

From Alzheimer Disease Research Center, Department of
Neurobiology, Care Sciences and Society
Karolinska Institutet, Stockholm, Sweden

Resource Utilization in Dementia - a Question of Collaboration

Erik Jedenius



**Karolinska
Institutet**

Stockholm 2010

***“...an economist is somebody who sees something
happen in practice and wonders if it will work in theory”***

*Ronald Regan, Actor, US president, patient and founder of the “Decade of the Brain,”
a multiple-billion project for research in Alzheimerdisease and other dementias.*

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet. Printed by Larserics, Stockholm

© Erik Jedenius, 2010

ISBN 978-91-7457-055-7

ABSTRACT - ENGLISH

Resource Utilization in Dementia - a Question of Collaboration

This doctoral thesis investigates one disease management program in dementia located in Kalmar, Sweden with regard to the resource utilization. Dementia is a devastating disease which mainly affects the elderly. As the disease progresses the need for support increases. Dementia is one of the most costly diseases in our society. Although our understanding of dementia has advanced we have yet to discover a cure for the disease. Nevertheless with our current knowledge we can accomplish a great deal. The challenge is to incorporate this knowledge in order to provide high quality care for the patients and the caregivers without creating an economic burden for the society. It is therefore of interest to evaluate this dementia management program which supports the patient and caregiver from diagnosis to death.

In Study I, the dementia management program in Kalmar was assessed. The program defined most of the expected new patients per year. And it was introduced within the existing budget, after reallocation of resources

In Study II, examined costs of dementia diagnose assessment. Further was the true cost per diagnosed patient. Identified for primary care and specialist level. The study found that the cost of diagnosing dementia is small compared to the total budget required to care for persons with dementia, estimated to be approximately 1% of the total yearly cost of dementia in Sweden.

In Study III, the use of selective psychotropic drugs in the elderly in Kalmar was compared with Swedish national data. The study found that after the introduction of the dementia management program, the use of dementia drugs increased, and the use of neuroleptics decreased. Furthermore the use of sedatives and drugs with anticholinergic effects was lower in Kalmar as compared to the whole of Sweden.

In Study IV, examined resource utilization in dementia management in the Kalmar municipality. The Älvsjö municipality and the whole of Sweden were used for comparisons. The results suggest that the cost of dementia care in the Kalmar municipality did not increase due to implementation of the dementia program. Furtherer suggest the cost for dementia to be from neutrally to lower for the municipality of Kalmar compare to the municipality's in all of Sweden.

The results from this investigation of the dementia management program in Kalmar, suggest that most of the new cases of dementia were diagnosed, treated and followed up. The cost of the program fell within the existing budget and no extra funding was required.

Resursutnyttjande/fördelning vid demenssjukdomar - en fråga om samarbete

Denna doktorsavhandling undersöker demensprogrammet i Kalmar län, och studerar resursutnyttjandet för demenssjukdomar inom Kalmar kommun. Dess primära fokus ligger på primärvården som i samarbete med specialister och Kalmar kommunen är gemensamt ansvariga för demensprogrammet. Programmets målsättning är att vara till gagn för patienterna och de anhörigas behov, från början till slutet av sjukdomen.

Demenssjukdomar är förödande tillstånd som främst drabbar äldre. I takt med sjukdomens progress ökar behovet av stödjande resurser. Idag är demenssjukdomar några av de mest kostsamma sjukdomarna för samhället. I och med ett ökat antal äldre i befolkningen, som i de flesta länder i världen, beräknas kostnaderna fortsätta stiga. Merparten av kostnaderna för demenssjukdomar härrör sig från de senare stadierna av sjukdomarna, där det främst faller inom kommunernas ansvarsområde. Utredning och insatta behandlingar faller oftast inom landstingets ansvar.

Kunskapen om demenssjukdomar har ökat genom åren. Under de senaste 20 åren har det gjorts banbrytande framsteg, men fortfarande finns ingen bot för någon av de olika demenssjukdomarna. Tack vare den omfattande kunskap vi har idag från molekylnivå till omvårdnad, finns mycket att göra för patienter med demenssjukdomar och deras anhöriga. Frågan är hur man skall omsätta denna kunskap till praktik. Hur vi skall organisera, samarbeta och styra vården för att stödja patienter och vårdgivare professionellt. Detta skall även ske med värdighet och inom ekonomiskt acceptabla ramar för samhället. Därför är det av vikt att studera vårdprogram för demenssjukdomar såsom det i Kalmar som följer patienten från diagnos till döden.

I studie I, analyseras demensprogrammet i Kalmar. Resultatet visar att demensprogrammet fann de flesta av de förväntade nya patienterna per år. Dessutom introducerades vårdprogrammet inom den befintliga budgeten. Detta gjordes tack vare en omfördelning av de befintliga resurserna utan att annan vård ansågs bli lidande.

I studie II, undersöks kostnaden för att ställa en demensdiagnos, både inom primär- och specialistvården i Kalmar. Den verkliga kostnaden per diagnostiserad patient beräknades. Dessutom att kostnaden för demensutredning till diagnos enligt denna modell utgör en procent av den totala årskostnaden för demenssjukdomar i Sverige.

I studie III, studeras användningen av utvalda psykofarmaka hos äldre i Kalmar jämfört med hela Sverige. Efter införandet av demensprogrammet, ökade som förväntat användningen av demensläkemedel, medan användningen av neuroleptika minskade. Samtidigt var användningen av lugnande medel och läkemedel med antikolinerg aktivitet lägre i Kalmar än jämfört med genomsnittet i Sverige.

I studie IV, analyseras den kommunala kostnaden för demenssjukdomar inom Kalmar kommun. Som jämförelse användes Älvsjö stadsdelsnämnd och kommunala kostnader från hela Sverige. Studien visar att kostnaden för demenssjukdomar i Kalmar kommun inte har ökat på grund av demensprogrammet. Analysen tyder på en kostnadsneutral eller en lägre kostnad för demenssjukdomar i Kalmar kommun jämfört med medelkommunen i Sverige.

Sammanfattningsvis visar resultaten i denna avhandling att ett demensprogram så som man har utformat det i Kalmar, tyder på att de flesta nya fall av demenssjukdomar som diagnostiseras, behandlas och följs upp. Kostnaderna för en demensdiagnos enligt modellen är rimliga. Läkemedelshandlingen för utvalda psykofarmaka är bättre för äldre jämfört med genomsnittet i Sverige. Kostnaden för kommunen har inte ökat, resultaten tyder på en lägre kostnad för demenssjukdomar i Kalmar kommun jämfört med Sverige. Kostnaden för programmet genomförs inom den befintliga budgeten utan extra tillskott av resurser, detta har genomförts genom en omfördelning och effektivisering av de befintliga resurserna.

LIST OF PUBLICATIONS

- I. A Swedish programme for dementia diagnostics in primary healthcare

- II. The cost of diagnosing dementia in a community setting

- III. Dementia Management Program in a Community Setting and the Use of Psychotropic Drugs in the Elderly Population

- IV. Direct Costs of Dementia in two Swedish Municipalities in Relation to a Dementia Management Programme

CONTENTS

| | | |
|-------|---|----|
| 1 | Prolog..... | 9 |
| 2 | Introduction | 10 |
| 2.1 | Dementia..... | 10 |
| 2.1.1 | Dementia in general | 10 |
| 2.1.2 | The diagnosis of dementia | 12 |
| 2.1.3 | Psycho-social intervention programs | 13 |
| 2.1.4 | Pharmacological treatment in dementia | 14 |
| 2.1.5 | The use of drugs in elderly..... | 15 |
| 2.1.6 | Disease-management programs in dementia care..... | 17 |
| 2.1.7 | Health economics and dementia | 19 |
| 2.1.8 | Impact on society | 19 |
| 2.2 | Funding, organization, governmental regulations, structure of care..... | 21 |
| 2.2.1 | Funding, organization and regulations | 21 |
| 2.2.2 | “Chain of care” | 22 |
| 2.2.3 | Disease-management program | 23 |
| 2.2.4 | Operations Management and Lean Production | 24 |
| 2.2.5 | Dementia care organization in Sweden | 25 |
| 2.3 | The setting and dementia management program in Kalmar | 28 |
| 3 | Hypotheses and Aims..... | 32 |
| 3.1 | Following hypotheses have been identified for this project..... | 32 |
| 3.2 | Aim of this thesis | 32 |
| 4 | Material and methods..... | 33 |
| 4.1 | Material and Study populations | 33 |
| 4.1.1 | Study 1 (paper I)..... | 33 |
| 4.1.2 | Study 2 (paper II) | 33 |
| 4.1.3 | Study 3 (paper III)..... | 34 |
| 4.1.4 | Study 4 (paper IV)..... | 34 |
| 4.2 | Methods and ethical approval | 34 |
| 4.2.1 | Study 1 (paper I)..... | 34 |
| 4.2.2 | Study 2 (paper II) | 34 |
| 4.2.3 | Study 3 (paper III)..... | 35 |
| 4.2.4 | Study 4 (paper IV)..... | 35 |
| 4.2.5 | Ethical approval | 36 |
| 4.2.6 | Statistical analysis | 36 |
| 5 | Main results, comments and related conclusions | 37 |
| 5.1 | Paper I..... | 37 |
| 5.1.1 | Hypothesis | 37 |
| 5.1.2 | Setting..... | 38 |
| 5.1.3 | Results | 38 |
| 5.1.4 | Comments..... | 39 |
| 5.1.5 | Conclusions | 40 |
| 5.2 | Paper II..... | 40 |
| 5.2.1 | Hypothesis | 40 |
| 5.2.2 | Setting..... | 40 |

| | | |
|-------|---|----|
| 5.2.3 | Results..... | 40 |
| 5.2.4 | Comments..... | 41 |
| 5.2.5 | Conclusions | 42 |
| 5.3 | Paper III..... | 42 |
| 5.3.1 | Hypothesis | 42 |
| 5.3.2 | Setting | 42 |
| 5.3.3 | Results..... | 43 |
| 5.3.4 | Comments..... | 44 |
| 5.3.5 | Conclusions | 44 |
| 5.4 | Paper IV | 45 |
| 5.4.1 | Hypothesis | 45 |
| 5.4.2 | Setting | 45 |
| 5.4.3 | Results..... | 45 |
| 5.4.4 | Comments..... | 47 |
| 5.4.5 | Conclusions | 47 |
| 6 | Discussion..... | 48 |
| 6.1 | Summary of main findings | 48 |
| 6.2 | Discussion of the main findings | 48 |
| 6.3 | Methodological issues, Limitations and Generalizability | 50 |
| 6.3.1 | Population..... | 50 |
| 6.3.2 | Organization | 50 |
| 6.3.3 | Establishing of the diagnose | 51 |
| 6.3.4 | Drugs utilization in elderly..... | 52 |
| 6.3.5 | Economical issues and resource utilization | 53 |
| 6.3.6 | Generalizability overall | 54 |
| 7 | Conclusions and further perspectives | 55 |
| 7.1 | Conclusions..... | 55 |
| 7.2 | Future perspectives | 55 |
| 8 | Epilogue..... | 57 |
| 9 | Acknowledgements | 58 |
| 10 | References..... | 60 |

