Health inequalities in care for persons with dementia

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"Peace cannot be kept by force. It can only be achieved by understanding."

– Albert Einstein –

POPULAR SCIENCE SUMMARY OF THE THESIS

Dementia, a chronic and progressive syndrome, is an umbrella term covering many neurodegenerative conditions, such as Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia, Parkinson disease's dementia and other dementias. It is estimated that in 2019, there were 55.2 million people worldwide living with dementia. The prevalence of dementia will reach 78 million people in 2030 and 139 million people in 2050.

In 2017, the World Health Organization (WHO) released a "Global action plan on the public health response to dementia", with an aim to enhance the quality of life for persons with dementia, their family and caregivers; as well as to reduce the negative effect of dementia on patients and the society. One of the main principles of the global action plan is universal health and social care coverage for persons with dementia, protecting the equal access to a continuum of promotion, prevention, diagnostics, and care for all persons with dementia. In 2021, the WHO again emphasized the importance of equality for persons with dementia in their "Global status report on the public health response to dementia".

The overall objective of this thesis was to examine the health inequality among persons with dementia regarding access to different types of care in Sweden. In separate studies, this doctoral thesis examined specific aspects such as costs of stroke rehabilitation, patient satisfaction with stroke care and rehabilitation, and the influence of socioeconomic positions and immigration on the provision of dementia diagnosis, medications, and long-term care.

In the **studies 1 and 2**, we compared inpatient stroke rehabilitation costs and patient satisfaction with stroke care between stroke patients with and without dementia. **Study 1** found that the proportion of stroke patients receiving inpatient rehabilitation was significantly lower in the dementia group, compared to the non-dementia group. Lower inpatient stroke rehabilitation costs were seen in persons with dementia. This was due to shorter length of stay in persons with dementia. The main finding of **study 2** was that lower satisfaction with stroke care was present in persons with dementia, compared to persons without dementia. **Studies 1 and 2** revealed health inequalities in stroke care and rehabilitation for persons with dementia. **Studies 3, 4 and 5** evaluated the dementia diagnostic process, the use of anti-dementia medications and long-term care for persons with dementia with different socioeconomic positions or immigration status. **Study 3** showed that persons with dementia from lower socioeconomic position were less likely to receive specific dementia diagnostic examinations, receive a specified dementia diagnosis, and be diagnosed at a memory clinic, in comparison with persons from higher socioeconomic positions. Meanwhile, in **study 4**, we concluded that education was significantly associated with the likelihood of receiving any kind of long-term care or home care, while income was not. Additionally, in **study 5**, immigration was found not to significantly affect the dementia diagnostic process or the prescription of anti-dementia medications.

In summary, we conclude that health inequalities in care for persons with dementia exist and should be assessed and controlled by health care policymakers. The expectations and experience with care of the individuals with dementia and their caregivers also need to be investigated. All these findings pertain to Sweden, a high-income country with historic tradition of long-term care and well-prepared care for persons with dementia. The research topic should be addressed from the context of lower- and middle-income countries, where two-third of persons with dementia are residing, and where health care systems are not as well-developed.

ABSTRACT

Health inequality is defined as any difference, disparity, or variation in all health-related aspects of individuals and groups. The World Health Organization regards ensuring equal access to promotion, prevention, diagnostics, and care for persons with dementia as a crucial goal in their global action plan for dementia. This thesis evaluated care for persons with dementia not only from a specific facet (cost of stroke rehabilitation and patient satisfaction), but also from an overall viewpoint (socioeconomic positions and immigration).

The overarching objective of this thesis was to explore the difference in care for persons with dementia in Sweden, in terms of costs of stroke rehabilitation, patient satisfaction with stroke care, socioeconomic positions and immigration.

Study 1 estimated inpatient stroke rehabilitation costs for persons with dementia, in comparison with persons without dementia. Our study showed that persons with dementia had significantly lower mean inpatient rehabilitation costs compared to their counterparts, with SEK 103,693/US$ 11,932 and SEK 130,057/US$ 14,966, respectively in the two groups. Persons with dementia had more comorbidities and poorer functioning, by comparison with non-dementia controls. The inpatient rehabilitation costs for persons with dementia were approximately 0.84 times the costs in persons without dementia. We also observed that stroke patients in the dementia group had significantly lower proportion of receiving inpatient stroke rehabilitation, compared to those in the non-dementia group.

Study 2 assessed whether persons with and without dementia were satisfied with stroke care and rehabilitation after suffering stroke. We discovered that persons with dementia, answering themselves, were less likely to be satisfied with acute stroke care, health care professionals' attitude, communication with doctors, and stroke information that they had received, but not regarding inpatient or outpatient rehabilitation. When their caregivers helped to report, persons with dementia had significantly lower satisfaction with all items, compared to their non-dementia controls. No significant association between proxy-reported satisfaction and dementia status was found, apart from satisfaction with outpatient rehabilitation as answered by the family.

Study 3 addressed the disparity in dementia diagnostics and anti-dementia medications among different socioeconomic positions. Our findings were that higher income persons with dementia were more likely to obtain the complete basic dementia diagnostic work-up, clock test, blood analysis, MMSE, CT-MRI, neuropsychological assessment, and occupational therapy assessment. Persons with dementia with higher education had a higher chance of acquiring these dementia examinations, apart from blood analysis and MMSE. Persons with dementia with higher education or income were more likely to be diagnosed at a memory clinic. There was no significant association between socioeconomic positions and the prescription of anti-dementia medications, except for the association between education and the use of memantine. This association showed that the highest educated persons with dementia had higher chance of receiving memantine.

Study 4 explored the association between the receipt of long-term care and socioeconomic positions of person with dementia. We found that higher educated persons with dementia were significantly more likely to acquire any kind of long-term care and home care, as well as had more monthly average number of home care hours, compared to lower educated persons with dementia. No significant association between income and the performance of any kind of long-term care or home care was found in this cohort. The receipt of institutional care was not significantly associated with either education or income. In the sub-group analysis, we observed that persons with dementia from lower socioeconomic positions and living alone were less likely to receive any kind of long-term care and home care. This association disappeared in persons with dementia living with another adult. Greater monthly average number of home care hours was found in cohabiting persons with dementia with higher income, but lower duration of home care hours was seen in individuals living alone.

Study 5 investigated how immigration status influenced the dementia diagnosis process and the use of anti-dementia medications. The main result of this study was that health inequalities in dementia diagnostics and the prescription of anti-dementia medications between Swedish-born and foreign-born persons with dementia were not obvious. Immigration was significantly associated with the receipt of complete basic dementia diagnostic work-up and the single diagnostic tests, the types of diagnostic unit and the prescription of anti-dementia medications. For instance, persons with dementia who were born in Asia, Africa and the other European countries had lower probability of receiving the complete basic dementia diagnostic work-up. However, most of these associations were not statistically significant anymore when adjusting for MMSE score.

To conclude, health inequalities in stroke care and rehabilitation were found, in which persons with dementia had lower inpatient stroke rehabilitation costs and lower satisfaction with stroke care, compared to persons without dementia. Socioeconomic inequalities in the dementia diagnostic process were shown by significantly lower likelihood of obtaining specific dementia diagnostic examinations, receiving a specified dementia diagnosis, and being diagnosed at a memory clinic in persons from lower socioeconomic positions. Meanwhile, socioeconomic inequalities in long-term care, as well as health inequalities in dementia diagnostic process and anti-dementia medications, were not profound regarding immigration in this study cohort.

LIST OF SCIENTIFIC PAPERS

I. **Hoang MT**, Kåreholt I, von Euler M, Jönsson L, von Koch L, Eriksdotter M, Garcia-Ptacek S. Costs of Inpatient Rehabilitation for Ischemic Stroke in Patients with Dementia: A Cohort Swedish Register-Based Study. 2020;73(3):967-79.

II. **Hoang MT**, Kåreholt I, von Euler M, von Koch L, Eriksdotter M, Garcia-Ptacek S. Satisfaction with Stroke Care Among Patients with Alzheimer's and Other Dementias: A Swedish Register-Based Study. Journal of Alzheimer's Disease. 2021;79:905-16.

III. **Hoang MT**, Kåreholt I, von Koch L, Xu H, Secnik J, Religa D, Tan ECK, Johnell K, Garcia-Ptacek S. Influence of Education and Income on Receipt of Dementia Care in Sweden. Journal of the American Medical Directors Association. 2021;22(10):2100-7.

IV. **Hoang MT**, Kåreholt I, Schön P, von Koch L, Xu H, Tan ECK, Johnell K, Eriksdotter M, Garcia-Ptacek S. Socioeconomic position and long-term care of persons with dementia. *Manuscript.*

V. **Hoang MT**, Kåreholt I, Lindgren E, von Koch L, Xu H, Tan ECK, Johnell K, Nagga K, Eriksdotter M, Garcia-Ptacek S. Immigration and disparity in dementia diagnostics and drug prescription. *Submitted.*

SCIENTIFIC PAPERS NOT INCLUDED IN THE THESIS

I. Xu H, Garcia-Ptacek S, Secnik J, Edlund AK, Westling K, **Hoang MT**, Johnell K, Tan ECK, Religa D, Eriksdotter M. Changes in Drug Prescribing Practices Are Associated With Improved Outcomes in Patients With Dementia in Sweden: Experience from the Swedish Dementia Registry 2008-2017. Journal of the American Medical Directors Association. 2021;22(7):1477-83.e3.

II. Roheger M, Xu H, **Hoang MT**, Eriksdotter M, Garcia-Ptacek S. Conversion between the Mini-Mental State Examination and the Montreal Cognitive Assessment for patients with different forms of dementia. Journal of the American Medical Directors Association. *In press*.

CONTENTS

LIST OF ABBREVIATIONS

ATC	Anatomical Therapeutic Chemical
CCI	Charlson Comorbidity Index
CDR	The Swedish Cause of Death Register
ChEIs	Cholinesterase inhibitors
CI	Confidence intervals
CT-MRI	Computed tomography/Magnetic resonance imaging
ICD	The International Classification of Diseases
LISA	The Swedish Longitudinal Integrated Database for Health Insurance and Labour Market Studies
MMSE	Mini-Mental State Examination
MoCA	The Montreal Cognitive Assessment
mRS	modified Rankin Scale
NPR	The Swedish National Patient Register
OR	Odds ratio
PDR	The Swedish Prescribed Drug Register
PWD	Persons with dementia
Riksstroke	The Swedish Stroke Register
RR	Rate ratio
RUDAS	The Rowland Universal Dementia Assessment Scale
SEP	Socioeconomic position
SSR	The Swedish Social Services Register
SveDem	The Swedish registry for cognitive/dementia disorders
WHO	World Health Organization

1 INTRODUCTION

Why explore health inequalities in care for persons with dementia?

Health inequality is defined as any difference, disparity or variation in the health care of people or groups. [1] In the "Global action plan on the public health response to dementia" released in 2017, the World Health Organization (WHO) indicated that assuring the equal access to a broad range of promoting, preventive, diagnostic and care services for all persons with dementia (PWD) is one of the main principles of the global action plan. [2] This issue is again highlighted in their "Global status report on the public health response to dementia" in 2021. [3]

According to a recent report from the WHO, about 55.2 million people worldwide are living with dementia. [3] The number of PWD will increase to 78 and 139 million people in 2030 and 2050, respectively. [3] At the individual level, dementia is a primary cause of disability and dependency, influencing not only patients themselves, but also their family, caregivers and communities. [2] At the societal level, dementia creates social and economic burdens, especially increasing costs of care and decreasing productivity. [2] The global cost of dementia in 2019 was estimated to be US$ 1.3 trillion, and projected to reach US$ 2.8 trillion by 2030. [3]

Thus, ensuring the equal access to care for all PWD is important for effective and efficient health care resource allocation. The overarching objective of this thesis was to assess the health equality in care for PWD in Sweden. As a Scandinavian country with democratic and egalitarian traditions, Sweden has a universal health coverage system. The Swedish health care system is mainly subsidized by the government, in which everyone can seek and receive treatment equally. Co-payments vary among regions in Sweden, however, they are not expensive (maximum SEK 1150 per individual per year). [4] Despite this universal health coverage, health inequality in care for persons with dementia persists. [5-10] In separate studies, we examined health inequality in care for PWD in two different ways: (1) health inequality in stroke care between persons with and without dementia after suffering from stroke (costs of stroke rehabilitation, and satisfaction with stroke care in PWD); (2) health inequality in care for the dementia population regarding their socioeconomic position (SEP) and immigration (the influence of SEP and immigration on dementia diagnostic process, medications and long-term care).

2 LITERATURE REVIEW

2.1 HEALTH INEQUALITY

2.1.1 Health inequality definition

Health inequalities is usually described as any difference, disparity or variation in health status or in the allocation of health care resources among population groups, regardless of whether it is just or unjust. [1, 11, 12] Health inequity is defined as any health inequality that is unfair, unjust but avoidable or remediable. [1, 11, 12] Health inequity is a normative concept, which depends on one's theory of justice, one's theory of society and one's reasoning of health inequalities. [1, 13] Health inequity cannot be precisely measured or monitored, because it is impossible to identify which differences are inequitable, or what proportion of a difference is unjust or unfair. [1, 13] In comparison, health inequality is a descriptive and measurable concept, and plays as an indirect means of assessing health inequity. [1, 13] Thus, in this thesis, we investigated health inequality in care, instead of health inequity.

2.1.2 General rationale of the thesis

Equal access to health care based on each person's needs is the policy in Sweden since 1982. [14] According to the Swedish Health and Medical Services Act 2017:30, all citizens and residents living in Sweden have the right to equal access to health care regardless of sex, SEP, geographical location of residence, nationality, ethnicity, as well as cultural, religious and linguistic background. [14]

Health inequalities in care and treatment of various diseases were found in many previous studies in Sweden as well as other countries with similar socioeconomic context. For example, a Swedish register-based study showed that adherence to statin treatment after stroke was less common among foreign-born patients, compared to Swedish-born patients. [15] Another Swedish nationwide study in 2021 found that higher educated persons with bipolar disorders were more likely to receive psychological therapies, and had lower likelihood of getting antipsychotics and antidepressants, compared to lower educated people. [16] Another study found that unemployed persons with heart failure had significantly lower access to angiotensin-converting enzyme inhibitors. [17]

Health inequalities in care for PWD in Sweden were mentioned in preceding studies from SveDem, regarding specific treatment of stroke for persons with dementia, types of dementia diagnosis unit, or cohabitation. [5-10] Meanwhile, in the latest report of the WHO or Alzheimer's Disease International, equal access to promoting, preventive, diagnostic and care services for all PWD is mentioned as one of the most important goals. [2, 3, 18] From a clinical viewpoint, health inequality is a signal of unmet care needs among PWD. From a public health perspective health inequality reflects a gap in the care process for PWD in Sweden. To our knowledge, no previous studies in Sweden explored how socioeconomic position and immigration affect the care and treatment for persons with dementia, considering baseline cognition. Costs of rehabilitation and patient satisfaction after stroke in persons with dementia were previously

understudied. This is the knowledge gap that this thesis addresses. In this thesis, we evaluated health inequality in care for PWD from several viewpoints. This thesis approached health inequality in care for PWD not only from a specific facet (stroke care and rehabilitation), but also from an overall perspective (SEP and immigration). Literature reviews on these topics were summarized below.

