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Aspects of treatment and care of nursing home residents

Aspects of treatment and care of nursing home residents

Challenges and possibilities

Beata Borgström Bolmsjö



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DOCTORAL DISSERTATION

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Title and subtitle: Aspects of treatment and care of Nursing Home Residents – challenges and possibilities		
<p><i>Background:</i> Elderly living in nursing homes (NHs) have multiple diseases as well as risk factors that may complicate optimal medication. Malnutrition and impaired renal function are two of those risk factors. Heart failure is common and may often not be treated or diagnosed adequately in elderly patients. The aim of this thesis was to explore different risk factors for elderly with multiple diseases, and to relate these risk factors to outcomes such as mortality, morbidity, and medical treatment to find factors for optimizing the care of this group of patients. Furthermore, a qualitative interview study was conducted to explore the General Practitioners' (GPs') experience of the work with elderly residents in NHs in Sweden. <i>Methods:</i> The data for papers I–III come from the SHADES (Study of Health and Drugs in the Elderly living in nursing homes in Sweden) study. SHADES is a Swedish prospective cohort study, with more than 400 elderly residents in 11 different nursing homes in Sweden enrolled between 2008 and 2011. The subjects were followed every six months with regular examinations including blood sample analyses, examinations with validated rating scales (Mini Nutritional Assessment (MNA) for nutritional status and Mini Mental State examination (MMSE) for cognitive evaluation), and with data collection from medical records concerning medications, diagnoses, hospital referrals and mortality. The qualitative study in paper IV was based on individual semi-structured interviews and a follow-up focus group discussion. In total 12 GPs were interviewed. The interviews were recorded digitally and transcribed verbatim. Further, the written text was systematically analysed with content analysis, with the process leading to the identification of categories and themes. Then the themes were discussed among the participating GPs in a focus group interview to develop the themes further. <i>Results:</i> The results in paper I show that the prevalence of patients with heart failure was 15.4% in the study population, but if BNP (B-type Natriuretic Peptide) values were used to select patients for further examination, the prevalence would probably be higher. The medical treatment of heart failure varied greatly and was often old-fashioned. The adherence to guidelines was generally low. The prevalence of malnutrition was 17.7% in the study population in paper II. About 40% were at risk of malnutrition and 41.6% had normal nutritional state. Malnutrition was associated with lower survival. In the survivors, the prevalence of malnutrition increased and after 24 months' follow-up about 24.6% of the population were malnourished. Factors influencing the nutritional state longitudinally were baseline BMI and hospitalization. In paper III, survival was significantly lower in the groups with lower renal function. Over 60% of the residents had impaired renal function. Those with impaired renal function were older, had a higher number of medications and a higher prevalence of heart failure. Higher numbers of medications, were associated with a greater risk of rapid decline in renal function. In paper IV, the GPs found working with elderly patients important and meaningful; the GPs strove for the patient's well-being with special consideration to the continuum of ageing. A continuous and well-functioning relationship between the GP and the nurse was crucial for the patients' well-being. <i>Conclusions:</i> In NH residents, there is a risk of misdiagnosis of heart failure and the treatment was seldom according to current guidelines. Malnutrition and impaired renal function were common and associated with lower survival. The work with elderly in NHs was prioritized and important for the GPs.</p>		
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Aspects on treatment and care of nursing home residents

Challenges and possibilities

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*To my beloved father Anders.
So far away, yet so close.
Thank you for letting your spirit guide me through this journey.*

Contents

Abstract	13
Abbreviations	15
Word definitions	16
Original papers	17
Introduction	19
Background	21
Demography	21
Frailty	21
SHADES	22
Heart failure	25
Malnutrition	26
Renal function	27
Nursing homes	28
The primary health care system and GPs in Sweden	29
GPs' experience of elderly care in NHs	30
Aims of the thesis	31
General aim	31
Specific aims	31
Materials and Methods	33
Study Design	33
Data collection (papers I–III)	34
Study participants	34
Methods of investigation	34
Specific data collection for paper I on heart failure	35
Specific data collection for paper II on malnutrition	35
Specific data collection for paper III on renal function	36
Statistical analyses	38
Specific statistical analyses for paper I on heart failure	38
Specific statistical analyses for paper II on malnutrition	38
Specific statistical analyses for paper III on renal function	38

Data collection (paper IV)	39
Study participants	39
Semi-structured interviews	39
Focus group	40
Qualitative analysis	40
Ethical considerations	43
Ethical considerations for papers I–III	43
Ethical consideration for paper IV	43
Findings	45
Main findings	45
Baseline population characteristics in SHADES	46
Heart Failure (paper I)	46
HF vs no HF	46
BNP	47
HF vs BNP >100 and no HF	47
Malnutrition (paper II)	48
Longitudinal data on nutritional status	49
Renal function (paper III)	50
Longitudinal data on renal function	51
Methods for estimation of GFR	52
GPs' experience of elderly care in NHs (paper IV)	52
Concern for the patient	53
Sustainable working conditions	55
Discussion	57
Heart failure	57
Malnutrition	59
Renal function	60
The GP perspective on elderly care	61
Strengths and limitations of papers I–III	63
Strengths and limitations of paper IV	63
Conclusions – challenges and possibilities for clinical implications	64
Future studies	66
Svensk sammanfattning	67
Delarbete I, hjärtsvikt.	67
Delarbete II, malnutrition	68
Delarbete III, njurfunktion	68
Delarbete IV, distriktsläkarnas upplevelse av äldrevården	69

Patientnytta	69
Acknowledgements	71
References	73

Abstract

Background: Elderly people living in nursing homes (NHs) have multiple diseases as well as risk factors that may complicate optimal medication. Malnutrition and impaired renal function are two of those risk factors. Heart failure is common and may often not be treated or diagnosed adequately in elderly patients.

Objectives: The aim of this thesis was to explore different risk factors for elderly with multiple diseases, and to relate these risk factors to outcomes such as mortality, morbidity and medical treatment to find factors for optimizing the care of this group of patients. Furthermore, a qualitative interview study was conducted to explore the General Practitioners' (GPs') experience of the work with elderly residents in nursing homes in Sweden.

Methods: The data for papers I–III come from the SHADES (Study of Health and Drugs in the Elderly living in nursing homes in Sweden) study. SHADES is a prospective cohort study, with more than 400 elderly residents in 11 different nursing homes in Sweden enrolled between 2008 and 2011. The subjects were followed every six months with regular examinations including blood sample analyses, examinations with validated rating scales (Mini Nutritional Assessment, (MNA) for nutritional status and Mini Mental State Examination (MMSE) for cognitive evaluation), and with data collection from medical records concerning medications, diagnoses, hospital referrals and mortality. The qualitative study in paper IV was based on individual semi-structured interviews and a follow-up focus group discussion with 12 GPs. Further, the written text from the interviews was systematically analysed with content analysis.

Results: The results in paper I show that the prevalence of patients with heart failure was 15.4% in the study population, but if BNP (B-type natriuretic peptide) values were used to select patients for further examination, the prevalence would probably be higher. The medical treatment of heart failure varied greatly and was often old-fashioned. The adherence to guidelines was generally low. The prevalence of malnutrition was 17.7% in the study population in paper II. About 40% were at risk of malnutrition and 41.6% had normal nutritional state. Malnutrition was associated with lower survival. In the survivors, the prevalence of malnutrition increased and after 24 months follow-up, about 24.6% of the population were malnourished. Factors influencing the nutritional state longitudinally were baseline BMI and hospitalization. In paper III, survival was significantly lower in the groups with

lower renal function. Over 60% of the residents had impaired renal function. Those with impaired renal function were older, had a higher number of medications and a higher prevalence of heart failure. Higher numbers of medications were associated with a greater risk of rapid decline in renal function. In paper IV, the GPs found working with elderly patients important and meaningful; the GPs strove for the patient's well-being with special consideration to the continuum of ageing. A continuous and well-functioning relationship between the GP and the nurse was crucial for the patients' well-being.

Conclusions: In NH residents there is a risk of misdiagnosis of heart failure and the treatment was seldom according to current guidelines. Malnutrition and impaired renal function were common and associated with lower survival. The work with elderly in NHs was engaging and important for the GPs.

Abbreviations

ACE inhibitor	Angiotensin-Converting-Enzyme inhibitor
ARB	Angiotensin II Receptor Blockers
ADL	Activities of Daily Living
BNP	B-type natriuretic peptide
BMI	Body Mass Index
CKD	Chronic Kidney Disease
EF	Ejection Fraction
eGFR	estimated Glomerular Filtration Rate
GFR	Glomerular Filtration Rate
GP	General Practitioner
HF	Heart Failure
MNA	Mini Nutritional Assessment
NYHA I-IV	New York Heart Association (NYHA) Functional Classification of heart failure: I Cardiac disease, no symptoms, no limitation in ordinary activity. II Mild symptoms and some limitation during ordinary activity. III Marked limitation in less-than-ordinary activity due to symptoms. Comfortable only at rest. IV Severe limitations. Symptoms also at rest.
NH	Nursing Home
PHC	Primary Health Care
PHCC	Primary Health Care Centre
SHADES	The Study on Health and Drugs in Elderly nursing home residents in Sweden

Word definitions

Elderly defined as persons over the age of 65 years, unless stated otherwise.

Frail elderly defined as persons over the age of 65 living in a nursing home, with the level of care needs only to be met in a long term care facility.

Older elderly defined as persons over the age of 80 years, unless stated otherwise.

Multimorbidity defined as two or more concurrent chronic diseases.

Polypharmacy defined as the concomitant use of five or more medicines.

Original papers

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

- I Bolmsjö BB, Mölsted S, Östgren CJ, Midlöv P: Prevalence and treatment of heart failure in Swedish nursing homes. *BMC Geriatrics*. 2013, 13:118
- II Borgström Bolmsjö B, Jakobsson U, Mölsted S, Östgren CJ, Midlöv P: The nutritional situation in Swedish nursing homes – a longitudinal study. *Archives of Gerontology and Geriatrics*. 2015, 60(1):128–33
- III Bolmsjö BB, Mölsted S, Gallagher M, Chalmers J, Östgren CJ, Midlöv P: Risk factors and consequences of decreased kidney function in nursing home residents – a longitudinal study. *Accepted February 24 2016. Geriatrics and Gerontology International*
- IV Bolmsjö BB, Strandberg EL, Midlöv P, Brorsson A: “It is meaningful; I feel that I can make a difference” – A qualitative study about GPs’ experiences of work at nursing homes in Sweden. *BMC Family Practice*. 2015,16:111.

Introduction

Elderly residents at nursing homes (NHs) in Sweden have in general many different diagnoses along with polypharmacy and several risk factors hampering optimal medical treatment [1]. Misdiagnosis, lack of continuity, lack of knowledge, malnutrition and impaired renal function are examples of risk factors for inappropriate medical treatment of the elderly.

There is a well-established association between multimorbidity and disability, which together create a great need for health care, and therefore demand well-functioning collaboration between the different parts of the health care system.

The National Board of Health and Welfare's summary of current research on elderly care concludes that there is a lack of knowledge and a need for thorough studies of the complex reality for the elderly people, in order to find ways to optimize the care of the elderly [2].

By following multimorbid residents in NHs longitudinally through rating scales, medical records and blood samples, different risk factors for potential adverse outcomes in medical treatment and care were studied and further related to morbidity and mortality.

The particular factors influencing the treatment and care of elderly residents in NHs studied in this thesis were:

- I The risk of misdiagnosis and inappropriate medication of heart failure.
- II Malnutrition and its longitudinal association with increased vulnerability.
- III Aspects of renal function and renal dysfunction.
- IV The attitudes to elderly care, studied from the general practitioners' perspective.

Background

Demography

The elderly population is steadily growing in the western world. The number of people over the age of 65 in Sweden is around 1.9 million, corresponding to around 20% of the population. The proportion of elderly people is continually rising and is expected to rise steadily to over 25% of the population by 2060 [3]. As the life expectancy of the Swedish population is projected to increase from 84 years for women and 80 years for men in 2014 to 89 years and 87 years respectively in 2060, the proportion of the oldest elderly (i.e. over the age of 80) with multicomplex needs will increase substantially [3].

Frailty

Frailty is a construct originally established by gerontologists to describe cumulative declines across different physiological systems that occur with ageing, leading to a state of diminished physiological reserve and increased vulnerability to stressors [4], as shown in figure 1. Different approaches to frailty exist and different screening criteria for frailty as a syndrome have been developed. An example of screening for frailty by Fried et al requires the presence of a critical mass (≥ 3) of the following clinical manifestations: weakness, weight loss, slow walking speed, fatigue, and low levels of activity [5]. This phenotype has been found to predict various poor clinical outcomes, including falls, the development of disability, hospitalization, and mortality. Although frailty frequently exists concurrently with disease and disability, the validation study of frailty based on this definition, showed that, it is independent and distinct from these characteristics [5].