LIST OF ABBREVIATIONS

| | |
|--------------|---|
| AChEI | Acetyl choline esterase inhibitors |
| AD | Alzheimer disease |
| ADL | Activities of daily living |
| AMPS | Assessment of motor and process skills |
| BPSD | Behavioral and Psychological Symptoms in Dementia |
| COI | Cost Of Illness |
| CPI | Consumer Price Index |
| CSF | Cerebral spinal fluid (analysis of amyloid β and tau proteins) |
| CT | Computerized tomography |
| CTR | Clinical trials research |
| DDD | Defined Daily Dose |
| DMP | Dementia-management program |
| DN | Dementia nurse |
| DSM-IV | Diagnostic and Statistical Manual of Mental Disorders – 4th Edition |
| ECG | Electro cardio gram |
| ED | Emergency Department |
| EEG | Electro-encephalogram |
| GP | General practitioner |
| GR | Geriatric clinic |
| ICD-10 | International Classification of Diseases, 10th Revision |
| IMED | Internal medicine |
| LTF | Long-term follow-up trial |
| MMSE | Mini-Mental State Examination |
| MPA-S | The Medical Products Agency-Sweden (Läkemedelsverket) |
| MRI | Magnetic resonance imaging |
| MT | Multi-modal treatment |
| NH | Nursing home |
| NINCDS–ADRDA | National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer’s Disease and Related Disorders Association |
| PCU | Primary care unit |
| PET | Positron emission tomography |
| PHC | Primary health care centers |
| QOL | Quality of life |
| QUALY | Quality-adjusted life years |
| RCT | Randomized clinical trial |
| SBU | The Swedish Council on Technology Assessment in Health Care |
| SOS | The Swedish National Board of Health and Welfare (Socialstyrelsen) |
| SPDR | Swedish Prescribed Drug Register |
| SPECT | Single positron emission tomography |
| SWO | Social welfare officer (Biståndshandläggare) |

1 PROLOG

Ten years ago I thought to identify Swedish examples of programs that provided quality dementia care. From previous experience I knew that programs designated as “centers of excellence” would be a good place to start. Three programs, representing three different geographical areas in Sweden appeared to exhibit dementia programs that were on the forefront of dementia care, Kalix and Piteå in the north and Kalmar in the south. Dementia care in Kalix and Kalmar was managed mainly on the primary care level, while in contrast, dementia care in Piteå was managed primarily in the geriatric center at the local hospital. At that time, dementia management programs in primary care were coming into focus, which is why I examined Kalix and Kalmar more in depth. These two communities addressed dementia management in primary care settings by assessing cognitive performance and integrating cognitive deficits into diagnostic and treatment evaluations. Subsequently they reported similar outcomes, as qualitative comments about the program, including:

- “Fewer patients showed behavioural problems related to dementia”
- “The use of neuroleptics and sedatives in the elderly was reduced“
- ” The need for supporting resources, particularly nursing home beds in the municipality, was reduced”
- “The need for acute intervention due to dementia was reduced”

These personal testimonials inspired me to further explore dementia management programming, particularly in Kalmar. They were the incentive behind this thesis.

As a symbol for this thesis I have chosen Queen Margaret’s seal from the Kalmar union document from 1397. This coat of arms has several meanings for me. First, it represents a period of 126 years of peace and collaboration in the Nordic region. Secondly, the three crowns in Queen Margaret’s coat of arms, could symbolize the three collaborating organizations in this thesis; primary care, the municipalities and specialist care all for the best to the patients with dementia and their caregivers. Finally this Nordic union was formalized in Kalmar, where most of the material from the thesis has its origin. Also, the illustration of “two upper crowns” could represent the dementias, as well as the organizational structure, including: care, governmental regulations, and economical base. The lower crown represents the contents of the dementia program in Kalmar.

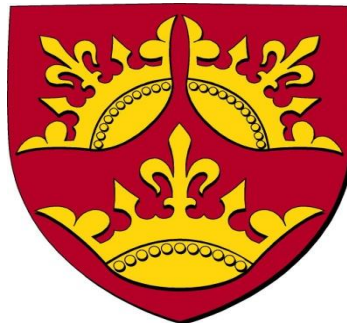


Figure 1. Coat of arms from Queen Magrethe’s seal (1353-1412). The three crowns represent the three countries of the Kalmar Union, Denmark, Norway and Sweden (Henrik Klackenbergh heraldry of Sweden and the artist Vladimir A Sagerlund, the National Archives and the regional state archives of Sweden (Riksarkivet)).

2 INTRODUCTION

2.1 DEMENTIA

2.1.1 Dementia in general

Kung Fu Tse is quoted as saying, “Learning without thinking is useless, thinking without learning is dangerous” (500 B.C, China), which illustrates the historical importance of memory and cognitive functions. It also points to the devastating situation that can occur when a person loses cognitive functions. Memory has been a challenge to understand. The philosopher Paul Ricœur (1913-2005) “The memory may be changing and insidious like a dream, but it is also our most important tool in contact with that which no longer exists. ” How to manage dementia has been studied to a lesser extent, perhaps partly owing to the lesser importance of studying a strata in society whose numbers were relatively small then. Or perhaps people with brain diseases were kept hidden within the family. This has changed in the last hundred years, as research has brought more knowledge about aging and disease, while the elderly population was much increased and a more accepting attitude toward the elderly came to be seen in society. The World Health Organisation has classified dementia as a major worldwide health challenge [1].

Dementia is widespread in modern society. from the prevalence of dementia worldwide in 2009 was estimated to be 34.4 million [2]. Anticipated incidence in 2040 is expected to increase to over 80 million [3]. There were approximately 150,000 individuals in Sweden in 2008 [4, 5]. This figure is expected to increase to 250,000 (+67%) individuals by 2050 [6] (Figure 2). As a result, the management of the disease is being given high priority by the authorities and politicians in Sweden. In 1997 dementia illnesses received priority degree 1B (=illness with reduction of the autonomy) [7], which is second only to acute myocardial infarction. The Medical Products Agency-Sweden (MPA-S) in 2002 recommended choline esterase inhibitors (AChEI) in treatment for mild to moderate Alzheimer disease (AD) [6]. Then the Swedish Council on Technology Assessment in Health Care (SBU) made their own recommendations for diagnosing and treating AD [8]; and recently the Swedish National Board of Health and Welfare (SOS) expressed support for such recommendations (SOS) [9]. These were in line with international recommendations from USA [10] and UK [11, 12].

Of the dementias, AD with or without vascular pathology accounts for 60-75% followed by pure vascular dementia, dementia with Lewy bodies and frontotemporal lobe dementia.

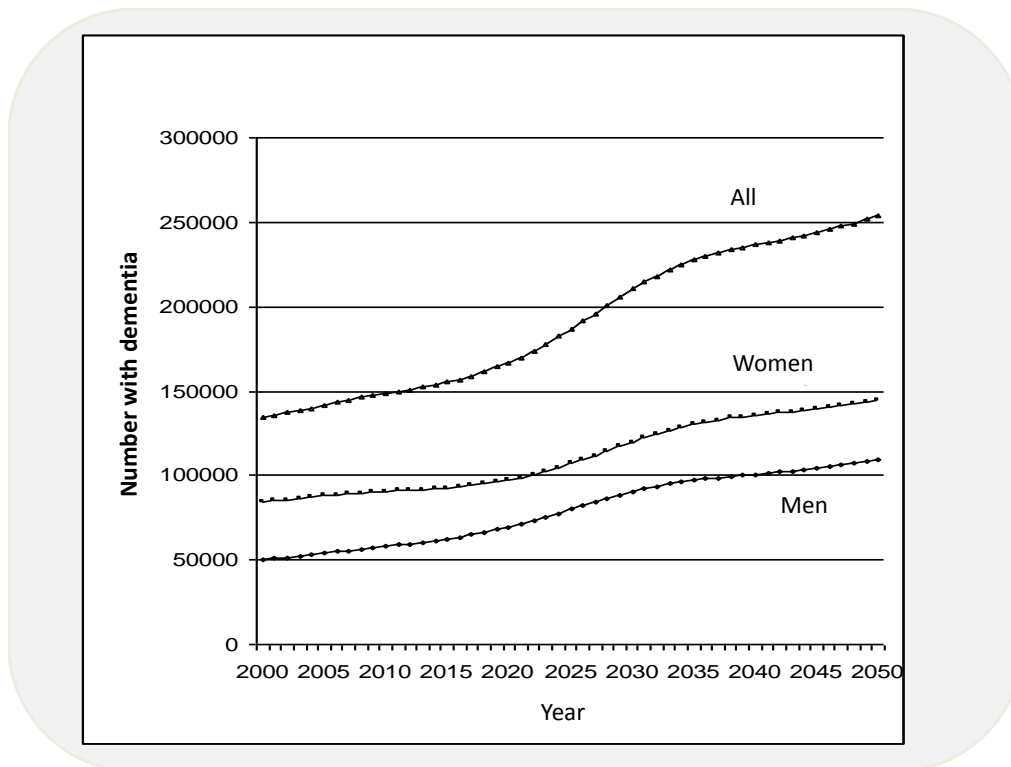


Figure 2. The estimated increase in individuals with dementia in Sweden up to 2050[13] (printed by permission from the Swedish National Board of Health and Welfare.2010).

The prevalence of dementia is 1% at 60 years of age and doubles every 5 years from the age 60 to reach a prevalence of 30-35% at the age of 85. Accordingly, the incidence of dementia in Sweden is approximately 25,000 per year [14].

A progressive disease, AD starts insidiously and progresses slowly (Figure 3). It is characterized by a wide range of symptoms both within the cognitive domain and the domain of everyday function, i.e. the activities of daily living (ADL). Behavioral disturbances and psychological symptoms in dementia (BPSD) [15] are important symptoms of the disease.

During the disease course cognition declines along with ADLs [18]. Simultaneously, the patients may develop affective symptoms, for example, depression, which can precede the cognitive symptoms by years. With increasing severity, BPSD may develop, e.g. psychotic symptoms and aggressive behavior. Such behavior is regarded as a main factor behind placement in a nursing home [19] and thus a cost driving factor. Most of the BPSD symptoms disappear in the final stages of the disease [20]. Moreover, new guidelines on BPSD have been drawn up by SBU and MPA-S, which emphasise investigation of the underlying causes of the symptoms and caution regarding pharmacological interventions [8, 21].