2.2 DEMENTIA

2.2.1 Dementia definition

Dementia is defined as an acquired brain syndrome featuring a deterioration of behavioral and cognitive function that: [19, 20]

(1) Interferes with the ability either to handle activities of daily living (ADL) or to work

(2) Embodies a deficit from prior higher degrees of functioning and performing

(3) Cannot be justified by delirium or major psychiatric disorders

(4) Is identified and diagnosed by an interview with the patient or their family or friend, together with an objective cognitive assessment

(5) Includes at minimum two of the below criteria, in which the patient:

- Cannot obtain and memorize new information

- Fails to complete complicated tasks demonstrating impaired executive function

- Has decreased visuospatial abilities

- Has damaged language abilities

- Presents changes in their personality or behavior

The impairment of at least two cognitive or behavioral domains distinguishes dementia from normal aging, intellectual disability, or single learning disorders. [19-21] The difference between dementia and mild cognitive impairment, a state of cognitive impairment with relatively preserved daily functioning, is the significant reduction in capacity to continue working and limitations in activities of daily living. [20-24] Dementia progression is heterogeneous within and between PWD, depending on the features of disease and patients. [25]

2.2.2 Dementia types

Dementia is an acquired syndrome, rather than a specific disease. Dementia, an umbrella term, includes many diseases, such as Alzheimer's dementia, vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia, Parkinson disease's dementia, and other dementias. [19, 21, 22, 26-28] Dementia might be dichotomized into neurodegenerative and non-neurodegenerative diseases. [22] However, PWD might have both neurodegenerative disease (e.g. Alzheimer's disease) and non-neurodegenerative disease (e.g. vascular dementia). [22]

Alzheimer's disease, the most prevalent dementia type with about 60-80% of all cases worldwide, is defined as a progressive loss of synapses and neurons, including the accumulation of amyloid plaques, neurofibrillary tangles, as well as substantial cholinergic deficits. [24, 29-32] Alzheimer's disease begins insidiously with memory deterioration and progresses with impairment in other cognitive functions, such as attention, language, reading or speaking. [19, 32, 33] The important risk factors of Alzheimer's disease include age, genetics and environment which lead to the increase of amyloid-β42, the increase of amyloid-β aggregation, the decrease of amyloid-β clearance, and thus, causing the neuronal cell death and the loss of synapses. [24, 33, 34] All these factors result in cognitive decline in a progressive manner. Familial Alzheimer's disease, an autosomal dominant disorder, starts in people less than 65 years old and is caused by the mutation of amyloid precursor protein (APP), presenilin 1 (PSEN1) and presenilin 2 (PSEN2) genes. [24, 33-35] Sporadic Alzheimer's disease, with onset age over 65 years, is caused by apolipoprotein E (APOE) ε4 allele, age and environmental factors (high cholesterol, high blood pressure or unhealthy living habits). [24, 33-35] Sporadic Alzheimer's disease accounts for 95-99% of cases of Alzheimer's disease. [24]

Vascular dementia typically refers to the loss of cognitive function caused by stroke and other vascular brain injuries where obstruction or reduction of blood flow to the brain causes oxygen and nutrient deprivation. [36, 37] The risk factors of vascular dementia encompass sociodemographic factors (such as sex, education), chronic conditions (such as diabetes, hypertension), and unhealthy lifestyle (such as smoking). [36, 37] Vascular dementia is the second most common dementia type, however, pure vascular dementia only accounts for less than 10%. [24, 36, 37] Vascular dementia is more commonly present in combination with Alzheimer's disease as mixed dementia. [24, 36, 37] Mixed dementia is a form including at least two different types of dementia occurring simultaneously. [19, 22, 38, 39] Apart from mixing with vascular dementia to constitute the most common type of mixed dementia, Alzheimer's disease also coexists with other types of dementias, such as dementia with Lewy bodies, frontotemporal dementia, or Parkinson disease's dementia. [36, 38, 39]

2.2.3 Dementia cost and epidemiology

The incidence and prevalence of dementia varies among studies and reports. [2, 3, 18, 40] A recent study published in the Lancet 2022 estimated that the number of PWD was 57.4 (95% CI 50.4-65.1) million cases worldwide in 2019. [40] The prevalence of dementia might reach 83.2 (95% CI 73.0-94.6) million cases in 2030, and 152.8 (95% CI 130.8-175.9) million cases in 2050. [40] The low- and middle-income countries accounted for about 60% of prevalent dementia cases and are predicted to have the majority of new cases in the future. [2, 3, 40] Despite the increasing incidence of dementia in low- and middle-income countries, the incidence of dementia in high-income countries is undergoing a downward trend. [2, 18, 40-42] More women are living with dementia than men, with female-to-male global ratio of 1.69. [40] Dementia has negative social and economic effects to all countries. Dementia is ranked as the seventh cause of death and disability worldwide. [3] The total global societal cost of dementia is about US$ 1.3 trillion in 2019, projected to reach US$ 1.7 trillion in 2030, equivalent to 1.1% global gross domestic

product. [2, 3] This proportion is estimated to be 0.2% in the low- and middle-income nations and 1.4% in the high-income nations. [2, 3]

In Sweden, there are approximately 150,000 PWD, with around 24,000-26,000 new cases every year. [43] Although the incidence of dementia is reported to decline, [44] the prevalence of dementia in Sweden is predicted to increase sharply after 2020 when many individuals born in the 1940s reach older ages. [45] Dementia causes a significant burden to the Swedish society and economy. In 2019, 6.1% of total deaths in Sweden were caused by dementia, making it among the top-ten causes of disability and death in Sweden. [46-48] In 2012, the societal costs of dementia were approximately SEK 62.9 billion (about US$ 6.6 billion) in Sweden. [49] A recent study in 2021 showed the direct and indirect mean lifetime costs per person with dementia was estimated to be about SEK 2.3 million (about US$ 240,000). [50]

2.3   DEMENTIA DIAGNOSTIC PROCESS

A clinical evaluation of a suspected dementia case includes a patient's medical history, a cognitive, physical, and neurological examination. [21, 22, 26, 27, 51] Medical history consists of questions about previous and current health status to the patient and their close family member or friend. [21, 22, 26, 27, 51] The medical history enables clinicians to assess the nature, magnitude, and course of cognitive changes. [51] The cognitive examination determines the patient's cognitive impairment regarding nature, presence, and severity. [51] Clinicians might evaluate cultural, educational, linguistic and other issues (for example depression and sleeping disorders), [51] together with screening tools, such as the Mini-Mental State Examination (MMSE), [52] the Montreal Cognitive Assessment (MoCA), [53] or the Rowland Universal Dementia Assessment Scale (RUDAS). [54] The neurologic examination is performed to assess neurocognitive problems such as aphasia, apraxia, and so on. [51] The neurological examination reveals issues pertaining consciousness, awareness, orientation and cognitive function, motor and sensory function, coordination, balance, or reflexes. [21, 22, 26, 27, 51] Because each type of dementia might have similar symptoms, determining the exact dementia type is difficult, particularly if the disease has progressed to an advanced stage. Thus, many people might be diagnosed with unspecified dementia. [21, 22, 26, 27, 51]

The Swedish National Board of Health and Welfare recommends using a complete basic dementia diagnostic work-up to diagnose dementia in the national guidelines for health and social care of dementia in Sweden. [45] The complete basic dementia diagnostic work-up includes completing the MMSE or similar cognitive screening test, the clock test, a blood analysis (calcium, TSH, and either homocysteine or B12 and folate), and neuro-imaging (computed tomography (CT) or magnetic resonance imaging (MRI) of the brain). [45] The MMSE is an assessment tool for cognitive functions, including information about attention, language, memory, orientation and visuospatial function. [45] The CT-MRI provides an image of the patient's brain to assess atrophy and other structural changes of the brain. [45] Furthermore, an assessment of functional ability is implemented by an occupational therapist, who will provide a structured interview for both the person and their family. [45] In Sweden, PWD might receive a dementia diagnosis at primary care centers, or nursing homes. According to the Swedish

registry for cognitive/dementia disorders – SveDem, around 89% of all newly registered PWD in 2020 received the complete basic dementia diagnostic work-up (96% diagnosed in memory clinic vs. 81% in primary care). [43]

2.4 DEMENTIA MANAGEMENT

The WHO recommends five principal purposes for dementia care: (1) diagnosing early to enable early and optimal care, (2) enhancing patients' mental and physical health, activity and well-being, (3) detecting and treating concomitant physical sickness, (4) recognizing and treating behavioral and psychological symptoms, and (5) supplying information and long-term support to caregivers. [29] The Swedish National Board of Health and Welfare also states that the objective of care for PWD is to facilitate daily life and optimize the quality of life for patients during different stages of dementia. [45] Care for PWD should be supplied through a patient-centered approach, in which the person with dementia is put in focus, not the diagnosis. [45] Currently, it is impossible to either cure or reduce the progressive course of dementia. [29] Both pharmacological and non-pharmacological approaches are used to relieve suffering caused by the cognitive and accompanying symptoms (e.g., in mood and behavior), as well as postponing progressive cognitive decline. [51] In addition, due to cognitive and physical impairment, long-term care is necessary for PWD to increase the quality of life and decrease the dependence in activities of daily living.

2.4.1 Pharmacological treatment

The USA Food and Drug Administration has approved six medications to alleviate symptoms of dementia. [21, 27, 45, 51, 55] Acetylcholinesterase inhibitors (donepezil, galantamine, and rivastigmine) are the first medications approved for dementia treatment. These medications inhibit acetylcholinesterase enzyme of the brain, resulting in the increase of acetylcholine abundance at the synaptic cleft for cholinergic neurotransmission. [51] Acetylcholinesterase inhibitors were shown to be associated with long-term modest but persistent cognitive benefits. [56] Donepezil, galantamine, and rivastigmine, which have similar efficacy, are prescribed for persons with mild-to-moderate dementia. [51] In addition, memantine, the NMDA receptor antagonist, is utilized to decrease or stabilize dementia symptoms by affecting chemicals transmitting messages among the brain's nerve cells. [21, 27, 45, 51] Memantine is prescribed alone or concomitantly with acetylcholinesterase inhibitors for persons with moderate-to-severe dementia. [21, 27, 45, 51] These medications are prescribed for persons with Alzheimer's disease or mixed dementia. For persons with vascular dementia, treatments focus on relieving cardiovascular risk factors, for instance heart failure, hypertension, and stroke. [37, 57] However, the American Heart Association/American Stroke Association recommends prescribing donepezil for persons with vascular dementia. [57] There are no specific pharmacological treatments available for persons with frontotemporal dementia. [51] Cholinesterase inhibitors can be prescribed for persons with Parkinson's disease with dementia and dementia with Lewy bodies. [51, 58, 59] In 2021, aducanumab, an amyloid beta-directed antibody indicated in Alzheimer's disease treatment, was approved by the USA Food and Drug Administration. [55] However, aducanumab was only approved under the accelerated approval pathway, in which

this medication is prescribed for patients with a serious or life-threatening illness that provides a meaningful therapeutic advantage over existing treatments. [55] In Europe, the European Medicines Agency has rejected a marketing authorization for aducanumab because of the lack of evidence regarding its efficacy and safety. [60] In Sweden, only acetylcholinesterase inhibitors and memantine are approved and prescribed in practice. [43, 61] According to the latest annual report of SveDem, in Sweden, about 62% of persons with mild-to-moderate Alzheimer's diagnosed in memory clinics and 63% of them diagnosed in primary care centers received acetylcholinesterase inhibitors. [43] Around 24% of persons with moderate-to-severe symptoms received memantine. [43]

Because dementia is usually accompanied by neuropsychiatric and behavioral problems, other medications, such as antidepressants or antipsychotics, are also prescribed to PWD. [21, 45, 51] A selective serotonin-reuptake inhibitor might be used for depression in PWD. [51] SveDem reported about 28% of SveDem-registered PWD were prescribed with antidepressants between 2007 and 2020. [43] Conventional antipsychotics, such as haloperidol, are not recommended. [62] Newer generation antipsychotics, such as risperidone, can be prescribed with caution due to their adverse events in older persons, such as risk for heart failure, stroke, or death. [63] From 2007 to 2020, the percentage of SveDem-registered PWD who were prescribed antipsychotics at memory clinic and primary care, increased from 3.3% at basic registration to 5.9% at fourth year follow-up. [43] In nursing homes, about 15% persons with dementia were treated with antipsychotics in 2020. [43]

2.4.2 Non-pharmacological treatment

A recent review on dementia management itemized non-pharmacological approaches to dementia: [51]

- Bathing and washing frequently to assure personal hygiene

- Communicating effectively by using assisting tools (such as visual aids)

- Doing physical exercise (such as gym, jogging, swimming, yoga)

- Ensuring safety both inside and outside the home

- Having a healthy diet (such as eating more vegetables, less salt)

- Having instructions for medical and advanced care

- Interacting with family, friends and other people

- Participating in activities to improve psychological health (such as yoga)

- Participating in activities which improve cognition (such as reading, writing)

- Preparing a plan for financial issues

- Preparing a plan for long-term care

- Sleeping well with sufficient number of hours.

Several observational studies and randomized controlled trials showed prospective advantages of these non-pharmacologic treatment for PWD. [51] Despite limited benefits, these interventions are inexpensive and generally safe. [51]

2.4.3 Long-term care

Long-term care is defined as "a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (ADL such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (instrumental ADL such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone)". [64, 65] Due to their disability and dependency, PWD are among people with high demand for long-term care.

Long-term care, which is also known as municipal care or social care in Sweden, is state-subsidized and provided for older person (from the age of 65 years old) or for any person with a disability. Municipalities not only provide long-term care services, but also take charge of inspecting providers, managing price and controlling quality. Private providers also supply long-term care services. About 4-5% of the long-term care cost is co-paid by the recipient. [66] Long-term care is provided according to need-based, rather than means-tested criteria. [66] Whenever in need, residents can request long-term care from the municipalities where they are living. The municipalities create eligibility criteria and make the decision on the types and degrees of long-term care that a person should receive. Long-term care includes home care and institutional care. Home care consists of home help with ADL (such as cleaning, shopping), personal care (such as clothing, toileting) and other additional services (such as day care, transportation, meals delivery and etc). [66] Institutional care encompasses nursing homes, residential care facilities as well as specialized group housing for PWD. [66] In Sweden, the implementation of the 1992 Community Care Reform has resulted in a decline of length of stay and number of beds in the hospitals. [66] This decrease has led to the higher demand on long-term care, especially home care among older people and people with disabilities.

2.5 STROKE IN RELATION TO DEMENTIA

2.5.1 Stroke definition & epidemiology

Stroke is defined as "a neurological deficit attributed to an acute focal injury of the central nervous system by a vascular cause, including cerebral infarction, intracerebral hemorrhage, and subarachnoid hemorrhage". [67, 68] Stroke usually arises when the blood flow to the brain is blocked by a blood clot in the brain, or by narrowing or rupturing of blood vessels. [67, 68] When a stroke arises, blood flow is not able to deliver nutrients and oxygen to a specific region of the

brain. [67, 68] Thus, stroke might result in death or focal neurological symptoms such as paralysis, loss of vision and/or speech, confusion, or cognitive issues. [67, 68] Stroke is frequently classified into ischemic stroke or hemorrhagic stroke. [67, 68] Ischemic stroke is defined as an episode of neurological dysfunction resulted from focal cerebral, retinal, or spinal infarction. [67, 68] Ischemic stroke arises when a blood vessel to the brain is obstructed by blood clots or other particles. [67, 68] Other stroke cases are haemorrhagic and caused by the rupture of cerebral arteries. [67, 68] These haemorrhages might be intracerebral or subarachnoid. [67, 68] Stroke caused by intracerebral hemorrhage is defined as rapidly developing clinical signs of neurological dysfunction due to a focal collection of blood within the brain parenchyma or ventricular system that is not resulted from trauma. [67, 68] Stroke caused by subarachnoid hemorrhage is defined as rapidly developing signs of neurological dysfunction and/or headache due to bleeding into the subarachnoid space that has not resulted from trauma. [67, 68]

A recent study showed that in 2019, the global incidence and prevalence of stroke were 101 million cases and 12.2 million cases, respectively. [69] Of these new cases, ischemic stroke accounted for 62.4% (7.6 million cases), intracerebral haemorrhage constituted 27.9% (3.4 million cases), and subarachnoid haemorrhage accounted for 9.7% (1.2 million cases). [69] Stroke was the third leading cause of death and disability, with about 6.5 million of deaths from stroke worldwide. [69] Around 5 million stroke patients were left permanently disabled. [69] More than 80% of deaths and disability from stroke were present in the low- and middle-income countries. [69]

In Sweden, the latest report showed that in 2020, there were about 27,000 new stroke cases, affecting about 25,400 persons. [70] It was estimated that about 6100 persons died as a result of stroke in 2020, an increase compared to 2019. [70] The stroke incidence in Sweden is decreasing, with the number of persons suffering from stroke in 100,000 population has declined by more than 40% over the last 15 years. [70] The proportion of stroke cases and death of stroke per 100,000 population in 2020 were higher in men, compared to women, with 47% and 38%, respectively. [70] In 2019, stroke was ranked number three in the causes of death and disability, causing 11.6% of total deaths in Sweden. [46, 47] Annually, over a million bed-days in hospitals, and a higher number of bed-days in nursing homes are occupied by patients with stroke in Sweden. [71] Stroke is the disease that utilized the most bed-days in Sweden. [71] The societal costs of stroke were estimated to be SEK 18.3 billion per year in Sweden. [71] Hence, stroke generates a great burden to the society and economy of Sweden.