The old and multimorbid should be prioritised for inclusion in future clinical trials on frailty to give a clear understanding of how a variety of care strategies and commonly used medications might positively or negatively influence frailty and poor outcomes in older adults [6].

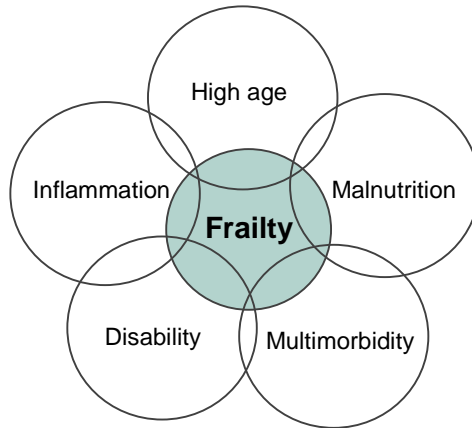


Figure 1. Model of frailty

SHADES

There are few longitudinal cohort studies focusing on residents at nursing homes (NHs) in general and the research conducted is generally cross-sectional with one specific focus, for example on medications or on a specific disease. To picture the multi-complex needs of the frail elderly at NHs, a broader longitudinal study called SHADES (The Study on Health and Drugs in Elderly NH residents in Sweden) was designed to include a wider range of risk factors and aspects of ageing. The general aim of SHADES was to describe and analyse mortality, morbidity, health conditions, and drug use among elderly individuals living in NHs. The results generated aimed to provide a better basis for improved and individual based care of the frail elderly, and could also be used in the planning of interventions to improve health care, optimize the use of medications, and decrease the need for acute hospital care.

SHADES was conducted with residents enrolled between 2008 and 2011 in 11 different NHs in Sweden (figure 2). The residents were examined every 6 months.

6-month examination

Blood pressure was measured three times in the right arm with the respondent sitting, with one minute apart. Weight was measured to the nearest 0.1 kg with scales

available at the NH. Information about height was given by the respondent or collected from medical record or other documents; if height was not known, it was measured at the first visit only.

Fasting venous blood samples were drawn and frozen for later analysis, with the exception of haemoglobin and p-glucose, which were analysed the same day. If the respondent had a history of diabetes HbA1c was also analysed directly.

Bacterial specimens for cultivation were collected serially between March 2008 and September 2010 by a study nurse on location. The samples were taken from: urine, the rectal mucosa, the groin, and active skin lesions.

The patients were tested with risk-assessment scales such as the Modified Norton Scale (MNS) [7], Mini Nutritional Assessment (MNA) [8] and Downton Fall Risk Index (DFRI) [9]. Cognitive functions were measured by Mini Mental State Examination (MMSE) [10], mood by Cornell Scale for Depression in Dementia (CSDD) [11] and caregiver burden (need of care) by SNAC [12]. All scores except MMSE were based on information obtained from a caregiver.

Diagnoses were collected both from the NH records and from medical charts. Diagnoses were coded according to the International Classification of Diseases (ICD-10) [13]. The daily dose of medications was registered and classified by therapeutic group based on the World Health Organization's Nordic Anatomical Therapeutic Chemical Classification Index codes (ATC code) [14]. Occasional treatment with antibiotics was also registered.

In addition hospital records for hospitalization were reviewed every 6 months.

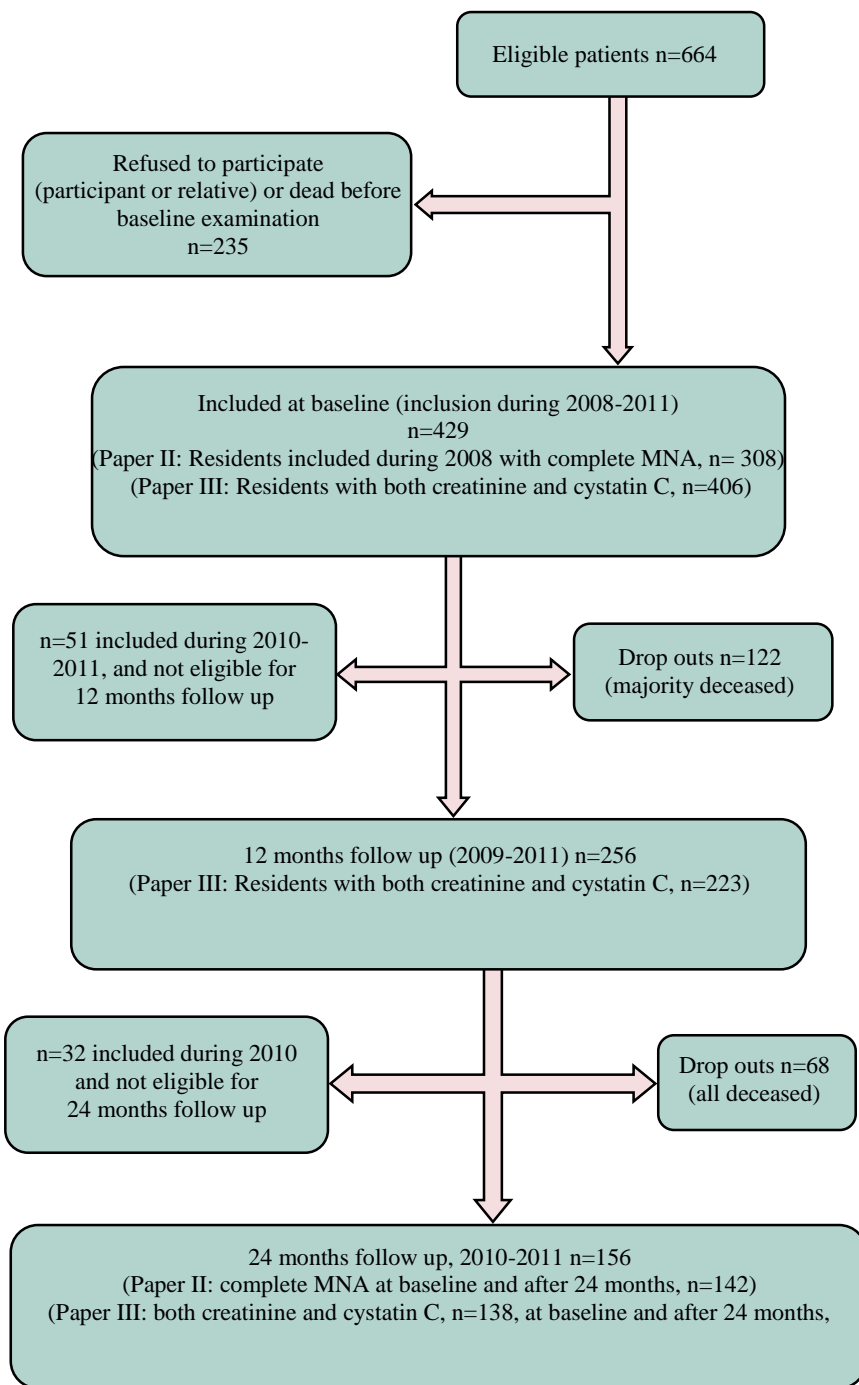


Figure 2. Flow chart of the SHADES study

Heart failure

The prevalence of Heart Failure (HF) in the elderly is hard to estimate accurately both because of the atypical presentation in elderly and because of the lack of large studies in this population [15-17]. Small studies on elderly in Europe have reported a prevalence of HF from 23% in NH residents in the Netherlands [18] up to almost 50% in 87–89-year-olds in the UK [15]. A larger population-based study in Sweden from 2001 shows a HF prevalence of 6.7% in men and women at the age of 75 [19].

HF in elderly is known to give diffuse but troublesome symptoms that are not always consistent with those symptoms that are usually associated with HF. The great variability in the detection and interpretation of signs and symptoms by physicians is associated with low sensitivity and specificity in the clinical diagnosis of HF in the elderly [20]. Therefore there could be a risk of misdiagnosis of HF in the elderly, both a risk that patients with HF are not diagnosed correctly as the diagnosis of HF is neglected, and a risk that some patients will be diagnosed with HF when the symptoms are actually associated with a different condition than HF. In both situations there is a significant risk that the patients may get the wrong medical treatment for their actual condition.

The first evaluation of HF should be based on a well-conducted medical history followed by a thorough physical examination and appropriate laboratory tests [16] and the final diagnosis of HF should be confirmed by echocardiography [21]. Symptoms such as fatigue, confusion, memory deficit, irritability, anorexia and a gradual reduction in level of activity are common manifestations of HF in individuals aged above 80 years [16]. Dementia is a common diagnosis in NHs, and a careful medical history may be difficult to conduct in residents with cognitive impairment. In the process of diagnosing HF the use of B-type natriuretic peptide (BNP) is gaining acceptance. BNP is a hormone produced mainly by ventricular cardiomyocytes. Its secretion is associated with stretching of myocardial fibres. Quantitative analysis of plasma concentrations of BNP is useful in helping to confirm the diagnosis, provide a prognosis, and guide treatment in patients with HF [16, 21]. There are several different confounders involved in the interpretation of BNP as BNP levels have been shown to rise with age, female sex and impaired renal function [22]. Studies of the use of BNP for further diagnosis of HF in an elderly population are limited. For a frail elderly person, transport to a hospital for echocardiographic examination may be strenuous and it is therefore important to limit unnecessary examinations outside the NH. If it was possible to use the detection of a raised BNP level in the elderly as an indicator to justify the confirmation of HF using echocardiography and to justify the cost and effort involved in the transfer to a hospital, this might facilitate the accurate diagnosis of HF.

If correctly diagnosed, HF is a condition in which pharmacological treatment can increase well-being and decrease morbidity [23]. Even though most clinical trials have included younger persons, the recommendations for medical treatment of elderly patients with HF do not differ from the general recommendations as shown in figure 3. As for all elderly, special attention should be paid to co-morbidities, the risk of polypharmacy, and renal function [23]. A study from Norway has shown that these recommendations were not widely used for medical treatment of HF in NH residents, and that NH residents with dementia were less likely to get adequate HF medications [24].

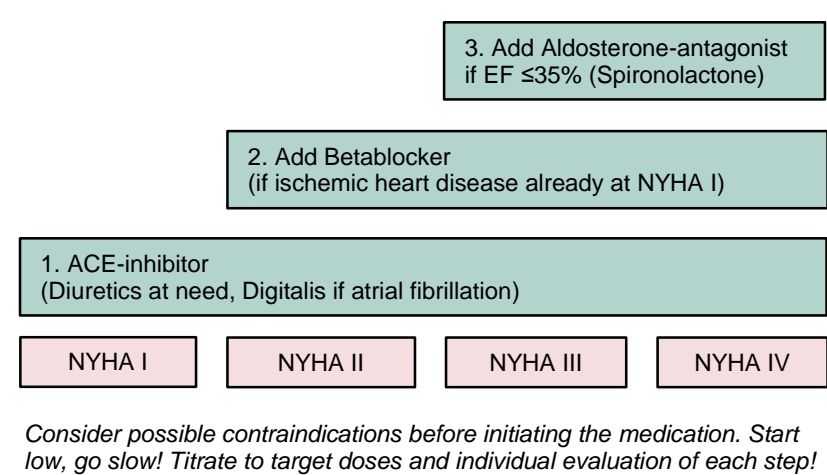


Figure 3. Treatment recommendations of heart failure of high evidence [23]

Malnutrition

Malnutrition is defined as inadequate nutritional status characterized by insufficient dietary intake, poor appetite, muscle wasting, and weight loss [25]. With advanced age, hormonal and neurohormonal transmitter regulation of food intake become altered, which leads to the physiologic anorexia of ageing [26]. Normal ageing is also characterized by changes in body composition, with loss of lean body mass, loss of bone density, loss of proprioception, and declining sensory function [25, 27]. Also, non-physiologic causes of weight loss in older persons are common. Social factors such as the monotony of institutional food, psychological factors such as

depression and loneliness, and medical factors such as polypharmacy and comorbidities can also contribute to anorexia [26].

The consequences of malnutrition are widely documented as pressure ulcers, poor wound healing, infectious complications, and hospital readmissions, which lead to increased morbidity and mortality [28-31]. Apart from illness, many other factors, such as impaired cognitive function, multimorbidity, eating difficulties, and female gender, are associated with malnutrition [31, 32]. With the wide range of vicious consequences of malnutrition, the fact that malnutrition also increases health care costs cannot be ignored [33].