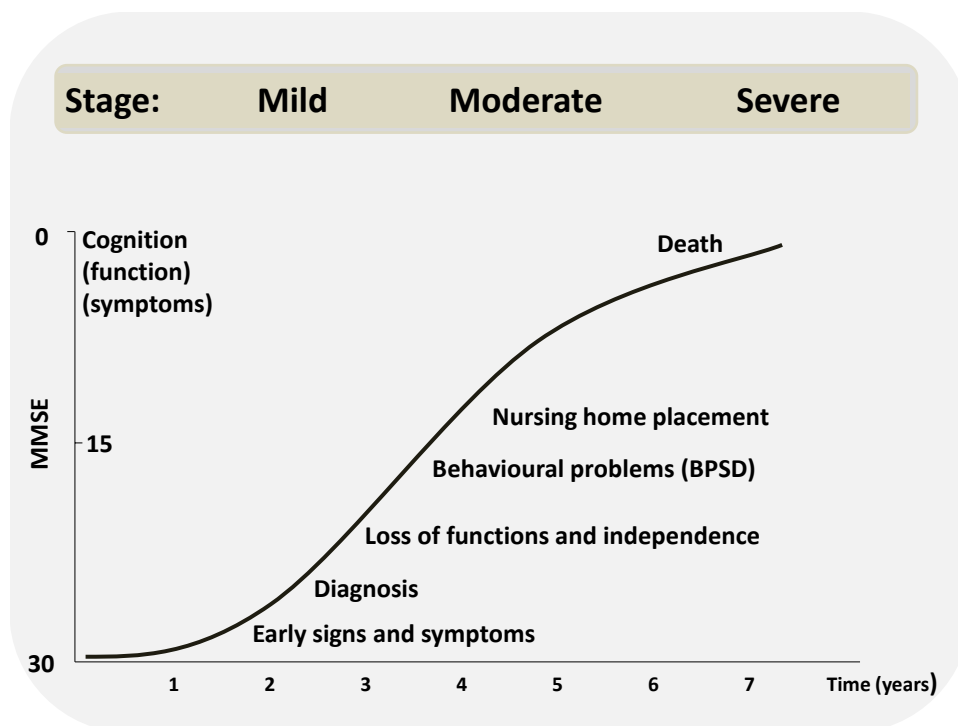


Figure 3. The cognitive decline in Alzheimer's disease in relation to duration and symptoms, nursing home placement and death [16, 17].

2.1.2 The diagnosis of dementia

A clinical diagnosis of dementia may be offered in the early part of the illness and further established many years before death [22, 23]. Diagnostic comparisons are best made on the basis of a comprehensive geriatric assessment [9].

The International Classification of Diseases, 10th revision (ICD-10) [24] and the Diagnostic and Statistical manual of Mental Disorders – 4th Edition (DSM IV) have established diagnostic criteria for dementia [10]. However, the National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) [25], was presented approximately 25 years ago and is still the golden standard in research on Alzheimer's disease and other dementias.

Dubois and co-workers have challenged these criteria during the last few years [26], based on new findings in magnetic resonance imaging (MRI) [8], molecular neuroimaging with single positron emission tomography (SPECT), positron emission tomography (PET), and cerebral fuel markers such as phospholysed β amyloid and Tau proteins CSF [27, 28].

A comprehensive geriatric assessment typically includes medical and social history; physical examination; assessment of everyday functioning, such as activities of daily level (ADL) and instrumental activities of daily living; laboratory tests; both blood

and CSF, electrocardiography (ECG), electroencephalography (EEG) and imaging study (CT scan, MRI, SPECT or PET); as well as cognitive testing. The SOS recommends the Mini Mental State Examination (MMSE) [29] and the Clock Test [9]. More extensive neuropsychologic assessments of cognitive function, especially memory and attention, lend support to the diagnosis. Whether the assessment leads to the correct diagnosis or not is always a matter of debate, especially if it is done at the primary care level and not by a specialist [30]. Proper training is essential to increase the diagnostic accuracy [31]. It is argued that the definitive diagnosis can only be confirmed with certainty by examining the brain at post mortem [22, 23]. However, in clinical cross-sectional studies, the diagnosis is always made at least months and often years before death. During the interval between diagnosis and autopsy new pathological changes occur in the brain.

In the recent launch of the new national dementia guidelines for Sweden, the SOS recommends two different levels of dementia investigation [9], namely: a preliminary assessment by the primary care physician and a more comprehensive assessment at the specialist level. The latter is particularly advised in complicated cases, for example that involve younger patients [9].

2.1.3 **Psycho-social intervention programs**

Presently there is extensive research into use of psycho-social intervention for persons with dementia [8]. However individual care remains the keystone in dementia treatment [9, 32]. Creating a social inventory can be an important tool to establish a knowledge base to guide future interventions. Various psycho-social interventions may be used at different stages of the disease (Figure 4) [33-35].

Early on, disease education and psychosocial interventions [36] are important for the patient and caregiver in order for them to cope with the physical, emotional and practical challenges of the disease. Memory training such as crossword puzzles, Sudoku and memory cards can also be of value and should be provided in order to train basic cognitive functions. Day care, with a mix of indoor and outdoor activities, should also be provided in order to maintain as normal a life as possible [37]. More research is required regarding psych-social intervention programs for younger patients who are still working in spite of a dementia diagnosis.

In the moderate phase of the disease coping strategies must be supported in order to keep up with the daily activities. Validation techniques and memory supporting strategies, as well as music and other sensory stimulation could be beneficial. Physical activity on both an individual level and in groups is also important, e.g. daily outdoor walks.

During the severe stage of the disease sensory stimulation techniques such as tactile stimulation could improve contact between the caregiver and the patient and at the same time have a calming effect on the patient. Activities that strengthen the patients' and caregivers' self confidence are also important[33-35].

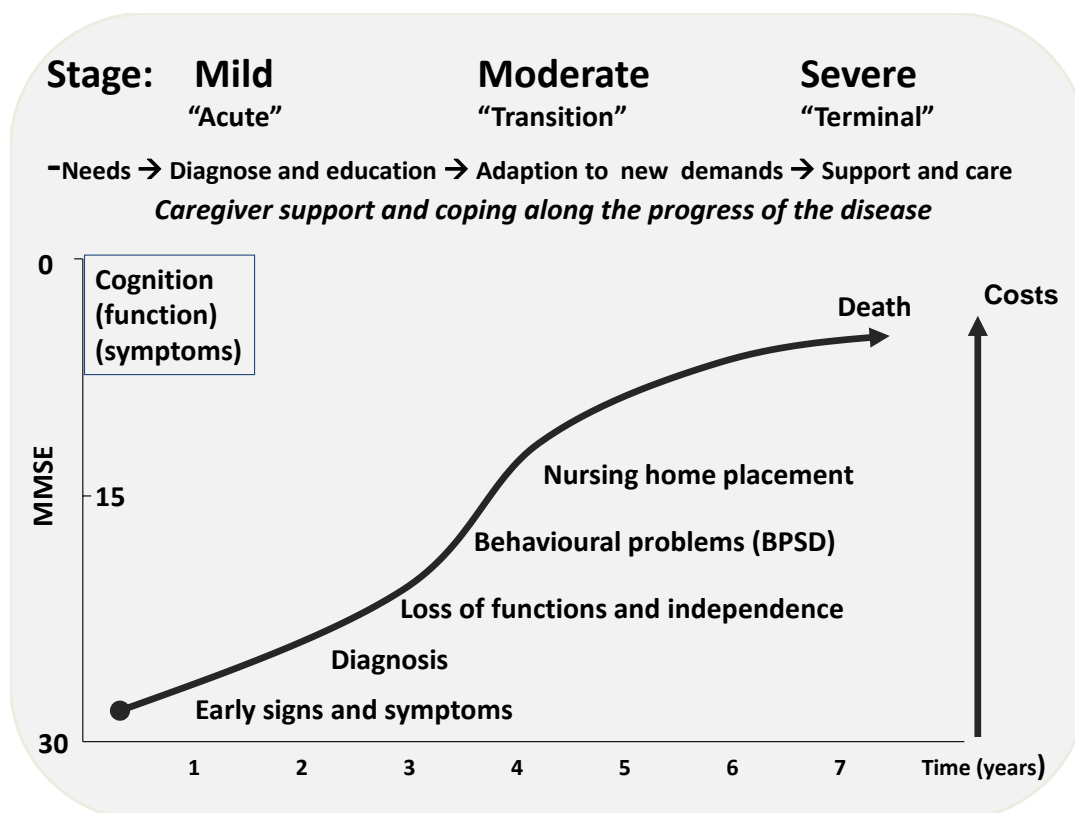


Figure 4. Further exploration of the figure 3 by Jost and Grossberg. In the mild stage investment in diagnosis, treatment and education to adaptation to the new situation, therefore labeling as acute in this sense. As the disease progress is also the needs of support, contributes to the increasing of costs. If treatment such as pharmacological and psycho-social intervention can move the illness curve to the left follows usually the cost curve along [76].

2.1.4 Pharmacological treatment in dementia

Pharmacologic treatment has an important role in treating symptoms in AD and helping to maintain cognitive ability, and therefore, has provided optimism regarding what possibilities exist of treating the disease, and thus bring new hope for this devastating condition. Pharmacological treatment should be part of the foundation for the care of dementia patients.

Acetylcholinesterase inhibitors (AChEI), such as tacrine, donepezile, rivastigmine and galantamine, act by inhibiting the enzyme acetylcholinesterase that breaks down the acetylcholine in the brain. In several studies these drugs have shown positive effects

on cognitive symptoms, global impression and ADL in mild to moderate AD, and in some studies even on BPSD symptoms [10, 19, 38-40]; as well as in severe AD [41].

The latest drug in the armamentarium is the non-competitive NMDA-receptor antagonist memantine, which has shown effects on symptoms occurring in moderate and severe AD [42]. New and promising disease-modulating drugs are currently under investigation [43].

Most health economy analyses regarding pharmacological treatment of dementia have suggested a cost-neutral [44] or even a cost-saving effect [45]. However, other authors remain skeptical about the health economic benefits of AChEI [46]. Nevertheless, there are now recommendations from the SBU, [8] and in 2010 from SOS [9], suggesting a more active approach towards treatment with AChIE and memantine. A more active approach with early diagnosis of AD and thus earlier treatment initiation may raise expectations of postponing nursing home placement [47] and hopefully improve quality of life for patients and caregivers. However, the treatment should be monitored and evaluated, and more research is needed.