2.5.2 The coexistence of dementia and stroke

Dementia and stroke frequently co-occur, even though the mechanism of comorbid conditions and pathological substrates remains unclear. Dementia was associated with higher likelihood of suffering a first stroke, approximately 10% of patients with first-ever stroke had dementia before stroke. [72, 73] The risk of suffering stroke after dementia increases parallel with the severity of dementia. [72, 74, 75] Many previous studies showed higher risk of dementia after stroke. [57, 73, 76-80] The absolute post-stroke dementia risk was 20% at 5 years, 30% at 15 years and 48% at 25 years of follow-up. [78] Stroke increased the risk of developing dementia by two. [57]

The co-occurrence of dementia and stroke might be explained by shared risk factors (e.g. hypertension, diabetes mellitus, and atrial fibrillation). [57, 73] PWD might undergo microvascular injuries, silent cerebrovascular diseases and have difficulty with taking care of their comorbidities and maintaining a healthy lifestyle; hence, possibly causing a stroke. [72] Brain damage after a stroke can logically lead to post-stroke dementia. [81, 82] Furthermore, the dysfunction of the neurovascular unit and cerebral blood flow in stroke patients are also two of the pathophysiological processes underlying dementia. [57, 81, 82]

2.5.3 Stroke care and rehabilitation

Stroke care should begin as soon as possible. In the acute phase of stroke, a standardized and efficient chain of care should be triggered. [83, 84] Recovery time after stroke is different among persons and stroke severity. At hospital, the patient might receive emergency care, treatment to prevent another stroke and rehabilitation to minimize disabilities, as well as increase recovery. [83] Stroke rehabilitation is defined as a set of processes that often include several disciplines aimed at enhancing stroke patients' functioning and quality of life. [85-87] Most stroke patients need help from a multi-disciplinary team, which can include doctors, nurses, therapists, psychologists and so on. [85-87] Each patient should be examined carefully by the team to determine the suitable rehabilitation approaches. [85-87]

Stroke rehabilitation should be initiated early, normally within 24 to 48 hours after stroke, to help the patient recover and return to independent living. [83-90] Stroke rehabilitation might start during acute stroke care and continue for the whole life among many stroke patients. [83-90] Stroke rehabilitation encompasses interventions improving independence and activities of daily living, examination and interventions for communication and cognitive impairments, and treatment of dysphagia. [85-87] Additionally, stroke rehabilitation combines prevention and interventions for medical and mental health complications, for example pneumonia, infection, deep vein thrombosis, malnourishment, depression and so on. [85-87]

The organization of stroke care and rehabilitation varies among regions and municipalities in Sweden. In general, in the beginning, stroke patients are admitted into the hospital to receive acute stroke care. Afterwards, they either continue to stay at the hospital and receive inpatient stroke rehabilitation or are discharged to their own home or a nursing home. [83, 91] At stroke patients' home, outpatient rehabilitation is then performed by a multidisciplinary team. [83, 91, 92] Furthermore, stroke patients may receive rehabilitation at the primary care center or at the hospital. The county councils provide acute stroke care, inpatient and outpatient rehabilitation at the hospital and primary care. [93, 94] The municipalities supply outpatient rehabilitation at stroke patients' home or nursing home, together with other kinds of long-term care. [93, 94] According to the Swedish national guidelines for stroke care 2009 (revised in 2020), stroke patients with mild to moderate disabilities can be discharged early and continue to receive rehabilitation at home coordinated by a multidisciplinary team. [83] Stroke patients with moderate to severe symptoms should receive inpatient rehabilitation after acute stroke care in the hospital. [83]

Previous studies showed there were significant differences in stroke care and rehabilitation between persons with and without dementia in Sweden. Persons ≤80 years old with dementia were less likely to receive thrombolysis. [95] Compared to persons without dementia, PWD suffering an ischemic stroke had equal access to stroke unit, but shorter length of stay at stroke unit and hospital in general. [6] PWD had significantly lower likelihood of receiving carotid ultrasound or assessment by the interdisciplinary stroke team (including an occupational therapist, a physiotherapist, and a speech therapist). [6]

2.5.4 Cost of stroke

The costs of stroke are different between countries. In the USA, the costs of stroke were estimated to be US$ 53.6 billion, in which US$ 33 billion was the direct medical expenditure. [96] The average costs per capita for the first 90 days after a stroke were US$ 15,000. [96] In the Netherlands, the average total costs of stroke care for each person for six months after a stroke were € 16,000. [96] In Sweden, the total societal costs of stroke were estimated to be about SEK 18.3 billion per year. [71] From a societal perspective, the costs for a first-ever stroke were € 69,685 and € 67,846 for women and men in Sweden. [97] Stroke rehabilitation, which generates direct medical costs, accounted for 40% of total costs for stroke care in Sweden. [94, 97, 98] In Switzerland, inpatient stroke rehabilitation accounted for the largest part (about 37%) of stroke care costs in the first year. [99] Bottacchi et al. 2012 indicated that inpatient rehabilitation, together with acute care represented the main cost driver (89.5% of stroke care direct costs in the first year). [100] Although stroke rehabilitation might reduce costs in the long run, it is still a high economic burden for society in the medium term.

Suffering dementia or neurologic impairment possibly influences costs of stroke care. Compared to persons without cognitive impairment, the stroke care costs of persons with moderate and severe cognitive impairment were 105% and 96% higher, respectively. [100] Previous studies showed that stroke care costs increased along with the severity of disability. [93, 101-103] Spieler et al. 2004 specified disability correlated with stroke inpatient rehabilitation costs. [102] In addition, PWD generated significantly higher costs of care, especially the cost of rehabilitation and informal medical care. [49, 104] However, there were no studies on the cost of inpatient stroke rehabilitation for PWD, which is a knowledge gap in Sweden. Hence, exploring the impact of dementia on the costs of stroke inpatient rehabilitation is necessary and an objective of this thesis.

2.5.5 Patient satisfaction with stroke care and rehabilitation

Patient satisfaction with health care services is an important health indicator, despite no consensus on how patient satisfaction is defined and no theory about explaining the meaning of satisfaction. [105-108] Patient satisfaction is influenced by their expectations and experience with the care that they obtained. Patient satisfaction not only reflects real differences in the supply of health care, [109] but also correlates with patients' trust in physicians. [110] Patients who were satisfied with health care services were more optimistic about their health status, were more adherent to the treatment, [105, 107, 111-113] and had better health outcomes. [105, 112] In many

countries, including Sweden, patient satisfaction is a health indicator for management of health care services in general and stroke care in particular. [114-116]

Patient satisfaction with stroke care is an essential factor that is collected and reported by the Swedish Stroke Register (Riksstroke). [71] Patient satisfaction with stroke care was evaluated in previous studies. Older age, depression, poor functioning, and poor subjective health are significantly associated predictors of lower patient satisfaction with stroke care. [109, 117] In addition, lower patient satisfaction was significantly associated with emotional distress and unmet care demands. [118, 119] Patients with higher satisfaction with stroke care were more likely to have better health outcomes and quality of life. [117, 119-121]

To our knowledge, PWD's satisfaction with stroke care has rarely been evaluated. [117, 122] There are no previous studies on patient satisfaction with stroke care among the dementia population, creating a knowledge gap that we want to address. Investigating satisfaction of PWD is necessary to quality management of stroke care for this large patient population. Particularly, a recent study showed that patient satisfaction reflected real differences in the supply of stroke care and occurred independently of other patient characteristics. [109] Furthermore, previous studies mentioned that the highest rates of dissatisfaction six months after stroke were with stroke care, rehabilitation, information received and services after discharge. [123, 124]

2.6 SOCIOECONOMIC POSITIONS

2.6.1 Definition

Socioeconomic position (SEP) is a popularly used term in health and epidemiological research. SEP is used interchangeably with other terms, such as socioeconomic status and social class, however, these concepts are different in theoretical bases and interpretation. [125-128] SEP is an aggregate concept which includes resource-based as well as prestige-based features. [127] The resource-based aspect of SEP implies the material and social resources such as education, income, wealth and et cetera. [127] The prestige-based aspect of SEP refers to a relative standing of each person in a social hierarchy, which relates to their education, income, and occupation. [127] SEP is a relational concept, describing how a person stands in relation to other people. [128] Social class is defined as social categories originating from interdependent economic relationships among people (for example: employer, employee, self-employed, and unemployed). [127] Socioeconomic status refers to the possession of material and social resources, such as education and income, without connecting to relative standing among individuals. [128] SEP is preferred in this thesis rather than socioeconomic status because socioeconomic status murks the differences between two aspects of SEP: social resources and prestige-related features. [127]

There are three reasons why SEP should be evaluated in health and epidemiological research. First, considering SEP helps policymakers managing the social distribution of a disease, introducing health policy, managing differences between social groups, and examining whether a policy is able to reduce health inequalities. [126] Second, investigating SEP could explain the

causal mechanisms by which SEP creates health inequalities. [126] Third, SEP is an important confounder when another predictor is the main objective of the study. [126]

There are various SEP indicators, measured at different degrees (individual, household, and neighborhood) and at various stages in the life course (infancy, childhood, adolescence etc.). [127] Education, income, and occupational class are the most common SEP indicators. [125-127] There is no single optimal SEP indicator because each element focuses on a particular characteristic of social stratification. [125-127, 129] Furthermore, SEP indicators are mutually related because they all describe the socioeconomic stratification. [125-127] Selecting SEP indicators depends on research questions of each study and mechanisms between SEP indicators and outcomes. [125] However, in reality, the selection might be driven by data availability. [125] In this doctoral thesis, we evaluated the association between SEP of PWD (measured as education and income) and dementia diagnostic process, anti-dementia medications, and long-term care for PWD.

2.6.2 Education

Education is the most commonly used SEP indicator in health and epidemiological research [125-127]. Education might be categorized as a process or as an outcome. [125, 130] The process of education happens in various settings and levels, such as home, school, community. [130] The outcome of education denotes a combination of knowledge, skills, and capacities which could affect the other SEP indicators. [130] The main focus of education in current health care research is education as an outcome (for instance: years of education, educational attainment, number of certificates completed and so on). [130] The mechanisms in which educational attainment might enhance health include three pathways: (1) Education improves health knowledge, literacy, and so on, thereby leading to habits that are good for health regarding nutrition, exercise, less use of drugs and alcohol and etc; (2) Education decides employment opportunities and related benefits, such as income, working conditions and so on; as a result, affecting health; (3) education influences social and psychological factors that affect health (for example: self-efficacy, social status and social networks). [125, 130, 131]

The strengths of this indicator are ease of measurement, high response rate, applicability to all people irrespective of their working environment (for instance, homemaker, unemployed, or retired), stability over persons' lifetime (regardless of changes in health status) and its relation to various health outcomes. [125-127] The limitation of education is that educational level differs among different birth cohorts or regions. [125] Moreover, educational opportunities have differed between men and women and been lower among minority groups in the past, and sometimes continue to differ in the present. [125] Another weakness of education is that in people who obtained their education in foreign countries, the extent, content, and usefulness of their education might diverge from education carried out in their home country. [125] Lastly, the quality of the education that a person experienced might not be displayed by the years of education or levels of education. [125]

2.6.3 Income

Income is defined as the amount of money which is earned monthly or annually from employment, government allowances, pensions, interests, investments or other assets. [130] Income is usually considered as the most straightforward indicator of SEP, yet is not a simple measure. [125-127] However, by comparison with education and occupational class, income is a sensitive issue which many people might want to hide or might be overstated. [125, 126] Income differs among countries, birth cohorts, and genders. Income encompasses wage earnings, dividends, interest, allowance, pensions, and so on. [127] Income has a cumulative impact over the lifespan, but might vary the most in the short term. [125, 126] Income after retirement largely reflects lifetime education. Income may affect health via several mechanisms: (1) accessing to better living standards, such as healthier food and better accommodation, (2) access to services which might improve health directly (such as health services, long-term care, recreation activities) or indirectly (such as education) and (3) encouraging self-esteem and social standing. Moreover, reverse causality between income and health happens, in which persons with poor health might lose their job or have lower working efficiency, hence suffering a loss of income. [125, 126, 130]

2.6.4 Dementia care and socioeconomic positions

Socioeconomic inequalities in health have been indicated in previous studies regarding various diseases and countries with similar socioeconomic context to Sweden. [17, 129, 132, 133] People from lower socioeconomic positions had significantly higher risk of morbidity and mortality. [129, 134-137] Socioeconomic inequalities in health continue to occur even in old age. [134-137] The association between dementia-related death and SEP was mentioned in several previous studies, but results were different among researched countries. A study on a Norwegian cohort showed that people with high and middle educational levels had significantly lower dementia-related mortality risk, compared with people with low educational level. [138] A recent study on Finnish population indicated that higher dementia-related mortality risk was found in persons with lower midlife education, occupational class, and household income. [139] Another study in the Netherlands also pointed out that people with lower disposable household income had significant higher dementia-related death rate. [140] However, previous studies in France and Sweden found that education or income had no significant association with dementia-related death risk. [141, 142] In terms of cognitive changes, a study in France showed that compared with PWD with low educational level, MMSE decreased faster in PWD with higher educational levels. [141] Regarding anti-dementia medications, a previous study in Sweden found that PWD with ≥15 years of education were more likely to get cholinesterase inhibitors or memantine, compared with PWD with ≤9 years of education. [143] A recent study in Wales showed that lower socioeconomic PWD experienced a longer time between dementia diagnosis and nursing home admission, compared to higher socioeconomic individuals. [144] A study in China mentioned that PWD had significantly lower chance of receiving care if they had lower educational or income level [145].

To our knowledge, few studies investigated the dementia diagnostic process, prescription of anti-dementia medication, long-term care among different educational or individual income levels. Thus, it is important to explore this topic, especially when previous studies showed that people from lower socioeconomic positions reported significantly higher levels of unmet health care needs than those in higher socioeconomic positions. [146-149] This is the third objective of this thesis.

2.7 IMMIGRATION

According to the International Organization for Migration, which belongs to the United Nations, immigration is defined as the movement into a new country different from one's country of nationality or usual residence, hence the country of destination effectively becomes the new country of usual residence. [150] Immigration, a social determinant of health, has gradually become an important factor in epidemiological and medical research [151, 152]. Immigrants always experience a stage of adaption in the new country before they integrate into the new society. Immigrants usually have lower SEP compared to the native citizens. [153]

In Sweden, immigrants, constituting a growing proportion of the total population, play an important role for the development of society. At the end of 2020, the number of foreign-born people in Sweden was 2,046,731 (accounting for 19.7% of total population). [154] The proportion of foreign-born citizens in Sweden increased from 4.0% in 1960 to 19.7% in 2020. [154] At the same stage, the proportion of people 65 years old and above increased from 11.8% to 20.1%. [154] It is predicted that the proportion of older people in Sweden who were foreign-born would increase to more than one-third in 2070. [155] Thus, it can be expected that the PWD in Sweden, who were born in other countries than Sweden, will increase sharply in the next decades.

Health inequalities among immigrants is a common research theme for many diseases in the USA and the UK. Hundreds of studies on this topic have been conducted with consistent findings about health inequalities between immigrants (or minority ethnic groups) and native citizens. Previous studies also showed health inequalities in Scandinavian countries, in which immigrants were less likely to access health care services compared to the natives. [156, 157] Although this research theme is less considered in Sweden, health inequalities between immigrants and native Swedes were mentioned in preceding studies. Poorer self-rated health was observed in the immigrants, compared to the natives. [158-160] Immigrants had lower likelihood of accessing to treatments for many diseases, such as myocardial infarction, strokes and so on. [15, 132, 161, 162] A recent qualitative study showed that health inequalities among immigrants in Sweden may be explained by miscommunication due to short meeting time, language barriers, different systems of cultural beliefs and practices and limited patient-caregiver trust. [163]

Regarding dementia, immigration affected long-term care services for PWD. [164-166] Immigrants were more likely to experience delayed dementia health care services, compared to the natives. [167] Inequalities in the supply of dementia care were identified in previous studies. [168, 169] In addition, immigrants were shown to experience delay in access to dementia diagnosis. [170, 171]

In Norway, immigrants from low- and middle-income countries were shown to have significantly lower likelihood of receiving a dementia diagnosis, compared to the natives. [172] Meanwhile, dementia diagnosis should be early because it enables patients to prepare their finances, care options and living conditions, and gives them access to treatment. [2, 173, 174] Other studies showed that immigrants were less likely to be prescribed anti-dementia drugs by comparison with native-born PWD. [166, 172, 175-178] Additionally, foreign-born PWD were less likely to access long-term care or live in nursing homes. [178-181] In Sweden, the health inequality in dementia diagnostics and the use of anti-dementia medications was understudied. A recent study in Sweden found that foreign-born PWD had lower likelihood of getting a specific dementia diagnosis or taking cholinesterase inhibitors. [182] Inequalities in health care services for PWD regarding education, income, sex, living areas were also mentioned in previous studies. [7, 9, 183, 184] Thus, investigating the impact of immigration on dementia diagnostic process and the prescription of anti-dementia medications is necessary and the final objective of this thesis.

3 RESEARCH AIMS

Overall aim

The overarching objective of this thesis was to examine the health inequality in care that is provided to PWD in Sweden. Corresponding to this objective, five studies were conducted:

Study 1

- Aim: To estimate inpatient stroke rehabilitation costs for PWD, in comparison with persons without dementia.
- Research question: Is the cost of inpatient stroke rehabilitation higher among persons with dementia, compared to non-dementia controls?
- Hypothesis: PWD had higher costs of inpatient stroke rehabilitation, compared to persons without dementia.

Study 2

- Aim: To assess the satisfaction with stroke care and rehabilitation among persons with and without dementia.
- Research question: Are persons with dementia satisfied with their stroke care compared non-dementia controls?
- Hypothesis: PWD were less likely to be satisfied with stroke care and rehabilitation, in comparison with persons without dementia.

Study 3

- Aim: To address the difference in dementia diagnostic process and anti-dementia medications in relation to SEP.
- Research question: What is the difference in dementia diagnostic process and anti-dementia medications among patients from different educational and income levels?
- Hypothesis: Lower socioeconomic PWD have lower likelihood of receiving dementia diagnosis and anti-dementia medications, compared to higher socioeconomic PWD.

Study 4

- Aim: To explore the association between the receipt of long-term care and SEP of person with dementia.
- Research question: Is education and income associated with the long-term care?
- Hypothesis: Higher socioeconomic PWD are more likely to receive long-term care, in comparison with lower socioeconomic PWD.

Study 5

- Aim: To investigate the impact of immigration on dementia diagnosis process and anti-dementia medications.

- Research question: Does immigration influence the dementia diagnostic process and the use of anti-dementia medications?
- Hypothesis: Immigrant PWD have lower likelihood of receiving dementia diagnosis and anti-dementia medications, compared to native-born PWD.