Malnutrition is common among NH residents all over the world, with recent reports showing a wide variation in prevalence from 15-40% [30, 34-36]. Since nutritional status depends on many different factors, one single parameter is not enough to identify malnutrition. Therefore, many different screening tools have been developed to assess nutritional status, considering several aspects simultaneously [37] and this may have contributed to the wide divergence in reported prevalence [36, 37]. The European Society for Clinical Nutrition and Metabolism (ESPEN) has recommended three different screening tools for nutritional assessment in different settings [38], of which the Mini Nutritional Assessment (MNA) seems to be best suited for NH residents [36]. The MNA was designed and validated to assess nutritional status in elderly individuals, with the capacity to detect risk of malnutrition at an early stage [8, 39].

Renal function

Impaired renal function is common in elderly NH residents [40] and is an important risk factor for adverse effects of medications, morbidity and mortality. Elucidating the role of decline in renal function outcomes for the elderly is challenging, with physiological changes from ageing that likely alter test performance, and with little data on the performance of formulae for renal function estimation in older elderly patients. With ageing comes progressive deterioration in renal function, as manifest in a decreasing glomerular filtration rate (GFR). The estimation of renal function in elderly is essential as deterioration in renal function is strongly associated with mortality, cardiovascular disease, hospitalization and with increasing susceptibility to adverse drug reactions [41-44].

Because the methods for the actual measurement of GFR are too demanding for routine clinical use, many different formulae have been developed to calculate estimated GFR (eGFR), based principally on the measurement of serum creatinine. The eGFR of elderly populations has not yet been well characterized, mainly

because the different formulae for estimating renal function have not been well validated for this population. Calculation of eGFR in the elderly, especially the frail elderly, poses many challenges. Physiological changes associated with ageing, such as frailty, sarcopenia, malnutrition, and extracellular volume loss are all likely to impact upon the estimation of renal function, especially when using creatinine based equations [45]. There is accumulating evidence that cystatin C is superior to creatinine as an endogenous marker for GFR as, unlike creatinine, cystatin C is independent of age, gender, body weight, height and diet [46]. A number of eGFR formulae have been developed for use in the general population including the creatinine-based MDRD [47] and the creatinine- and cystatin-C-based CKD-EPI, with the latter being increasingly recognized as the preferred formula [48, 49]. In addition, in Sweden the national guidelines for estimating GFR recommend the use of the mean value of the creatinine based revised Lund-Malmö equation (LM-rev) and the cystatin-C-based CAPA formula [50]. However, the optimal method to use in elderly patients in NHs, the nature and degree of renal dysfunction, and the association between renal dysfunction and adverse outcomes remains unclear.

Nursing homes

Nursing homes (NHs) serve as long-term care facilities for frail elderly in many countries, including Sweden. The quantity and quality of NHs differs between countries and there are large differences concerning the contribution of physicians and nurses [51]. An international survey from 2013 showed that about one third of NHs around the world have physicians paying regular visits. This survey also confirmed that the residents in NHs are multimorbid and frail, with 82% of the residents taking six or more medications a day [52]. The use of potentially inappropriate medications is also higher in residents in NHs compared to people in community dwellings [53].

About 90,000 individuals over the age of 65 live in NHs in Sweden. This represents less than 5% of the population 65 years and older [54], and hence is the part of the elderly population needing most care. As NH residents are a vulnerable group with multi-complex needs, difficult medical decisions have to be considered, along with dignity-conserving aspects [55].

Coordination of services for the elderly in Swedish NHs faces a great challenge as municipalities are responsible for social care, nursing and rehabilitation while the county councils are responsible for medical care, usually through weekly visits by a General Practitioner (GP) from the local primary health care centre (PHCC).

The registered nurse is employed by the municipality along with the other nursing staff at the NH. The GP, employed by the county, cooperates in the medical care of the NH residents. There is no obvious party taking the responsibility for coordination of long-term care and for integration between health care and social welfare, which has created uncertainty about the responsibility and accompanying discontent. In addition the IT environment underpinning primary and long term care for elderly is characterized by lack of cooperation between systems hampering the sharing of patient records across providers [56].

During the last few decades private entrepreneurs have been running an increasing share of the NHs as the municipalities made elderly care open to competition. However, the funding and supervision of elderly care rests with the municipalities regardless of whether the NH is run by the municipality itself or by a private company. According to the Health and Medical Services Act, health care services should be available to all members of the society, ensuring a high standard of health care on equal terms. The national system of taxation ensures that financial resources in relation to needs are almost equal in all local authorities and independent of the local tax base [57].

The primary health care system and GPs in Sweden

Primary health care (PHC) forms the foundation of the health care system in Sweden. PHC is delivered by more than 1100 public (owned by the county councils) and private (mostly owned by companies or cooperatives) Primary Health Care Centres (PHCC) throughout the country [58]. Payment to PHC providers is generally based on capitation for registered patients, supplemented with their estimated “illness burden”, fee-for-service and performance-based payments. The health system is primarily funded through national and local taxation.

There are more than 30,000 physicians in Sweden, and around 5 000 (17%) work as General Practitioners (GPs), most of whom are specialists in general practice [58]. The proportion of GPs to other physicians, only 1/6, is remarkably low compared to countries such as France, Germany and the Netherlands which have 40% GPs among their physicians. Still, more than half of the doctor visits made by the Swedish population per year are to a GP [59]. This contradiction constitutes a major challenge for the PHC system in Sweden. In addition, a large proportion of the GPs will retire in the coming years and there are not enough qualified young GPs to replace them. Hence, there is a need to develop effective strategies for the GP workforce to manage the situation [60, 61].

GPs' experience of elderly care in NHs

In most cases one GP takes care of all residents at a NH and pays weekly visits. The GP meets with the nurse and they have a discussion about the patients. In addition the nurse will have identified patients that are in need of a medical assessment. Usually, the GP is contacted by phone or fax in between the weekly visits for more acute consultations. During the rest of the week, the GP generally works with outpatients at the PHCC.

Research from NHs has shown that the subjects seldom have adequate pharmacological treatment according to diagnosis and often have polypharmacy and/or inappropriate medical treatment with regard to declining renal function [62, 63]. One reason for this is suggested to be lack of knowledge [64] and GPs have expressed a need for clear information on the benefit/risk ratio of preventive medication in the very old and frail [65]. Other explanations are lack of time and insufficient economic resources [66, 67]. Research from the UK, where one NH may have many different GPs because of the tradition of keeping the same personal GP over the years, showed that regular medical rounds by the doctor were preferred by NH managers but were increasingly being replaced by visits on request due to the GPs' increasing workload [68].

In elderly people, the gradual development of dependence is often accompanied by "social watersheds", of which admission to a NH is perhaps the clearest [69]. Although the purpose of the NH care is not clearly stated, it is proposed to enable the residents to have the best possible quality of life reframed by frailty and dependency. This may be evident to many practitioners and nursing staff but not to all, and may not be as clear to the residents and relatives. Extensive curative/preventive drug therapy, as well as absence of (or late shift to) end-of-life care is fairly common [70]. Decisions regarding the hospital admission of NH residents and decisions on palliative care approach may present a difficult dilemma for the GP. There is a need for further research to find strategies to optimize hospital admissions and possibly to avoid inappropriate admissions [71].

Even though the systems of elderly care differ between countries there is a major need for in-depth research on the workforce and quality of care in NHs to recognize opportunities for strategic improvement and to highlight priorities for education [52]. As the doctor-nurse relationship in health care institutions is very important for the efficiency of the system [72], it is of great interest to shed light on this link also in NHs. A previous Swedish qualitative study in this field illustrates the problems of inappropriate hospital admissions of NH residents [73] but the focus has mainly been on the experience of the nurses. The GPs' experience of the work with NHs in Sweden had not been studied before the current study was carried out.

Aims of the thesis

General aim

In this thesis aspects of treatment and care of nursing home residents were studied, aiming to pinpoint risk factor areas in need of greater observation. Further, the thesis aimed to identify possibilities for improving the medical treatment of the elderly and to identify obstacles to good quality of care.

Specific aims

- To explore the prevalence of heart failure in nursing homes in Sweden, with special consideration for the risk of neglected heart failure diagnoses, by using BNP measurements. Secondly, to explore medications and the adherence to guidelines for the treatment of Heart Failure in the elderly. (Paper I)
- To longitudinally describe the nutritional status in elderly people living in Nursing Homes and the association between nutritional status and mortality, and further to explore factors associated with changes in nutritional status over time. (Paper II)
- To study the relationship of deterioration in renal function with major outcomes in Nursing Home residents. Secondly, to seek to compare the formulae recommended in Sweden for eGFR, with internationally more recommended methods in a nursing home population. (Paper III)
- To illustrate the General Practitioners' experience of the work with elderly living in nursing homes, to get further input on the physicians' perspective in elderly care. (Paper IV)

Materials and Methods

Study Design

Papers I–III were based on the longitudinal cohort study, SHADES. Paper IV was a qualitative study based on semi-structured interviews and a focus group discussion with GPs working in NHs. An overview of the studies is presented in table 1.

Table 1.
Overview of the papers

Paper	I	II	III	IV
Design	Longitudinal cohort study	Longitudinal cohort study	Longitudinal cohort study	Qualitative study
Participants	NH residents (n=429)	NH residents (n=318)	NH residents (n=429)	GPs from southern Sweden (n=12)
Outcomes	Prevalence of HF Prevalence of BNP \geq 100ng/L One-year mortality Description of medications for HF	Prevalence of malnutrition Longitudinal changes in nutritional state Association between nutritional status and survival	Prevalence of impaired renal function Factors associated with deteriorating renal function Comparison between recommended eGFR equations	Experiences of the work with elderly in NH
Data collection methods	Data collected from the patients included in SHADES	Data collected from the patients included in SHADES	Data collected from the patients included in SHADES	Semi-structured interviews and a focus group interview
Data analysis	Student's T-test Mann Whitney U-test Chi-Square test One-way ANOVA Binary logistic regression analysis	Student's T-test Mann Whitney U-test Chi-Square test One-way ANOVA Kaplan-Meier survival curves	One-way ANOVA Chi-square test Cox regression analysis Multiple logistic regression analysis IntraClass-Correlation calculation Kappa statistics	Thematic content analysis

Data collection (papers I–III)

Study participants

Eleven NHs were selected for participation in the SHADES study. The NHs were situated in three different cities in the south part of Sweden (Linköping, Jönköping, and Eslöv), and were chosen by having staff interested in participating in the study and within a convenient distance for the study researchers. However, there are no fundamental differences between NHs in Sweden [57], and therefore this selection was still regarded as generalizable for NHs in Sweden. All residents of the 11 selected NHs were invited to join the study and when included residents moved or died, the next person moving in to the NH was asked to participate. During 2008–2011, 429 patients were included in the SHADES study. The mean age of the participants was 85.0 years, with a range between 65 and 101 years.

Exclusion criteria

Patients who lived at the nursing home temporarily for short-term rehabilitation or palliative care were excluded. Persons with language difficulties and persons under the age of 65 were also excluded. The flow chart of subjects included, and those subjects who were excluded, moved, or died, are presented in figure 2.

Methods of investigation

Participants were examined at baseline of the study by specially trained nurses who also collected data from medical charts for diagnoses and current medical treatment.

Diagnoses collected from the patients records were coded according the Swedish version of the 10th version of the International Classification of Diseases (ICD-10) [13]. Medications were registered and classified by therapeutic group based on the World Health Organization's Nordic Anatomical Therapeutic Chemical Classification Index codes (ATC code) [14] and daily dose. At need medications were not recorded.

The in-person testing of participants included measurement of pulse, blood pressure, weight and height, and questionnaires. The in-person testing was performed by the study nurses with assistance of the staff at the nursing home. To measure cognitive function, the Mini Mental State Examination (MMSE) was used [10]. The MMSE consists of 21 questions that measure orientation, memory, naming, constructional ability, and attention. The scores range from 0 to 30, with a score of 23 or lower indicating cognitive dysfunction.

Blood samples were drawn every six months and were analysed at the hospital in Jönköping by high-pressure liquid chromatography.

Specific data collection for paper I on heart failure

The subjects with the ICD-10 code I50 in their patient record at inclusion were selected as patients with HF diagnoses.

For BNP measurements, a cut off value of 100 ng/L was used as it is suggested to have a satisfactory negative predictive value and satisfactory sensitivity for determining the need for further investigation of HF in PHC [74].

