.¹⁰³

In the first study, content analysis was used. This method of qualitative analysis was first used as a kind of quantitative method for measuring the space taken by for instance hymns or advertisements in newspaper and magazine articles.¹⁰⁴

Content analysis is used by a wide range of researchers, in communications to public health studies, including gerontology and psychiatry and its use has shown steady growth.¹⁰⁰

Like in any other type of qualitative method you begin the analysis with reading all text to get an overall understanding. This step is followed by a more thoroughly reading, segment by segment to identify sequences containing relevant information, the so-called "units of meaning". These units are then condensed enabling assignment to a common feature, what are termed, here, as "preliminary codes". Throughout, these preliminary codes are continuously being questioned and reorganised: Do they share a logical meaning with each other, or with other meaning groups (units of meaning)? Is there reason to reorganise? These preliminary codes are then further categorized, which helps explain larger segments of text and to get a better understanding of the text as a whole. The codes, subcategories and categories are labelled, based on the content.

The last step in interpretation is to lift from the written manifest description of the content, to a higher level of abstraction or interpretation, incorporating latent meaning. From this abstracted level a theme is discerned.

Digitized content, in the form of electronic word files were examined to identify "units of meaning". These units collected and incorporated into an excel-document to facilitate naming preliminary codes and arrange text for

comparison within and between categories (For an example of the analytic process see Appendix, Table 5).

In Paper III and IV the method of grounded theory (GT) was used to analyze and interpret the data.^{86 105} GT aims to generate theories to explain how phenomena are interrelated and grounded in data.

Initially, analytic steps in GT and content analysis appear similar: text is read line by line to find relevant information, meaningful text sequences are named, and preliminary categories are developed. The process of condensing and categorizing raw data is also similar. However, in GT your focus is more dynamic: What is going on? What is the underlying process? How does the research participant(s) act while involved in this process? What are the consequences of the process?¹⁰⁵ In this way, the method is well suited to describe social interactions and processes relevant to the research questions of Papers III and IV.

While creating categories, one begins with an axial, or focused, coding to explain the categories more fully and the variations within the category. What is the “core” of “axis” of the category? Around which centre or “axis” does the category spin?¹⁰⁵ During the analysis of data continuous comparisons are made between and within the preliminary categories to see if the categories fit in a meaningful way.

In content analysis all the data is typically available before analysing it.¹⁰¹ However, in GT, data collection and data analysis often occur simultaneously.^{86 105} The findings and the questions they raise as you attempt to describe the categories, prompt you to where to sample new material to your study (such as new persons to interview or where to make the next observations). As the amount of data increases, you continue to organize into categories and subcategories until no new category emerges and the broadness of the categories are well described (called saturation).^{86 105}

An important tool in GT is memo writing. Memo writing is a kind of continuous and intermediate analysis of data, and consists of, after data-collection, noting thoughts, suggested comparisons and connections, and reflections that occurred while you gathered data.¹⁰⁵ Memos help you to formulate integrative diagrams and guide your thinking on how to interpret data and whether to collect more data.

The goal of all these analytical actions in GT – as in content analysis – is to find ways to understand the text fully and to condense the material in a way that makes it possible to grasp the whole.

3.3.2 Statistical methods

In all papers there were tables with descriptive statistics, but to a higher degree in paper II.

In paper II a comparison of the age between the responding and non-responding groups using the T-test and a comparison of the gender were made using Pearsons' chi-square test with SPSS version 15.

The responding group were described more thoroughly with simple descriptive statistics and when appropriate Pearson's chi-square test to look for differences between background data such as educational background, marital status and age-groups and preferred and actual role in patient participation.

To examine the disagreement between the two subscales in the CPS, preferred role and actual-role, the discrepancy scores and the weighted kappa (κ_w) was calculated.

- 1) Discrepancy scores were calculated by subtracting actual role score from preferred role score to give a score for each patient ranging from "0" (no discrepancy) to "-4" (preferred the most active role but all decisions were made by the physician) to +4 (preferred the most passive role but the patient had to make the decision on their own).
- 2) Weighted kappa (κ_w) is a method where results weighted differently depending on the distance between – in this case – the preferred and actual role in medical decision making. Kappa-statistics is taking into account the possibility of agreement due to chance.¹⁰⁶

The κ_w value is presented together with a 95% confidence interval (CI). There are no absolute definitions of the interpretation of κ_w , but the values are usually interpreted as poor if $\kappa_w < 0.20$, fair if $\kappa_w = 0.21-0.40$, moderate if $\kappa_w = 0.41-0.60$, good if $\kappa_w = 0.61-0.80$, and very good if $\kappa_w = 0.81-1.00$ ¹⁰⁷.

3.3.3 Integration of results

The thesis describes different aspects of patient participation: from the view of the patients', the professionals' and observed by the researchers. To be able to integrate the results I did a re- analysis of all results and made new categories leading to a suggestion of a model to explain the conditions for frail elderly patients' to participate. Comparisons between the different categories were made. Variation and similarities were searched for. Finally possible relationships emerged. The first categories of results became the direct answers on the main research questions': What did patient participation mean to frail elderly patients, what were the important barriers and what were the preferences for participation in medical decision making – the last categories emerged on a more interpretive level on the basis of frequent reflexions when interpreting the findings in all the papers and were related to the patients and the health care providers perception of the health care system and the feelings expressed by the health care staff when taking care of frail elderly patients.

On the basis of the integrated results it was then possible to make a suggestion to a model how to improve frail elderly patients participation in medical decision making and thereby improve the quality of their care.

3.3.4 Validity and rigour

The purposeful sampling in Paper I was done to achieve different aspects of the patients' view of patient participation i.e. to capture a wide range of perspectives relating to the phenomenon. The participants in the qualitative Papers (I, III and IV) differed in background data such as age (although all above 75 years), sex, marital status and the data material was collected in different geographical contexts, which facilitates transferability.

Doing qualitative studies it is important to try and look at the research question from different angles to strengthen and support the findings and to develop comprehensive understanding of a phenomenon. ⁹⁸ This method of increasing validity in qualitative research is called triangulation. ¹⁰⁸

Triangulation was applied through several data sources and in paper III and IV several data collection methods. ¹⁰⁸

In the beginning the interviews were scrutinised by the supervisor in order to develop the author's interview technique. All interviews were transcribed verbatim and could therefore be read in full text.

In the focus group interviews in paper III the discussion were summarised at the end of each focus group interview to ensure that there were no misunderstandings between what the physicians had meant to tell and what the researches had perceived that they had been told.

The analysis of the qualitative papers (I, III and IV) were done by several researchers, at the beginning independently in order to be as neutral as possible, to analyse without influence on each other's analysis. There were continuing meetings and discussions of preliminary results throughout the data collection period until agreement on the main findings. This was to enhance critical analysis of data.

For the study in Paper II a questionnaire was developed, derived mostly on the basis of the CPS, which was modified by inclusion of additional questions. Content validity ^{109 110} was examined by having an expert panel of two physicians and three nurses, all with more than 15 years of geriatric experience. Then - to get further validity - the questions were then tested by e-mail to fifteen (ten out of fifteen responded) geriatric academic and non-academic experts from all over Sweden with in between 10 and 25 years of geriatric experience for their opinion on relevance and the usability of the questions. After minor adjustments the questionnaire was tested on healthy individuals and finally, the questions were tested on four frail, elderly patients to insure face-validity. ¹⁰⁹ They demonstrated they could answer the questions without difficulty.

The quantitative results in Paper III were not analysed until all interviews and observations had been completed so they would not influence the qualitative interpretation.

3.4 Ethical Considerations

In Papers I, II, and IV we reported on studies of frail, elderly patients who all had extensive histories of hospital care. As described in the introduction, many of them had had severe illness and had suffered from fatigue. Moreover, this patient group was associated with high mortality.

Interviews can be a burden to respondents, both physically and psychologically. At the same time, many patients enjoy being listened to and being given the chance to explain their views about their experiences of the health care.