2.1.5 The use of drugs in elderly

Internationally and in Sweden heavy drug use by elderly has been an important discussion topic [48-55]. Drug related problems in elderly are common, not to mention drug-disease interactions [56, 57]. Risk of side effects such as falls [58, 59] is of concern. Further the elderly are vulnerable to adverse drug reactions due to age related physiological changes, including reduced metabolic and renal clearance resulting in increased drug levels, as well as increased sensitivity to drugs due to pharmacodynamic changes in many organs. Adverse drug reactions have been shown to cause a significant part of acute hospital admissions of elderly [60]. In Sweden, 9% of the population is aged 75 years and older [61], accounting for 38% of the total amount of drugs in Defined Daily Dosages (DDD) [62, 63]. This is equivalent to one quarter of the total cost of drugs for Swedish society. Elderly in Swedish nursing homes today receive on average ten or more different drugs daily [64, 65], creating the likelihood of increased risk of drug-drug interactions and other drug related problems [66]. Several studies suggest that patients with dementia receive more psychotropic drugs compared with the elderly in general [67]. At the same time, the number of patients with dementia is increasing [14]. There is also a consensus that elderly patients who are already suffering from cognitive disturbances due to dementia, are more vulnerable to anticholinergic effects in medication [10, 64, 65, 68-73]. The increase of intensity and variability of symptoms associated with dementia progression is connected to an increased use of drugs with psychotropic action [74]. This is problematic, as the elderly are especially vulnerable to the side effects of drugs [75]. These drugs include dementia drugs (AChEI and memantine), neuroleptics, sedatives, antidepressants and selected anticholinergic drugs (Table 1). Antidepressants and dementia agents are considered to have primarily positive

cognitive effects, whereas sedatives and neuroleptics may have detrimental influence on cognition. For example, agents with anticholinergic activity may precipitate delirium in the elderly. Taken together, this knowledge of drugs in elderly may be a platform for the implementation of new programs designed to target special populations, such as patients at risk of dementia.

| ATC-code | Class | Agent |
|-----------------|--------------------------------------|--|
| G04BD | Urinary antispasmodics | emeprone oxybutynine tolerodine |
| N05AA | Antipsychotics, low potency | chlorpromazine |
| N05AC02 | Antipsychotics, low potency | thioridazine |
| N05AC03 | Antipsychotics, intermediate potency | melperone |
| N05BB01 | Anxiolytics, | hydroxyzine |
| N06AA | Antidepressants, non-selective | imipramine chlomipramine crimipramine lofepramine amitriptyline nortriptyline protriptyline maprotiline |

Table 1. Agents with significant anticholinergic activity, frequently used by older people in Swede.

2.1.6 Disease-management programs in dementia care

Disease-Management Program, or specifically Dementia Care Networks, contents of broad-ranging aspects of the disease addressing, cost, the multi-modal range of resources, and so on (Figure 4). The latter, Multi modal treatment (MT), incorporates diagnostics, patient and caregiver education, drug monitoring and other functions. There is no cure for AD or some of the other dementia diseases. In addition there is also debate on the effects of symptomatic treatment in AD. Of course there is an ongoing search for what is the cause of dementia symptoms, and secondly to set early diagnoses in order to treat the symptoms early, educate both the patient and the caregiver. But finally make it possible for the patient to set up final decision for their life's when they still have the cognitive possibility's to decisions by self in a dignified way.

Studies on the use of MT in dementia care have focused primarily on outcome, e.g. of caregiver interventions, of length of time an individual is able to remain in the community and not in the nursing home. Several groups have reported quality of treatment improvement by caregiver education [77-83] (Table 2). However, many of these publications use a broader definition of a disease managing program. Further, emphasize the need for collaboration between the different organizations, among stakeholders from healthcare, municipality, and private organizations, who are together needed to improve the quality of life for the patient and his/her caregiver [9, 77, 84]. In addition, studies point to the importance of competence, both clinically and managerially, or as leaders; as well as professional education of those responsible for managing these [85]. Some recent publications emphasize the role of the case manager in the geriatric sector [86, 87]. In addition, the influence of caregiver burden has been investigated and this demonstrated that the effect was sustained for at least 6 to 12 months, especially if the intervention was initiated early in the disease [36]. A database on dementia programs has been set up in the United Kingdom [88]. Among its resources is an education program, as well as a computer-assistive decision-support system for general practitioners, which aims to improve early diagnosis and build concordance with guidelines [89]. Findings are mixed in regards to effects on improving caregiver stress and depression [90].

| Author | Year | N | Population | Method | Effect variable | Program | Time | Effect and main conclusion |
|--------------------------|----------------------|------|---|--------------|---------------------------------------|---|-----------------|--|
| Andre'n, Elmstål | 2008 | 308 | Demented (MMSE average 19) | CTR | Time to NH | Psychosocial education to caregivers | 5 years | Prolonged time to NHP in the intervention group |
| Brodaty et. al. | 1989 | 96 | AD and no AD, mild and moderate | RCT | General health of careers. Time to NH | Caregiver education vs. memory retraining vs. controllers | 1 year | Caregiver education, reduces psychological morbidity and longer in home living vs. memory retraining |
| | 1991 | | | LTF | Time to NH and costs | | 3 years | Caregiver program still superior fewer deaths in the training group. Lowest cost in the dementia careers program. |
| | 1993 | | | LTF | Survival and time to NH | | 5 years | Caregiver training early in the disease, better outcome and later NH placement. |
| | 1997 | | | LTF | Survival and time to NH | | 8 year | Caregiver training early in the disease, pat lives longer and later NH placement |
| Burns et. al. | 2003 | 167 | Caregiver of demented | RCT | QOL | Caregiver stress-coping education. | 2 year | Primary intervention with stress coping reduces caregiver stress. |
| Callahan et. al. | 2006 | 153 | Dementia patients (MMMSE average 18 (+5.8)) | RCT | NPI | 1 year care and management study in primary care. With a interdisciplinary team | 18 months | Intervention patients more received AChEI and antidepressant drugs. Fewer incidences with BPSD. Caregivers lower distress, depression and patients has lower BPSD score, no difference in NHP. |
| Chiverton, Cane | 1989 | 40 | Spouses to patients with AD | CTR | Coping skills | Caregiver education | 4 week | No difference in coping ability. Caregiver more competent in facing the disease progression and knowledge in the intervention group. |
| Drummond, Mohide et.al. | 1991 | 60 | Spouses caring for elderly at home | RCT | Caregiver QOL /QUALY | Caregiver support programme | 6 months | No difference in QOL. Cost per QALY Can\$20,000 favorable the intervention group |
| Eloniemi-Sulkava et. al. | 2001 | 100 | Demented in need for support (MMSE 14,4 and 15,3) | RCT | Time to NH | Nurse case management supporting program | 2 year | NH-placement was less in the intervention group in the beginning but similar in the end of the trial. |
| Fisher, Lieberman | 1999 | 164 | Demented resided in a home setting at baseline | LTF | Time to NH | No | 2 year | High family emotional express etc predicted NHP. |
| Gaugler et. al. | 2003 | 3944 | Demented resided in a home setting at baseline | LTF | Time to NH | No | 3 year | Burden and self related health predicted NHP. |
| Gaugler et. al. | 2003 | 400 | Demented using day care centers | CTR | Care giving time | Adult day service | 3 months | Day care use reduce behavioral problem, care giving time and distress. |
| Gilley et. al. | 2004 | 410 | Patients resided in a home setting at baseline | LTF | Time to NH | No | 4 year | Cognitive impairment and behavioral symptoms predict NHP. |
| Graff et.al. | 2008 | 135 | Older demented | RCT | Cost effectiveness | Occupational therapy | 3 months | Intervention cost effective due to lower cost of informal care giving |
| Herbet et. al. | 1993 | 41 | Caregiver of demented | RCT | Caregiver burden and knowledge | Support programme for caregivers | 8 months | No lower distress for caregivers but higher knowledge about the disease in the support group |
| Lawton et. al. | 1989 | 642 | AD (MMSE 13.7,12,7 (range 6-30)) | CTR | QOL for Caregiver burden and NHP | Respite service for caregivers | 1 year | Respite care increased not QOL for caregivers, but prolong time to NH, and increased QOL for careers |
| Martikainen et. al.. | 2004 | | AD | Markov model | Cost and caregiver QOL | Cognitive-behavioral family intervention | 5 year | Program cost beneficial over ordinal care. Caregiver better QOL. |
| Melis et. al. | 2008 | 151 | Fragile elderly with and without Dementia | RCT | Cost | Geriatric intervention program | 6 months | Effective program at reasonable cost. |
| Mittleman et. al. | 1993 1995 1996 | 206 | Spouses to patients with AD | RCT | NH placements | Comprehension counseling | | Reduced socioeconomic burden, depression in careers and 329 days longer to NH in the treatment group. |
| Mohide et. al. | 1990 | 60 | Caregiver of moderate to severe demented | RCT | Caregiver depression and anxiety | Caregiver education and support program | 8 months | No reduction of Depression and anxiety but higher QOL, and some longer time to NH. |
| Wimo et. al. | 1993 | 55 | Demented in day care vs. waiting list | CTR | NH placement | Day care | 1 years | Daycare postponed NH-placement. |
| Wimo et al | 1994 | 55 | Demented in day care vs. waiting list | CTR | QOL, costs | Day care | 1 year | Lower cost per day for day care patients no difference in QOL. |
| Wolfs et.al. | 2007 | 230 | Patients with psycho geriatric problems | CTR | QOL | Multidisciplinary diagnostic facility | 6 and 12 months | QOL improver in intervention group. |

Table 2. Multi modal treatment programs in dementia some additional cost analysis and long term follow [78, 79, 86, 87, 91-113](RCT=Randomize clinical trial, CTR=Clinical trial, LTF=Long term follow up, QOL=Quality of life, QUALY=Quality adjusted life years and NH=Nursing homes).

2.1.7 Health economics and dementia

The already high cost of dementia care is expected to increase dramatically due to a rising incidence rate [114], prompting interest by government leaders in identifying cost-effective strategies for assessment and treatment. Empirical studies have been lacking [8]. In order to study long-term cost-effectiveness of treatments for society, economic models are frequently that are based on estimating the costs of the decline in cognitive function [76, 115]. Alternatively, other models focus on other variables, such as impairment in everyday functioning, typically measured by ADL [116]. A study on AD, BPSD and costs found 30% of the costs of AD is related to managing of BPSD [19]. This is noteworthy, as these non-specific symptoms are the main factor behind the inability of patients to remain in their homes thus leading to nursing home placement [15]. In addition, studies that analyzed relative costs associated with selected types of dementia, including vascular dementia and Lewy-body dementia, suggest greater costs when compared with pure AD [117, 118].