One-year mortality was calculated by number of deaths over number of person-year lived over one year. For mortality calculation, mortality dates were collected from Swedish Total Population Register on 15 March 2012.

Specific data collection for paper II on malnutrition

For this study, all residents from the two first inclusion periods of the SHADES study, were included. The residents included later in the SHADES were not included as the nutritional status was to be observed during two years, which could not be done for the residents included later than the first year of the study. In total, 318 residents were included in the SHADES during the first year.

Nutritional status was evaluated with the MNA [8]. The MNA is a validated test composed of simple measurements and brief questions specially designed for a geriatric population [8, 39]. For measures in the MNA such as mid-arm circumference (MAC) and calf circumference (CC), as well as for questionnaire responses, a specific MNA manual developed for Swedish settings was used [75]. Residents were assessed using the MNA assessment at baseline and at 24 months after inclusion. Nutritional status was assessed in a two-step process. In the first step the MNA-SF (Mini Nutritional Assessment-Short Form) was used [76]. The MNA-SF is a screening tool developed from the MNA. The threshold for well-nourished subjects is ≥ 11 . Subjects with scores less than 11 were then further evaluated with the full MNA to confirm the nutritional status as being at risk of malnutrition (MNA score between 17 and 23.5) or malnourished (MNA < 17).

For survival calculations, mortality dates were collected from the Swedish Total Population Register on 15 March 2012.

Specific data collection for paper III on renal function

Kidney function was assessed by estimating glomerular filtration rate (GFR) according to recently updated Swedish guidelines [77] which are also now incorporated in the clinical routine for the laboratory analysis of eGFR in Sweden. The estimated GFR (eGFR) was calculated as the average of (1) the GFR estimated from creatinine based on the revised equations for eGFR from the Lund-Malmö Study cohort [78] and (2) the GFR estimated from cystatin C with the CAPA formula [50]. The GFR was also estimated using the MDRD [47] formula and the CKD-EPI equation [48] for comparison with the recommended Swedish formula. The equations used for eGFR are shown in table 2.

From the eGFR values, the subjects were divided into groups according to the National Kidney Foundations staging of chronic kidney disease (CKD); eGFR ≥ 60 ml/min/1.73 m² as CKD stage 1+2 (normal renal function or mild reduction), eGFR 30–59 ml/min/1.73m² as CKD stage 3 A+B (moderate reduction), and eGFR <30 ml/min/1.73 m² as CKD stage 4+5 (severe reduction or renal failure).

A decrease in eGFR of > 3 ml/min/1.73 m² per year was considered a rapid decline of renal function as in previous studies [79].

For survival calculations, mortality dates were collected from the Swedish Total Population Register on 15 May 2015.

Table 2
eGFR equations used for paper III

Equation name	Sex	eGFR equation
CAPA	Male and female	$130 \times (\text{cystatin C}^{-1.069}) \times (\text{age}^{-0.017}) - 7$
CKD-EPI	Female	<p><i>If creatinine $\leq 62 \mu\text{mol/L}$ and cystatin C $\leq 0.8 \text{ mg/L}$:</i></p> $130 \times (\text{creatinine}/62)^{-0.248} \times (\text{cystatin C}/0.8)^{-0.375} \times 0.995^{\text{age}}$ <p><i>If creatinine $\leq 62 \mu\text{mol/L}$ and cystatin C $> 0.8 \text{ mg/L}$:</i></p> $130 \times (\text{creatinine}/62)^{-0.248} \times (\text{cystatin C}/0.8)^{-0.711} \times 0.995^{\text{age}}$ <p><i>If creatinine $> 62 \mu\text{mol/L}$ and cystatin C $\leq 0.8 \text{ mg/L}$:</i></p> $130 \times (\text{creatinine}/62)^{-0.601} \times (\text{cystatin C}/0.8)^{-0.375} \times 0.995^{\text{age}}$ <p><i>If creatinine $> 62 \mu\text{mol/L}$ and cystatin C $> 0.8 \text{ mg/L}$:</i></p> $130 \times (\text{creatinine}/62)^{-0.601} \times (\text{cystatin C}/0.8)^{-0.711} \times 0.995^{\text{age}}$
CKD-EPI	Male	<p><i>If creatinine $\leq 80 \mu\text{mol/L}$ and cystatin C $\leq 0.8 \text{ mg/L}$:</i></p> $135 \times (\text{creatinine}/62)^{-0.207} \times (\text{cystatin C}/0.8)^{-0.375} \times 0.995^{\text{age}}$ <p><i>If creatinine $\leq 80 \mu\text{mol/L}$ and cystatin C $> 0.8 \text{ mg/L}$:</i></p> $135 \times (\text{creatinine}/62)^{-0.207} \times (\text{cystatin C}/0.8)^{-0.711} \times 0.995^{\text{age}}$ <p><i>If creatinine $> 80 \mu\text{mol/L}$ and cystatin C $\leq 0.8 \text{ mg/L}$:</i></p> $135 \times (\text{creatinine}/62)^{-0.601} \times (\text{cystatin C}/0.8)^{-0.375} \times 0.995^{\text{age}}$ <p><i>If creatinine $> 80 \mu\text{mol/L}$ and cystatin C $> 0.8 \text{ mg/L}$:</i></p> $135 \times (\text{creatinine}/62)^{-0.601} \times (\text{cystatin C}/0.8)^{-0.711} \times 0.995^{\text{age}}$
LM-rev	Female	$e^{(X - 0.0158 \times \text{age} + 0.438 \times \ln(\text{age}))}$ <p><i>If creatinine $< 150 \mu\text{mol/L}$:</i></p> $X = 2.50 + 0.0121(150 - \text{creatinine})$ <p><i>If creatinine $\geq 150 \mu\text{mol/L}$:</i></p> $X = 2.50 - 0.926 \times \ln(\text{creatinine}/150)$
LM-rev	Male	$e^{(X - 0.0158 \times \text{age} + 0.438 \times \ln(\text{age}))}$ <p><i>If creatinine $< 180 \mu\text{mol/L}$:</i></p> $X = 2.56 + 0.00968 \times (180 - \text{creatinine})$ <p><i>If creatinine $\geq 180 \mu\text{mol/L}$:</i></p> $X = 2.56 - 0.926 \times \ln(\text{creatinine}/180)$
MDRD*	Female	$175 \times ((\text{creatinine}/88.4)^{(-1.154)}) \times (\text{age}^{(-0.203)}) \times 0.742$
MDRD*	Male	$175 \times ((\text{creatinine}/88.4)^{(-1.154)}) \times (\text{age}^{(-0.203)})$

*the equation can be adjusted for African Americans, but this was not relevant for the participants in the SHADES study

Statistical analyses

The data collected in the study were analysed using the SPSS Statistics 20 (SPSS, Inc. Chicago, IL). Differences between groups were tested using Student's T-test and the Mann-Whitney U test for continuous variables and the Chi-square test for discrete variables.

For calculating differences between several groups the one-way ANOVA test was performed for continuous variables and Chi-square test for discrete variables, using the Bonferroni correction for mass significance [80].

Specific statistical analyses for paper I on heart failure

Binary logistic regression analysis with the Enter method was performed to observe differences between the groups with HF diagnosis and the group with no HF diagnosis but with BNP >100 ng/L. The goodness-of-fit of the regression model was tested with the Hosmer and Lemeshow test, and with Nagelkerke R².

One-year mortality was calculated by number of deaths over number of person-years lived over one year. For mortality comparisons the population was divided into age strata, gender, and HF diagnosis.

Specific statistical analyses for paper II on malnutrition

Survival functions were presented as Kaplan-Meier survival curves. Differences in survival between groups were tested with the log-rank test.

Specific statistical analyses for paper III on renal function

Multiple variable logistic regression analysis with the Enter method was performed for observing factors associated with a declining kidney function of >3 mL/min/1.73 m² per year compared to those with more stable kidney function (1=rapidly declining kidney function, 0=stable kidney function). The goodness-of-fit of the regression model was tested with the Hosmer and Lemeshow test, and with Nagelkerke R².

A Cox Regression analysis with a survival plot of the different CKD groups with adjustment for age, HF and number of medications, was created for survival calculations.

For tests for agreement of the different formulas for eGFR, the IntraClassCorrelation (ICC) Coefficient was determined as eGFR is a continuous variable.

An interrater reliability analysis using the Kappa statistic was performed to determine consistency among CKD groups.

For ICC values and Kappa values 0.20 was considered as slight agreement, 0.21–0.40 was taken as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement [81].

Data collection (paper IV)

Study participants

We used purposive sampling by identifying GPs with varying NH experiences. The only inclusion criterion was that the GP was working in a NH and wanted to participate in the study. In total 12 GPs participated, three men and nine women. They had been working in PHC for between two and 38 years. The GPs worked at NHs situated in different cities as well as in smaller towns and villages in the south part of Sweden. All GPs made weekly visits to the NH and had responsibility for between 24 and 100 patients each.

Semi-structured interviews

We developed an interview guide according to Kvale [82]. This guide was developed based on the aim of the study regarding how the GPs experience their work with the elderly. Three main areas with accompanying research questions were stated as follows; 1) Describe the work at the NH. 2) How is the work at the NH valued and appreciated? 3) What is the objective of your work at the NH? These areas originated from the clinical practice and have been problematized in previous studies [67, 68]. Interview questions were developed from these research questions. The interview questions were short, simple and open to encourage the discourse.

The interviews were situated at a place that the GP felt was most convenient. Seven of the interviews were conducted at the PHCC where the GP worked. Three interviews were conducted at the research centre where the first author works and in one case in the first author's home, and in another case at the home of the interviewee. The interviews lasted for about 35–40 minutes.

The interviews were recorded digitally, thereafter transcribed verbatim by the first author and a research assistant.

Focus group

Two main themes were derived when analysing the interviews. To deepen these themes a focus group discussion with the interviewed participants was held. All of the 12 GPs were invited to the focus group discussion. Ten of the GPs were interested in participating but on the day of the meeting four of them reported well-founded reasons for absence (other work commitments, maternity leave and illness). A total of six GPs, three men and three women, with different lengths of experience participated in the focus group meeting.

The focus group discussion was held at the research centre where the authors work and lasted for around 90 min with a short break. The discussion was moderated by one of the co-authors as she had prior experience of moderating focus groups and is not a GP, which was thought could give more depth to the discussion. The first author assisted the moderator and took notes during the discussion to recall impressions during the conversation. The moderator based the discussion on the themes derived from the analysis of the interviews and used open-ended questions, thus allowing the participants to talk freely about the topic.

The focus group discussion was recorded and thereafter transcribed verbatim by a research assistant.

Qualitative analysis

The analysis was performed stepwise according to Malterud [83]. First the text was read through several times in order to get to know the content. Thereafter, preliminary themes were derived from the interviews and through systematic text condensation meaning units connected with the preliminary themes were identified. The meaning units were condensed while preserving the essence of the meaning unit and then labelled with a code.

The codes were carefully sorted into subcategories and further into categories with internal homogeneity. The codes and categories were thought through and discussed among the co-researchers, and themes were derived from the manifest meaning of the content.

An example of the text condensation in meaning units is shown in table 3. The text from the focus group discussion was analysed similarly, although the codes were matched to the pre-existing categories and themes.

Table 3.
Example of text condensation and coding

Meaning unit	Condensed meaning unit	Coding	Category
GP8: <i>"Many medications, antibiotics and the like are given (to the patients) which they receive instead of the nursing care they actually need."</i>	Medicines are used instead of nursing care	Medicalization	Care needs and medicalization
GP11: <i>"There is a focus on the doctor. And as I have very little chance to help the patient because what the patient actually is in need of is basic care needs, and now when he (the patient) feels bad...well... if one as a doctor then becomes 'help needed' (as wanting to help) as someone says, a patient can get very many medications."</i>	A service-minded doctor may prescribe too many medicines	Medicines vs. basic needs	
GP1: <i>"No but it means that I sometimes have to compromise with what I really believe in... So it feels like it is a negotiation from all sides. So that they know what position I have and I know what position they have. Where I know that they are liberal with antibiotics, but you have to..., well I don't want to say that I am a realist and not able to do what I want, but I am more careful about saying yes and no to things, and instead think about their (the nursing staff's) conditions."</i>	The doctor needs to be careful in the dialogue about ordinations	Negotiations about medicines	

Ethical considerations

Ethical considerations for papers I–III

The study protocol for SHADES was approved by the Regional Ethics Review Board at Linköping University (date: 18 October, 2007; case number M150-07).

Informed consent was obtained from all participants. If the patient could not understand the information and give informed consent this was obtained from next of kin. The included patients could withdraw from the study at any time. All data were unidentified and presented on a group level. The risk of harm for the included patients was considered to be over all low and the gain of new knowledge valuable.