It is important not to exclude elderly patients from research on the basis of co- or multi-morbidity, which previously was customary because of the challenges brought by this complexity.¹¹¹ It is therefore also a matter of good ethics to try and overcome difficulties to learn more about this high health care consuming group.¹¹²

In both verbal and written information it was stressed that no information from the interviews could lead back to the patient records and that all participation in the study was voluntary. The researchers were not in any way connected to medical care of the patients in any of the studies.

In paper II ethical approval was given to the researchers to get list' of patients fulfilling the SNCE-criteria through the Data Care Warehouse of the County Council and also to phone the patients without having consent to do so. This could be perceived as intruding. The motivation for this procedure was the low response rate to questionnaires in this group of patients on which there are little research.¹¹³ Phone calls were only made by experienced health care staff and as soon as an answer were obtained it was stressed by the health care professional that all participation was voluntary and the interviewer asked for informed consent to perform the interview.

Similarly, before focus group interviews, physicians were informed that all participation was voluntary, and that all the material from the interviews would remain confidential, including that researchers would not be able to connect specific statements to a named person. For this particular study, no application for ethical approval was done as it was considered that all the physicians acted on their free will and were free to choose not to participate in the focus group interview.

Our study reported in Paper IV risked being a disturbance to health care staff because of the burden of time. Voluntary participation was stressed to both patients and staff. Patients expressed, in writing, their informed consent prior to any interviewing.

The studies reported in Papers I, II and IV were approved by the the Research Ethical Committee at the Faculty of Health Sciences, Linköping University. (Dnr M104-08, Dnr M 87-09, Dnr 2011/337-31).

4 RESULTS

4.1 *Patient participation*

- meaning, roles and preferences according to the frail elderly patients'

In Paper I it was reported that, to the elderly patients, participation in medical decision making, above all, meant that they experienced sharing of information and were participant to good communication.

They want the health care staff, especially the physicians, to take the time and explain to them about diagnostic procedures and considerations.

They also want to be given the chance to share and explain their own thoughts about symptoms and illnesses. Yet, we found diversity among respondents, in that, some were curious about their treatments and investigations and asked questions frequently to be informed, while other patients seemed to indicate a preference not to be involved.

This quotation is from a male, 88 year-old patient, who lived at home with his wife, as he described to the interviewer an example of good participation, and explained his satisfaction with it:

Interviewer: Have you ever been participating in planning of your health care while in hospital?

Patient: Yes, I have had a by-pass operation and then I was allowed to participate – but not now.

Interviewer: In which way did you participate when you were by-pass operated?

Patient: Well, they came to me. They draw up some lines to show which vessels they should replace. They showed me all they had planned – they explained exactly.

Interviewer: Then you felt that you participated in your care?

Patient: I really did.

This patient felt he was participating when they explained the surgery in such detail.

Overall, the patients do not often express a desire to participate in choosing between alternative treatment options; they do not think they have the skills

or the information to do so. Yet, they want their consideration to be taken into account.

There are also many expressions of good confidence in the health care together with gratitude. Patients expressed sympathy for health care personnel having to work so hard due to staff shortages.

Patient participation is studied further (Paper II) by investigating what are role in decision making elderly patients prefer. ¹¹⁴

Thirty-three percent of 156 frail, elderly patients queried indicated preference for a passive role, exemplified by the following statement: "... my physician make(s) the final decision about my treatment but consider(s) my opinion"; 28% indicated preference shared decision making. but the preferences are evenly distributed between the five alternatives with the exception of the alternative when the patients wants to make his or her decision (4%) by themselves. Twenty percent wants the more active role "I prefer to make the final selection of treatment after seriously considering the doctor's opinion" – for distribution of preferred roles in medical decision making please see figure 5.

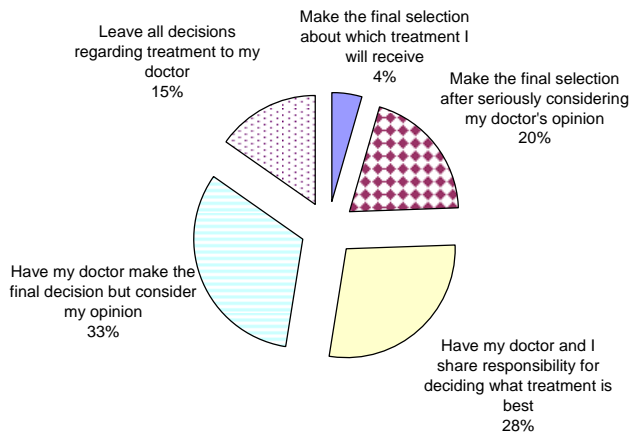


Figure 5: Preferred role in decision making using the five alternatives in the CPS-scale

The results, thus, show that given the limited number of choices that express various "types of participation", preferences for participation in medical

decision making vary and is almost evenly distributed between four of five of the possible roles apart from the most active role “I prefer to make the decision about which treatment I will receive”.

When, in Paper II, the relation between preferred and actual role in medical decision making and the demographic data (age, gender and educational level) were examined, there were no significant differences between the demographic background data and the preferred or actual role in medical decision making.

4.2 Barriers to participation

In Paper II, based on results of a cross-sectional study of 156 frail-elderly patients, we reported several potential barriers to an elderly patient’s participation in medical decision making.

The most common barrier mentioned by the patients (35%) was personal illness. The second most common barrier, was difficulty understanding medical information. Furthermore, we found that 20% indicated that this was exacerbated when patients had difficulty information due to differences in quality of spoken-Swedish, sometimes with a foreign.

Lack of continuity amongst the physicians due to working schedules was a barrier to participation in medical decision making. Often several physicians were simultaneously involved in treating the same patient (Paper I, II, and III) not always drawing the same conclusions of treatment alternatives. Discussions among physicians in the focus group sessions indicated that the physicians were well aware of this discontinuity. Furthermore, when asked their preference were they themselves, or their parents, in need of care, the overall view was that discontinuity is among the most important issue to address participation in decision-making (Paper III).

In Figure 6 the barriers found in paper I and quantified in paper II is shown together with a grading of the importance of the barrier.

The physicians were asked in the focus groups about barriers just as had the patients, and also asked for an estimation of the barriers’ importance. Twenty-three of thirty physicians answered, and they estimated that most of the frail elderly patients are not too ill to participate in medical decision making. The physicians are well aware of the different treatment strategies between them

and the difficulties of understanding the medical information as a problem for participation in medical decision making for the patients’.

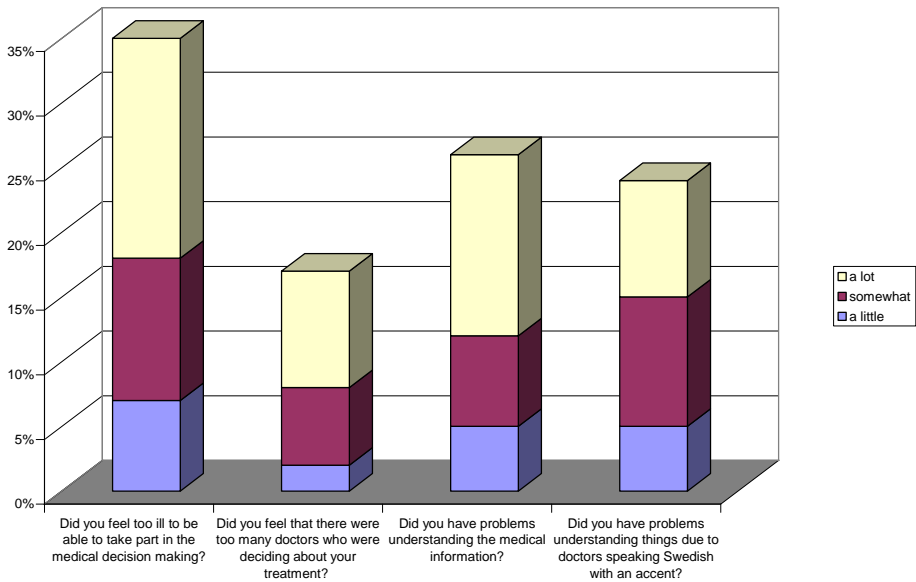


Figure 6: The frequency of barriers to participation in medical decision making and their importance (n=155).