When evaluating health economic studies it has been important to consider whether both care of the patients and education of caregivers are taken into account. Both positive and cost-neutral studies are presented (Table 2) [119]. Most of this cost analyses is performed in models due to methodological issues to not catch the long term effects, has been debated [120], and double-blind randomized trials are recommended. Studies have reported 80-85% of the economic burden for dementia care in the Swedish health care system are shouldered by municipalities; and making this a concern for all [13, 14]. Moreover, suggests caregiver education and dementia day care centers can provide economical benefit and perhaps prolong the length of time leading to nursing home placement (Table 2) [36, 121]. Furthermore, suggest the SOS in the National dementia guidelines, multi modal economical consequences for the county council and municipalities respectively, both in context of short and long term effects. [32].

Quality of life (QOL) for patients and caregivers has been difficult to investigate. Jönsson and associates suggested (2006) that the patients are rather stable in the perception of QOL during the progression of the illness. In contrast to the proxy-reported utilities where the patients QOL similar in the milder phase but lower than the patients in the more severe stages of the illness [122]. There is a general high consensus related to the effects with caregiver education and support, in order to enhance the QOL of the caregiver. But more research related to the QOL in patients related to treatment seems to be needed [123].

2.1.8 Impact on society

The incidence of dementia disorders, and the increasing severity of this chronic disease over time, will together create even greater burden on patients, caregivers and

society[124]. The total cost worldwide is estimated to 156.2 billion USD, 119 billion € [125]. In UK dementia costs over 1% of the total gross domestic product, and stands as one of the most costly diseases [126]. In line with this, the total cost of dementia care in Sweden was estimated to be 5 billions € in 2005, with 85% of the cost being borne by the local municipalities. The incidence of dementia disorders is expected to rise to 250,000 by 2050 and costs will increase accordingly [14].

The need for support for the patient and his/her caregiver will increase following the loss of the patient's abilities [124]. Many caregivers are dissatisfied with the support from professionals and society while they concern themselves with day-to-day management [2, 127]. The optimal organization response to the need for care and support services is a "chain" of professionals (Figure 6) having a variety of different skills [128]. In the early stages of the disease, the identification of cognitive decline, loss of attention and sensitivity to stress are often the symptoms that set the diagnostic process in motion [129]. The first line in the diagnostic process is usually the primary care unit or a municipal administration alternative a social worker, social or a welfare officer. Once the diagnosis has been established, it is important to offer support and education for the patient and his/her caregiver to cope with the new situation this presents. This might be done either within the primary care setting or at the specialist level. As functional loss progresses caregivers may become overwhelmed by the burden to care for the patient. At such a time added support from the municipality should be made available to compensate. Costs consequently increase as the more severe stages of the illness emerge (Figure 4) [130]. Some examples of these types of support are help from municipalities staff in the patient's own home, day care centres, temporary stays in a nursing home, and permanent residence in a nursing home. Several different professionals are simultaneously involved in the care of dementia patients, ranging from specialists to GPs to various types of nursing professionals and skilled workers, physiotherapists, occupational therapists, social workers, social welfare officers, municipal coordinators, municipal officers, municipal administrators, etc. This implies that several different and parallel organizations hold responsibilities, which require communication and close collaboration in order to obtain a satisfactory outcome during the illness progress [131]. Moreover, regional and country differences in organization and culture, influences how economical investigations are to be undertaken. Subsequently, when data is collected it is difficult to analyze and report generalized results from health economical analyses from country to country [132].

2.2 FUNDING, ORGANIZATION, GOVERNMENTAL REGULATIONS, STRUCTURE OF CARE

2.2.1 Funding, organization and regulations

Funding will usually follow parallel the organization like parallel pipes (Figure 5). Decentralized organization and management models follow a Nordic tradition and corresponds to this pattern of funding [133]. The needs of the patient and his/her caregiver should guide the work and planning of the organization [7]. Over the course of disease management the management responsibility may shift among various stakeholders. Funding has to be obtained and should benefit the patient through until the final stages of the disease. Provision is made for this by “Hälso och sjukvårdslagen,” a county council and municipal organization role. Further regulation of municipality social and welfare activities embody the social services law, known as, “Socialtjänstlagen,” as well as “Lagen om Stöd och Service till vissa funktionshindrade” that benefits individuals with disabilities, patients younger than 65 years.

One can argue pro and con for a decentralized organization and for general laws and regulations regulate and guide disease management programs. The positive with local budget could be the commitment to the own sphere of activities and two have control of resources and costs. But it also has a conflict to have an overall outlook of long term investments and general needs for the patients and the community [133].

Governmental regulations and the service organization guidelines may sometimes conflict (rising e.g. in ethical conflict, such as determining the balance of the medical needs versus the autonomy of the patient). Day-to-day management of such conflicts is necessary. However, a further intent with the laws and regulations is to bridge the general needs between different stakeholders and minimize local variations. Swedish social law and welfare has launched new recommendations stipulating that persons with dementia shall be taken care of from early recognition and diagnosis onto the final stages of the disease. Further, it is mandated that a local organization should be set up in order to harmonize the process, though the effectiveness of these is unknown [9].

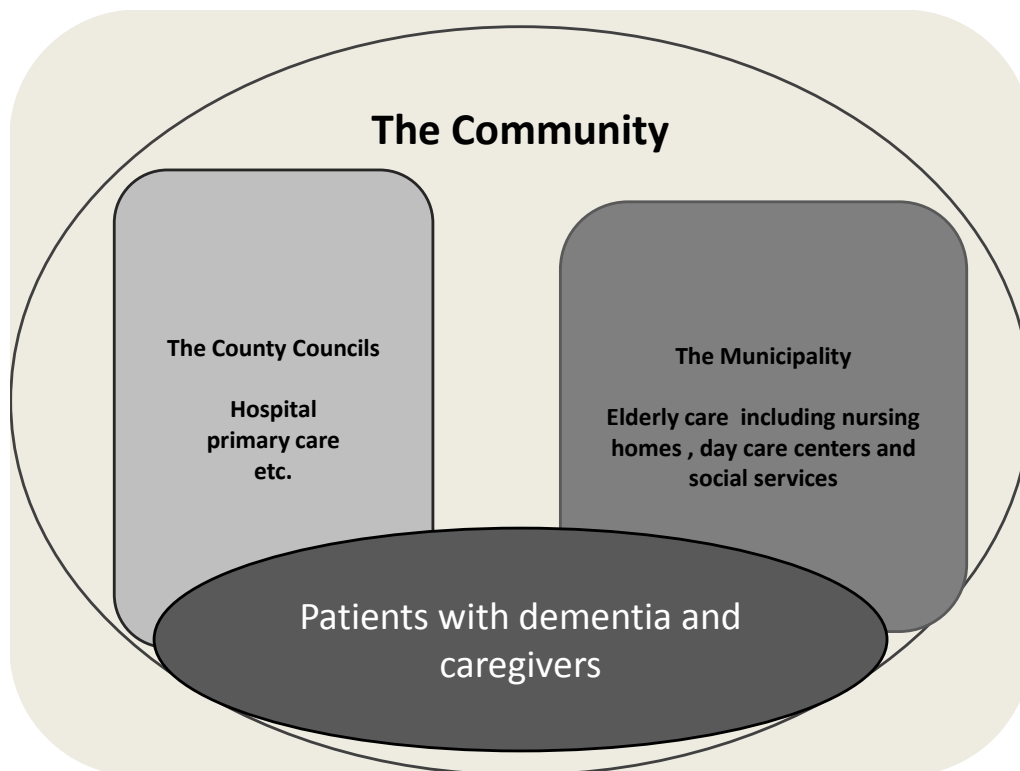


Figure 5: Organization and funding are like “pipes” with no formal interaction despite the changing needs of the patient.

2.2.2 “Chain of care”

Logistics can be described as the management of the flow of goods, services, information and other resources including people. The term comes from the military history, and is associated with optimizing support for soldiers [134]. A focus on optimizing service delivery has been to minimize costs by improving logistic flow of items, goods or services from A to B to C etc. In the health care sector a term denoting this is medical logistic management. The complexity of the health care with the variety of independent factors, is a challenge to analyse and organize [135].

In this study the Disease-Management Program is offered as one step to further implement a “logistic health chain,” especially with regard to chronic diseases, such as dementia. One must contend with numbers of different professionals and organizations that become involved during the course of disease (Figure 6). Creating demands that range across a number of domains, and which call for a variety of different provider types must operate within a chain of care incorporating a multi-functional network [84]. Additionally, there is the problem of untimely, or late, observation suggesting that indeed a problem is present. Olofsdottir and associates suggested (2001) that the patient who has received a dementia diagnosis had visited primary care at least 5 times the previous year [129, 136].

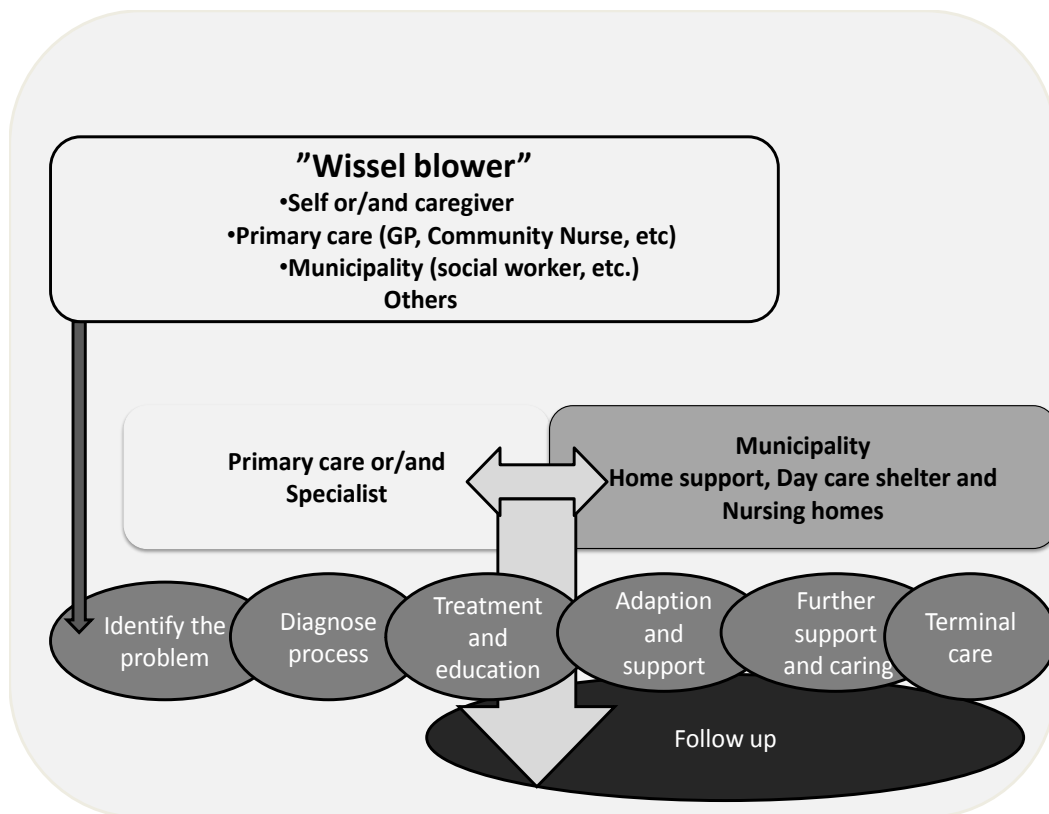


Figure 6. The dementia process presented in a logistic perspective “chain of kneads and care”. From identify the problem, symptoms and to be noticed/visible as a patients. To the final stages of totally dependency and high level of caring, associated with high costs.