4 MATERIALS AND METHODS

4.1 DATA SOURCES

In this thesis, five observational open-cohort studies were performed, employing data based on the combination of various Swedish national and quality registers:

4.1.1 The Swedish registry for cognitive/dementia disorders (SveDem)

SveDem is a nationwide quality-of-care register for dementia disorders in Sweden (https://www.ucr.uu.se/svedem/). SveDem was initiated in 2007 for the purpose of collecting data on people with dementia to be able to improve and develop the care of PWD in Sweden. [185, 186] The goal is to create a nationwide tool for equal and best treatment of PWD. [185, 186]

PWD, registered in SveDem, are diagnosed according to the International Classification of Diseases, Tenth Revision (ICD-10) codes. [185] Dementia diagnoses in SveDem include early- and late-onset Alzheimer's disease, vascular dementia, mixed dementia, Lewy body dementia, frontotemporal dementia, Parkinson disease's dementia, unspecified dementia (when specific dementia types cannot be diagnosed), and other dementias (consisting of rare dementia types, such as corticobasal degeneration, Huntington's disease and et cetera). [185, 186]

SveDem contains information at registration and annual follow-ups, regarding sociodemographics (age, sex, living conditions), dementia diagnostic process (dementia examinations, place of diagnosis, type of dementia diagnosis), cognition (MMSE, MoCA, RUDAS), medication (cholinesterase inhibitors, memantine, antipsychotics), and so on. [185, 186] SveDem registers PWD from all memory clinics in Sweden, 78% primary care centers (over a total of 910 centers) and 1113 municipal units. [185, 186] Since 2007, there have over 100,000 basic registrations and more than 90,000 follow-ups, making SveDem to be world's largest clinical cohort for PWD. [43]

4.1.2 The Swedish Stroke Register (Riksstroke)

Riksstroke, a national quality register for stroke care (https://www.riksstroke.org/eng/), has been established since 1994. [71] The aim of Riksstroke is to promote high and consistent quality of stroke care in Sweden. [71] Risstroke registers patients diagnosed with ischemic stroke (ICD-10 I63), intracerebral hemorrhage (ICD-10 I61) or unspecified acute cerebrovascular event (ICD-10 I64). All hospitals that care for patients with acute stroke have participated in Riksstroke. [187] Data of each patient are collected at onset, during the hospital stay and at discharge. [187] Follow-up questionnaires are utilized to gather information of patients after three months and twelve months of stroke onset. [187] Riksstroke collects the continuum of stroke care, covering secondary prevention, acute management, rehabilitation, and family and community support. [187] Until 2018, over 531,156 stroke events were registered, making Riksstroke the world's largest clinical stroke register. [71]

4.1.3 The Swedish Longitudinal Integrated Database for Health Insurance and Labour Market Studies (LISA)

LISA was started from 1990, with the aim to provide a tool for statistical research in health and labour market. [188] LISA collects information of all persons ≥15 years old living in Sweden by 31st of December of each calendar year. [188] LISA accumulates data from many registers in Sweden, such as the total population register or the education register. [188] More than 500 variables in LISA may be classified into sociodemographic, education and training, occupation, income and social security, family, workplace and business. [188]

4.1.4 The Swedish Social Services Register (SSR)

SSR was initiated in 2007, comprising statistics on long-term care for the elderly and persons with disabilities, in accordance with the Social Services Act. [189, 190] Long-term care, which is reported monthly, encompasses home care (home help with activities of daily living, personal care and additional services) and institutional care (nursing homes, residential care facilities and specialized group homes for PWD). [189, 190] Between 2007 and 2012 (except for 2009), the statistics were based on the decision of long-term care for from municipalities. [191, 192] From 2014 to 2019, only implemented decision of long-term care were reported. [191, 192] There is no official information in 2009 and 2013 because the National Board of Health and Welfare changed the data collection and several municipalities had difficulty providing correct information. [191, 192] Until 2019, about 401,000 elderly people and 57,200 persons with disabilities who receive at least one kind of long-term care have been registered in the SSR. [191, 192]

4.1.5 The Swedish National Patient Register (NPR)

The NPR, initiated by the National Board of Health and Welfare, aims to collect information regarding health care episodes in inpatient somatic and psychiatric care (since 1964), as well as outpatient specialist care (since 2001). [193, 194] In 1984, the Swedish government decided to make NPR mandatory for all county councils. [193, 194] The NPR covers all inpatient care from 1987 and outpatient specialist clinics (including day surgery and psychiatric care from both private and public caregivers) from 2001. [193, 194] Data in the NPR can be categorized into four different groups: patient data (age, sex, place of residence), geographical data (county council, hospital), administrative data (inpatient, outpatient) and medical data (diagnosis, cause of injury). [193, 194]

4.1.6 The Swedish Prescribed Drug Register (PDR)

The PDR was established in 2005, with the purpose to increase patient safety in drug utilization. [195] The PDR records all prescribed medications dispensed at pharmacies in Sweden. [195] Data in the PDR can be divided into these categories: sociodemographic, product (ATC code, drug

name, strength), prescription (quantity, strength, date of prescription), costs and prescriber. [195] Over-the-counter drugs or inpatient dispensations are not registered in the PDR.

4.1.7 The Swedish Cause of Death Register (CDR)

The CDR was established in 1911, although recording cause of death has been done in Sweden since 1751. [196] The electronic CDR is available from 1952, which is used for descriptions of the population's health, as a basis for efforts in health care and for research. [196] The cause of death register is updated annually. The register collects all deaths that have occurred in Sweden, no matter this person is a resident of Sweden or not. [196] Residents of Sweden who died abroad were also registered in the CDR. [196] Every death registered in the CDR is derived from the death certificate, which is issued by a doctor. [196] Data in the CDR includes sociodemographics, date of death, place of death, the underlying cause of death based on ICD codes, and up to 48 contributing causes of death. [196]

4.2 PATIENT SELECTION

Study 1

In this study, 58,154 PWD registered in SveDem (2007-2014) were linked with Riksstroke (2010-2014) to have two research groups (Figure 1).
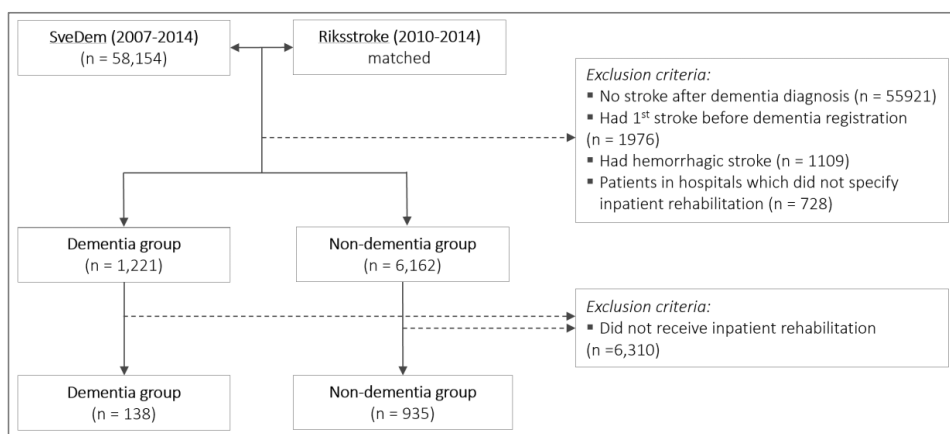

Figure 1. Patient selection of study 1 [183]

The dementia group comprised PWD who had a first ischemic stroke after dementia diagnosis. The controls included non-dementia persons who suffered from a first ischemic stroke. Non-dementia controls were individuals who were neither registered in SveDem, nor had dementia diagnoses in the NPR and did not receive anti-dementia medications. In nine hospitals (out of 74 hospitals in our study), inpatient rehabilitation is included and indistinguishable from acute care. Therefore, patients in these hospitals were also excluded. This study assessed the cost of

inpatient rehabilitation; thus, we excluded patients who did not receive inpatient stroke rehabilitation. Finally, 1073 selected participants were available for the analysis.

Study 2

A total of 321,022 PWD identified in SveDem, the NPR and the PDR (2007-2017) were matched with Riksstroke (2007-2017) to create two research groups. The dementia group was defined as persons who were registered in SveDem or registered with dementia diagnoses in the NPR, or who received anti-dementia medications (Anatomical Therapeutic Chemical Classification (ATC) System codes N06DX and N06DA) in the PDR. Only PWD suffering a first stroke (ICD codes I61, I63 & I64) after the dementia diagnosis were selected. The non-dementia group included persons without dementia suffering a first stroke. Because patient satisfaction was collected three months after stroke onset, persons who had died within three months after the stroke were excluded. This left 5,932 persons in the dementia group and 39,457 counterparts for analysis (Figure 2).
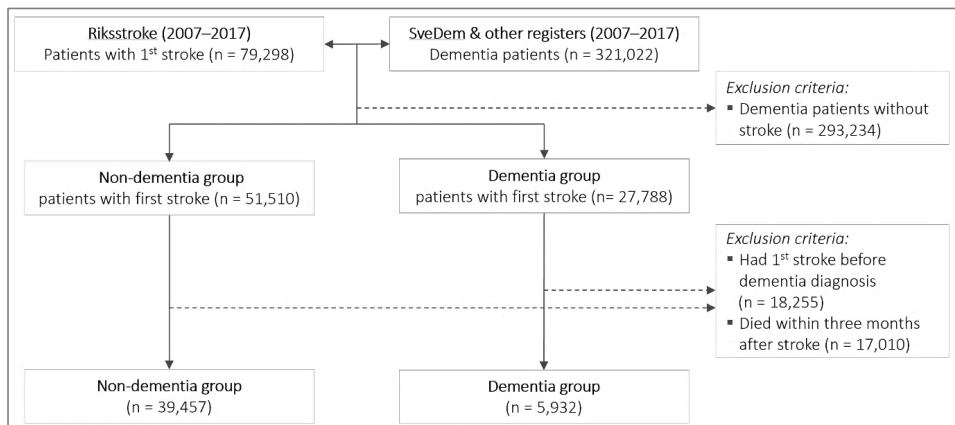

Figure 2. Patient selection of study 2 [197]

Study 3

In study 3, SveDem (2007-2018) were merged with LISA (2006-2017) to extract socioeconomic information of 80,004 PWD one year before dementia diagnosis (Figure 3). PWD from 65 years old were included in this study. Because this is the most common age limit of retirement, we supposed that PWD's income was stable after this age. PWD who had individual disposable income below SEK 57,200 per year were excluded. We assumed that SEK 57,200 is the lowest income of people from 65 years old, according to the elderly care allowances for persons having no or low pensions in Sweden. [198] In Sweden, persons with no or low pensions would receive the elderly care allowance from the government. In 2019, the elderly care allowance was about SEK 57,200 per year. [23] This implies that the lowest

reasonable individual income is SEK 57,200 per year. Thus, PWD with income below this threshold or negative income were excluded. These people are likely to live off capital and their income does not represent their SEP. This left 74,414 PWD for the final analysis.
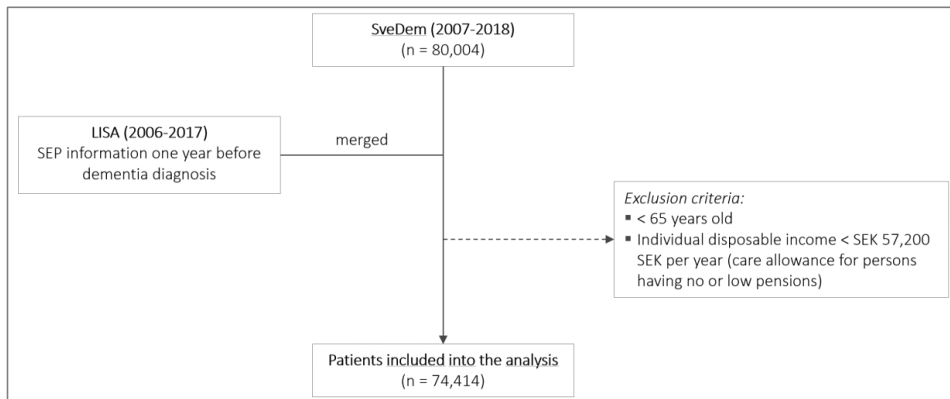
Figure 3. Patient selection of study 3

Study 4

As can be seen from Figure 4, this study used data of 25,759 PWD registered in SveDem (2014-2016) and linked with LISA (2013-2015) and the SSR (2013-2017).
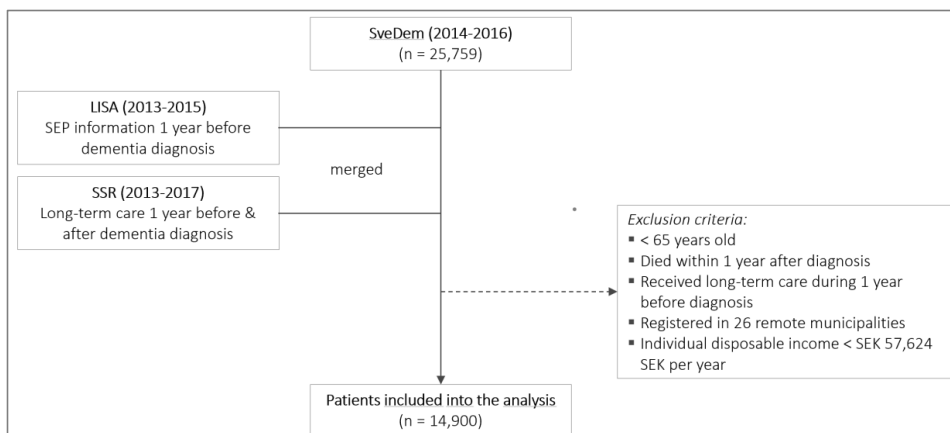
Figure 4. Patient selection of study 4

Inclusion criteria were (1) PWD should be 65 years old or older at the time of dementia diagnosis. We assumed that PWD had less fluctuations in income after this age, since it is the most common retirement age, (2) PWD should be still alive one year after dementia diagnosis, (3) PWD should not receive any kind of long-term care in the year before dementia diagnosis. To obtain the data with reliable quality, we only selected PWD registered in the SSR 2013-2017. PWD registered in 26 (about 9% of total 290) smaller and mostly rural municipalities were also excluded because of unreliable information in these municipalities. In addition, PWD

who had individual disposable income less than SEK 57,624 per year were excluded. We assumed that SEK 57,624 is the lowest income of people from 65 years old, according to the elderly care allowances for persons having no or low pensions in 2020 in Sweden. [198] There were 14,900 PWD selected to constitute the study cohort.

Study 5

A total of 74,303 PWD registered in SveDem (2007-2017) were merged with LISA (2006-2016) to retrieve information on region of birth and SEP one year before dementia diagnosis. Persons less than 65 years old at the time of dementia diagnosis were excluded (n = 3,739). People with individual disposable income less than SEK 57,624 per year were not included in the study (n = 685). We also excluded 153 persons without the information about region of birth. This study comprised 70,318 PWD for the final analysis (Figure 5).
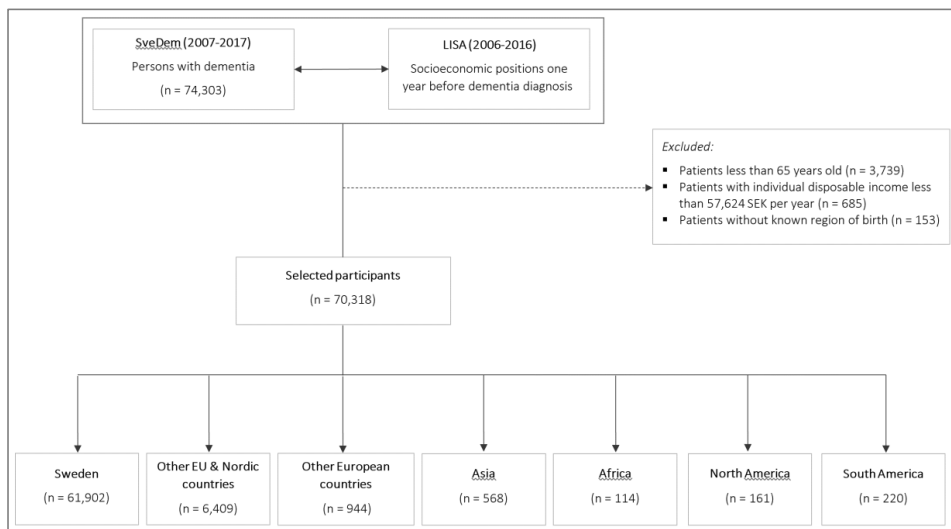
Figure 5. Patient selection of study 5

4.3 EXPOSURES

4.3.1 Dementia

In this thesis, PWD were defined as persons who were registered in SveDem, or had any dementia diagnosis in the NPR, or received any anti-dementia medication (ATC codes N06DX and N06DA) in the PDR. All dementia diagnosis types were included. Early- and late-onset Alzheimer's disease were merged into one group, called "Alzheimer's disease".