Main barriers to participation in medical decision making according to the physicians’ and the health care staff is lack of time to discuss medical information with the patient. Hospitals demand quick turnover of beds, affording little time to engage patients in discussing information that concerns their health choices, and that embodies the value in patient participation.

A barrier mentioned by some of the physicians was that premises are not conducive to promoting patient-doctor communication, especially in the emergency rooms. One physician described the newly rebuilt emergency ward, thusly:

Look at our emergency ward. It is new and everything is fine. There is an examination table and you, yourself, have some kind of stool to sit on or perhaps you have to stand up over the patient to give information. There is no place to have a proper conversation.

4.3 Agreement between preferred and actual roles in participation and information

As many as 15 % of the 156 patients studied (Paper II) said they found it difficult to ask questions about their treatment; and 45% would have accepted more information about their care than they got during their last stay in hospital. ¹¹⁴ Patients expressed finding it a bit strange that the physicians' did not inform them more about the tests and investigations that were being made on their bodies. Mostly, they did not confront their health care professionals with this. ⁹⁴

In Paper II we reported results of the cross-sectional survey in which we asked patients about their last hospital stay and what role they preferred, in regard to participation in medical decision making, and what their role actually became. The distribution of discrepancy scores (the distance between the preferred and the actual degree of participation) is displayed in Figure 7, forty-two percent of the patients actualized the same level of participation that they self-reportedly preferred. Twenty-seven percent of patients selected an added statement, not initially in the CPS, "I was not asked of my opinion". More patients (35%) indicated by the selection of level that their actual role was more passive than active.

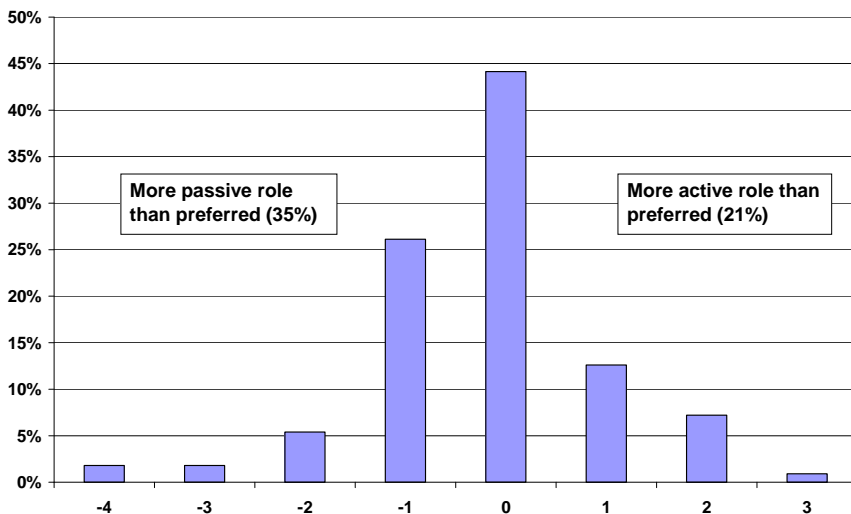


Figure 7: Discrepancy score between preferred and actual role in medical decision making (n=111)

When calculating discrepancy scores and kappa-statistics this can only be done, when the patients have answered one of the five original questions in the CPS-scale in both the preferred and the actual role in medical decision making. This is why the number of respondents calculated on are 111 and not 153 (three patients did not answer on the actual role and 42 patients (27%) chose the modifying alternative in the actual role during last stay in hospital: "I was not asked of my opinion").

Agreement between self-ratings of preferred and actual role level was examined by using weighted kappa, giving the result indicated moderate agreement ($\kappa_w = 0.57$; 95% CI: 0.45–0.69).¹⁰⁶

As the main barrier to participation in medical decision making in 27% of the patients is that the patients claimed that they are too ill to participate, a special description was done on these patients. The results show that 31 % of the patients that was not asked for their opinion had stated that they were *not* too ill to participate and 19% answered that they did not know.

4.4 The health care system

Generally, the patients expressed confidence in their health care providers, but there were also expressions, like, "I will have to be content", implying that there were not alternatives.

But how do the elderly patients view health care? When they described their participation some elderly patients also expressed a strong view of a hierarchical structure concerning the physicians and the hospitals. The physicians are believed to be on top of the social ladder and, therefore, patients expressed the view that physicians would not want to take the time to communicate with them as patients. However, most patients expressed that they found it natural that the time would be taken to exchange information and communicate in order to enhance participation in medical decision making.

Patients know that doctors and other healthcare professionals undergo extended education, and they attribute power to such persons, while they, the patients, are unable to influence, nor participate in medical decision making. This is illustrated in the following quotation:

Interviewer: Did you feel that you were participating in your care and the discharge planning?

Patient: Did you say discharge planning? That is up to the hospital to decide. "Good luck", they say. "Tomorrow you can go home in that car". You will just have to go home. You cannot have any outburst in there. One should like to, but you don't do it.

The frail elderly patient sometimes feels unwelcome in this "institution". They feel that they take time from the personnel that are stressed and overloaded, they feel sorry for them. They sometimes feel that the staffs just want to get rid of them (Paper I and IV). Some physicians declared that they felt troubled by their work with this population. Here, a physician compares frail elderly with truly acute patients.

We have got enough trouble with the patients that are really sick!

Patients described how they did not feel that they participated in discharge discussions (see Papers I and IV). They described how they sometimes felt overruled, not listened to and treated with a lack of respect due to their age which was difficult for them to accept.

The interviews and observations in our studies reported in Papers I, II and III that patients sometimes do not know who exactly makes decisions about their care. This was concluded from the many references by patients to the anonymous "them" or "hospital" that decides.^{94 115} They face a challenge to question decisions if they do not know who is responsible.

In Paper III, it was reported how a lot of the senior physicians maintained this obscurity by expressing their own decisions as if they did not, in fact, make them, rather absent authorities were responsible. We observed words were used that implied less unilateral, personal authority, such as, saying "we" or "one", instead of "I". For example, one senior consultant said, "We think that it might be possible to continue treatment at home". Occasionally, they used even more nonspecific phrasing, such as, this comment by another senior consultant, "It could be imagined that it will be good to come home today".

4.5 *The frustrated professionals*

When discussing the elderly patients' participation in medical decision making (Paper III) with the physicians it was not always easy to ensure they would focus on the core subject. They were instead more willing to discuss

their frustration and the challenges they experienced as they attempted to provide good care, including to incorporate adjustments that would be advantageous.

Physicians expressed feeling challenged by lack of time and lack of available beds, which they experienced as impediments to taking care of their frail, elderly patients. They expressed lacking competence to take care of the complex medical needs in the specialty-focused wards. They affirmed the need for longer in-care time and for a redirection to a more holistic style of care, which they felt ill-suited for. They expressed that, if they had requisite competence and took the time to go thoroughly through all illnesses and medications, it would take more time and occupy more beds, thereby creating problems for other patients seeking accessibility.

They want geriatric services to take care of these patients and they want to consult geriatricians about medications when these patients stay on their ward. They want to be able to offer them a bed when they come to the emergency room to sort out medical problems – not send them home as fast as possible. And, above all, they stressed the need for continuity.

Lack of time is frequently mentioned as a reason why it is difficult to take care of frail elderly patients and let them participate in medical decision making, but there are other challenges. The relatives come with their opinions, sometimes wanting to protect the patient from information; and in this way, participate. However, this situation also provides an opportunity to engage the patients. Relatives require additional time and effort.

Several physicians cited policies in the health care system that make difficult adjusting care for individual needs.

The physicians expressed feeling haunted by the remuneration system, which they know is focused on health care production, specifically accessibility to care, as well as quota of investigations and treatments. Comments such as “(that they felt like they were) doing nothing” when taking care of frail elderly patients, indicated the low status, attributed to taking care of frail, elderly patients.