Ethical consideration for paper IV

The study protocol was approved by the Regional Ethics Review Board at Lund University (date 16 April, 2014; case number: 2014/219). The decision from the board was that paper IV did not need ethical approval.

The GPs received written information about the study and provided written and oral consent when participating in the interview. Data was collected with a digital recorder and the interviews were anonymized prior to transcription. The results were presented so that specific individuals could not be singled out or identified

Findings

Main findings

- The point prevalence of HF in NH residents in Sweden was 15.4%, although the prevalence may have been higher if BNP measurements had been used to select patients for further investigation. The HF diagnosis in subjects with cognitive impairment may in some cases have been neglected. The use of medications in the patients with HF diagnoses was not in accordance with current guidelines regarding the use of HF medications in elderly individuals. (Paper I)
- It was found that about 60% of the population at Swedish NH were either malnourished or at risk of malnutrition. Moreover, the prevalence of malnutrition and risk of malnutrition increased over time and was associated with lower survival. BMI and weight were higher in the group with deteriorating MNA status over time. (Paper II)
- More than half of the residents in a NH population had moderate renal dysfunction corresponding to CKD 3A+B. The residents with impaired kidney function had a higher number of medications (mainly cardiovascular drugs) and also had a higher prevalence of HF. The strongest factor associated with a rapid decline in renal function was the number of medications the patient used. With a lower eGFR, the mortality was higher in the NH residents. (Paper III)
- Working with NH patients was considered important and meaningful, with the GPs striving for the patient's well-being with special consideration to the continuum of ageing. A continuous and well-functioning relationship between the GP and the nurse was crucial for the patients' and the GPs' well-being. (Paper IV)

Baseline population characteristics in SHADES

The baseline characteristics of the population in the SHADES study are presented in table 4.

Table 4.
Baseline characteristics of the SHADES population

Parameter	Value
Age in years	85.0±7.0 (65–101)
Sex, female n (%)	305 (71.1)
Hb (g/L), n=331	125.7±14.2 (86–191)
BMI (kg/m ²), n=420	24.9±5.1 (12.1–53.1)
Number of medications	6.9±3.1 (0–16)
MMSE, n=349	17.3±6.3 (3–30)
Numbers stated as mean ± SD (range min-max), n=429 unless stated otherwise	

Heart Failure (paper I)

HF vs no HF

The point prevalence of diagnoses of HF in the patient records at the time of inclusion was 15.4%. The characteristics of the subjects with HF diagnoses, compared to the subjects without HF diagnoses were quite similar, although the population with HF diagnoses was older than the population without HF diagnoses and the BNP values were higher ($p<0.05$). The eGFR as well as blood pressure levels were lower in the group with HF diagnoses ($p<0.05$). The group with diagnosed HF had a trend towards higher MMSE scores compared to the group without diagnosed HF, but the difference was not significant ($p=0.06$).

One-year mortality rate for the study population was 34.2%. One-year mortality rate in the group with diagnosed HF was significantly higher than in the non-HF patients (52.9% vs. 31.1%, respectively, $p=0.02$). When the groups were divided into gender, the mortality was still higher in the HF group than in the non-HF group, and the difference was also significant when divided into age strata.

BNP

The study population was divided into quartiles based on BNP level and only 32% of the subjects in the fourth BNP quartile (with highest BNP values, mean 471.2 ng/L \pm 492.3ng/L, range 192–4200 ng/L, n=100) had been diagnosed with HF. The subjects in the fourth quartile were more likely to be treated with Beta-blockers, Digoxin and loop diuretics ($p<0.05$). The groups did not differ in the treatment with ACE inhibitors/ARBs or Spironolactone. The medical treatment for the patients in the different BNP quartiles is presented in table 5.

HF vs BNP >100 and no HF

Based on the recommended BNP cut-off for HF of >100 ng/L, 196 subjects in the study population had BNP values above the threshold, while only 66 had the diagnosis in the medical charts. In the group with no HF diagnosis at the time of inclusion the mean BNP level was 143.2 ng/L, and 154 subjects in this group could have been suitable for further examination with echocardiography. The patients with diagnosed HF used more drugs than the subjects without HF diagnoses but with BNP >100ng/L (8.5 vs. 7.0 medications on average, $p<0.001$). The most commonly used medications were loop diuretics followed by Beta-blockers in the HF group (used in 75.8% and 59.1% of the subjects respectively) and Beta-blockers followed by loop diuretics in the non-HF group with BNP>100 ng/L (used in 45.5% and 32.5% of the subjects respectively). Treatment with ACE inhibitors/ARBs were used in 50% of the subjects with HF diagnosis and in 14.9% in subjects without HF diagnosis but with BNP>100 ng/L. Subjects with diagnosis of HF were more likely to be treated with ACE inhibitors/ARBs, Spironolactone and loop diuretics ($p<0.05$). For the treatment with Digoxin and Beta-blockers the groups were similar. Comparison of the groups with HF diagnosis and no HF diagnosis but with BNP>100 ng/L, found the mortality to be similar (46.2% vs. 52.8%, $p=0.29$).

Table 5

Total number of medications and HF medication in the study population, divided into quartiles based on BNP

BNP quartile range (ng/L)	1 10–51 (n=100)	2 52–102 (n=101)	3 103–191 (n=101)	4 192–4200 (n=100)	p value
ACE inhibitors/ARBs n (%)	14 (14)	20 (19.8)	20 (19.8)	28 (28)	0.11
Beta-blockers n (%)	14 (14)	31 (30.7)	45 (44.6)	54 (54)	<0.001 a, b, c, e
Spironolactone n (%)	9 (9)	4 (4)	7 (6.9)	7 (7)	0.56
Digoxin n (%)	2 (2)	1 (1)	13 (12.9)	14 (14)	<0.001 b, c, d, e
Furosemide/loop diuretics n (%)	27 (27)	39.6 (40)	36 (35.6)	50 (50)	0.009 c
Loop diuretics with simultaneous ACE inhibitor/ARB treatment n (%)	6 (6)	15 (14.9)	13 (12.9)	20 (20)	0.034 c
Significant difference between BNP quartiles 1-4, is presented as:					
1 and 2: a					
1 and 3: b					
1 and 4: c					
2 and 3: d					
2 and 4: e					
3 and 4: f					

Malnutrition (paper II)

Of the included NH residents, 308 had complete MNA/MNA-SF data. The mean age of the participants was 85.0 years (range 65–101 years).

At inclusion in the study, 41.6% of the participants (n=128) were well nourished, 40.3% (n=124) were at risk of malnutrition, and 17.7% (n=56) were malnourished according to the MNA results.

Malnourished subjects were older, had lower weight, BMI, haemoglobin levels, diastolic blood pressure, and MMSE scores, and were more likely to have a dementia diagnosis and/or Parkinson's disease ($p<0.01$). The survival rate differed significantly between the three groups, as shown in figure 4.

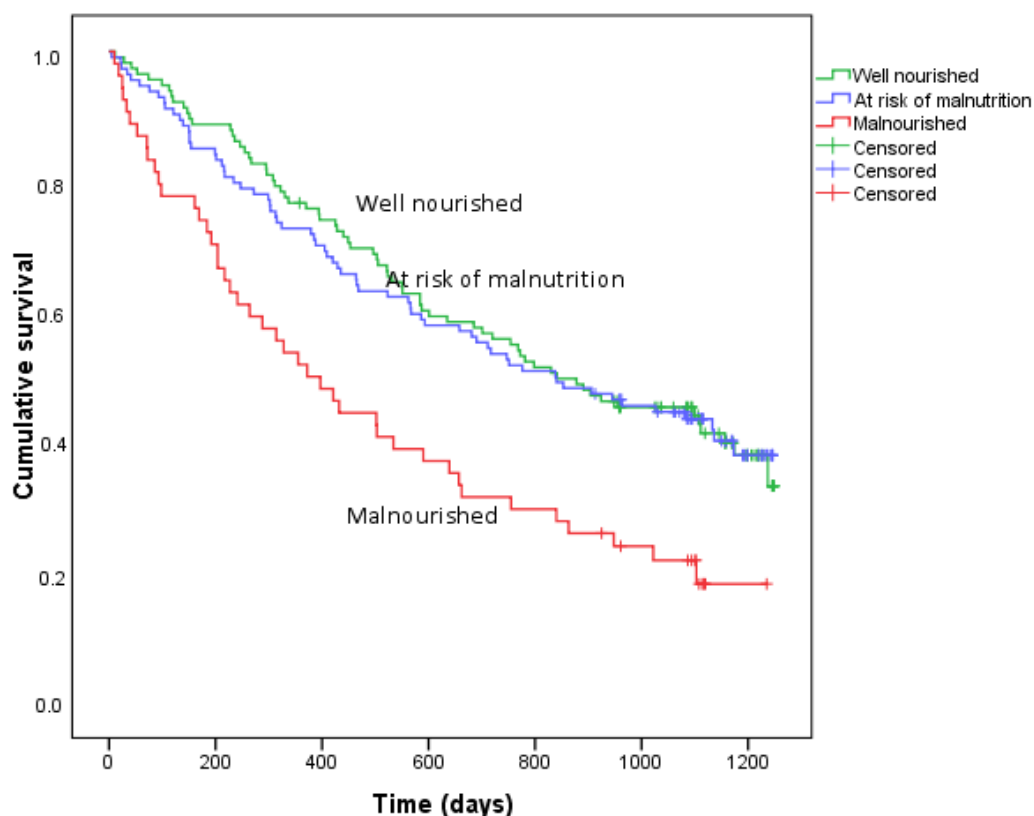


Figure 4. Kaplan-Meier survival curves according to Mini Nutritional Assessment category at baseline. ($p < 0.001$, log rank test)

Longitudinal data on nutritional status

After 24 months 153 residents had died, and 10 did not want to participate further, leaving 142 participants with complete MNA data at baseline and after 24 months. The group of participants who survived 24 months represents a population of better nutritional state at baseline, where only 10.6% were malnourished, 43.0% were at risk of malnutrition, and 46.5% were well nourished at baseline. Over time, there was a shift toward lower MNA scores, where 24.6% ($n=35$) were malnourished, 47.2% ($n=67$) were at risk of malnutrition, and 28.2% of participants ($n=40$) were well nourished after 24 months. During the 24-month follow-up, 38.7% of the participants showed a decline in nutritional state; 61.3% had an improved or stable nutritional state. The factors that significantly differed between the groups were weight and BMI: weight and BMI were higher ($p < 0.05$) in the group with a decline

in nutritional state compared to the group with improved or stable nutritional state. In addition, diastolic blood pressure and haemoglobin levels were also higher in the group with deteriorating nutritional state ($p<0.05$). Hospitalization during the 24-month observation period was more common in the group with deteriorating MNA status ($p<0.05$).

Renal function (paper III)

The study included 429 subjects, of whom 406 subjects had complete blood samples for calculating eGFR. More than half of the residents had an eGFR between 30–59 mL/min/1.73 m², which is referred to as CKD 3A+B. Less than 10% had an eGFR <30 mL/min/1.73 m² (CKD 4+5), and about 40% had an eGFR \geq 60 mL/min/1.73 m² (CKD 1+2).

The subjects in the different CKD stages differed significantly ($p<0.001$) regarding age, number of medications and presence of heart failure, where the patients with lowest renal function stage had more medications, as well as being older and more likely to have HF.