4.3.2 Education

Education was the highest level that a patient attained and was retrieved from LISA. [188] Education in LISA comprised six levels: compulsory education <9 years, compulsory education 9 years, upper secondary, college/university <3 years, college/university ≥3 years, and research education. Immigrants' education is acquired from the Swedish Migration

Agency, Government-sponsored Swedish language courses for immigrants and the Swedish Public Employment Agency. [188] When immigrants participate in any educational activity in Sweden, the new level of education will be synchronized and overwrite the older one, via their personal identity number. [188]

4.3.3 Income

Individual disposable income, extracted from LISA, was defined as the total income that a person received minus taxes (including all types of income and allowances). [188] Disposable income of PWD one year before dementia diagnosis was inflated into 2019 value (Study 3) or 2020 value (Study 4 & 5) with the inflation rate from the Swedish Consumer Price Index. [199] The inflated income was then classified into quintiles (Study 3) or trichotomized (Study 4 & 5). Income in this thesis was listed as multiples of SEK 100. For example, a value of 10 is equal to SEK 1000.

4.3.4 Immigration

Immigration was displayed by region of birth, which was extracted from the LISA. Before 1947, all children who were born abroad were registered as foreign-born. [188] Since 1947, children who were born abroad, but to a mother registered as living in Sweden have been recorded as born in Sweden. [188] From 1998, this policy also applies for a child born abroad, but to a father registered in Sweden. [188] Region of birth in LISA includes Sweden, the other Nordic countries (Denmark, Finland, Iceland and Norway), EU countries (except Denmark, Finland and Sweden), Europe (except EU and the Nordic countries), Africa, Asia, Oceania, North America, South America and Soviet Union (when existing). Region of birth was then re-categorized, depending on the purpose of each study.

4.3.5 Other covariates

Age at dementia diagnosis, sex (men/women), cohabitation (living alone or living with a partner), living areas (urban, intermediate, or rural) were extracted from SveDem or LISA. Comorbidities were extracted from the NPR and summarized as the Charlson Comorbidity Index. [200] This index is a weighted sum of medical diagnoses, created with a coding algorithm by Hude Quan et al. [201] Other covariates, including primary ADL, consciousness (shown by the Reaction Level Scale), the modified Rankin Scale (mRS) and so on, were described in our published articles. [183, 197, 202]

4.4 OUTCOMES

4.4.1 Cost of inpatient stroke rehabilitation

The cost analysis was performed from the Swedish health care perspective. Because of the data availability, we only evaluated direct costs of inpatient rehabilitation. This omits informal care costs and outpatient rehabilitation costs. The cost of inpatient stroke rehabilitation of each patient was calculated by multiplying days in inpatient rehabilitation with average unit cost of inpatient stay. The number of days staying in the rehabilitation unit was available in Riksstroke.

The average cost per bed-day in a rehabilitation unit was SEK 6,932 in 2017, which was extracted from the cost per patient database of Swedish Municipalities and County Councils (Sveriges Kommuner och Landsting). [203] The unit cost was converted to 2018 value (SEK 7,091) with inflation rate from Swedish Consumer Price Index. [199]

4.4.2 Patient satisfaction

Patient satisfaction comprised satisfaction with 1. acute stroke care at hospital, 2. inpatient rehabilitation, 3. outpatient rehabilitation, 4. health care professionals' attitude, 5. communication with doctors and 6. stroke information. These data were retrieved from Riksstroke three-months follow-up report, which is a questionnaire sent to patients' homes or a telephone survey conducted by health care professionals at the hospital where patients received care for stroke [187]. Patients could complete the survey by themselves or with the help from caregivers (their family or health care professionals). If patients cannot answer, their family or health care professionals (when the patient was cared for in an institution) were asked to answer the survey. [187] Options to answer the questionnaire included *very satisfied, satisfied, dissatisfied, very dissatisfied, had a need but did not receive care, did not need care* or *don't know*. *Had a need but did not receive care* was regarded as the lowest level of satisfaction. *Don't know* was recoded as missing.

4.4.3 Dementia diagnostic process

The complete basic dementia diagnosis work-up is recommended by the Swedish Board of Health and Welfare when diagnosing PWD. [204] It consists of the completion of all four tests followed in SveDem: clock test, blood test (calcium, TSH, and either homocysteine or B12 and folate), MMSE, computed tomography/magnetic resonance (CT-MRI). An interview, physical and psychological exam and structured interview with a knowledgeable person close to the patient are also part of the basic work-up but not recorded in SveDem. Other individual tests recorded in SveDem and included in this thesis were neuropsychological assessment, occupational therapy assessment and physiotherapist assessment. Types of diagnostic unit encompassed primary care and memory clinic. Dementia diagnoses are coded with ICD-10 codes in SveDem. In this thesis, we categorized dementia diagnoses as specified dementia diagnoses (including Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease & other dementia), as opposed to unspecified dementia.

4.4.4 Medications

Medications were extracted from SveDem and the PDR. Anti-dementia medications include cholinesterase inhibitors (donepezil (N06DA02), galantamine (N06DA04) and rivastigmine (N06DA03) and memantine (N06DX01). In addition, the prescription of antipsychotics (N05A) was examined in our thesis.

4.4.5 Long-term care

Long-term care variables were extracted from the SSR. Long-term care covers home care and institutional care. Home care encompasses home help with ADL (e.g. cooking, cleaning, laundry, shopping, etc), personal care (e.g. bathing, dressing, toileting, etc) and additional services (e.g. day care, home health care, housing adaptions, assistive devices, transportation, meal delivery, short-time institutional care, etc). [66] Institutional care includes nursing homes, residential care facilities and specialized group homes for PWD. [66] In Study 4, outcomes were the receipt of any kind of long-term care, institutional care, home care and the monthly average hours of home care.

4.5 STATISTICAL ANALYSIS

All statistical analyses in this thesis were performed with the Statistical Package for the Social Sciences software version 25 (IBM Corporation, Armonk, NY), STATA version 15.1 (StataCorp, College Station, TX), and SAS version 9.4 (SAS Institute Inc, Cary, NC). In all studies, categorical variables were presented as number of cases and percentages. Pearson's Chi-square test or Fisher's exact test was applied in univariate comparison. Numerical variables were presented with means and standard deviation if normally distributed, or with median and interquartile range if not. Student t-test, Mann-Whitney U test, one-way ANOVA, or Kruskal-Wallis test was utilized to analyze the difference between research groups. All statistical tests were two tailed with a p-value smaller than 0.05 considered statistically significant. Results in the regression models were presented as odds ratio (OR), rate ratio (RR), and 95% confidence interval (95% CI).

Study 1

Binary logistic regression was used to evaluate the association between the likelihood of obtaining inpatient stroke rehabilitation and having dementia. The association between costs of inpatient stroke rehabilitation and having dementia was explored by simple linear regressions. Multiple linear regression was performed to adjust for other covariates, such as age at stroke, sex, living situations before stroke, consciousness at hospital admission, pre-stroke ADL and comorbidities, complications during acute care and days in acute care. Propensity score matching was used for sensitivity analysis. Propensity scores were estimated by binary logistic regression with having dementia (yes-no) as dependent variable and the above covariates as independent variables. Participants in the two research groups were nearest-neighbor matched with 0.01 tolerance. Then, another simple linear regression model was then run in the matched cohort. Due to the violation of normal distribution, a natural log transformation of the cost was applied to fix this problem in regression models.

Study 2

Ordinal logistic regression was applied because the dependent variable – patient satisfaction-- is an ordinal variable. Analyses were stratified by who answered the questionnaire (PWD answering themselves, PWD answering with the help of their caregivers, PWD's family, or

health care professionals on behalf of PWD). Regression models were unadjusted and partly adjusted for age at time of stroke and sex, and fully controlled for age at stroke date, sex, pre-stroke CCI, attributes during acute care (consciousness at hospital admission, complications, days in acute care, and place of discharge after acute care), and characteristics three month after stroke (mRS, having difficulty with reading, speaking, writing, feeling depressed, having fatigue, having pain, and self-rated health).

Study 3

This study used binary logistic regression to explore the association between dementia diagnostic process and anti-dementia medications as outcomes and SEP (education or income) as independent variables. One regression model was adjusted for age at dementia diagnosis, sex, region of birth, living alone, dementia types (except for this variable as outcome), CCI, types of diagnostic unit (except for this variable as outcome) and MMSE scores (except for the complete basic dementia diagnostic work-up and MMSE as outcome). The other model was controlled for the above covariates and additionally adjusted for education (if income was the independent variable) or income (if education was the independent variable). Spearman's correlation was conducted for education and income ($r = 0.36$, $p < 0.001$). Wald test was run after each regression model to assess whether the overall association between outcomes and SEP was statistically significant or not.

Study 4

The association between long-term care and SEP were examined with zero-inflated negative binomial regression (for home care as the outcome) and binary logistic regression (for any kind of long-term care and institutional care as outcomes). The first model was adjusted for age at dementia diagnosis, sex, living areas, living alone, CCI, MMSE score, types of diagnostic unit, and dementia types. The remaining model was fully controlled for the above covariates and additionally controlled for education (if income was the independent variable) or income (if education was the independent variable). Wald test was applied after the regression models to evaluate whether the overall association between outcomes and SEP indicators was statistically significant or not. Sub-group analyses were performed based on sex and living alone.

Study 5

We employed multinomial logistic regression to evaluate the likelihood of receiving MMSE among Swedish-born and foreign-born PWD. An ordinal logistic regression model was performed to assess the cognitive function (shown by MMSE score) between Swedish-born and foreign-born PWD. To examine the association between each outcome and region of birth, we used binary logistic regression. Dementia diagnosis process and medications were regressed on regions of birth and adjusted for age at dementia diagnosis, sex, types of municipalities that patients lived, cohabitation, comorbidities, education, and income. In these models, we only considered PWD who received MMSE (n = 67,573). We wanted to evaluate how cognitive function of the PWD influenced the association between region of birth and each outcome.

Thus, we did not adjust for MMSE score in the first binary logistic regression model; but controlled for MMSE score in the second model. Post-estimation was performed with the Wald test to examine the overall association of region of birth and each outcome. Interaction between sex and region of birth was checked but not presented because it had no or small effects.

4.6 ETHICAL CONSIDERATIONS

Our thesis was approved by the Swedish Ethical Review Authority, with these following ethical approval number: 2015/743-31 (Study 1 & 2) and 2017/501-31 (Study 3, 4 & 5). All studies were conducted in compliance with the Declaration of Helsinki. [205]

4.6.1 Benefit

The thesis benefits the whole population, including the participants included in these studies; instead of benefiting them directly. Results regarding health inequalities in care of PWD will provide evidence to researchers and policymakers to utilize health care resources effectively and efficiently. Allocating scarce resources optimally to the society will ensure quality of care and health equality between individuals. Thus, the PWD of this thesis may acquire advantages in an indirect manner.

4.6.2 Risk

There were no direct health risks for PWD participating in this thesis. With a retrospective observational study design, the data were collected via registries. The health status of PWD was not negatively influenced because no health care interventions were applied to them. Although there is no risk or physical danger for PWD in these studies, the research faces potential ethical dilemmas regarding respect of autonomy and privacy.

In the theory of ethics for medical research, respect of autonomy means that study participants make their own decisions, without coercion. However, in this thesis, the participants did not know anything about the thesis or the use of their data for research. They were not introduced about the purposes, procedures, results of the study. They did not receive information about the objectives and application of the study or have choices of voluntary participate in the study or not. In national registers like the NPR, the PDR, the CDR, or LISA, their registration was mandatory by the government. In quality-of-care registers like SveDem and Riksstroke, patients and their partners were informed about their inclusion in the register and knew that their data might be used for research purposes. They could withdraw their information from the registers at any time. Despite the paradox with autonomy, the informed consent is infeasible to conduct in register-based research. Moreover, the ethical issues of each study were evaluated in detail by the Swedish Ethical Review Authority and informed consent was waived by the review board.

In terms of confidentiality, the study used the participants' health care information without their knowledge and acceptance. These issues create the ethical dilemmas in the thesis. Nonetheless, the identification of participants was pseudonymized and blinded to researchers by the Swedish

National Board of Health and Welfare - Socialstyrelsen. Furthermore, the data of participants were pseudonymized, stored and analyzed on encrypted servers and computers which were administered by the information-technology center of Karolinska Institutet. Only researchers in the group, with Karolinska Institutet account and laptop, can access if they were allowed by the administrator. Thus, patient identity was strictly confidential.

In summary, this thesis was valid and meaningful to science and public health. The selected participants of these studies were not harmed. Moreover, they may acquire indirect benefits from the research's contribution to the wellbeing of the population. Potential ethical issues were under control and the thesis was approved by the Swedish Ethical Review Authority.

5 RESULTS

5.1 STUDY 1. COST OF INPATIENT STROKE REHABILITATION

We found that the place of discharge after acute stroke care was significantly different between persons with and without dementia. PWD were less likely to receive inpatient stroke rehabilitation (26% lower odds), in comparison with controls. There were 16.8% and 19.7% of persons with and without dementia, respectively, discharged to inpatient stroke rehabilitation after acute stroke care.

The average cost of inpatient stroke rehabilitation of the PWD was significantly lower compared to that of persons without dementia: mean SEK 103,693/US$ 11,932 vs SEK 130,057/US$ 14,966 (median SEK 92,183/US$ 10,607 vs SEK 106,365/US$ 12,239). In the crude linear regression model, the inpatient stroke rehabilitation cost of PWD was 0.84 times of the cost of persons without dementia (Table 1). The adjusted linear regression model showed similar results, with costs in dementia group 0.86 times of the cost in persons without dementia. Having complications during acute stroke care and length of stay in acute stroke care also presented a significant association with the cost of inpatient stroke rehabilitation. Sensitivity analysis on the regression model after using propensity score matching supported the above result as well, with lower costs in PWD compared to their non-dementia controls (0.76 times).

Table 1. Cost of inpatient stroke rehabilitation in relationship with dementia [183]

	Model 1 (n = 1,073)	Model 2 (n = 1,056)	Model 3 (n = 263)
Dementia	0.84 (0.73 − 0.95) *	0.86 (0.75 − 0.98) *	0.76 (0.64 − 0.89) *
Age at stroke		1.00 (0.99 − 1.01)	
Sex (men)		0.93 (0.85 − 1.02)	
Living situation before stroke			
home without help		reference	
home with help		0.95 (0.84 − 1.06)	
institution		0.79 (0.65 − 0.95) *	
Clothing before stroke			
without help		reference	
with help		0.93 (0.69 − 1.24)	
Mobility before stroke			
without help in- & outdoors		reference	
without help only indoors		1.17 (0.98 − 1.40)	
with help		0.84 (0.70 − 1.00)	
Toileting before stroke			
without help		reference	
with help		1.30 (0.95 − 1.79)	
Comorbidities before stroke			
atrial fibrillation		1.06 (0.95 − 1.18)	
diabetes		1.08 (0.96 − 1.22)	
femur fracture		1.04 (0.89 − 1.21)	
heart failure		0.96 (0.85 − 1.09)	
hypertension		0.92 (0.84 − 1.01)	
Consciousness at hospital admission			
fully awake		reference	
drowsy		1.12 (0.97 − 1.29)	
unconscious		0.90 (0.77 − 1.06)	
Complications during acute care		1.30 (1.08 − 1.56) *	
Days in acute care		1.02 (1.01 − 1.03) *	

Data presented as ratios (e^β) and 95% confidence interval. A natural logarithm transformation of the cost was applied to fix the violation of normal distribution in regression models. Then, exponentiation was performed to see the relationship between inpatient stroke rehabilitation cost and dementia in each regression model.

Model 1: Simple linear regression model, unadjusted

Model 2: Multiple linear regression model, adjusted for age at stroke, sex, living situation before stroke, pre-stroke activities of daily living, pre-stroke comorbidities, consciousness at hospital admission, having complications during acute care and number of days in acute care

Model 3: Linear regression model (after implementing propensity score matching with the risk for dementia)

* $p < 0.05$

5.2 STUDY 2. SATISFACTION OF PERSONS WITH DEMENTIA WITH STROKE CARE AND REHABILITATION

As can be seen from Table 2, PWD was less likely to be satisfied with stroke care, compared to persons without dementia, when they answered the questionnaire by themselves or with the help of the caregivers. In the fully adjusted models (model 3), PWD who reported themselves, had significantly lower likelihood of satisfaction with acute stroke care at hospital (OR 0.71, 95% CI 0.60-0.85), health care professionals' attitude (OR 0.79, 95% CI 0.66-0.96), communication with doctors (OR 0.78, 95% CI 0.66-0.92), and stroke information (OR 0.62, 95% CI 0.52-0.74). The association with satisfaction with inpatient and outpatient rehabilitation was not statistically significant in the fully adjusted model.

When caregivers helped patients answer the questionnaire, all satisfaction items were significantly associated with dementia status. PWD were significantly less satisfied with acute stroke care at hospital (OR 0.84, 95% CI 0.75-0.95), inpatient rehabilitation (OR 0.76, 95% CI 0.66-0.87), outpatient rehabilitation (OR 0.73, 95% CI 0.64-0.84), health care professionals' attitude (OR 0.84, 95% CI 0.75-0.94), communication with doctors (OR 0.87, 95% CI 0.77-0.98), and stroke information (OR 0.89, 95% CI 0.79-1.00).

When patients' family or health care professionals answered on behalf of patients, there was no significant association between satisfaction and dementia status in the fully adjusted model, except for satisfaction with outpatient rehabilitation reported by patients' family, that was significantly lower in PWD, compared to persons without dementia (OR 0.71, 95% CI 0.59-0.86).