Frail elderly patients are instead perceived as “bed-blockers” disturbing the main tasks of the ward depending on the medical speciality - as one physician expresses:

It can be an orthopaedic, surgical or internal medical condition but nobody wants the patient as our remuneration system is built on the more of these patients you can avoid- the better economical results for your department. Now I will be even harder, so it is important to effectively try to avoid these patients that will not give you any money, i.e.

be tough at the emergency ward and your boss will reward you. It is not a good system we have created, not making the frail elderly feel welcome. I think that many of these patients feel unwelcome, because they are regarded by us physicians' as just a cost. You are educated as a physician to take care of people, but you end up with the "knife in your back"—it is not good.

In the observational study (Paper IV) it was noticed how, when examining patients on their wards, the physicians tried to find one or a few illnesses that were medically treatable. If unable to identify these treatable conditions, they sought to discharge the patient as fast as possible, or identify medical conditions that could be better addressed to another medical service, and make the referral.

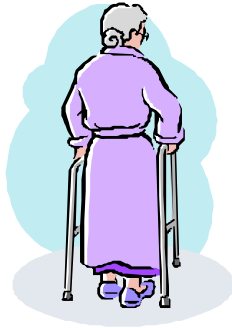
In Paper IV, it was reported that different discharging policies were apparent among different physicians observed. Some physicians allowed their patients to stay a day or two longer if needed so that social support could be arranged, a kindness, perhaps, that would earn them the attribution by nurses that they were "...warm-hearted and kind". Other physicians, described as "cold" or "harder", discharged patients promptly when "there was no more to be done medically", indicating they would discharge when there was a lack of need for them to stay in hospital and occupy a hospital bed, despite symptoms. Both patients and nurses had generally to submit to these particular discharge policies, although sometimes both the patients and the nurses opposed this.

Frustration with the lack of beds for frail elderly was sometimes accompanied by other feelings, such as, "bad conscience".. As another nurse expressed, describing her experience sending a frail and elderly patient home after a short in-hospital stay or a visit on the emergency room, "My heart is bleeding."

These studies identified numerous reasons why it was difficult for the elderly patient to participate in medical decision making. A summary of barriers to participation is shown in Figure 8.

Issues stressed by the patients':

- Being too ill
- Not being able to understand the information
- Doctor speaking with a foreign accent
- The hierachical structure of the hospitals
- Lack of continuity



Issues stressed by the health care staff:

- Lack of time
- Inappropriate remunerationssystem for frail elderly patients
- Lack of geriatric competence and a holistic view
- Patient-related conditions:
 - Multimorbidity
 - Functional declines
 - Relatives
- Premisses and routines not adopted to communication
- Lack of continuity

Figure 8: Barriers to participation in medical decision making

4.6 Frail and elderly patients participation in medical decision making

-a suggestion for a model to understand the conditions in a larger perspective

Through describing the conditions for frail, elderly patient to participate in medical decision making (Paper I to IV), this thesis reveals more systemic, institutional-based conditions may be important to consider, including:

The hospital as an overriding “institution of power” that is not easily challenged, whether by patients or professionals.

Barriers include (Figure 8): personal illness, complexity of care and treatment, stress in the clinical workplace, rapid turnover of beds, communication difficulties, complex social and family involvement (both positive and negative), discontinuities in care, and lack of competence in geriatrics.

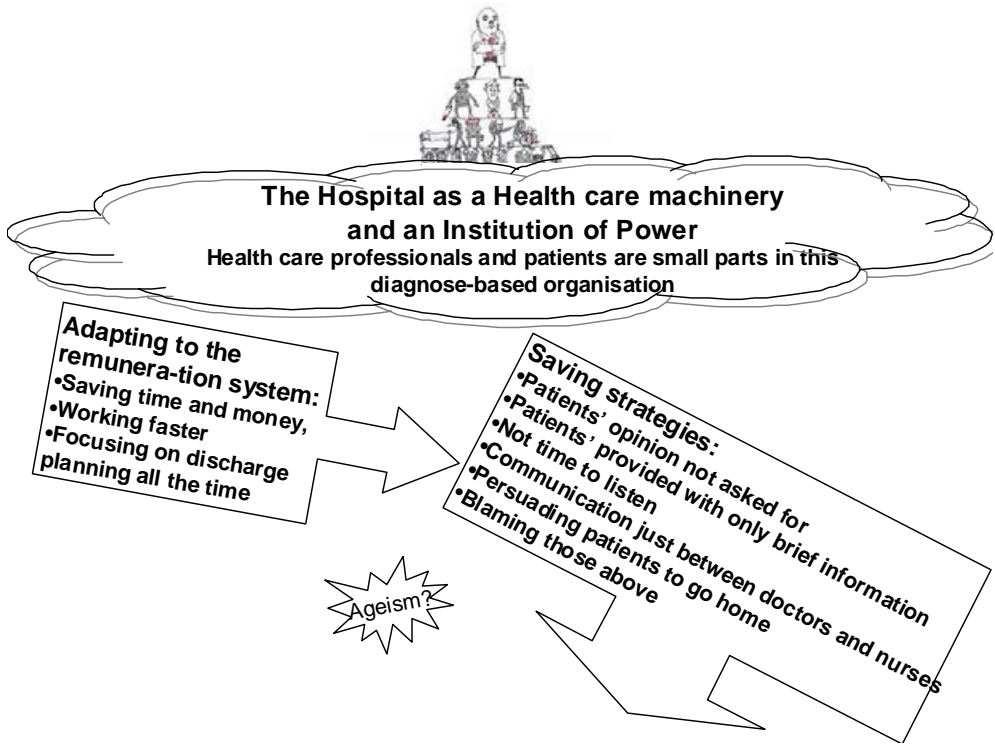
The patients’ perceive they are a burden and less worthy than younger patients.

Patients feel intimidated by the system and don't have the energy to fight.

The continuous pressure to turnover hospital beds contributes to the physicians focusing on rapid discharges. In Figure 9 is displayed an integrative diagram of reactions by health care professionals to the health care organisation and the remuneration system, consequences for the patient and health care staff.

The hospitals are, in practice, divided among diagnosis-based wards. The health care professionals comprise a small part of this health care institution, one which both patients and professionals find difficulty to influence.

As a consequence the patients do not feel that they are listened to and informed properly. They feel that the staffs want to get rid of them showing it by short communication and the rapid discharges. Nor do the health care staff feel satisfied with the situation either. They express feeling guilty about not being able to provide good care to their frail, elderly patients, and still fulfil the demands of the “Power of Institution”.



Consequences of chosen strategies:

To the patient:

- Lack of patient participation in medical decision- making
- Hastily informed
- Feel they are a burden to the stressed personnel
- Feeling unwelcome
- Do not feel a sense of participation

To the Health care professionals: Feelings of frustration and guilt.

Figure 9: Integrative diagramme of conditions influencing frail, elderly patient participation in medical decision making

5 DISCUSSION

5.1 *Discussion of results*

5.1.1 The participation in medical decision making

The main finding of this thesis is that there are several factors that influence frail, elderly patient participation in medical decision making. The overriding “institution of power” appears to exert influence in even small decisions and influences what strategies are utilized in the wards, requiring professionals to prioritise patients, which may motivate avoiding care for elderly while encouraging care of younger, mono-diagnosed patients. These results are discussed on a macro-level, later on.

However, let’s start, here, on a micro-level. This thesis has shown that frail, elderly patients endorse more passive than active roles in participation in medical decision making than preferred (Paper II). This is a significant finding because most of the earlier research found that older patients prefer a less active role in making treatment decisions than younger ones^{45 84 116} – but not to the low degree they actually got (Paper II).

In Papers I and II, it was reported that the preference for degree of participation varied individually, indicating that one cannot generalise the preferences for participation in medical decision making even in this frail group of elderly patients.

There appears to be agreement across various patient groups, including frail elderly, about the meaning of participation in medical decision making.⁷⁰

^{71 116-118}

As reported in Paper II, “Being too ill” was the single most important barrier to participating in medical decision making.

It is important to be aware that there are dynamic dimensions of participation related to the health status^{71 119 120} and as a consequence of the seriousness of their illnesses the frail elderly patients’ therefore often have to resign and give in to medical decisions made by others.