Looking at the different medications according to different groups of comorbidities such as diabetes, cardiovascular and neurological disorders, only the residents taking cardiovascular medications were more likely to have impaired renal function. As significant differences between the CKD groups at baseline were found regarding number of medications, prevalence of HF, and age, a Cox Regression analysis with a survival plot of the different CKD groups with the correction for age, HF, and number of medications, showed a lower survival for the group with impaired renal function. (Figure 5)

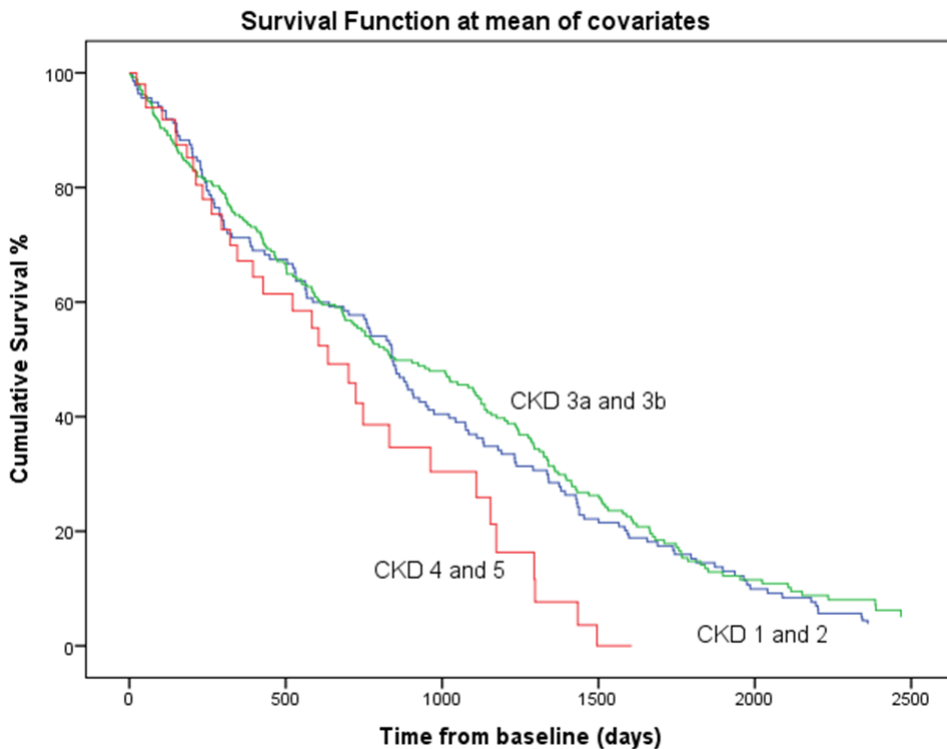


Figure 5

Survival functions of different CKD stages, with Cox Regression analysis corrected for age, number of medications and heart failure

Longitudinal data on renal function

The mean eGFR decreased from 54.0 mL/min/1.73 m² (n=406) to 51.2 mL/min/1.73 m² (n=225) in 12 months and to 50.7 mL/min/1.73 m² in 24 months (n=139). In general eGFR decreased by 3.7 mL/min/1.73 m² in one year and by 6 mL/min/1.73 m² over two years. The eGFR fell by 3 mL/min/1.73 m² in one year, in more than half of the population (54%).

A binary logistic regression analysis showed that the number of medications taken was a risk factor for declining kidney function of > 3 mL/min/1.73 m² in one year, with an OR of 1.2 (95% CI 1.06–1.36, *p*=0.003). For every medication more an individual received the greater the risk of rapidly declining kidney function.

Methods for estimation of GFR

The ICC (IntraClassCorrelation) coefficient showed a strong agreement between CKD-EPI and the LM-rev+CAPA formulae with an ICC coefficient of 0.98 ($p<0.001$). The ICC coefficient showed a strong agreement also in the individuals with $eGFR \leq 30$ ml/min/1.73m² (ICC coefficient 0.97, $p<0.001$). The correlation was weaker between the MDRD and CKD-Epi formula (ICC value 0.70, $p<0.001$) as well as between the MDRD and the LM-rev+CAPA (ICC value 0.66, $p<0.001$). The reclassification reliability for the CKD groups with the two different formulae (CKD-EPI and the LM-rev+CAPA) was found to be excellent with a Kappa value of 0.91 ($p < 0.001$).

When the subjects were divided into groups as malnourished and not malnourished and then compared by the ICC values for the different formulas, the ICC value between CAPA-LM-rev formula and the MDRD for the malnourished group was 0.51 ($p < 0.001$) and the ICC value for the CAPA-LM rev and MDRD for the non-malnourished group was 0.70 ($p < 0.001$). The ICC value for CAPA-LM-rev and CKD-EPI was consistently 0.98 ($p < 0.001$) both in the malnourished group and in the non-malnourished group. The relationship between mean values of eGFR in malnourished and not malnourished groups is showed in table 6.

Table 6.
Mean eGFR using different equations (ml/min/1.73 m2)

	All (n=406)	Not malnourished (n=341)	Malnourished (n=65)
eGFR from CAPA+LM-rev	54.0±15.9 (8.1-90.3)	53.6±16.1 (8.1-90.3)	56.0±14.7 (21.1-87.3)
eGFR from CKD-Epi	54.3±17.9 (6.6-94.0)	53.8±18.1 (6.6-94.2)	57.0±17.1 (19.1-93.3)
eGFR from MDRD	67.7±24.9 (7.6-163.7)	66.0±24.4 (7.6-163.7)	76.8±27.2 (29.1-146.9)

GPs' experience of elderly care in NHs (paper IV)

The picture that emerged from the interviews was that the main concern expressed by GPs who work at NHs was the well-being of the patients. The nurse at the NH was seen as a key person for the patients at the NH and served as a mediator, negotiator, and coordinator who was striving for their well-being.

The GPs described discordance between the demand from staff for medications and the patients' actual need of nursing care. The doctors wanted more nursing care and the nursing staff wanted more medications. This paradox was most evident for the

GPs when encountering the powerlessness of not being able to fulfil the existential needs of the NH patients such as holding their hand or keeping them company.

Despite this, the GPs found their work with NHs enjoyable. It seemed to be a pleasant variation to everyday tasks at the PHCC and gave much-needed freedom to decide their own time schedule. Despite the fact that the patients at the NH suffered from multiple illnesses, which could lead to difficult decisions being made, the doctors felt confident in the role by having a comprehensive view of the patient combined with reliable support from the nurse at the NH.

Two main themes were identified in the process of analysing the interviews: concern for the patient and sustainable working conditions. These themes contained three and four categories respectively as shown in table 7.

The focus group discussion added some deeper understanding to the pre-existing categories and themes. However, no new categories or themes emerged from the analysis of the focus group discussion.

Table 7
Categories and themes

Categories	Themes
The continuum of ageing	Concern for the patient
Care needs and medicalization	
The nurse as a key person for the well-being of the patient	
Holism	Sustainable working conditions
Collaboration	
Freedom and variation	
Meaningfulness	

Concern for the patient

The GPs were all careful to describe their concern for the patient based on the prevailing circumstances of caring for an older person during the end of life stage.

“I want to give the patients a good quality of life, and I follow them in the continuum of ageing, with their progressive weakness and adapt medical interventions for this.”(GP 10)

The GPs strove for less pain, less anguish and less loneliness for the patients to achieve the best possible well-being, often with help from the nurse. The GPs had

different coping strategies to manage their concern for the patient. The first category included in this theme was: **The continuum of ageing** (Table 7). The GPs were careful to explain the different perspective they took when working with the elderly at NHs.

“...the first priority is definitely to reduce suffering, reduce anxiety...try to make life meaningful for the patient. Diseases are secondary.” (GP4)

The aim was not to cure diseases but to give the best possible quality of life to the patient during the latter stages of life. This way of taking care of the patients could often be interfered with by relatives, who had other opinions, but the GPs felt confident in their perspective. Furthermore, the GPs usually could continue with their focus on well-being when communicating with the relatives about their anxiety regarding end of life care. There seemed to be a large variation in how the GPs approach medications for elderly patients since guidelines around withdrawal of medications, and medications in general for the elderly, were perceived to be largely absent.

The second category was: **Care needs and medicalization**. The GPs were careful to note that they wanted the patients to have as few medications as possible as they believed that many medicines had exhausted their impact when the patients were this old. The doctor's part in deprescribing medicines along with highlighting the need of nursing care was often hard to manage. The GPs were frustrated about the care needs of the patients, which they thought could not be replaced by medicines.

“It is not optimal that a patient gets a sedative drug instead of someone that holds her hand, but it is as good as it can get because there is no other way. That is frustrating of course, and sad, that I can't influence this in any way.” (GP 2)

The GPs' opinions were that the staff at the NH often asked for medicines to solve problems that were not in fact medical. Here a paradox was found as the employees at the NH were demanding more medicines and the GPs were demanding more nursing care. There was a need for ingenuity and for the GPs to be focused on solutions. The GPs could see that resources were lacking for nursing care and felt that the problem often was on a different level in the organization, where the doctor had no influence. The conflict about medications was often managed by the nurse which leads into the third category in this theme: **The nurse is a key person for the patients' well-being**. The GPs ability to provide well-being for the patients at the NH was described as being dependent on knowing the nurse at the NH.

“and I notice how doubtful I get of my own profession when not knowing the nurse. It is hard to know if she calls for too much action or not...” (GP1)

If the nurse was confident in her role with a good knowledge of the patients' needs and level of care, the GPs felt that they could provide the patients with good quality of care.

"for everything to work optimally it is necessary that the nurse knows the patient, she is the key person." (GP7)

A continuous relationship between the nurse and the GP rendered productive discussions on patients' needs, as well as good communication strategies without irrelevant disturbances during the week. A confident nurse, with a thorough knowledge of the patients, could in many cases help the doctors to avoid unnecessary and sometimes harmful referrals to hospital. The nurse was also seen as a messenger for important information about the patients, as well as for wishes and demands from the other staff at the NH and from the patients' relatives. Sometimes this role of the nurse had to be more as a mediator when opinions about the patients' needs diverged. The picture of the nurse was also as a coordinator regarding the patient and the NH. With well-prepared wards and well-functioning routines the GPs felt they could do an efficient job focusing on the well-being of the patient.

Sustainable working conditions

The GPs found their work at NHs enjoyable. The work was seen as important and meaningful for the GPs as they felt that they could make a difference for the NH patients. In addition, the work also gave a nice variation to everyday tasks at the PHCC. The commitment at NHs provided a salutogenic work situation for the GPs.

The first category was (Table 7): **Holism**. The definition of holism in General Practice is proposed as treating health problems in their physical, social, cultural and existential dimension. The GP has to recognize all these dimensions at the same time and has to be able to give the right weight to them as illness and pathologies are modified by these dimensions [84]. The GPs in this study felt that they had a much better overall picture of the patients at the NH, compared to when they met an elderly patient at the PHCC.

"...so I think I can make more correct decisions at the NH, when I meet the patient in that environment" (GP2)

The doctors had regular meetings with their patients. They got thorough information about them from the nurse, staff and relatives and were provided with an accurate list of medications. This provided a holistic view of the patients which helped the GP to make better medical decisions, and with more informed decisions the doctor was more satisfied. When the GPs felt they had a good overall picture of the patient

it was easier to avoid unnecessary actions and instead wait and see and follow up the condition.

The second category of GP satisfaction was: **Collaboration**. The GPs felt that the work at the PHCC was very lonely as due to stress it was often not possible to see any colleagues at all. Their work at the NHs differed in that way.

“the thing with talking to the nurses, talking to the relatives, you work together, that is actually quite enjoyable...” (GP8)

At the NH the GP sat down with the nurse and the nursing staff to discuss the patients. This created a less lonely situation for the GP, which was appreciated. Even though the GPs appreciated the collaboration with the nurse at the NH they were all united in that the necessary collegial discussions with other GPs involved in NHs were largely absent, but would be fruitful for their work. The GPs learnt by doing as they had not had previous schooling or introduction by other colleagues to the work at the NH. In the interviews, particularly during the focus group discussion, there was a clear wish for a thorough introduction to the work at the NH by a senior colleague and thereafter recurring meetings with other NH doctors for discussions on elderly care.

Freedom and variation was the third category. This was also viewed in comparison with the work at the PHCC.

“It is like a relief compared to the PHCC, that you get to go away from the PHCC every week and go to the NH, and it also gives you an opportunity to make your own priorities” (GP12)

The GPs felt that the work at the PHCC was rather punctuated and gave no room for flexibility. The work at the NH could be more varied from week-to-week depending on the workload, which created a welcome possibility for shared decision making about their time schedule.

The fourth category was: **Meaningfulness**. The GPs felt that their work at the NH was very important and meaningful.

“ to help people in that situation, it gives me a feeling of having accomplished something good, almost every time I am there” (GP11)

They felt that they made a difference trying to give the elderly the best possible well-being in the latter stages of life. Even if many medications could have exhausted their impact in the elderly patient, the doctor's part was to pinpoint where the care needs went beyond medications. The GPs were also satisfied with the fact that they often could prioritize the patients they felt were in most need of care, which gave them opportunities to use their time in the best possible way.

Discussion

This thesis shows that there was a high prevalence of malnutrition as well as impaired renal function in Swedish NHs, both conditions increasing over time. There was a risk of neglected diagnosis of HF and a need of guidelines for diagnosis of this condition in the elderly. HF medications were rarely prescribed to the NH patients according to international guidelines. As the number of medications used was associated with worsening of renal function, it is important that the patients have correct medications according to correct diagnosis and that inappropriate medications are deprescribed. The GPs involved in the residents' medical care felt that they were making a meaningful contribution to elderly care and that it is crucial to preserve a continuous relationship between the NH nurse and the responsible GP.