2.2.3 Disease-management program

Disease-management programs are often described in the literature as "a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are significant. [137-139]"

Disease-management programs are usually planned using both cost and service quality components, mandated to reduce costs and improve quality of life (QOL) (Figure 8). This is achieved by preventing or minimizing the effects of various conditions through integrative care and assessment [140]. These have evolved from managed care and typically concern chronic diseases and conditions, ombining the evidence-based quality care with costs. Typical disease-management programs have been set up to manage chronic diseases, such as cardiac and pulmonary diseases, hypertension, obesity, diabetes mellitus, asthma, cancer and depression[138].

Disease-management programs have come about often with the support of caring organizations associated with specific diseases. Often research has provided important information that led to one or another group starting such as program. Investigation of the quality of these programs must rely on local cooperation, though disease-management programs can be regional, national, or even international. All have unique political and social interests with may influence the aim to examine quality. Learning from organization development and the management of change in

organization, one should not be surprised if there is resistance to developing a disease-management programs. Resistance may be observed, for example, when physicians and others health care personal are forced to participate in a program, or when the program restricts the choices decisions about care [140].

Disease-management programs incorporate monitoring and evaluation functions. The their goal is not necessarily to cure but to improve quality of life for the patients, and caregivers without increasing costs (Figure 7). A similar concept in dementia- and stroke-care is the term “health services delivery networks” [84, 90, 141].

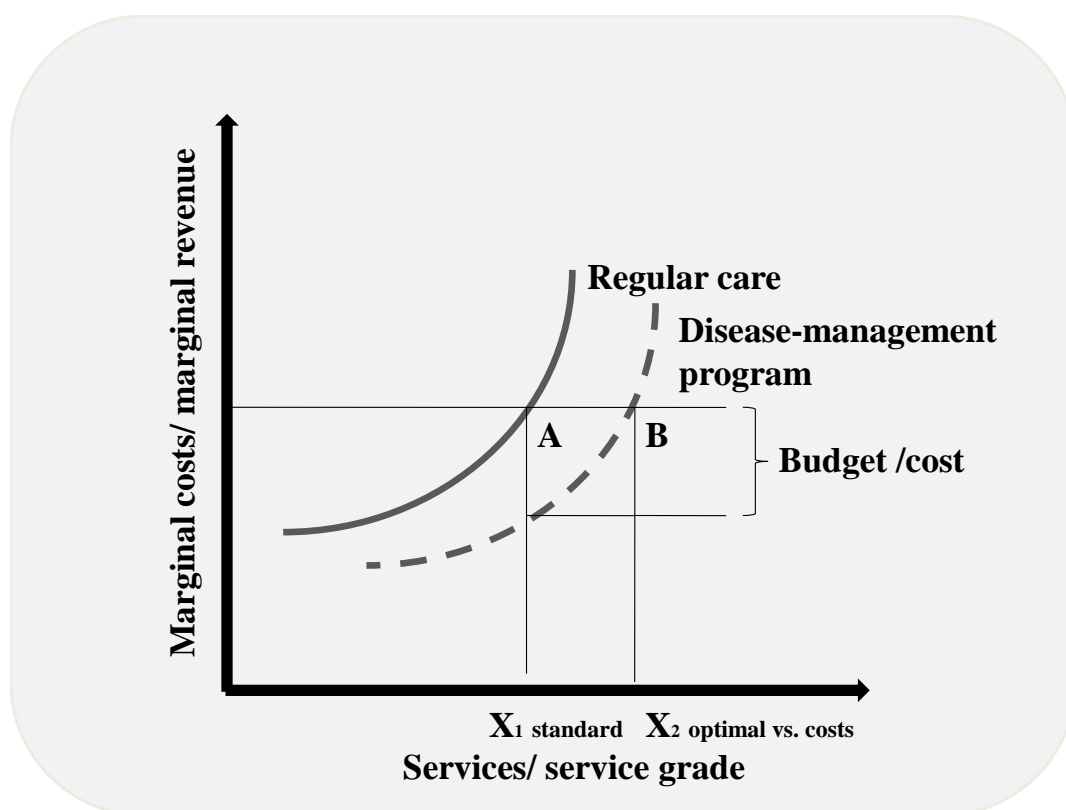


Figure 7. Modelling the theoretical effect of disease-management programs; for the same investment recourse utilization and higher service grade and a flexibility of reducing costs without decrease the initial service grade (modification from figure by Folland et al [140]).

2.2.4 Operations Management and Lean Production

The organization in pipes (Figure 6) where is not always followed the patient flow. To overcome this can an operation management (OM) system been set, in order to set up the chain of care in the logistic framework. Thus is the program strengthen [140]. The positive with this framework is too justified sometimes locally unpopular decisions who increases the costs in one organization but lower the costs in another.

Further is framework of OM a guaranty to the political and higher organizations levels to ensure the quality and equality overall treatment. The logistic care chain and the management program can be followed, majored and evaluated.

In order to improve the production cold the concept of Lean Production be of interest. The concept was first introduced in the automobile manufacturing industry during the 1980's, mainly at Toyota. It embodies a general customer focus and aims to achieve regular improvement in production. Recently Lean Production was introduced in the health sector in a process framework. Lean Production suggests to consists of five central elements or statements. First, the organization can always be better with involvement from the co-workers. Secondly, to eliminate all unnecessary actions, this improves work flow, and enables standardization. Third, establish general and attainable goals. Fourth, perform regular measurements and give feedback. Finally, implement regular improvements in the process [142]. Overall, Lean Production can provide a platform collaboration and communication, and help to form a higher-quality productive process.

2.2.5 Dementia care organization in Sweden

The care of persons with dementia in Sweden is shared between the county councils the municipality's (Figure 5).

2.2.5.1 *County council*

2.2.5.1.1 "Memory clinic"

Memory clinics provide specialist care in dementia assessment and care planning, and are mainly located in hospitals. With respect to managing dementia assessment and care, specialists were originally primarily geriatricians, though gero-psychiatrists and neurologists have performed much of these services as well. Patients are referred out of primary care practice to these specialists, though referral may occur directly to the specialist while bypassing primary care[9]. In addition, day assistants in the dementia diagnostic process are may include neuropsychologists, who perform tests of various cognitive domains, and physiotherapists who observe the ADL.

2.2.5.1.2 Primary care

The Primary Care Units (PCU) are multidisciplinary organizations that include physicians and are typically organized by catchment area, serving a pool of subscribers or members. Such PCUs serve healthcare needs from "cradle to grave.". Additionally, PCUs act as "gatekeepers" coordinating access to other components of

the health care system [140], e.g. directing patients to the appropriate and most cost effective treatment.

Barriers to optimal performance of these units have been identified, including: lack of support, time and financial constraints, stigma, diagnostic challenges, and disclosing the diagnose [143]. Patients may visit the PCU frequently before the diagnosis of dementia is made [144]. Thus, PCUs have a unique opportunity to identify dementia early in its course.

Diagnosing dementia accurately is also an issue. Some studies have suggested that the rates of accurate diagnoses may improve with education, and even be an instrument helping to detect new cases [145, 146], others suggests mixed results with training [147]. Thus in the recommendation from the SOS suggests the primary care be responsible in the basic level of the dementia investigation [32].

2.2.5.1.3 Emergency- and further -department

Patients who are cognitively impaired may present in any number of ways in the hospital, e.g.in the emergency department (ED). Nevertheless, these patients are frequent visitors to primary care units [8, 144, 148, 149]. Furthermore, in the period before turning up at the ED, elderly patients have lost most of their social contacts resulting in isolation [150, 151]. A study on elderly patients undergoing the transition from homecare to nursing home care report corresponding increase in visits to the ED, mostly due to falls, fever, cardiovascular diseases, gastrointestinal problems and cognitive impairment [152]. Such cognitively impaired patients also present to medicine, orthopedic, psychiatric service though more studying of this issue is necessary. Thus is a further factor complicating the rehabilitating process for example after a hip fracture has been a debate of a longer rehabilitation period [153-155].

2.2.5.2 *Support care governed by Municipality*

Most municipalities are more directly involved in managing dementia care, which should be understood to provide a mixture of care and support to patient and caregiver. Home care, for example, is supported by the municipality. In addition, municipalities may support sheltered-day-care services, both to provide relief to the caregivers and to provide daily activity to the patient. Under some conditions, nursing home placement, whether for temporary or permanent lengths, may be supported by the municipalities. In the more severe stage is often placement to nursing home necessary temporarily or permanently.

2.2.5.2.1 Day care center

New dementia guidelines in Sweden strongly recommend day care centers. These sites may be helpful in providing services, including memory training and rehabilitation, which may also provide respite for caregivers [9].

2.2.5.2.2 Home service support

In order that cognitively impaired remain home as long as possible home service support should be utilized. A project has been described in which special dementia team were developed to provide home support to patient and caregivers [131]. The efficacy of such programs need to be further evaluated..

2.2.5.2.3 Technical devices and support

In recent years technical devices have been increasingly used within the domain of dementia care, including special clocks, mobile telephones, GPS-devices that assist with supervision, as well as sophisticated robots that may have roles in certain activities within their repertoire. More research will be needed to see the pros and cons of their use. Further also the legal aspects e. g. the autonomy of the patient has to be addressed.

2.2.5.2.4 Nursing home

Having the prospect of an advancing course of dementia patients and their families are likely to face a decision to move to a nursing home. This kind of support is the most costly form of care in the dementia chain [14]. On other hand support in the own living at home might be more costly. Nursing home support can provide care for full 24-hour days. Municipalities invest also in temporary nursing homes. This inpatient type of could be a temporary support for tree times as many patients.