Communication difficulty was cited as a barrier, which may have to do with sensory deficits or cognitive decline.^{121 122} Quality of communication with

one who exhibits cognitive or communicative impairment can be improved by use of communication strategies, as well as by educating personnel in the understanding of cognitive problems and how they are manifest.¹²³ More meaningful and dignified communication has benefits for both patient and health care provider.¹²⁴ Even patients with dementia may want, and they should, have the opportunity to participate in medical decision making. This was previously concluded in a study, which noted especially, the importance of making possible such opportunities in the early phases of disease.¹²⁵ Patients generally report wanting more information than they are getting.^{49 116} In Papers I and II it was showed to be a concern to the group of frail elderly patients we studied.

Age and cognitive decline should not be a reason to presume that the patient does not want to participate in medical decision making or be informed.

In Paper II we reported that as many as 27% of patient respondents had never been invited to participate in treatment decisions. In half of the cases these patients expressed that it was because of their bad health condition, but one-third of the patients who had not been invited to participate did not perceive themselves as actually being too ill to participate.

By the calculation of discrepancy scores and by the kappa-statistics it was shown that the agreement between preferred and actual role was moderate. This result leaves room for improvement of quality of care regarding patient participation.

Despite these incongruence a lot of the patients expressed confidence in their care and the decisions that were made (Papers I and IV). However, in both Paper I and IV, it was reported that it was not possible for patients to influence decisions even if desired.

5.1.2 The special barrier of language

Our studies showed that an obstacle to good communication was the difficulty patients had in understanding physicians who spoke Swedish with an unfamiliar accent. Elderly patients with hearing problems have even more difficulty than many other patient groups in dealing with this issue.

In the EU, physicians move freely between countries to serve career needs. The language barrier is not a matter of concern only in Sweden, but is a growing international matter. For instance, physicians in the U.K. and in other

Nordic countries have expressed alarm over potential effects of language skills on quality of care.¹²⁶⁻¹³⁰

European Union policy has had an influence. Legislation has been brought in the EU that makes it illegal for medical administrations in the EU - binding also the Swedish National Board of Health and Welfare (Socialstyrelsen) - to systematically test for language ability of physicians from elsewhere in the EU when they register. In Sweden the responsibility rests with the employer (in this case, the County Councils), who may lack adequate knowledge on how to judge the linguistic capacity. Meanwhile, the administrators are also facing critical physician shortages, for example in primary care, psychiatry and geriatrics. These specialities demand communication competence.

5.1.3 Money rules

The patients described how different physicians were making different treatment decisions at the same time and how the physicians did not know them as patients and their illnesses (paper I and II). In case the physicians' did not communicate with each other, it was leading to contradictory information and prescriptions, which left the patients' confused or that they gave up their attempts to understand. This is a consequence of the lack of continuity and lack of communication between care-givers. The fact that physicians, when asked to consider central changes in health care of the frail elderly patients, frequently mentioned this barrier shows its importance. Fragmented care is a major concern in healthcare today,^{24 131 132} and especially so with these patients, among whom high incidences of memory and learning problems, making communication about medications, illnesses and preferences quite challenging.¹³³

Good communication about health-related problems with elderly patients is essential in order to develop knowledge about age-related physiological changes (gerontology), normal aging, and the most common age-related diseases (geriatrics). Cognitive decline is especially important to consider, as a quarter of patients over 70 years-of-age who present for acute admission have dementia¹³⁴. It is difficult to segregate consequences of normal ageing and diseases in the aged person – and without proper education it becomes even more difficult.

Today, the educational level of all health care professionals in gerontology and geriatrics is low.⁴¹⁻⁴⁴ For instance, in Sweden, only about one and a half

weeks are dedicated to geriatrics out of six and half *years* of training to become a physician.⁴² The National Board of Health and Welfare are well aware of the incongruence between the gerontologic and geriatric skill level of caregivers and the educational program response in this area,^{43 44} However, so far no special funding or strategic effort has been specified that enables the universities to allocate more resources for the training of health care staff in gerontology and geriatrics.

Studies show that patients survive longer and are more independent when cared for on geriatric wards with team-based care.^{35 135-138} Unfortunately, most geriatric patients' are taken care of on acute, non-geriatric wards that aim to focus on one or a few diagnoses at time, a consequence of having too few geriatric beds in Sweden.¹³¹

The issues of this thesis concern also the macro-level. Evidence supports the benefit of shifting from the mono-diagnosis hospital system to more holistic care concerning these patients. However, the remuneration system appears to be an obstacle. The Swedish remuneration system stresses performance measures concerning time-expenditure. An institutional value to make accessible care for all patients can create exclusionary pressures that affect the elderly. This is because to see all patients who appear, the system has to reduce the length of time-in-service. With the elderly patient, it is not possible to simply deal with one problem and have the patient on his way. There is clear competition, here, for the few beds – young against old, simple diagnosis against multimorbidity, and so on. Moreover, a service that is weighted toward serving the younger patient over the elder will often show better performance data, e.g. shorter service time and often better treatment efficacy.

The present remuneration system in Sweden rewards the short health interventions¹³⁹ that do not encourage a holistic view. Time-consuming activities, such as thoroughly reading all the medical records of the patient to be familiar with all diseases and medications, counselling to enhance coping strategies for the frail elderly patients and their families as the health inevitably declines, engaging in multi professional team-conferences and taking time to communicate with interdisciplinary team members or even outside providers such as the municipality.

It is known to the overriding health care system that such communication activities are lacking¹⁴⁰ why there have been a development of the health care

legislation to ensure good and sufficient communications, but legislation has not allocated funding to promote improvement in this area.

That money rules is no new discovery – in 1986 James Buchanan was given the Nobel Prize for his development of the theory of economic and political decision-making ¹⁴¹, and the conclusion that ethics and policymaking do not guide human acts as much as money does. It should not therefore be surprising that care for the frail elderly is in poor shape.

Perhaps no optimal reimbursement system for health care exists; if that were the case, it would probably be in use.

5.1.4 Working environment and the institution of power

In the focus group interviews presented and discussed in Paper III the physicians gave expression like “the frail elderly patient being worthless”; and yet, they also expressed feelings of frustration and guilt that they could not help achieve “good care” to them and with that comes participation.

Providers knew the benefit of patient participation, but did not give this priority perhaps for fear of getting poor performance ratings. They felt part of a “health care production machine” that did not adapt to patient needs. Moreover, they expressed helplessness to do nothing about it. Thus it seems that not only are frail elderly not respected; but also, personnel are subjected to a bad working environment, which increases risk of stress and burn-out.

The findings from our first study found that, to the patients, hospitals are an “institution of power”. ¹⁴² Patients do not question this “institution” because they feel that their medical knowledge is inferior to that of the doctor, and do not dare to ask questions about their illnesses of fear of challenging this powerful institution. ¹⁴³ But, the patients were not alone in expressing this sort of feeling, physicians made similar characterizations of the system (Paper III). They expressed dissatisfaction about routines and reimbursement systems, but also helplessness, that they did not have the power to change these conditions.

It was found that it was not clear to the patients who made the decisions about the care, and it was observed how the physicians actively contributed to this “collusion of anonymity” by trying not to take full responsibility for decisions ¹⁴⁴ avoiding personal pronouns in sentences about their decisions, just as if someone else but themselves had made the decisions instead of using the word “I”. This further increases the risk of not being able to participate in

medical decision making by doing communication more difficult as it was not clear to the patient whom to talk to when to discuss decisions. Perhaps it also felt better for the physician as they knew that the decisions were often not in line with the preferences (paper IV). The way of expressing the discharge decisions by the physicians might be a way of not feeling the whole responsibility for their own decisions – and in a way it was not – it was the natural consequence of the lack of beds due to economical cut downs together with the remunerations system.

As it seemed unclear to both patients' and professionals who makes decisions and on which grounds, it is difficult to question or react on these decisions. The consequence might be a loss of the basis of quality improvements from patients and professionals - the most important source to get improvements in health care from. These findings of the physicians trying to express themselves as if they do not make the decisions themselves are unique and could have important implications on how we should develop communication and leadership in health care.