“as a doctor, you have to see the person, not only the patient. You can't just come out there in a rush and run around. I want a more thorough picture of the patient to be able to give good medical care.” (GP3, paper IV)

Heart failure

Paper I on HF in NH residents shed light on the troublesome task of the diagnosing and the managing of chronic conditions in NH residents. Even though there is evidence for treatment of HF, still many residents with HF or non-diagnosed HF with diffuse symptoms of congestion often only get furosemide, also shown in previous studies [24]. The reason for this could be multifaceted, such as practical difficulties with impossible transport of a vulnerable resident to the hospital for echocardiography or worries about the resident's renal function and consequently the avoidance of the ACE-inhibitors recommended for HF. It may also be because the physicians involved in elderly care lack information about latest evidence and know-how, or because of the shortage of large intervention studies in this age group to convince the responsible physician that there are more beneficial medications than furosemide.

A literature review from 2010 showed a HF prevalence of 20% in elderly patients living in nursing homes [53]. The prevalence of HF was determined in five studies and the range was 15–20% [85-88], with the exception of one study that showed a

prevalence of 45% [89]. In this last study, HF was diagnosed after a thorough examination by a clinical geriatrician, while only information from medical records was used to confirm the diagnosis of HF in the other studies. This suggests that there are patients with undiagnosed HF that is clinically evident when the patients are more thoroughly examined. Those results can be compatible with ours as the point prevalence of patients in our study with diagnosed HF in their patient record at baseline was 15.4% but, according to BNP levels, the prevalence might have been closer to 50% if further examinations had been conducted in subjects with BNP values above the suggested cut-off for HF. More thorough examinations and echocardiography were shown to give HF patients a more accurate diagnosis. In a study from the UK [90], the presence of HF was determined by the addition of a portable on-site echocardiograph. The point prevalence of HF in this study was 22.8%, and additional results showed that most cases of HF were previously undiagnosed. Moreover, three-quarters of previously recorded cases were not confirmed.

Because of the great cost and hospitalization burden of HF, screening tests for left ventricular dysfunction among high-risk subjects (such as frail elderly persons) are required to enable implementation of intervention protocols [91]. With the suggested cut-off value for BNP, the negative predictive value is high and the BNP value could be used to exclude patients from further examination [74]. Studies underline the confounders of age, gender and an impaired renal function when using the BNP value for elderly patients with HF [74, 92]. Although in our study, the subjects with BNP values >100 ng/L without HF diagnosis did not differ in gender, age, nor renal function from the subjects with HF diagnosis. This could emphasize the need of further screening of the patients with BNP values >100 ng/L with echocardiography to avoid neglected HF. Cognitive impairment is a common consequence of HF [93] and is known to be an independent prognostic marker for HF outcome since it affects quality of life, morbidity and mortality [94]. In our study, the individuals with HF diagnoses had a trend towards higher scores in the MMSE test compared to patients without HF diagnoses. The patients with low MMSE scores may not have been able to express their symptoms of HF, which could have been one reason why possible HF diagnoses could have been disregarded.

If correctly diagnosed, HF is a condition in which pharmacological treatment can increase quality of life and decrease morbidity [23]. Even though most clinical trials have included younger persons, the recommendations for medical treatment of elderly patients with HF do not differ from the general recommendations (figure 3). Special attention should be paid to co-morbidities, the risk of polypharmacy and renal function [23]. The guidelines recommend ACE inhibitors/ARBs as the first-line HF treatment, with the use of diuretics as a complement when there is volume overload [23]. The proportion of patients receiving ACE inhibitors/ARBs should

therefore ideally have been higher in our study population, especially considering how common the use of loop diuretics was. However the use of ACE-inhibitors in about 50% of the patients with diagnosed HF shows a substantial increase compared to a NH study from 2000 [24], suggesting that the awareness and use of ACE-inhibitors over the last decade is raised.

The use of loop diuretics may activate the renin-angiotensin-aldosterone system [95] which plays an important role in the progression of HF, and it may also lower the GFR by decreasing the intravascular volume. It is also known to cause electrolyte imbalances [23]. Therefore, routine use of diuretics without signs of fluid retention should be avoided and has even been shown to be associated with worse outcomes in patients with HF [96].

The mortality of the patients with diagnosed HF was higher than in the non HF group. This underlines that HF is important to take into consideration in the elderly. The mortality in the group with BNP >100 ng/L was similar to the group with HF, which could indicate that there are patients with unrecognized HF in this group.

“I have only had one course on elderly and medications, and that was long ago. But I still use the notes from that class.” (GP1, paper IV)

Malnutrition

The relationship between malnutrition and ageing is complex and in the medical science this is often considered to be a part of nursing care and therefore to a certain extent ignored by physicians as they may feel it is someone else’s responsibility. However the association of malnutrition with vast medical consequences cannot be ignored.

The prevalence of malnutrition of around 18% in our study is in concordance with the findings in Guigoz’s review from 2006, including a large sample of studies of patients in different settings and in different countries, which showed a prevalence of malnutrition of $21\pm0.5\%$ in institutionalized elderly people [97] as well as the findings of a previous Swedish study [34].

“Frail elderly syndrome” is, as previously discussed, a frequently used term that has many definitions but that is clinically characterized by muscle wasting, poor balance and mobility, and decreases in cognitive performance. With the complexity of its clinical manifestations, Parkinson’s disease is suggested to be the prototype of this condition [34]. Our results show that both dementia and Parkinson’s disease were more common in the malnourished group of patients, which concurs with the concept of frailty in this group. According to an Asian study, deteriorating MNA is

associated with poor basic ADL status and hospitalization [98]. This was also seen in our study but it should be noted that acute disease or psychological stress is an item in the MNA that could influence this association. As both overweight and underweight have been shown to indicate poor nutritional status [99] it is not contradictory that our longitudinal results show that the group with higher BMI and higher weight were more likely to experience a deterioration in MNA status. The fact that the group of survivors had a better nutritional state also makes it more logical that the participants who lost weight during the period were those with higher baseline BMI values and weights.

"I would like to see more staff around the elderly residents. I would like the old lady to have a nursing staff member next to her at the table when I pass the dining room. It is not like that. Sometimes it is all empty next to her..." (GP2, paper IV)

Renal function

Deteriorating renal function is crucial to consider when prescribing medications and limited renal function leads to adverse outcomes and the need to deprescribe medications.

The prevalence of CKD 4+5 of around 10% in our study is similar to findings from NHs in the US [100]. A longitudinal study on elderly Swedish women showed a decline of eGFR of 16 ml/min/1.73 m² per decade in women aged 75–85, and the decline appears to be non-linear [101]. The decline seems to be even more pronounced in our population with 3.7 ml/min/1.73 m² per year which might be expected as we studied older NH residents. Our results are also consistent with findings from NHs in Turkey where a decline in eGFR was associated with cardiovascular disease and mortality [41]. However in all three of the above-mentioned studies the eGFR was based on creatinine alone, which may have overestimated the eGFR in an elderly population [41, 100, 101]. More than half of our NH population had a rapidly declining renal function, which is considerably greater than reports from another study where only about 24% of the population had rapidly declining renal function [79], although that population was on average 15 years younger than ours.

Our study shows that the formulae using the combination of both creatinine and cystatin C agreed well with each other but not as well with the creatinine-based MDRD as previously reported [102].

Age, the number of patients with HF, and the number of medications were significantly higher in the population with lower eGFR. The relationship between increasing age and decreasing renal function is well established and it could be

questioned whether a decreased eGFR in elderly is pathological or simply physiological, though it is clear that an eGFR <60 ml/min/1.73 m² is associated with a high frequency of chronic disorders, hospitalization and mortality, and is therefore important to document [103, 104]. As the most important factor for rapidly declining renal function seem to be the number of medications, it is important to note that elderly people living in nuNHs often use many different medications, including many cardiovascular drugs [63]. It must be acknowledged, however, that the association between multiple medications and a rapidly declining renal function may not be causal, and could reflect the association with other comorbidities. Indeed, the association is strongest for the patients with cardiovascular drugs ($p<0.001$), but not significant for the use of multiple drugs for a wider variety of comorbidities. The association between a high number of medications and rapidly declining renal function may be partly due to the polypharmacy itself, but we suggest that this also reflects the association with underlying morbidity, particularly cardiovascular.

“As soon as a problem arises, I take a look at the medication list and figure out which one to deprescribe” (GP10, paper IV)

The GP perspective on elderly care

Hospital physicians in Sweden are often frustrated when taking care of elderly NH patients admitted to hospitals because the patients are “too complex and time-consuming to fit in” [105]. The physicians feel they lack the holistic view of the patient and with an inadequate remuneration system and inappropriate routines the care of the elderly patients at hospitals in Sweden is not adapted for elderly with multimorbidity [105]. The situation for hospitalized elderly needs to be improved but it also shows the importance of stable care at the NH, without inappropriate admissions to the hospital. To optimize the care of the elderly at NH we suggest that the relationship between the GP and the NH nurse should be prioritized, with avoidance of unnecessary transfers of nurses and GPs between different departments and services, and it is important to reflect on the fact that a continuous relationship is beneficial.

There is a lack of professional networks of GPs working with elderly care. The GPs set up their own individual way of working with elderly in NH. This is also seen in a recent questionnaire survey, where only 64% of the GPs involved in NHs felt adequately trained for the task [106]. This seems unfruitful and it would be beneficial for the profession to have both professional networks and national guidelines.

The theme “Concern for the patient” could be interpreted in Lazarus and Folkmann’s [60] perspective on coping strategies in stress. Stress arises when there is an imbalance of resources and demands, and their theory describes the emotion-focused coping strategies and the problem-focused coping strategies for dealing with stress. The emotion-focused coping strategies are that the individual needs to handle and face his or her own emotions in the situation. Thereafter, the coping strategy can be to create an emotional distance from the situation or try to find a positive glimpse in a hopeless matter. Here, the doctors were careful to note that they are dealing with the continuum of ageing/end-of-life care. This perspective seems to be well established and in agreement with their own feelings, and this seems to make the decisions about e.g. referring to the hospital or CPR (Cardio Pulmonary Resuscitation) more straight forward.

“I have done much thinking about how I want to be treated in that situation, and I have talked to my relatives about it. If I get seriously ill and suffer from dementia, please don’t fight to prolong my life for eternity” (GP2)

But when it came to concerns about the patients’ medicalization and care needs it seemed to be harder for the doctors to deal with stress. Problem-focused coping strategies mean that you try to change a situation to be able to deal with it. Here, the doctors wanted to change the system. They wanted more resources, more nursing staff and further education for the nursing staff to solve the problem and minimize their stress in the powerlessness situation. Also, the nurse as a key person could help the GP in coping with this stress.

“I want to get away from giving medicines because of lack of resources in the nursing staff. There is a tendency for this, with too much focus on the doctor.” (GP11)

The GPs found their NH work enjoyable despite complicated patients, relatives and nursing staff with different demands. This can be seen through Antonovsky’s salutogenic perspective: Sense of Coherence [61]. This is a theory of how an individual can deal with stress, describing three components important for the sense of coherence: 1. Comprehensibility, 2. Manageability and 3. Meaningfulness. Comprehensibility refers to a sense that you can understand events in your situation and this can be seen in our category “holism”. The GPs felt they had a holistic view of the patients, which gave them a reliable comprehension of the situation. Manageability is a belief that you have the ability, resources and help necessary to make things manageable and within your control. In our results this is seen in the categories collaboration and freedom and variation, where the GPs described good support from the NH nurse. They described having control over their time schedule and that they could make their own priorities, thus making their task manageable. Meaningfulness is a sense that there is a good reason or purpose to care about what happens. In the category meaningfulness this was described as very important for

the GPs' satisfaction in that they felt that they made an important difference for the patients in NH.

"I believe and I think that it is extremely important and I think that one can contribute greatly to the well-being of the patient in many ways" (GP7, paper IV)

Strengths and limitations of papers I–III

The SHADES study is unique in that the population studied was old and frail, with a mean age of 85 years. In most other studies, this group is excluded [107]. Over 400 patients were studied, which provided substantial data for mapping the study population. Since the patients were living in NHs, the reports of medications and compliance with medications may have been more reliable than in other settings. SHADES followed elderly subjects over time in their regular care setting, while most other studies have been either cross-sectional [30] or confined to hospitalized patients [108]. With regard to the high mortality rate in this age group, our longitudinal setting is unique.