2.3 THE SETTING AND DEMENTIA MANAGEMENT PROGRAM IN KALMAR

Kalmar, Sweden, has approximately 60,000 inhabitants and age distribution similar to Sweden as a whole. A dementia-management program (DMP) was established that involved the primary care system, specialists, and the social welfare officer (SWO), the latter which represented Kalmar municipality [75]. Implementation began in 1998 at the point of the primary care system. Earlier the task of diagnosing dementia was handled by the geriatrician. The municipality had a caring organisation according to normal setting in Sweden.

The preliminary reason for implicate the program was to change focus from the historically “ad hoc” to a “costumer need” solution within the primary care. Studies had demonstrated that patients not yet having been diagnosed but who nevertheless demonstrated cognitive impairment were frequent visitors to primary care and needed to be identified early [129, 144]. An operations manager was appointed to focus on dementia care programming and was mandated to set up a multi-disciplinary dementia team.

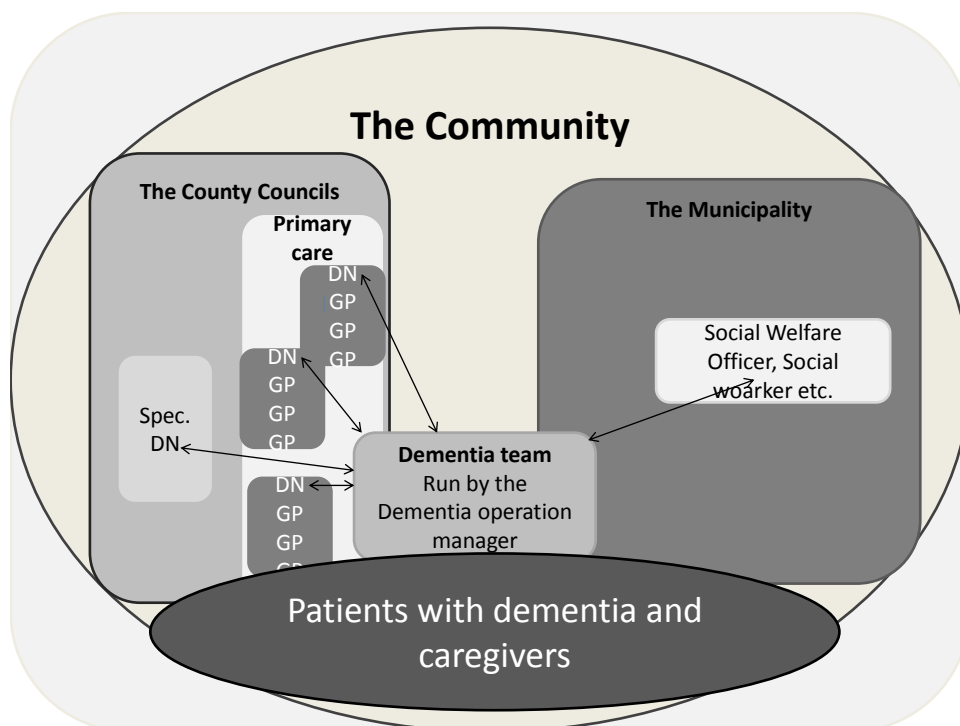


Figure 8. The Dementia team in Kalmar works cross functionally in-between and over the organizations and economical boundaries. The primary care and specialists is in the main domain of the county council. Where's the municipality acts separately.

When these began data was not easily available, for instance the number of patients visiting the primary care system was not known. Moreover, guidelines for the process of clinical evaluation of patients with neurocognitive impairment were absent. Nor were there guidelines for managing patients with dementia within the organisation. Lines of authority were not described, and there was a lack of accountability over how

services were being monitored and resources being allocated. The organisation was vertically-organized (parallel organizational bodies with no organized collaboration in-between). There were no formal mechanisms for collaboration between geriatric specialists and the municipality that would help to make more efficient the support of patients and caregivers.

The operation manager organized a team and identified a single nurse from each PCU who was appointed Dementia Nurse (DN) to collaborate with a dedicated SWO from the municipal organisation (Figure 8). The team was supposed to work cross functionally (work over the formal organization) and collaborate horizontal (instead of vertical) between the different organisations for the benefit for the patients and caregivers.

Initially, an inventory of the patients with a dementia diagnosis was made and 538 patients were identified as having either an established or a possible diagnosis of dementia. The calculated prevalence of individuals with dementia in an area of 60,000 inhabitants is over 900 patients within Kalmar municipality. Education programming was started in the primary care organisation and included the GP, municipal nurses, assistant nurses and the home care and nursing home staff. Educational programs were extended to political and administrative officers, both within the county council and the municipality, in order to gain system-wide support.

The main components of the DMP were early identification, diagnosis, treatment and follow up. In order to minimize the number of individuals involved in the patient management process. The process of assessment began with all new cases were referred directly to the DN, obtaining a health history from the patient and caregiver, enabling the GP assigns and “established diagnosis” of dementia based on ICD-10. Standard operating procedures (SOP) were established that incorporated a basic diagnostic battery, including medical and social history, physical examination, laboratory tests, ECG and CT scan (Table 3).

| Basic assessment | Supplementary assessment as required |
|---|---|
| <ul style="list-style-type: none"> • Patient and relatives informed that assessment has been initiated • Medical history • Life and social history • S-TSH • Electrolyte status incl. calcium • Blood status • Blood glucose • P-Homocysteine • MMSE • Clock test • Orthostatic blood pressure series • Medical examination incl. neurological status • Drug monitoring vs. indications and potential risks • ECG • CT scan of brain • Guardianship certification • Driving license assessment • Possession of firearms • Care planning • Patient and relatives informed of the results of the assessment | <ul style="list-style-type: none"> • Cholesterol • Liver status • Liquor analysis • EEG • Neuropsychological testing • AMPS • Driving license test |

Table 3. The Standard Operating Procedure (SOP) in establishing dementia diagnose in primary care setting[156].

The DMP aimed to standardize diagnostic procedures, including: comprehensive reviews of drug and medical history, cognitive performance screening , using the Mini-mental Status Examination (MMSE) and the Clock Test, physiotherapy and occupational therapy assessment, as well as assessment by a psychologist if needed.

The SWO is introduced early during the assessment process to assist in planning and to offer support. Younger patients (below 65 years) and other cases considered more complex were to be referred to the specialist for further evaluation and diagnosis (Figure 9). The diagnosed patients were offered medical treatments and psycho-social intervention.

A mechanism was created so that the team could regularly monitor patient progress. The team focused on continued improvement of the monitoring mechanism (Figure 6). As in Lean Production [142], all co-workers were involved in this process. A schema of functional flow of actions was developed. Feedback sessions were incorporated with the regular program monitoring results. In order to a attainable goal. It is notable that the dementia management programs today suitable in the context of the newly presented Swedish dementia guidelines [32].

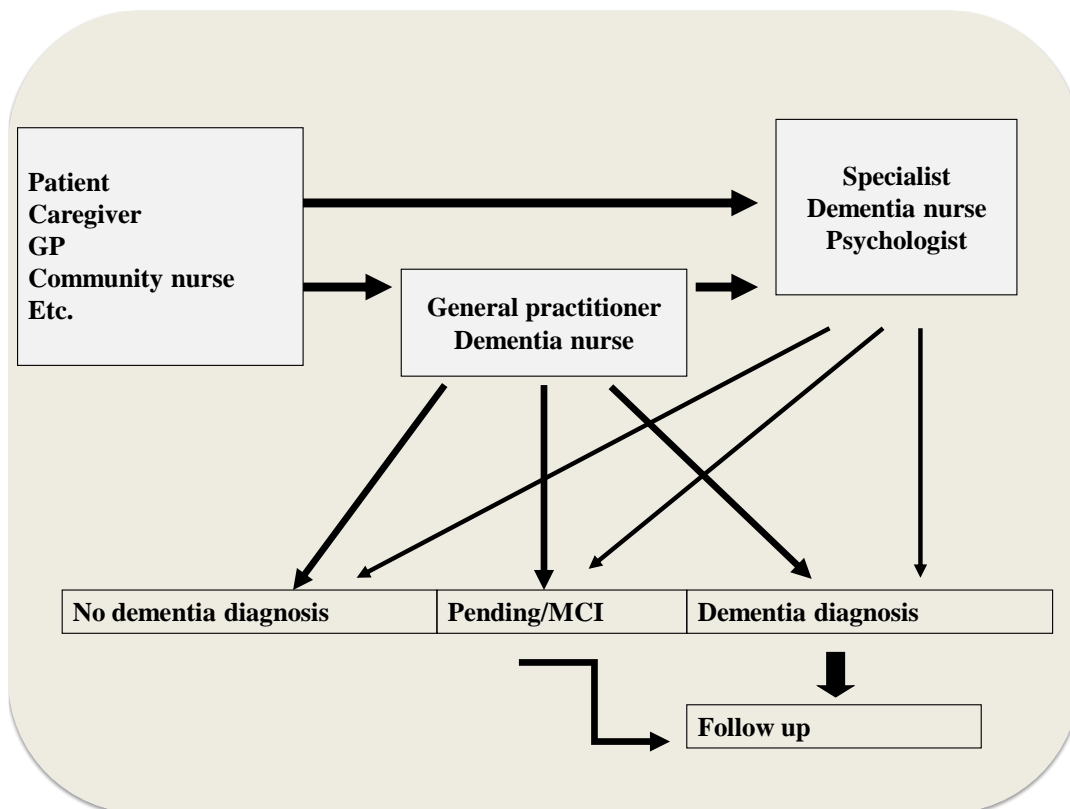


Figure 9. Flow of patients in the Kalmar dementia investigation programme, part of the response of the county council, but also is usually the SWO involved in the process early even without that it is necessary with support from the municipality. But it is of help in linking to the future needs of support.

A role of the DN is to guide the patient and his/her caregiver through the health care system, to inform about them about different aspects of the disease and to support the families in the day-to-day care. In addition, the DN is responsible for setting up educational programs for caregivers and for patients in the early stages of dementia. The education is usually performed in groups divided in two parts. The first part has three sections (I, II, III): I, dementia diseases, what happens in the brain pathology and epidemiology. II, what help is available from the municipality? III, coping strategies for daily life and best practice of treatment and the care about the persons needs. The caregiver may request further education and meetings which the municipality then provides.

Once diagnoses are established, treatment is started, and is continued through the “follow-up phase.” The DN becomes responsible to set up and manage regular appointments, most of which are attended by the DN. However, at least once a year the patient is seen by the GP. Moreover the DN is also responsible for managing appointments concerning other co-morbid medical conditions [157] . However, the responsibility of medical care shifts over to the municipality if and when the patient becomes a regular nursing home resident.