5.1.5 Ethics in the care of the frail elderly patients

In all papers there were expressions of the patients' saying that they did not feel welcome in hospital. It was discouraging to recurrently hear how that these patients perceived that the health care staff just "wanted to get rid of them". Consider the statement by one physician, about the distinction between the frail elderly versus the group of patients that were "really ill". This is hard to understand taking the high mortality rate into account.

Lack of time was cited by the physicians as a problem that discouraged personalizing care. Perhaps this mediated by stress. In any case, – it could also be a way to avoid communication with a group of patients that they were not so convenient to work with because of medical complexity, or, perhaps, an expression of an ageist attitude (Papers III and IV). In Paper IV it was written that we observed differences in communication style when patients were younger versus older patients. Communication appeared to be more on equal terms and more thorough when conducted with younger patients. This could partly be due to a "culture gap", as discussed in the introduction. Professionals in health care do not have the same framework as the patients' and it takes a greater effort to achieve good communication.

It is important that time be allotted for communication with the patient and other health-care givers. Discharges should be planned with the best

interest of the patient in mind, rather than arbitrary decisions, incompetence, or lack of beds.

In many parts of the world people see the elderly as feeble in mind and body, and as economic burdens on society.¹⁴⁵ Unfortunately, this sentiment is shared by health care professionals.¹⁴⁶ However, it is possible to change attitudes through education.^{146 147} It is, therefore, important to educate the health care professionals in gerontology and geriatrics so that they will be able to meet the demand to treat the frail elderly patient. Geriatrics must be elevated in status.

148-150

Ageism in the Western World could be confronted with research and education ¹⁵¹ but aging research is complex due to its multifaceted. In medical research, for example in clinical trials of potential new drug treatment, frail, elderly patients are almost always excluded due to contraindications caused by co- and multimorbidity. ¹¹¹ Drug manufacturers are financing many clinical trials and their interest in the matter—or lack of it—is a key consideration. ¹¹² In the EU, the European Forum for Good Clinical Practice produced “A Proposal for Guidance on Medical Research for and with Older People in Europe”, ¹⁵² and one its main goals is to ensure appropriate healthcare and research protections for Europe’s elderly populations. ¹⁵²

Frail, elderly patients are one of the most ill populations in society, with a mortality rate of around 30% in a year.¹⁰ Therefore, hospital care should be a priority for this group of patients. ¹

From an ethical point of view, how could one explain health care’s refusal to become better organised to take care of this frail group of patients, whose number is increasing faster than any other age group. And yet, with all their illness, fatigue, and lack of political voice, how could society avoid responsibility? As long ago as 1997, the Swedish Parliament ratified the Priority Commissions’ work of an ethical platform. ¹⁵³ This platform pointed out the importance of care for people with reduced autonomy and established that prioritising on the basis on high chronological age is unacceptable, though admitting that the ability to benefit from treatment must be taken into account when deciding about treatment. ¹⁵⁴ It seems that Sweden is far away from fulfilling the intentions of that ethical platform given the findings in this thesis.

5.2 *Methodological discussion*

There are several criteria after which you judge the quality of qualitative research. The overarching goal is validity of the research built on four primary criteria: credibility, authenticity, criticality and integrity. ^{98 155}

5.2.1 **Sampling**

In the first and third study (Paper I and III), the aim was to select participants through purposeful sampling. You can not know for sure that all important criteria have been considered and that patients who agree to participate in a one-to-one interview is representative.

A consecutive sampling was used in the second study (Paper II) with the help of patient identification by the Data Ware House of Östergötland. Although you should not influence the sampling as a researcher you can not know if the patients who consented to participate in the survey were representative of your intended population. The response rate was above 50%, which in this group of patients is acceptable. Probably, they were less ill than the non-responders, the former having the strength to considerate and answer the questions.

In the third study (Paper III) the focus group interviews were used to generate data. The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview. ¹⁵⁶ When group dynamics work well, the research can take new and unexpected directions ¹⁵⁶ – which it did in this case by revealing the frustration associated with frail elderly patients not being welcome in hospital as a consequence of the remuneration system.

A modified theoretical sampling in study 4 (Paper IV) were used to create a heterogeneous data by interviewing/observing in different medical departments, but the sampling and the questioning was also guided by collecting data, memo-writing and field-notes. The first observations/interviews were obtained using sampling of convenience – hence called “modified” theoretical sampling. The data was obtained through observation. This method can help overcome the discrepancy between what people do and what they say, but there is a risk that the observers influence the object observed. ¹⁵⁷

Still, it is a Swedish context which limits an international transferring of results to other countries with different routines of care and

remuneration systems than found in Sweden. However, with experience in two European geriatric organisations (EUGMS and UEMS-GMS) I have gained knowledge of similar discussions and problems in other European countries. This is the reason why this thesis is written in English hoping that the results could be used outside Sweden in other countries similar to the Swedish context.

The interview studies (Papers I and II) were not done during hospitalization, and yet the subject concerned hospital experience, thus a limitation is that recall bias might have been present, especially in study 2, when length between inpatient period and interview was approximately 3 months.

5.2.2 The frail elderly patients

The designation frail elderly patients, elderly patients and elderly with multimorbidities are used in common language without sharp distinctions.

In Sweden the words “elderly with multimorbidity” (in Swedish: “multisjuka äldre”) and “The most ill elderly” is used (In Swedish: “de mest sjuka äldre”) and not so much the term frail (“sköra”) which in the Swedish language is more associated with something of fragile porcelain.

As designated in the introduction there is a lack of consensus for the definition of “frail elderly” in the academic world – and if you choose one of the most accepted definitions by, for example, Fried and Rockwood,^{7 14} there is today no way you can identify these patients through registers of care. This is a problem because identification can be done without many resources. In Sweden, the “register of care-definition” made by SNCE is often used despite the knowledge that this definition is not totally congruent with the more widely accepted definition of frail elderly. There is, nevertheless, a great overlap between the two definitions: Describing patients identified by the SNCE-definition is complex,^{5 131 158} 75% suffers from fatigue,⁵ nearly 50 % have had a weight loss on average of 8 kg the past year,⁵ many have low physical activity.¹⁵⁸ Such characteristics that identify frailty by the SNCE-definition overlap with the clinical syndrome of frailty according to Fried¹⁴ and/or the more frail groups according to the Clinical Frailty Scale.⁷ On top of this, it is known that the patients identified by the SNCE definition are associated with high health care consumption.^{158 159}

By all these facts I dare to draw the conclusion that the majority, though not all, of elderly patients identified by the SNCE criteria also fulfil the more international accepted definitions of frailty. Thus, it has been appropriate to

use SNCE in the context of this thesis, and simply modify the Swedish concept of “Elderly with multimorbidity” to adopt the more internationally accepted, “frail elder”.

5.2.3 The quantitative data collection and analysis

For the data collection in the second study (Paper II), the CPS was used with an additional item added about the actual role in decision making, namely, the statement, “I was not asked for my opinion”. This modification violated the original questionnaire, potentially impacting both validity¹⁰⁹ and reliability.¹⁶⁰ We did not perform new validation studies. However, the additional question was needed to learn about patients who had not been invited to participate. The item was found to be so important that it justified the violation. Indeed, the item was selected by 27% of the patients. Until today, no other instrument that is taking this specific condition into account has been found.

When calculating the value of the weighted kappa, we used discrepancy scores to examine the agreement between preferred and actual role in medical decision making. The newly added item was selected as the alternative of actual role in medical decision making, but had to be excluded as it should not be statistical possible to calculate a discrepancy score or kappa value when there was no obvious alternative or role to compare with.

The questionnaire used in the second study (Paper II) to obtain knowledge of the preferred and actual information seeking roles had weaknesses (Appendix, table 4). Some of the statements were more a result, rather than a role and there was also a shift in focus between the preferred and actual role for instance between: “I would like to receive more information about my treatment without having to ask” to “I would like to have had more information” – and “without having to ask” was not included. As a consequence it was not possible to draw conclusions from that part of the questionnaire or calculate meaningful discrepancy- or kappa-statistics. At the same time the question gave important results.