Sensitivity analyses were performed in persons with Alzheimer's disease or mixed dementia compared to non-dementia controls. When patients reported themselves, satisfaction with acute stroke care and health care professionals' attitude was significantly associated with Alzheimer's disease or mixed dementia status. Persons with Alzheimer's disease or mixed dementia had significantly lower likelihood of reporting satisfied. When patients reported with their caregivers' help, persons with Alzheimer's disease or mixed dementia were less likely to be satisfied with acute stroke care, inpatient rehabilitation, outpatient rehabilitation and health care professionals' attitude, compared to controls. The significant association did not exist in proxy-reported satisfaction, apart from health care professionals-reported satisfaction with outpatient rehabilitation.

Table 2. Association between dementia and patient satisfaction with stroke care [197]

	Patients answered themselves	Patients answered with caregivers' help	Patients' family answered	Health care professionals answered
Acute stroke care *				
Model 1	0.56 (0.47 − 0.67) ‡	0.70 (0.63 − 0.78) ‡	0.86 (0.75 − 0.99) §	1.24 (0.71 − 2.18)
Model 2	0.56 (0.47 − 0.66) ‡	0.69 (0.62 − 0.77) ‡	0.87 (0.75 − 1.00) §	1.24 (0.70 − 2.19)
Model 3	0.71 (0.60 − 0.85) ‡	0.84 (0.75 − 0.95) §	0.94 (0.80 − 1.10)	1.67 (0.84 − 3.33)
Inpatient rehabilitation †				
Model 1	0.74 (0.60 − 0.91) §	0.60 (0.52 − 0.68) ‡	0.68 (0.58 − 0.81) ‡	0.53 (0.27 − 1.04)
Model 2	0.72 (0.58 − 0.89) §	0.57 (0.50 − 0.65) ‡	0.68 (0.58 − 0.81) ‡	0.54 (0.27 − 1.07)
Model 3	0.93 (0.75 − 1.16)	0.76 (0.66 − 0.87) ‡	0.86 (0.71 − 1.04)	0.77 (0.31 − 1.88)
Outpatient rehabilitation †				
Model 1	0.78 (0.62 − 0.99) §	0.66 (0.58 − 0.75) ‡	0.68 (0.57 − 0.80) ‡	1.10 (0.62 − 1.96)
Model 2	0.76 (0.60 − 0.96) §	0.62 (0.55 − 0.71) ‡	0.67 (0.56 − 0.79) ‡	1.08 (0.61 − 1.94)
Model 3	0.93 (0.73 − 1.18)	0.73 (0.64 − 0.84) ‡	0.71 (0.59 − 0.86) ‡	1.13 (0.56 − 2.26)
Health care professionals' attitude *				
Model 1	0.62 (0.52 − 0.75) ‡	0.70 (0.63 − 0.78) ‡	0.89 (0.78 − 1.02)	1.03 (0.57 − 1.83)
Model 2	0.62 (0.52 − 0.74) ‡	0.69 (0.62 − 0.77) ‡	0.89 (0.78 − 1.03)	1.06 (0.59 − 1.92)
Model 3	0.79 (0.66 − 0.96) §	0.84 (0.75 − 0.94) §	0.99 (0.85 − 1.16)	1.36 (0.65 − 2.84)
Communication with doctors †				
Model 1	0.63 (0.54 − 0.75) ‡	0.78 (0.70 − 0.88) ‡	0.89 (0.77 − 1.03)	0.72 (0.39 − 1.35)
Model 2	0.62 (0.53 − 0.74) ‡	0.76 (0.68 − 0.85) ‡	0.88 (0.76 − 1.02)	0.70 (0.37 − 1.31)
Model 3	0.78 (0.66 − 0.92) §	0.87 (0.77 − 0.98) §	0.96 (0.82 − 1.13)	0.52 (0.23 − 1.15)
Stroke information †				
Model 1	0.53 (0.44 − 0.62) ‡	0.79 (0.71 − 0.89) ‡	0.73 (0.63 − 0.85) ‡	0.69 (0.35 − 1.37)
Model 2	0.51 (0.43 − 0.60) ‡	0.74 (0.66 − 0.83) ‡	0.73 (0.62 − 0.84) ‡	0.73 (0.37 − 1.45)
Model 3	0.62 (0.52 − 0.74) ‡	0.89 (0.79 − 1.00) §	0.85 (0.72 − 1.00)	0.72 (0.31 − 1.66)

Data are presented as odds ratios (95% confidence intervals), which represent levels of satisfaction among persons with and without dementia.

Model 1: Unadjusted ordinal logistic regression model

Model 2: Multivariable ordinal logistic regression model (adjusted by age at stroke and sex)

Model 3: Multivariable ordinal logistic regression model (adjusted by age at stroke, sex and pre-stroke characteristic: Charlson Comorbidity Index; features during acute care: consciousness at hospital admission, complications, length of stay in acute care, discharge places after acute care; characteristics three month after stroke: modified Rankin Scale, self-rated health and having difficulty with reading, speaking, writing)

* Patients satisfaction levels included *very dissatisfied, dissatisfied, satisfied, and very satisfied.*

† Patient satisfaction levels encompassed *had a need but did not receive, very dissatisfied, dissatisfied, satisfied, and very satisfied*.

‡ p < 0.001

§ p < 0.05

The publication is available at IOS Press through http://dx.doi.org/10.3233/jad-200976

5.3 STUDY 3. SOCIOECONOMIC POSITIONS, DEMENTIA DIAGNOSTIC PROCESS AND ANTI-DEMENTIA MEDICATIONS

In Figure 6, PWD with higher education were more likely to receive diagnostic examinations, even when controlling for income. For example, compared to PWD with compulsory education < 9 years, PWD with university ≥3 years were more likely to receive: the complete basic dementia diagnostic work-up (OR 1.19; 95% CI 1.10-1.29), or CT-MRI (OR 1.23; 95% CI 1.09-1.39). When controlling for income, no significant association between getting blood analysis or MMSE and education was present. Higher educated PWD were more likely to receive neuropsychological assessment and occupational therapy assessment, in comparison with lower educated PWD. PWD with university ≥3 years had higher likelihood of acquiring a diagnosis in memory clinic, compared to PWD with compulsory education < 9 years (OR 2.16; 95% CI 2.02-2.31). The association between being diagnosed with specified dementia and higher education was statistically significant, however, no longer significant when adjusting for income. No statistically significant association between education and the use of cholinesterase inhibitors was found. Compared to PWD with the lowest education, PWD with highest education had higher likelihood of using memantine (OR 1.16; 95% CI 1.04-1.29).

As shown in Figure 7, the likelihood of receiving any type of dementia diagnostic examination was significantly predicted by income, when both controlling (Model 1) for and not controlling (Model 2) for education. Compared with lowest income PWD, highest income PWD were more likely to get the complete basic dementia diagnostic work-up (OR 1.35; 95% CI 1.26-1.46) and most individual tests. The odds of getting a diagnosis at a memory clinic for individuals in the highest income category was two times higher than that of persons in the lowest income group: (OR 2.03; 95% CI 1.91-2.16). PWD in the highest income quintile presented higher likelihood of getting a specified dementia diagnosis, in comparison with PWD in the lowest income group (OR 1.33; 95% CI 1.24-1.43). Income had no statistically significant association with the use of cholinesterase inhibitors or memantine.
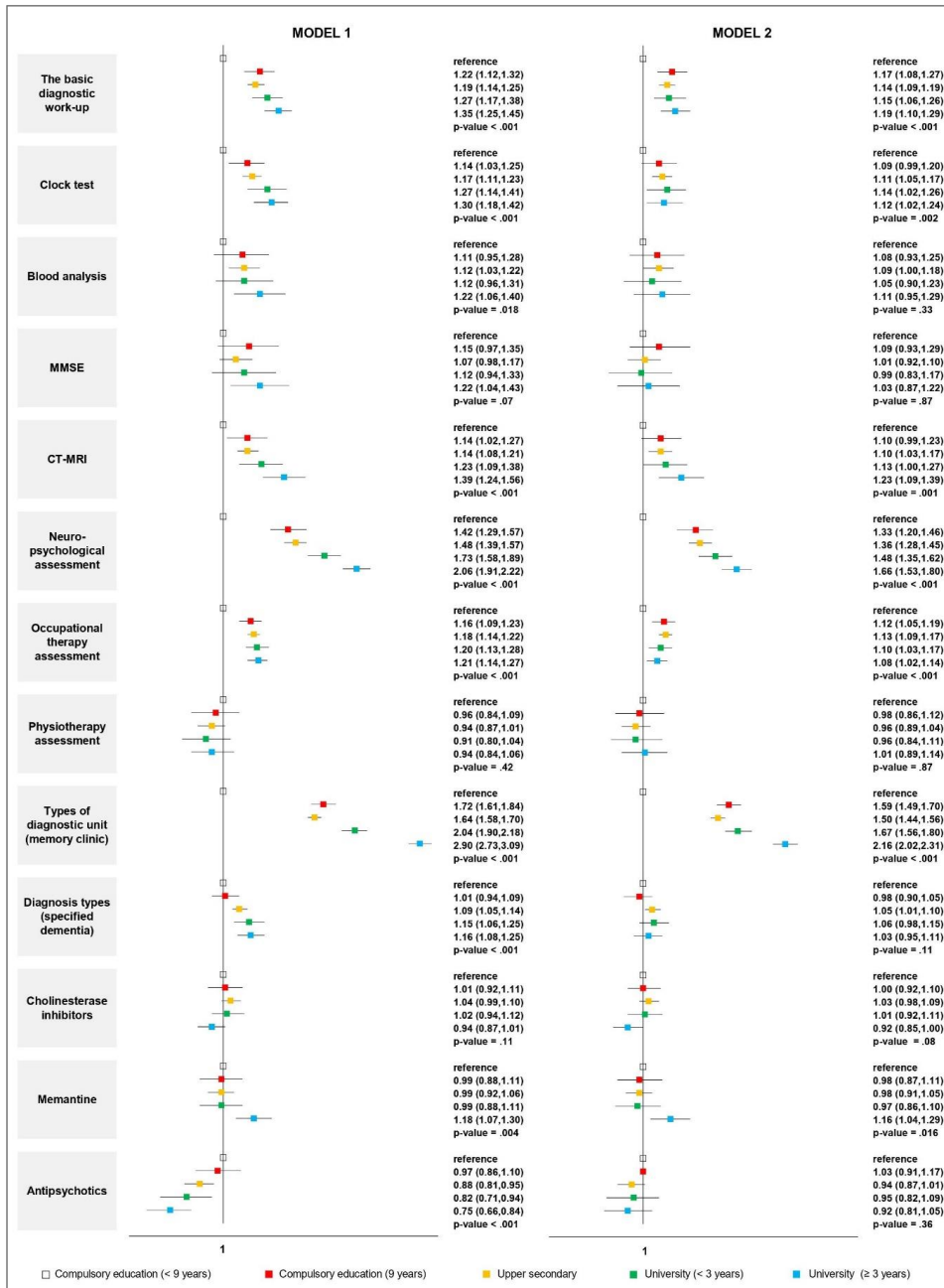
Figure 6. Dementia diagnostics and medication prescription in association with education [202]

For all graphs, data were presented as odds ratios (95% confidence interval). Model 1: Binary logistic regression, controlled for age, sex, regions of birth, living alone, dementia types (except for diagnosis types as dependent variable), Charlson Comorbidity Index, types of diagnostic unit (except for types of diagnostic unit as outcome) and MMSE scores (except for the basic diagnostic work-up and MMSE as dependent variables). Model 2: Binary logistic regression, controlled for other variables like Model 1 and additionally adjusted for disposable individual income. Only patients with Alzheimer's disease or mixed dementia were analyzed (E1 = 13080, E2 = 2687, E3 = 13574, E4 = 2919, E5 = 4335).

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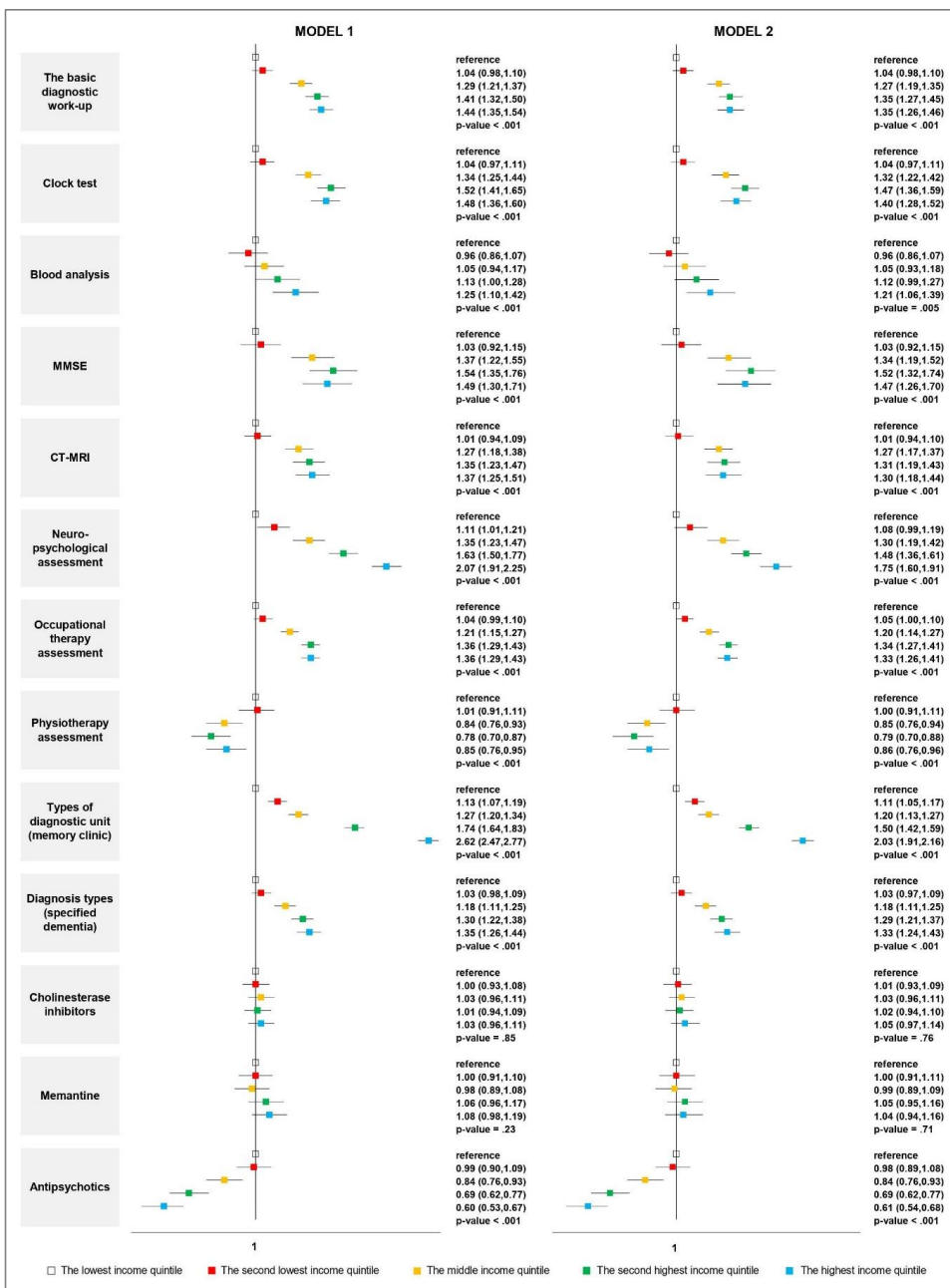
Figure 7. Dementia diagnostics and medication prescription in association with disposable individual income [202].

For all graphs, data were presented as odds ratios (95% confidence interval). Model 1: Binary logistic regression, controlled for age, sex, regions of birth, controlled for age, sex, regions of birth, living alone, dementia types (except for diagnosis types as dependent variable), Charlson Comorbidity Index, types of diagnostic unit (except for types of diagnostic unit as outcome) and MMSE scores (except for the basic diagnostic work-up and MMSE as dependent variables). Model 2: Binary logistic regression, controlled for other variables like Model 1 and additionally adjusted for education. Only patients with Alzheimer's disease or mixed dementia were analyzed (I1 = 7138, I2 = 6882, I3 = 7059, I4 = 7696, I5 = 8357).

5.4 STUDY 4. SOCIOECONOMIC POSITIONS AND LONG-TERM CARE FOR PERSONS WITH DEMENTIA

Table 3 presented the association between education and the receipt of long-term care. Education was significantly associated with the receipt of any kind of long-term care. By comparison with PWD with compulsory education, PWD with a university level had significantly higher chance of receiving any kind of long-term care (OR 1.23, 95% CI 1.05-1.45). Education was not significantly associated with the receipt of institutional care in this cohort. University-educated PWD had significantly higher chance of receiving home care, compared to compulsory-educated PWD (OR 1.20, 95% CI 1.02-1.42). PWD's education displayed a significant association with the monthly average number of home care hours. In comparison with PWD with compulsory education, the monthly average number of home care hours was statistically significantly higher in PWD with a university degree (RR 1.39, 95% CI 1.18-1.63) or PWD with upper secondary degree (RR 1.10, 95% CI 1.01-1.21). When stratifying by whether patients were living alone, these associations were statistically significant in PWD who lived alone, but were not significant in the cohabiting individuals.