The study is limited in that the sample of NHs was not randomly selected, but rather selected for reasons of convenience from three different areas in Sweden, with NHs whose staffs were interested in joining the project being asked to participate. However, the NHs included did not differ notably from other NHs in Sweden [1]. There is limited access to NHs in Sweden and consequently the population in NHs represents the group of elderly individuals in society in greatest need of care [57]. Therefore, the results cannot be generalized to the overall population in this age group.

It is also important to note that these results are from an observational study so that they are limited to generating hypotheses, and cannot be used to infer causality.

Strengths and limitations of paper IV

Semi-structured interviews with a colleague have both strengths and weaknesses. On one hand there is a mutual respect and understanding of the basics in the profession. On the other hand there can be things left unspoken that are built into the profession and which cannot be seen from the outside. Therefore the co-author with a different profession was chosen to moderate the focus group. In view of the preconceptions of the first author as being a GP, involved in other NH studies, the co-researchers (also GPs, and one behavioural scientist) viewed the material in

every step of the process of analysing data to supplement each other's statements and interpretations in order to achieve trustworthiness [109].

In this study we used a sample of GPs from the south of Sweden which means that the results are best interpreted in similar settings, but not necessarily transferable to other countries where NHs may have a different structure. The interviewed GPs were of different ages and had diverse types of experience which increased the transferability [83]. Only three of the 12 GPs were male, which created a gender imbalance in the group. Working with NH in Sweden is usually optional for a GP. All of the 12 interviewed GPs were interested in elderly care and found their work interesting and important. This may have been reflected in our study, giving a more positive picture of the work at NH. The focus group was created to deepen the themes derived from the interviews, and maybe to develop new categories. The participating GPs were all satisfied when the categories and themes derived from the interviews were presented. This can be seen as a confirmation of our results which created a thorough member check, strengthening the credibility of our study. The fact that no new categories evolved during the focus group discussion could be because the participants already had said the essence during the interviews, or that the pre-existing themes did not inspire any further discussion.

Conclusions – challenges and possibilities for clinical implications

- We suggest that the estimated prevalence of diagnosed HF in NH in Sweden would be higher if BNP measurements were used to select patients for further investigation. The use of medications in the patients with HF diagnoses was not in accordance with current guidelines regarding use of HF medications in elderly individuals. The **challenge** for the clinical practitioners is to manage without too many burdensome investigations for the elderly patient, to be more careful in diagnosing patients with HF and when HF is diagnosed, to treat the patients according to guidelines. The **possibilities** for a better quality of life for the patients increase if they are correctly diagnosed as the chance of getting more accurate treatment for the condition then increases.
- We found that malnutrition and risk of malnutrition were common in elderly NH residents. Moreover, the prevalence of malnutrition and risk of malnutrition increased over time and was associated with lower survival. The **challenge** for the future is to intervene with nutritional programs at right time, in the right individuals to prevent malnutrition. As BMI and weight were higher in the group with deteriorating MNA status, it is

important to evaluate nutritional state with validated assessment tools, and nutritional interventions should be considered also in better nourished groups, as well as in malnourished individuals, as there then is a **possibility** to prevent declines in nutritional state over time.

- Impaired renal function was common in the NH population and it is important to diagnose this, as it is associated with higher mortality. Polypharmacy was associated with increased risk of rapidly declining renal function. It is therefore important to adjust doses based on accurate renal function and it is a **challenge** for the physicians to prescribe adequate medications. In 2013 the National Board of Health and Welfare recommended a Swedish standard for calculating eGFR. This is now in use in many health care facilities, where as a physician you can order eGFR from the laboratory and get this calculated from a blood sample of cystatin C and creatinine. The use in elderly was stated as being in need of further studies. We did not have the possibility to compare the eGFR with GFR of invasive measurements because of practical reasons. We were nevertheless able to show that the eGFR from the recommended Swedish formula was in excellent agreement with the CKD-EPI formula, also based on both cystatin C and creatinine. For practitioners this provides a **possibility** to get an accurate eGFR to adjust drug dosage in the elderly residents. When the physician can trust the eGFR calculation, the physician will have the **possibility** to both prescribe and deprescribe medications in a safer way. As we showed that more than half of the population has an eGFR over 30 ml/min/1.73m², this may open for a possibility that more HF patients could in fact be treated with ACE-inhibitors with careful monitoring of the renal function and electrolyte balance, as recommended in the guidelines [23].
- GPs involved with elderly care at NHs focused on the well-being of the patients and found their work enjoyable and important for the patients at the NH. There is a **challenge** in the different perspectives on nursing care vs. medications between the GP and the staff and there is a need for guidelines and discussions as well as further research on this topic. The striving for the well-being of the patient was eased if there was a good and continuous relationship with the NH nurse. To achieve the best **possibilities** for future elderly care, the preservation of continuous relations between GPs and nursing staff should be prioritized as well as the creating of GP networks. The feeling of satisfaction about the task, such as creating a positive sense of coherence for the GPs, is important to investigate further. The low number of active GPs together with high retirement rates among GPs in Sweden is a **challenge** for future PHC and there is a need for a more solid recruitment base. The GPs in this study present a sense of coherence larger at the NH than at the PHCC. If this could be extrapolated and studied further

then this could perhaps provide **possibilities** to better organize the work for GPs at the PHCC and serve to recruit more doctors to PHC.

Future studies

Studies in frail elderly are important for future health care. The use of BNP for further selection of potential patients with HF and the results of HF treatment according to guidelines would be interesting to further evaluate in a NH population.

The process of a continuous deteriorating nutritional state over the years in a NH population would be interesting to study when intervening with nutritional supplementation.

Future studies of the equations for estimation of GFR in the elderly should preferably be further studied compared to invasive measures of GFR in NH populations.

For better cooperation in NH a qualitative study on prescribing medications in NH would be interesting to initiate including, not only GPs, but nurses and nursing staff as well.

Svensk sammanfattning

Allteftersom medellivslängden ökar, ökar också behovet av kunskap om den äldre befolkningen och dess vårdbehov. Äldre patienter på särskilda boenden (SÄBO) har i hög grad många sjukdomar men samtidigt riskfaktorer som försvårar optimal medicinsk behandling och diagnostik. Undernäring/malnutrition, eventuell hjärtsvikt och nedsatt njurfunktion är exempel på riskfaktorer som bör tas i beaktande vid läkemedelsbehandling hos äldre.

Tre delarbeten i avhandlingen utgår från SHADES (Study of Health and Drugs in the Elderly in nursing homes in Sweden) som är en individbaserad prospektiv studie som utformats för att beskriva hälsotillstånd, livskvalité, sjukvårdsbehov samt läkemedelsbehandling över tid, hos äldre boende på SÄBO. Studien utgick från patienter boende på 11 olika SÄBO i tre städer i södra Sverige: Eslöv, Jönköping och Linköping, som inkluderades mellan 2008 och 2011. Patienterna följdes över tid, och med sex månaders intervall togs blodprov, utfördes upprepade skattningsskalor och inhämtades läkemedelsuppgifter så att betydelsen av olika riskfaktorer kunde studeras och relateras till utfall som död, sjuklighet, och läkemedelsbehandling.

För att finna en djupare förståelse och ytterligare perspektiv utfördes delarbete IV som en kvalitativ intervjustudie där distriktsläkares upplevelse av arbetet med äldre studerades.

Delarbete I, hjärtsvikt.

Hjärtsvikt är en mycket vanlig och symptomgivande diagnos hos den äldre populationen men är ofta underbehandlat och feldiagnosticerat med ökad sjuklighet och dödlighet som följd. Hos hjärtsviktpatienter över 80 år skiljer sig ofta symtombilden jämfört med yngre patienter. Konfusion, minnessvikt, trötthet och sänkt aktivitetsnivå kan vara de främsta tecknen på sviktande hjärtfunktion hos äldre hjärtsviktpatienter. Diagnostiken av hjärtsvikt baseras på symtombilden samt fastställs med hjälp av ultraljud (UKG). Laborativa data som BNP (B-type Natriuretic Peptide) kan vara av värde i diagnostiken men det finns fortfarande inget enhetligt sätt att bedöma detta på som led i utredningen av hjärtsvikt hos äldre. När hjärtsvikt är diagnosticerat kan medicinsk behandling öka livskvaliteten och minska sjukligheten. Även om de flesta kliniska studier är gjorda på yngre patienter, skiljer

sig inte behandlingsrekommendationerna för äldre patienter med hjärtsvikt förutsatt att man tar hänsyn till samsjuklighet, njurfunktion och övrig läkemedelsbehandling. Målsättningen med vår studie var att kartlägga hjärtsviktsprevalensen hos boende på SÄBO i Sverige, och i samband med detta även undersöka eventuell underdiagnostik genom att samtidigt bedöma patienternas BNP-värden. En ytterligare målsättning var att undersöka patienternas läkemedelsbehandling och se hur denna stämmer överens med aktuella riktlinjer för hjärtsviktsbehandling. Vår studie visar att prevalensen av patienter med diagnosen hjärtsvikt på SÄBO i Sverige är 15,4 % men den förväntade prevalensen av hjärtsvikt torde vara betydligt högre om man utgick ifrån BNP-värden för vidare diagnostik. Läkemedelsbehandlingen vid hjärtsvikt varierade mycket och var i många fall omodern. Följsamheten till gällande behandlingsrekommendationer var generellt låg.

Delarbete II, malnutrition

Undernäring/malnutrition är vanligt hos äldre patienter på SÄBO. Orsaken till malnutrition kan vara bakomliggande somatiska sjukdomar men även psykologiska faktorer, polyfarmaci och hur omgivningen ser ut spelar roll. Åldrandet i sig leder till avmagring efter hand men i vilken utsträckning det kan kopplas till malnutrition är inte klarlagt. Malnutrition leder både till ökad sjuklighet och ökad dödlighet.

Vi ser i vår studie att prevalensen malnutrition uppgår till ca 18 % på SÄBO i Sverige. Ungefär 40 % löper risk för malnutrition och knappt 42 % har normalt nutritionsstatus. Malnutrition är korrelerat till sämre överlevnad. Hos de som överlever ökar malnutritionsprevalensen efter 24 månaders uppföljning och är då 24,6 %. Faktorer som påverkar nutritionsstatus i negativ riktning över tid är högre utgångs-BMI och sjukhusinläggningar.

Delarbete III, njurfunktion

En väl fungerande njurfunktion är av central betydelse för hälsan. Njurfunktionen avtar med åldern. Nedsatt njurfunktion medför kraftigt ökad risk för död och sjuklighet i främst kardiovaskulära sjukdomar. Sänkt njurfunktion leder även till ökad risk för biverkningar av läkemedel samt ökad risk för att läkemedlen leder till ytterligare njurskada. Det är viktigt för läkare att enkelt och säkert kunna göra en bedömning av patienternas njurfunktion inför ställningstagande till insättning eller utsättning av läkemedel.

Över 60 % av de boende hade försämrad njurfunktion. De med sämre njurfunktion var generellt äldre, hade fler läkemedel och i högre utsträckning hjärtsvikt. Ju fler läkemedel desto högre var risken att njurfunktionen sänktes över tid. De formler

som har tagits fram och rekommenderas av SBU för skattning av njurfunktionen hos yngre var i utomordentlig överensstämmelse med den mer internationellt använda kreatinin- och Cystatin C-baserade CKD-EPI-ekvationen även hos de äldre.

Delarbete IV, distriktsläkarnas upplevelse av äldrevården

En kvalitativ intervjustudie genomfördes med 12 distriktsläkare med ansvar för patienter på SÄBO. Efter den första analysen diskuterades resultaten tillsammans med distriktsläkarna och delarbetsförfattarna vid en fokusgruppsintervju. Texten från intervjuerna och fokusgruppen tolkades med kvalitativ innehållsanalys.

Bilden som framkom ur distriktsläkarnas berättelser var att de fann arbetet med äldre på SÄBO meningsfullt och viktigt. Det sågs som ett behagligt alternativ till det övriga arbetet på vårdcentralen. Trots att patienterna är betydligt sjukare och att svåra beslut behövde fattas, så kände sig läkaren tryggare i sin roll på äldreboendet jämfört med på vårdcentralen tack vare en bättre helhetssyn på patienten och med allsidig och pålitlig information kring patienten från SÄBO-sköterskan. Betydelsen av kontinuitet i läkare-sjuksköterska relationen och ett stort behov av kollegiala nätverk poängterades nog.

Patientnytta

Eftersom det tydligt föreligger en brist på vetenskapliga studier på sköra äldre patienter så vill vi med detta avhandlingsarbete belysa faktorer som kan påverkas för att optimera vården av äldre patienter och identifiera problemområden där riktade insatser kan förbättra äldrevården.

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