5.2.4 The qualitative data collection and analysis

My first interviews were scrutinised by the supervisor to explore ways to generate further questions during next interview. As an example, from the beginning, in the first study (Paper I), I learned how to shift from my “normal”

deductive questioning as a physician to an inductive role of active listening and observing, to become skilled in qualitative interview technique.

In the first study (Paper I) qualitative content analysis was used that focused on the subject and context, and which emphasised differences between and similarities within codes and categories.¹⁰¹ Its main focus was not – as for instance GT – on the process and interactions. As a newcomer in qualitative methodology it was easier for me to understand this method with its roots in quantitative methodology.

In the third and fourth studies (Papers III and IV), social interactions and processes were studied, for which GT was the natural choice of qualitative analytical method.^{86 105} However, GT is not one single methodology but have several orientations, which makes it hard to use as different orientations claims for different directions.

To judge credibility, results must reflect participant's experiences. To accomplish this several precautions were taken before each interview, including: a) insure that all participation was voluntary and – in case of patients interviewed – that no information would go back to the journal or care-givers involved; b) defer time and place according to the participants' wishes; c) as much as possible maintain a calm environment during interviews, without disturbances; and, d) demonstrate a listening and interesting attitude as interviewer to enable the participants to talk freely.

During the interviews it was important that the research questions were being explored. Therefore, to help bring and maintain focus during interviews, a guide or observational list of questions was developed, which we improved upon as data in the first, third and fourth studies was being sampled. It is not totally in line with GT to use an interview guide as this can influence the inductive method. It was only used to ensure that key areas were discussed, and it was modified as interviews progressed to accommodate probing questions. To enhance credibility and authenticity several researchers participated in data collection and analysis went on until all agreed on the main findings in the Papers.

A main criterion to ensure quality of qualitative research is integrity. Here my background as a geriatrician was useful – but talking in “own interest” when interpreting the findings and describing the results of the papers and ending up with the demands of more geriatric competence and more wards working with a SBC. But other authors have also expressed some similar results as in

my thesis ^{5 24 132 159}, that is a strength. There were also different interpreters on the data material.

It was known to most of the health care staff sampled in studies reported in Papers III and IV that I am a geriatrician and that the focus in the research was patient participation. This might have influenced expressions from and behaviours of the participants. In order to diminish that risk in study 4 (Paper IV) most of the observations was recorded by a district nurse to diminish that risk – but this gave me on the other hand more indirect information as I did not make most of the observations myself which I later analysed. To diminish this problem of data collection, there were frequent meetings and discussions, in the beginning after each observation, in order to discuss findings and make suggestions for new foci to observe or questions to include.

5.3 Further research

The dynamic dimension of preference for participation in medical decision making should be studied further in longitudinal studies. Do humans have the same preferences over time or does it change as we grow old? Or, does it change as a consequence of not being able to express preferences when we become more ill, and if so, how can we change the care to be more considerate of ill patients' preferences?

Modest research on physicians' attitudes toward frail, elderly patients was found. As they are powerful persons in developing healthcare it should be interesting to know more about their attitudes to be able to understand why the health care is not better adapted to these patient's needs. Is it because of lack of knowledge or education, or more a result of low status assigned to geriatrics and elderly patients?

There should be development and research on a new remuneration system. From the remuneration of isolated production of separate health care "products" (operations/treatments) to a remuneration of a more comprehensive approach with focus on quality of life and preservation of functioning. And there should be research and development on which ways "new" system should live together with the existing system as the goals in many cases contradict (continuity of care givers/easy access, communication/time expenditure)

5.4 What this thesis adds

The findings in this thesis are that the care is not adapted to facilitate patient participation by the frail elderly and that this group of patients participate less in medical decision making than preferred. On a macro level, the thesis has shown that the care is not adapted to the needs of this group of patients. This is not a new finding. It has been well shown in numerous reports and has been described in the newspapers and reported in interviews with health care professionals. What this thesis adds is the proposal to a model to further understand the consequences of the organisation of care, and its remunerations system, for the quality of care of frail elderly patients, and that a useful approach is to study patient participation in medical decision making.

5.4.1 Suggestions for a model to improve patient participation and care of frail elderly patients in hospital

Leaving the focus on patient participation there are a need of a reconstruction of hospital care for frail elderly patients. They need:

- Wards performing situation-based care with focus on all the patients' needs. These wards must have multiprofessional teams to be able to perform CGA, which is needed to plan and follow up the patients' needs medically, psychologically and socially, and must be organised to ensure the best possible continuity of health care.
- Health care professionals with appropriate skills in geriatrics and gerontology.
- Reconstruction of the remuneration system so that monetary incentive is provided to take care of frail elderly, and thereby support a system with a holistic view of patients in care. This remuneration system should probably have outcomes that focus on quality of life and preservation of functional capacity.

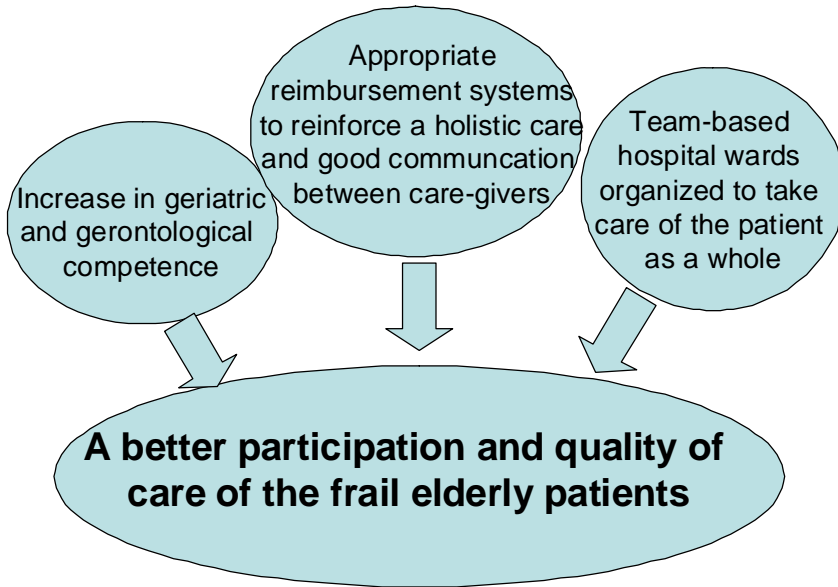


Figure 10: A suggestion for a model to improve participation and quality of care of frail elderly patients' in hospital.

5.4.2 Important facts to consider when developing a new remuneration system

One of the biggest barriers to accomplish the new remuneration system mentioned in the suggestion is that the identification of frail elderly patients on an individual level is difficult. This could be partly overcome by using the Swedish SNCE-definition, and together with this identification engage care-givers involved, including the patients and the relatives, to contribute to judgements of whether frailty is present or not. This could be done on a nurse level with physician consultation.

When a patient has been classified as frail a care program that includes hospital wards should be in place to ensure holistic perspective (SBC), and which focuses on quality of life and independence.

6 CONCLUSION

The finding of this thesis is that, generally, elderly patients want to participate more in medical decision making than is the case currently. However, because individual preferences for participation are highly variable, it is not possible to generalise the preferences.

The interviewed physicians stressed that the hospitals are not organised or remunerated to take care of frail elderly patients with high quality, this despite this group representing the fastest growing part of the population by age. This was confirmed by observations done in the hospital wards and by interviewing frail, elderly patients. The reasons for these quality problems are many, and include:

- The acute, non-geriatric hospital wards are organised on the basis on medical specialities focusing on one or a few illnesses at a time and not being able to take a holistic view.
- A lack of knowledge of gerontology and geriatrics.
- The remuneration system favours “health care production” and accessibility – not continuity and communication.

The care of frail elderly patients’ has long been described as fragmented, costly and undignified. ¹⁶¹ ¹⁶² This thesis describes some of the reasons for this. It will now be a challenge for future health care to improve and advance education in gerontology and geriatrics and also, it will be a challenge to shift hospitals from diagnosis-based organisations of care to situation-based organisations of care. The remuneration system must be updated to deal more effectively with frail elderly patients.