Table 3. Education in relation to long-term care

		Model 1	Model 2
Long-term care	Compulsory education	reference	reference
(OR, 95% CI)	Upper secondary	1.09 (0.99,1.20)	1.10 (0.99,1.21)
	University	1.21 (1.04,1.41) *	1.23 (1.05,1.45) *
	p-value [a]	0.027	0.023
Institutional care only	Compulsory education	reference	reference
(OR, 95% CI)	Upper secondary	0.89 (0.73,1.09)	0.87 (0.71,1.07)
	University	1.03 (0.74,1.45)	0.97 (0.68,1.38)
	p-value [a]	0.475	0.407
Home care			
Estimate of use	Compulsory education	reference	reference
(OR, 95% CI)	Upper secondary	1.08 (0.98, 1.19)	1.08 (0.97, 1.19)
	University	1.22 (1.04, 1.43) *	1.20 (1.02, 1.42) *
	p-value [a]	0.036	0.075
Monthly average number of home	Compulsory education	reference	reference
care hours (RR, 95% CI)	Upper secondary	1.09 (1.01, 1.20) *	1.10 (1.01, 1.21) *
	University	1.35 (1.16, 1.57) *	1.39 (1.18, 1.63) *
	p-value [a]	< 0.001	< 0.001

Binary logistic regression was employed for long-term care and institutional care.

Zero-inflated negative binomial regression was used for home care.

Model 1: controlled for age, sex, living areas, living alone, Charlson Comorbidity Index, MMSE score, types of diagnostic unit, and dementia types.

Model 2: additionally controlled for disposable individual income

[a] Wald test was used to examine the overall significant association of education levels with outcomes.

* p-value is less than 0.05

As can be seen from Table 4, income was not statistically significant associated with the receipt of home care, institutional care or any kind of long-term care. When stratifying by living alone,

statistically significant association between income and long-term care was found neither in PWD living alone nor in cohabiting PWD. By comparison with PWD in the lowest income group, higher monthly average number of home care hours were found in PWD in the middle-income group, when cohabiting (RR 1.33, 95% CI 1.07-1.66), however lower duration when they lived alone (RR 0.81, 95% CI 0.71-0.93).

Table 4. Income in relation to long-term care

		Model 1	Model 2
Long-term care	The lowest income tertile	reference	reference
(OR, 95% CI)	The middle income tertile	0.95 (0.85,1.06)	0.94 (0.84,1.05)
	The highest income tertile	1.01 (0.90,1.14)	0.97 (0.85,1.09)
	p-value [a]	0.528	0.573
Institutional care only	The lowest income tertile	reference	reference
(OR, 95% CI)	The middle income tertile	0.89 (0.71,1.12)	0.89 (0.71,1.12)
	The highest income tertile	1.11 (0.86,1.42)	1.12 (0.86,1.45)
	p-value [a]	0.192	0.184
Home care only			
Estimate of use	The lowest income tertile	reference	reference
(OR, 95% CI)	The middle income tertile	0.96 (0.86, 1.08)	0.95 (0.85, 1.07)
	The highest income tertile	1.07 (0.94, 1.21)	1.03 (0.91, 1.18)
	p-value [a]	0.205	0.373
Monthly average number of	The lowest income tertile	reference	reference
home care hours (RR, 95% CI)	The middle income tertile	0.97 (0.87, 1.08)	0.96 (0.86, 1.07)
	The highest income tertile	1.03 (0.91, 1.16)	0.93 (0.83, 1.06)
	p-value [a]	0.541	0.549

Binary logistic regression was employed for long-term care and institutional care.

Zero-inflated negative binomial regression was used for home care.

Model 1: controlled for age, sex, living areas, living alone, Charlson Comorbidity Index, MMSE score, types of diagnostic unit and dementia types.

Model 2: additionally controlled for education

[a] Wald test was used to examine the overall significant association of income with outcomes.

5.5 STUDY 5. IMMIGRATION, DEMENTIA DIAGNOSTIC PROCESS AND ANTI-DEMENTIA MEDICATIONS

As shown in Table 5, in comparison with Swedish-born PWD, foreign-born PWD were more likely not to receive MMSE: born in Asia (OR 1.64, 95% CI 1.13-2.38), South America (OR 1.97, 95% CI 1.15-3.38) and the other European countries (OR 1.75, 95% CI 1.34-2.29). Compared to the natives, foreign-born people (apart from North and South America) had a significantly higher probability of not receiving MMSE. The ordinal logistic regression model presented that a significantly lower MMSE scores among foreign-born PWD, by comparison with the native Swedes.

Table 5. MMSE in relation to region of birth

	Multinomial logistic regression model		Ordinal logistic regression model
	(Reference group: PWD received MMSE)		
	PWD cannot perform MMSE	*PWD did not receive MMSE*	*(Odds ratio of having higher MMSE score)*
Sweden	reference	reference	reference
Other EU & Nordic countries	1.48 (1.27,1.73)	1.04 (0.91,1.19)	0.66 (0.63,0.69)
Other Europe countries	5.37 (4.30,6.70)	1.75 (1.34,2.29)	0.23 (0.20,0.26)
Asia	6.16 (4.70,8.07)	1.64 (1.13,2.38)	0.22 (0.19,0.26)
Africa	7.25 (4.26,12.35)	1.25 (0.50,3.15)	0.13 (0.09,0.19)
North America	1.36 (0.55,3.34)	1.67 (0.87,3.20)	0.92 (0.69,1.21)
South America	1.34 (0.65,2.76)	1.97 (1.15,3.38)	0.46 (0.36,0.58)
p-value	< 0.001	< 0.001	< 0.001

Data were presented as or odds ratios (ordinal logistic regression) (95% confidence interval). Both regression models were adjusted for age, sex, living alone, living areas (urban/intermediate/rural), education, income, Charlson Comorbidity Index and type of diagnosis unit.

p-values were calculated by Wald test.

Fully adjusted logistic regression showed that the performance of complete basic dementia diagnostic work-up was significantly associated with region of birth (Figure 8). Model 1 showed that in comparison to the native Swedes, foreign-born people were less likely to obtain the complete basic dementia diagnostic work-up: born in Africa (OR 0.47, 95% CI 0.30-0.74), Asia (OR 0.57, 95% CI 0.46-0.71) and the other European countries (OR 0.60, 95% CI 0.51-0.71). However, when adjusting for MMSE score, these associations were no longer significant (Model 2). The same pattern of lower likelihood of receiving the clock test among people born in Asia, Africa and the other European countries was found. Region of birth was not significantly associated with the performance of blood analysis. There was a statistically significant association between region of birth and receiving a diagnosis at a memory clinic. Compared to Swedish-born persons, South American-born PWD were more likely to be diagnosed in memory clinics (OR 2.78, 95% CI 1.80-4.30). In contrast, people born in the other European countries had significantly lower chance of being diagnosed in memory clinics (OR 0.74, 95% CI 0.63-0.87). Regarding the use of anti-dementia medications, there was a significant association between region of birth and the use of antipsychotics, cholinesterase inhibitors and memantine, but this association was not significant anymore when adjusting for MMSE score.
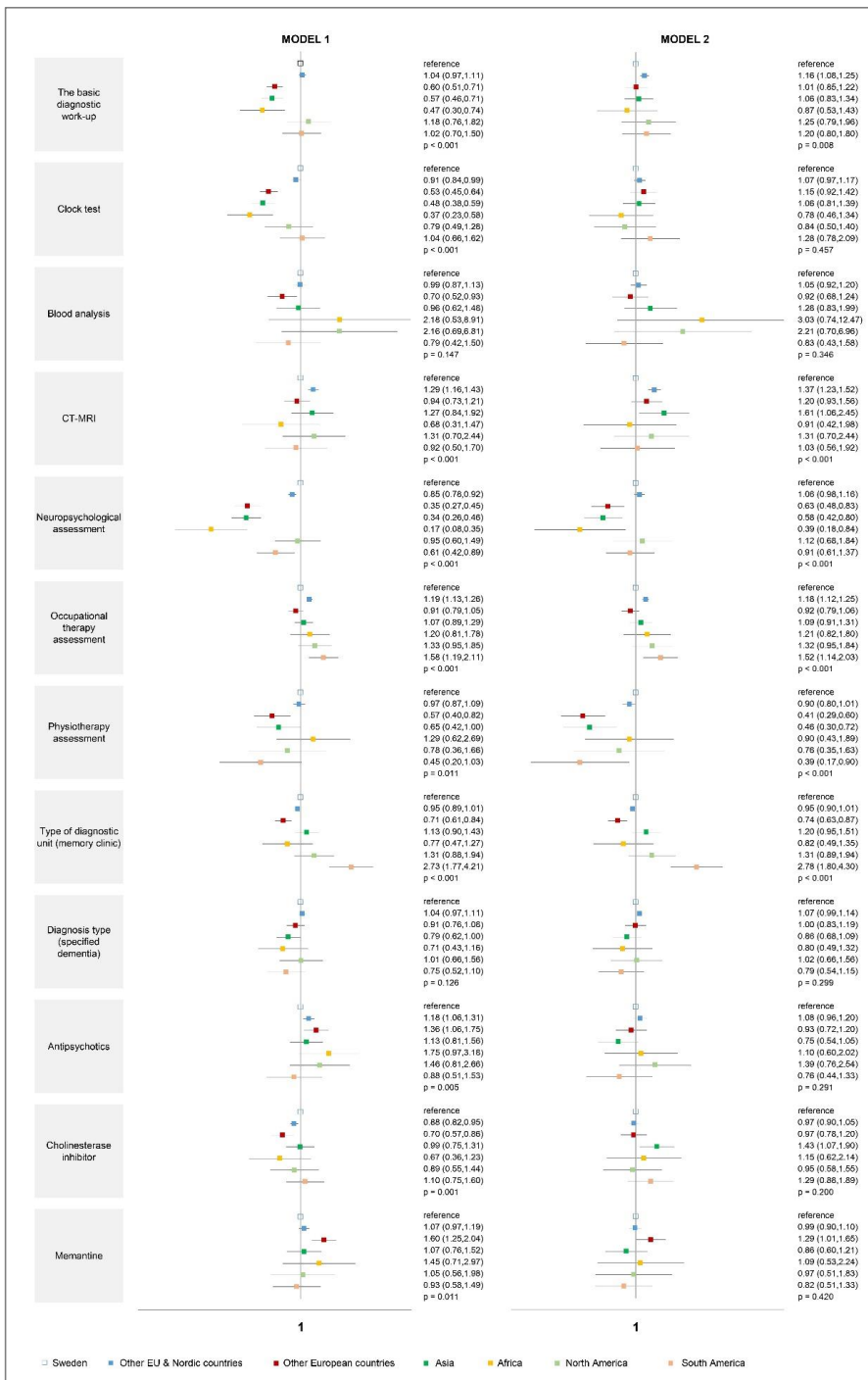
Figure 8. Dementia diagnostics & medication prescription in relation to region of birth in PWD receiving MMSE

Data were presented as odds ratios (95% confidence interval). Model 1 was adjusted for age, sex, living alone, living areas, education, income, Charlson Comorbidity Index and type of diagnosis unit (except for type of diagnosis unit as the outcome). Model 2 was additionally controlled for MMSE score. These models did not include persons who did not receive MMSE. Only patients with Alzheimer's disease or mixed dementia were analyzed for Cholinesterase inhibitors and Memantine (n = 34,150). p-value was calculated by Wald test.

6 DISCUSSION

This doctoral thesis aimed to investigate the health inequality in care for PWD not only from a specific angle (stroke care and rehabilitation), but also from an overall viewpoint (SEP and immigration). We observed that inequalities occurred in stroke care and rehabilitation between persons with and without dementia; and were also present in dementia diagnostics and medications prescription between different SEP or regions of birth.

6.1 INEQUALITIES IN STROKE CARE AND REHABILITATION BETWEEN PERSONS WITH AND WITHOUT DEMENTIA

From main findings of Studies 1 and 2, it can be concluded that there were inequalities in stroke care and rehabilitation between persons with and without dementia when they suffered from stroke. This finding was in accordance with previous studies, in which inequalities in stroke care and rehabilitation were identified in Sweden as well. [6, 75, 92, 95, 183, 206]

In Study 1, we found that persons with a dementia diagnosis before stroke had significantly lower inpatient stroke rehabilitation costs, by comparison with individuals without dementia. Meanwhile, our data showed that PWD had significantly worse functioning, health status and were more dependent in ADL both before and after suffering from a stroke, compared to their non-dementia counterparts. This finding on lower costs is against popular beliefs and results of previous studies in which higher inpatient care costs or stroke rehabilitation costs were significantly more frequent among people with more pronounced disabilities. [93, 100-103, 207]

One probable reason for our finding is that health care expenditure was unequally distributed to patients who were more disadvantaged. This could be due to health care professionals' beliefs, who decide the time and the place to discharge patients. Health care professionals might think that PWD had lower potential to benefit from the inpatient rehabilitation, thus they probably discharged PWD earlier to nursing homes or primary care centers. Additionally, there are similar approaches in care and rehabilitation for dementia and stroke. The Swedish National Guidelines for Dementia Care also propose cognitive and physical training for ADL in PWD. [45] Thus, clinicians might decrease the length of stay at inpatient stroke rehabilitation because after acute stroke care, PWD were discharged to nursing homes or primary care centers where they already received dementia care prior to stroke in order to resume interventions to maintain their functioning, which was deemed adequate for stroke rehabilitation as well.

In Study 2, we detected that PWD who answered the satisfaction questionnaire by themselves or with the help of their caregivers, were significantly less satisfied with stroke care and rehabilitation, compared to persons without dementia. Lower satisfaction with stroke care and rehabilitation among PWD should be cautiously interpreted because the nature of satisfaction is subjective. Expectations and experience with the care or rehabilitation also influenced how PWD rate their satisfaction. Being more disabled and more dependent in ADL as well as having poorer self-reported health status, PWD could possibly rank lower satisfaction with stroke care and rehabilitation, compared to people without dementia. Because PWD had poorer memory

and more severe cognitive impairment, they might not remember how or whether they underwent care and rehabilitation after suffering stroke.

However, it is impossible to neglect that lower patient satisfaction might be explained by the fact that unfulfilled care needs were higher in PWD and their caregivers, compared to persons without dementia. This argument is reasonable because preceding studies showed that lower patient satisfaction was significantly predicted by unmet care needs. [118, 119] Moreover, Riksstroke also pointed out that not obtaining any care or rehabilitation after discharge from the hospital resulted in patient dissatisfaction. [208] Furthermore, lower patient satisfaction in PWD possibly derived from inequalities in the provision of stroke care and rehabilitation between persons with and without dementia. The organization and delivery of stroke care services have been shown to influence patient satisfaction. [117] This finding revealed a gap in the supply of stroke care and rehabilitation for PWD, in comparison with general stroke patients.

6.2 SOCIOECONOMIC INEQUALITIES IN DEMENTIA DIAGNOSTICS AND MEDICATIONS PRESCRIPTIONS

The main results of Studies 3 and 4 enabled us to conclude that inequalities in dementia diagnostics, medications prescriptions and long-term care occurred among PWD from different educational or income levels. Income was shown to be the more decisive socioeconomic factor in the association with dementia diagnostic process, compared to education. In the relationship with long-term care, education was more decisive, meanwhile income did not show any significant association.

Regarding dementia diagnostics, we saw that higher income PWD had significantly higher chance of receiving the complete basic dementia diagnostic work-up, clock test, blood analysis, MMSE, CT-MRI, physiotherapy assessment and neuropsychological assessment. PWD with higher education were more likely to obtain these dementia examinations, except for blood analysis and MMSE. PWD with higher education or income were more likely to be diagnosed at a memory clinic. Getting a specified dementia diagnosis was significantly associated with income (both when controlling and not controlling for education), but not with education (when adjusting for income).

About the prescription of anti-dementia medications, our analysis showed that neither education nor income were significantly associated with the use of anticholinesterase inhibitors, memantine and antipsychotics. The only exception was that university educated PWD had significantly higher likelihood of using memantine, compared to compulsory educated PWD.

In terms of long-term care, we observed that PWD with higher education had significantly higher chance of obtaining any kind of long-term care, home care, and have greater duration of home care hours, by comparison with PWD with lower education. There was no significant association between income and home care, institutional care or any kind of long-term care. It can be interpreted that universal health coverage together with low co-payment from the

patients assured the equal access to care of every person, regardless of income. Neither education nor income were significantly associated with the receipt of institutional care. The sub-group analysis on living alone pointed that among PWD living alone, both higher education or higher income was significantly associated with higher chance of acquiring any kind of long-term, care or home care. However, these association was not significant in cohabiting PWD.