7 SAMMANFATTNING PÅ SVENSKA

Det övergripande syftet med denna avhandling är att öka kunskapen om multisjuka äldres, eng. *frail elderly patients*, preferenser gällande deltagandet i medicinska beslut och att studera sjukvårdspersonalens tankar kring multisjuka äldres förutsättningar och önskemål att delta i beslutsfattandet när de är på sjukhus. Delaktigheten är viktig för att uppnå bra behandlingsresultat^{52 58 83} och är det etiskt korrekta sättet att arbeta, vilket tydligt framgår av den svenska hälso- och sjukvårdslagen. Multisjuka äldre är i detta arbete definierat som personer ≥ 75 år som har vårdats ≥ 3 gånger på sjukhus senaste året och har ≥ 3 diagnoser.

Få studier om delaktighet har fokuserats till de äldre patienter och ingen till gruppen multisjuka äldre. Dessa har mer begränsade förutsättningar att delta i medicinska beslut på grund av t.ex. hörselnedsättningar och nedsatta minnesfunktioner. Ytterligare faktorer som påverkar situationen är förekomst av ålderism och att sjukhusvården är strikt uppdelad i medicinska specialiteter – något som inte stämmer särskilt väl med de multisjuka äldres komplexa sjukdomsbild.

Studiematerialet till artiklarna består av information från multisjuka äldre på sjukhus eller nyligen utskrivna från sjukhus och sjukhuspersonal som arbetar med multisjuka äldre patienter. I avhandlingen har flera metoder använts beroende på frågeställningarna i de olika artiklarna. I tre av artiklarna är metoden mest kvalitativ (artikel I, III och IV) och i en artikel (II) är metoden kvantitativ. De kvalitativa metoderna består av intervjuer med 24 patienter (I och IV) samt intervjuer med personal (artikel III och IV). I artikel III användes fokusgruppsintervjuer med läkare och i studie IV användes utöver intervjuer observation på vårdavdelningar. De kvalitativa analysmetoderna är kvalitativ innehållsanalys och grundad teori. Den kvantitativa studien är analyserad med viktad kappa statistik och beskrivande statistik.

Huvudresultatet var att de multisjuka äldre deltar mindre i medicinska beslut än de vill samt att de har olika önskemål om graden av delaktighet (artikel II). Resultaten från artikel I visar att multisjuka äldre uppfattar delaktighet på samma sätt som andra patientgrupper där information, som sjukvårdspersonal ger sig tillräcklig tid att förmedla, kommunikation och att bli lyssnad på är centrala begrepp.

En huvudanledning till att patienterna inte kan delta i medicinska beslut är att de är för sjuka (artikel II). Dessutom finns svårigheter att förstå den

medicinska informationen – inte minst när den förmedlas av läkare som inte talar tydlig svenska (artikel I, II och IV).

Det fanns moderat överensstämmelse mellan önskad delaktighet och faktisk delaktighet i medicinska beslut (artikel II). Trots detta uttrycker de multisjuka äldre patienterna ofta tacksamhet och förtroende för sjukvården (artikel I och IV), men också att de tycker synd om den jäktade personalen.

De multisjuka äldre patienterna känner sig inte alltid välkomna på sjukhuset utan snarare som en belastning för den stressade personalen (artikel I och IV). Sjukvårdspersonal uttrycker frustration och har dåligt samvete över att de, på grund av brist på tid och för få sängar, inte tycker att de kan ta hand om multisjuka äldre på ett bra sätt (artikel III). Särskilt läkarna känner att de är fångade i ett system mellan å ena sidan de multisjuka äldre patienternas behov och å andra sidan ersättningssystemet för sjukvården, vilket belönar snabb handläggning och sjukvårdsproduktion i termer av antal undersökningar, operationer och hög tillgänglighet istället för att gynna ett helhetstänk, som bl.a. innefattar tidskrävande kommunikation med patienter, närstående och andra involverade vårdgivare (artikel III).

Både patienterna och vårdpersonalen upplever sjukvården som en sorts övergripande maktinstitution som det är svårt att ha inflytande över eller ifrågasätta (artikel I och III) och att man därför får finna sig i besluten.

Sammanfattningsvis visar denna avhandling att det finns ett antal hinder för de multisjuka äldre att vara delaktiga i medicinska beslut, vilket i sin tur begränsar förutsättningarna för en god vård. I avhandlingens resultat presenteras ett förslag till en modell som förklarar varför det ser ut som det gör, bl.a. som en konsekvens av sjukvårdens ersättningssystem och organisation som inte gynnar ett helhetstänkande. Sjukvårdspersonalen försöker anpassa sig till ersättningssystemet och organisationen genom att hantera och skriva ut patienterna snabbt och enbart ta hand om ett eller ett fåtal sjukdomstillstånd åt gången. Slutligen presenteras ett förslag till en modell för att förbättra vården av multisjuka äldre. Modellen bygger på ökad geriatrisk kompetens, ett ersättningssystem för vården av dessa patienter som gynnar ett helhetstänk, samt att flera vårdavdelningar ändrar arbetssätt från dagens diagnosbaserade vård till en situationsbaserad vård för att med god kvalitet kunna möta denna växande patientgrupp på sjukhus.

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9 APPENDICES

Datamaterial

Table 1: Demographics of patients interviewed in Paper IV (n= 9):

Patient	Age (mean 85.7 yr)	Gender
A	90	f
B	90	f
C	88	m
D	82	m
E	90	m
F	84	m
G	79	m
H	87	f
J	76	m
M	91	f

Questionnaires

Table 2: The Control Preferences Scale – modified by question F (Paper II):

-
- A I prefer to make the decision about which treatment I will receive
 - B I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
 - C I prefer that my doctor and I share responsibility for deciding which treatment is best for me
 - D I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion
 - E I prefer to leave all decisions regarding treatment to my doctor

After asking about the preferred role, we asked about the actual role the patient played during the present hospitalisation by using the same items in the past form. The CPS-scale was then modified by adding the postulation:

- F I was not asked about my opinion
-

Table 3: Barriers to participation of medical decision making (Paper II)

1. Did you feel too ill to be able to take part in the medical decision making?
2. Did you feel that there were too many doctors who were deciding about your treatment?
3. Did you have problems understanding the medical information?
4. Did you have problems understanding things due to doctors speaking Swedish with an accent?

To estimate the importance of these barriers, all the patients who answered "Yes" or "Don't know" to any of the questions were further asked whether the barrier affected them "a little", "somewhat", or "a lot".

Table 4: How is your preferred way of information seeking (Paper II)?

- A. I ask questions about my medical treatment without hesitating.
- B. I would like to receive more information about my treatment without having to ask.
- C. I find it difficult to ask questions about my treatment.

How was the actual way of information seeking during the last hospital stay?

- A. I asked for information about my medical treatment.
 - B. I would like to have had more information.
 - C. I did not want to know about my medical treatment.
-

Dataanalysis

Table 5: Analytical process of the interviews in Paper I (content analysis):

Meaning unit (MU)	Condensed transcription	Code	Sub-category	Category
<p>I: Did you feel that you could influence the care? Are you participating in your care? P: No. No, and you can't do that either. It is all new and it is not the same doctors. You don't know nothing and they often don't understand each other either. One doctor one day and another the next.</p>	<p>I: Are you participating in your care? P: No. No, and you can't do that either. It is all new and it is not the same physicians.</p>	<p>Lack of continuity, new physicians</p>	<p>Different physicians with different treatment strategies</p>	<p>Conditions that impair communication</p>
<p>I: Did you get the help you wanted when you were admitted to hospital? P: No, not the first time. They made some tests and in the morning there were one physician and she said that I should need warfarine, but at the afternoon there was another physician who said that we should not care because warfarine is dangerous stuff and nothing to use. And that palpitation is a condition the 80% of all 80+ suffers from</p>	<p>I: Did you get the help you wanted when you were admitted to hospital? P: .In the morning there were one physician and she said that I should need warfarine, but at the afternoon there was another physician..</p>	<p>Different attitudes to treatment with warfarine</p>	<p>Lack of continuity and communication between physicians</p>	

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