Socioeconomic inequalities in dementia diagnostics, medication prescriptions and long-term care might be explained by the following reasons. The first plausible explanation is that different perceptions of dementia between high and low socioeconomic PWD (perhaps, their family as well) affect how they receive diagnosis and treatment. PWD with high education or income were possibly aware of dementia diagnosis and treatment, could have better communications skills, and might be more familiar with navigating the health and social care system [143]. This probably enabled higher socioeconomic PWD to have higher expectations on the dementia diagnostic process, anti-dementia medications and long-term care, in comparison with lower socioeconomic PWD. As seen in the study cohort, PWD with higher SEP probably sought care earlier because they had lower age and better cognitive function (shown by higher MMSE score) at dementia diagnosis, compared to lower socioeconomic PWD. As a result, specific dementia diagnoses were easier to administer in persons with mild dementia who can fully participate in the diagnostic process, which may also lead to more testing. Furthermore, one justification that might be controversial and less frequent, but should not be omitted is that lower-educated PWD (or their family) might consider dementia as a normal aging issue (normalizing views) or a shameful matter that needs to be disguised (stigmatizing views). [209] This fact might prevent them from seeking diagnosis, treatment, and long-term care early.

The impact of cohabitation on the likelihood of receiving dementia diagnosis, anti-dementia medications and long-term care might be an alternative reason. The proportion of PWD who lived alone decreased when the levels of education and income increased in both studies. Our analysis showed that when PWD lived alone, lower likelihood of receiving long-term care or lower duration of home care hours were found in people with lower education or income levels. PWD who live alone are usually in need of more care and should receive more care from the municipalities. However, our studies showed the opposite results, in which significant inequalities in care occurred among PWD living alone, not in cohabiting PWD. It might be plausible that partners or other adults might support PWD to navigate the health and social care system, as well as care for them in daily life. [10] Thus, the inequalities were more frequent in individuals living alone, by comparison with ones living with another adult.

In addition, differences in geographical location (urban vs. rural) might cause the inequalities in long-term care between low- and high- socioeconomic PWD. In our study, PWD with lower education had lower proportion living in urban areas, whereas PWD with higher education had lower percentage of residing in rural areas. Recent studies pointed out that when older people lived in rural areas, they were significantly less likely to be hospitalized or acquire long-term care. [8, 210] Unfulfilled care needs were more frequent among PWD living in the rural locations,

compared to individuals living in urban locations. [211, 212] It should be noticed that geographical location was adjusted for in our regression models. What is more, a recent study also explored time between dementia diagnosis and long-term care by living areas and found that PWD residing in rural locations were more likely to wait longer to access institutional care. [144]

Finally, these socioeconomic inequalities could denote unfulfilled care demands. Previously, unmet health care needs among lower socioeconomic individuals in Sweden were reported in other studies. [146-149] Lower socioeconomic PWD might not know how to seek care for dementia and what kind of care, diagnostic test or treatment is available for them. Furthermore, differences in diagnosis, treatment and long-term care among SEP probably implies unequal allocation of health care resources and unequal provision of care between lower and higher socioeconomic PWD. Various policies improving quality of care for older people, especially for PWD, have been implemented by the Swedish government. In a recent national plan for quality in health and social care for older people, the government concentrates on promoting effectiveness and quality of long-term care, as well as evaluating people's demands on long-term care in a flexible manner. [66] The national plan also recommends "ageing in place" policy, which is a combination of home care and primary care, in order to support PWD with more pronounced disabilities. In addition, health and social care in Sweden are mainly subsidized by the government through the policy of universal health coverage.

It is remarkable that with a universal health care system, as well as a long-standing tradition of providing long-term care, inequalities in care still appeared among PWD with different socioeconomic levels. The transition from institutional care to home care in Sweden has happened for many years. In 2012, it was estimated that around 58% of PWD (91,900 out of 158,000) in Sweden were living at home. [49] These figures might be a consequence of the Community Care Reform which was implemented since 1992, leading to a decline in the quantity of beds and duration of stay at the hospitals in Sweden. [66] Shifting from institutional care to home care is reasonable because home care is less expensive. A recent study showed that about 60% of societal costs of dementia in Sweden were spent on institutional care. [49] The transition to home care in PWD is the growing tendency in other countries, similar to Sweden. [213] Previous studies on this trend found better quality of life and higher independence in ADL among PWD living at home, compared to individuals living in the institutional care. [213, 214] Thus, the socioeconomic inequalities in the provision of dementia diagnosis, anti-dementia medications and long-term care are noticeable findings, highlighting issues in the health and social care system of Sweden and other countries with similar contexts.

6.3 INEQUALITIES IN DEMENTIA DIAGNOSTICS AND MEDICATION PRESCRIPTIONS AMONG DIFFERENT IMMIGRATION STATUS

In Study 5, we identified that health inequalities in dementia diagnostic process and anti-dementia medications were not clear when investigating the effect of immigration. Swedish-born persons were more likely to receive a complete basic dementia diagnostic work-up, clock test or MMSE, compared to persons born in other regions of the world. However, most of these differences was not significant when controlling for MMSE scores. Adjusting for MMSE score

is important because the severity of cognitive impairment influences the decision of doctors on the selection of diagnostics examinations and the use of anti-dementia medications. A previous study showed that the selection of dementia diagnostic examinations was affected by age and the degree of cognitive impairment. [215] Due to unobvious inequalities, the main findings of this study should be discussed with caution.

Culture and language proficiency might explain inequalities in dementia diagnostics and the use of anti-dementia medications between Swedish-born and foreign-born PWD. Although bilingual health providers and trained medical interpreters are available in health and social care services in Sweden, foreign-born PWD probably found it difficult to seek appropriate care services and consultancy if they had poor acculturation or were not proficient in using Swedish or English. [216] Moreover, performing MMSE (or MoCA, RUDAS) and the clock test with the translation of an interpreter might affect the reliability and validity of these tests. On the contrary, no significant difference in terms of blood analysis and CT-MRI was found, possibly due to the fact that language proficiency was less important in these examinations.

Another plausible explanation is that foreign-born PWD might face difficulties with navigating health and social care system and local transportation, hindering them from accessing care services early and optimally. [217, 218] In a previous study, foreign-born residents were shown to visit the hospital less regularly, in comparison with native people. [219] In several immigrant groups, people have a tradition of acquiring informal care from their family, instead of seeking care from the community, and thus, there might be unawareness of health and social care services that they should receive. [220-222] Moreover, by comparison with Swedish-born people, immigrants were shown to hesitate in looking for formal care and obtain care later. [223]

Health literacy factors might also be an alternative explanation for the lower access to dementia diagnostics and medications in foreign-born people. Individuals' viewpoints on dementia may span between normalizing and stigmatizing. [209] People with normalizing perspectives might regard dementia as a normal and foreseeable part of aging, hence, difficult to avoid. [209] On the other hand, stigmatizing views may lead to seek concealment. [209, 224] Such perceptions may keep some foreign-born PWD from looking for dementia diagnosis and medications. In our study, the MMSE scores at the time of diagnosis among PWD born in Asia, Africa and the other European countries were significantly lower, compared to those among Swedish-born PWD. This may mean that they sought care for dementia care later compared to the Swedish-born citizens or reflect language difficulties or lower educational attainment.

Finally, the impact of SEP might also explain the inequalities in dementia diagnostic process and medications. In this study, PWD born in Asia, Africa, South America and the other European countries were among those with the lowest education or income levels. Even though education of most of Asian- and African-born PWD was missing, lower education levels seemed to be most frequent in these two groups, because missing data on education might imply lower educational levels. Additionally, preceding studies in this thesis found that lower education or income was significantly associated with lower probability of acquiring dementia diagnosis or the use of anti-dementia medications. [202]

6.4 METHODOLOGICAL CONSIDERATIONS

6.4.1 Strengths

The main strength of this thesis is the combination of numerous population-based registries and quality-of-care registers in Sweden. Therefore, the findings of this thesis are representative of the Swedish population. In addition, the quality-of-care registers in this thesis, SveDem and Riksstroke, are the world largest registers of their kind, with long follow-up. This feature allowed us to conduct rigorous analyses on the care, diagnosis, and medications for PWD.

6.4.2 Limitations

The accuracy of any study could be evaluated by its precision and validity. Precision implies the lack of random error or random variation. [225] Random errors might originate from the method of sampling participants or measuring variables. [225, 226] In Studies 1, 2 and 3, the unbalanced sample size among study groups might affect the precision of the estimates, as can be seen by wide confidence intervals and large standard deviation of the estimates. In addition, it can decrease the power of the test (the probability of correctly rejecting the null hypothesis when it is false). However, the unbalanced sample size does not invalidate the results. The unequal sample size among groups did not affect the statistical tests because it is not an assumption of these tests.

Validity refers to the lack of systematic errors, so-called bias. [225] Validity includes two components: internal validity and external validity (also known as generalizability). [225] External validity implies the ability to generalize study findings to other populations in other places and at other times. [225, 226] With a register-based study design, collecting longitudinal data for many years, the generalizability and representativeness of this thesis were assured by the national scale of the data. These findings can be generalized to other high-income countries with similar health care systems to Sweden. However, with other low- and middle-income countries, the results of this thesis might be difficult to extrapolate. Thus, these findings should be interpreted with caution when applying them to other countries, especially countries without universal health coverage or low- and middle-income countries.

Internal validity answers the question of whether a difference in the outcome was caused by the exposure (high internal validity) or by systematic errors (low internal validity). [225, 226] Violations of internal validity can be categorized into three groups: confounding, selection bias and information bias.

Confounding

Confounding variables are covariates that are associated with both exposure and outcome of the study. [225] By contrast with mediators, confounders are not on the causal pathway of exposure and outcome. Confounding variables are unavoidable features of an observational study. Confounders might cause distortion, leading to the overestimation or underestimation of the estimates. [225] In this thesis, we attempted to control for confounders with different methods.

In Study 1, we adjusted for age at stroke, sex, living situations before stroke, consciousness at hospital admission, pre-stroke ADL and comorbidities, complications during acute care and days in acute care, and employed propensity score matching for dementia and non-dementia groups. In Study 2, we controlled for age at stroke date, sex and pre-stroke CCI, attributes during acute care, characteristics three month after stroke and stratified the analysis by who answered the questionnaire (PWD answering themselves, PWD answering with the help of their caregivers, PWD's family, or health care professionals on behalf of PWD). In Study 3 and 5, we added the potential confounders into the regression models, including age at dementia diagnosis, sex, region of birth, living alone, dementia types (except for this variable as outcome), CCI, types of diagnostic unit (except for this variable as outcome) and MMSE scores (except for the complete basic dementia diagnostic work-up and MMSE as outcome). In Study 4, adjustment and stratification were used to control for the confounders.

Selection bias

Selection bias is caused either by procedures utilized for choosing participants or by factors that affect study participation. [225] In selection bias, the estimate between exposure and outcome of included participants differs from that of all persons who should have been theoretically eligible for study, including those who do not participate. [225] In Studies 1, 3, 4, 5, only PWD registered in SveDem were selected for the analysis. There were still PWD registered in the NPR, PDR, but not present in SveDem. Although the coverage rate of SveDem increases through years, SveDem captures approximately 35% of all estimated incident PWD in Sweden. [43] However, the actual incidence of dementia as diagnosed could be smaller, potentially resulting in higher coverage for SveDem. Also, about 50% of dementia diagnoses are not detected since people do not seek medical help for these symptoms, thus making the real coverage of SveDem much larger. [186] In addition, because of the nature of dementia, it is impossible to have a complete coverage for all patients as in some other diseases. In our data that PWD registered in SveDem had significantly higher education and income, compared to PWD not registered in SveDem (unpublished personal observations). This might make our findings more generalizable towards people with high SEP. In these studies, we selected PWD registered in SveDem because SveDem contains information about cognitive impairment of patients, as shown by MMSE, that were not available in other registers. The degree of cognitive impairment is an important covariate in this thesis, affecting the dementia diagnosis, medications and long-term care that the PWD should receive. Thus, we selected PWD registered in SveDem because its benefits surpassed its limitations of generalization.

Information bias

Information bias refers to measurement errors in the needed information, resulting in misclassification of exposure and outcome. [225] Misclassification of stroke patients or PWD might appear in this thesis. We tried to overcome this problem by combining SveDem and Riksstroke with other registers, such as the NPR or PDR, to define the stroke patients or persons with and without dementia. In addition, we adjusted for types of dementia diagnosis in all studies. Types of dementia diagnosis were retrieved from SveDem at basic registration, which

was shown to be rarely changed (about 5%). [43] However, misclassification of dementia types might occur in this thesis. Moreover, recall bias might appear in Study 2, in which outcome variables were based on patient-reported questionnaires of Riksstroke. Worse memory and cognitive impairment after stroke possibly hinder both persons with and without dementia from remembering which care and rehabilitation that they received. The concept of rehabilitation might not be clear for all patients. This might affect their satisfaction with care and rehabilitation. Although we addressed this problem by stratifying by the respondents of the survey, it is impossible to neglect that recall bias might underestimate or overestimate the results of these studies.

7 CONCLUSIONS

This doctoral thesis evaluated health inequality in care for PWD from a specific perspective (stroke care and rehabilitation for PWD) to a general viewpoint (dementia diagnostic process, anti-dementia medications, and long-term care for PWD from different SEP or with different immigration status). Here are the main conclusions:

- PWD had significantly lower cost of inpatient stroke rehabilitation, by comparison with persons without dementia, as a result of shorter rehabilitation stay. However, controlling for socio-demographic features, pre-stroke living places, consciousness at hospital admission, pre-stroke ADL, complications, comorbidities, and length of stay at acute care, there were no significant difference in the probability of obtaining inpatient stroke rehabilitation after acute stroke care between persons with and without dementia.

- After suffering stroke, PWD were significantly less satisfied with acute stroke care, inpatient and outpatient rehabilitation, health care professionals' attitude, communication with doctors and stroke information, by comparison with persons without dementia.

- Lower socioeconomic PWD were less likely to get dementia diagnostic examinations, receive a specified dementia diagnosis, and be diagnosed at a memory clinic. No significant association between SEP and prescription of anti-dementia medication was present, apart from the association between higher education and the prescription of memantine.

- PWD with higher education had higher likelihood of getting any kind of long-term care, home care, and receiving greater duration of home care hours, in comparison with their lower-educated peers. Income did not show any significant association with any kind of long-term care or home care. The provision of institutional care was not significantly associated with either education or income.

- Swedish-born citizens were more likely to receive a basic dementia diagnostic work-up, clock test and MMSE than persons born in other regions. However, this significant association between immigration and dementia diagnosis disappeared when controlling for MMSE scores. No significant association between immigration and the prescription of anti-dementia medications was found in this cohort.

8 POINTS OF PERSPECTIVE

This thesis showed that inequalities in care existed not only among PWD, but also between them and persons without dementia. Our two first studies, and previous studies in Sweden, showed inequalities in stroke care and rehabilitation between persons with and without dementia. In this study cohort, socioeconomic inequalities were evidently present in the dementia diagnostic process, but not profound in the use of anti-dementia treatment or the receipt of long-term care. Meanwhile, the receipt of dementia diagnostic process and anti-dementia treatment was not considerably affected by immigration status. We considered these results from two different angles:

A viewpoint of Swedish health care system

Our findings underline the need of quality management in care for PWD in Sweden. Inequalities might reveal a gap in the quality of care for PWD. Among population of PWD, people with lower socioeconomic positions accounted for a larger proportion and usually have more severe cognitive impairment. In addition, the aim of SveDem is to create a nationwide tool for equal and best treatment of PWD. Therefore, reporting this issue in the SveDem annual report and conducting additional studies on inequalities in care for PWD is crucial. Studies and reports based on SveDem and other quality registers would help the policymakers recognize the impact of their policies on patients and adjust policies corresponding to scientific evidence and patient expectations.

Furthermore, inequalities in stroke care and rehabilitation probably reflect unmet needs in the PWD. Unmet needs were probably caused by the difference in care and rehabilitation services, or lower quantity and quality of care and rehabilitation services. Moreover, unmet care needs might result from the fact that PWD need different adaptations to standard stroke care and rehabilitation. Thus, it is necessary for policymakers and health care professionals to evaluate and tailor the provision of stroke care and rehabilitation for PWD to optimize their health outcomes and satisfaction. Studies and reports on the delivery of stroke care and rehabilitation specifically for PWD should be conducted. Additionally, evaluating general care trajectories for PWD, such as duration of long-term care, waiting time to receive long-term care and so on, is essential. It not only enables the removal of inequalities in care, but also to improve quality of care for PWD.

A perspective of global health

Sweden, a country with a universal health care system and long tradition of long-term care for PWD, still presented inequalities. This means that universal health coverage cannot completely solve the problem of health inequality. This fact is a warning for health equality for PWD in other countries, especially in low and middle-income countries. The incidence of dementia in developed and aging populated countries like Sweden is decreasing although the prevalence is still increasing due to population aging. Meanwhile, developing countries will possibly face demographic challenges of an aging population in the next decades. Dementia will potentially

be a huge challenge for both the economies and health care systems of developing countries sooner or later. In low- and middle- income countries, long-term care is not well established. This transfers the pressure of care for PWD to their family, as informal care.

According to the WHO, everyone should have equal access to health care services whenever and wherever they need them, without financial constraints. With more scarce health resources and worse health care systems, health equity and equality for dementia care in developing countries is an issue. The WHO also considers health equity and equal access to promotion, prevention, diagnostics, and treatment for PWD is as an essential principle in their action plan for dementia. Thus, socioeconomic themes in dementia care should be studied and reported not only in developed and aging-populated countries, but also in developing nations. Unfortunately, registers are not available and register-based studies are limited in low- and middle-income countries. It is necessary to establish quality-of-care registers in these countries with the aim to improve quality of care and provide evidence in the policymaking process.

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