3 HYPOTHESES AND AIMS

3.1 FOLLOWING HYPOTHESES HAVE BEEN IDENTIFIED FOR THIS PROJECT

- The dementia management program is reliable to define most of the new patients per year. (Paper I)
- What is the (mean) cost of a complete assessment for dementia at the level of (specialist or PCU), and how does this compare with the total cost of dementia assessment, treatment, and care during the full course of disease? (Paper II)
- The dementia management program has additional influence on prescription patterns in the elderly population, to a more proper use of psychotropic, including sedatives, dementia drugs and drugs with anticholinergic properties. (Paper III)
- Implementation of dementia management programs does not increase cost burden of managing dementia for the municipality. (Paper IV)
- The dementia management program is at least cost neutral when applied in both county council and municipality. (Paper I, III and IV)

3.2 AIM OF THIS THESIS

The aim of this thesis is to identify and describe the dementia management program, and to evaluate it with respect to health economic costs and benefits. In doing so this thesis will advance understanding about some aspects of the relationship between stakeholders, as for example, cost-sharing between county councils and municipalities. Such evaluation requires a deeper understanding of the Kalmar DMP organization structure and process that influence the full scope of activities associated with its responsibilities in dementia care and overall disease management. Further, this thesis aims to develop understanding of how to promote optimal care and treatment of dementia patients both from the clinical and economical perspective. In order to investigate these aims the following questions were defined:

- Can the program identify the number of new patient with dementia per year in the area?
- What is the cost of a dementia diagnose with this program?
- Has the use of selective psychotropic drugs used by elderly changed after the introduction of the dementia program? If so in what direction?
- What are the costs of dementia for the municipality after the introduction of the dementia program?
- Is it possible to implement the DMP including collaboration between primary care, specialist care and the municipality within the existing allocation of funding and resources?

4 MATERIAL AND METHODS

4.1 MATERIAL AND STUDY POPULATIONS

4.1.1 Study 1 (paper I)

In study 1, patients from the inventory which were based on data obtained in 1997 with defined as having either an established or a possible dementia diagnosis (n=538). The sample from DN records in Kalmar, including the number of (new or existing cases) cases exhibiting possible dementia cases from 1999 to 2005 , (n= 1500). Further, all patients with their first registered dementia diagnosis between 1995 and 2005 in Kalmar County council are entered into the central diagnosis database (n=1307), with a dementia diagnose. According to the SOS, the prevalence of dementia is defined as the average duration (by years) [158]. Descriptive statistics of from the general Swedish population and the local Kalmar populartion was obtained from Statistic of Sweden [159].

4.1.2 Study 2 (paper II)

The second study described patients referred for dementia assessment between January 2004 and April. Thirty consecutively referred patients undergoing dementia assessment beginning in January 2004, along with ten consecutive patients referred for specialist assessment of dementia at Kalmar county hospital were analyzed (Figure 10).

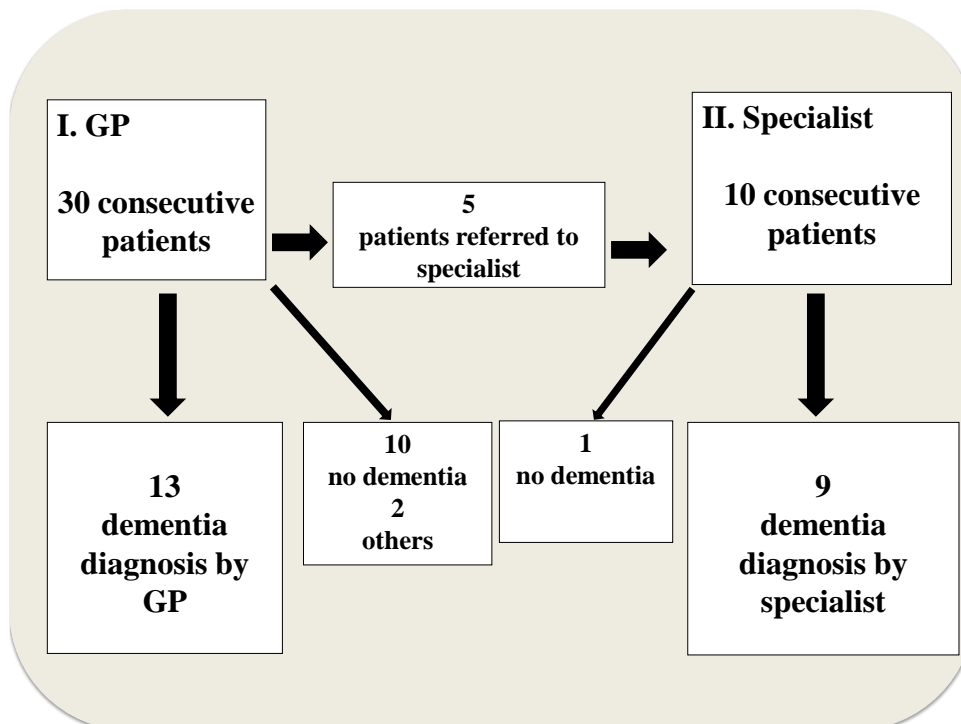


Figure 10. Patient distribution in study 2 (paper II)

4.1.3 **Study 3 (paper III)**

The third study examined elderly patients (75 years and over) who were receiving prescribed drugs from Swedish pharmacies during the period from 2000 to 2005. These included dementia drugs, neuroleptic, sedative, antidepressant drugs, as well as other drugs with significant anticholinergic properties.

4.1.4 **Study 4 (paper IV)**

The fourth study described a sample of patients who had been diagnosed with dementia who were utilizing municipality resources in Kalmar (2002-Q2 2004; n=570) and Älvsjö (2003-2005; n=187).

4.2 METHODS AND ETHICAL APPROVAL

The project involves both a retrospective and prospective analyses. Specific discussion of the methods used will be presented in the separate papers. Later in this thesis analyses will be presented. A triangulated model [160-162] is used in order to analyze the DMP in Kalmar with a multidimensional perspective.

4.2.1 **Study 1 (paper I)**

The study was both retrospective and prospective, including several components: firstly, a comparison of the demographics of Kalmar compared with Sweden as a whole; secondly, analysing the diagnostic investigations of individuals with cognitive impairment in Kalmar municipality; thirdly, an analysis of patients' contacts with the PHC. Finally, we analysed all known dementia patients in 2005 in the area. Furthermore, we compared the estimated incidence and prevalence figures for dementia in the municipality of Kalmar with Sweden as a whole.

4.2.2 **Study 2 (paper II)**

We carried out a prospective time and resource utilisation study in order to identify the total costs associated with the diagnostic process for dementia within the dementia program. This was done both at specialist and primary care level.

4.2.3 Study 3 (paper III)

The study is a retrospective population based drug utilization analysis with a longitudinal and cross sectional. In order to identify drug consumption in the elderly (75 years and elderly [163]), we selected the following types of drugs for further investigation: dementia drugs, antidepressants, sedatives, neuroleptics, sedatives and drugs with significant anticholinergic properties as they are often used by the elderly population and are known to have both positive and negative effects [64, 68, 164], especially when used together. To obtain comparable data between Kalmar municipality and Sweden as a whole, we analysed the use of drugs sold at Swedish pharmacies, expressed as DDDs [63] per 1000 inhabitants and year. This measures the quantity of drugs used in this population. The collection of data covers the period from the year 2000 to 2005, when the Dementia Program was fully implemented. Furthermore, in order to analyse prescription habits (how many were using a specific drug in the population), we also performed a cross sectional analysis of the Swedish Prescribed Drug Register (SPDR) [165]. We analysed individual-based data from individuals aged 75 years and older who were registered in the SPDR during October-December 2005. Based on, information from the three-month period, including the date when the prescription was issued, the amount of drug received, and the prescribed dosage, the current drug use on december 31, 2005 could be estimated [163, 166].

4.2.4 Study 4 (paper IV)

Study four reports on analysis of direct costs for dementia care, i.e. cost-of-illness (COI) on both retrospective and prospective with a municipality economic perspective. Direct costs of the county councils, costs of informal care and indirect costs due to production losses of patients were not included. The main focus was on Kalmar municipality. In order to examine representativeness of the area and potential program effects in terms of direct costs we included comparisons as contrasts to Kalmar with Älvsjö municipality and Sweden as a whole [14]. Älvsjö was selected due to not have a dementia program such as in Kalmar. We used a cost analysis model with three basic components: volumes of used resources (including all major municipality costs related to the dementia care i.e. help in home, day-care centres and nursing homes, both on temporary and permanent basis (A) [14], unit costs for each resource (B) and an estimate of the number with dementia that used these resources (C): ($A*B*C=MC$). The source for the quantities of used resources is the formal support decision by the SWO. An increase by 20% for estimated overhead costs was included. In addition, we compared these findings with the estimated cost of illness of dementia in Sweden [14]. In order to compare socioeconomic status between the areas figures about education and income proportions were obtained from Statistic Sweden [159] All costs are adjusted to the year of 2002 based on the Consumer price index (CPI).

4.2.5 Ethical approval

The study was approved by the ethic committees in Linköping, Dnr. 03-494 (paper I-IV), Karolinska Institutet, Stockholm Dnr 2006/948-31 (paper III) and Karolinska Institutet Dnr 239/03 (Paper IV).

4.2.6 Statistical analysis

4.2.6.1 Study 1 and 4 (paper I and IV)

The statistical software package SPSS version X and Microsoft Excel were used for the statistical analyses. All variables were summarized using standard descriptive statistics such as mean, standard deviation, and frequency. Comparisons between national and local data (gender, age, diagnoses and frequency of patients with dementia and costs) are based upon population data.

4.2.6.2 Study 2 (paper II)

The calculation was done on 30 patients in primary care and 10 patients at the specialist level. The true patient cost calculation was based on the average cost of dementia investigations for all patients who received a dementia diagnosis including the cost for those who did not receive a dementia diagnosis divided by the number of patients diagnosed with dementia.

4.2.6.3 Study 3 (paper III)

No analyses of statistical significance were performed, as the data are based on whole populations. A logistic regression analysis was used in the cross-sectional part, in order to analyze the use of neuroleptics, anxiolytics, sedatives, selective serotonin reuptake inhibitors (SSRIs), dementia agents and drugs with anticholinergic properties in Kalmar compared to Sweden as a whole. Adjustments were made for age, gender and number of drugs. The relationships are expressed as odds ratios (ORs) with 95% confidence intervals (CIs).

5 MAIN RESULTS, COMMENTS AND RELATED CONCLUSIONS

The primary findings from the four papers outlined above are summarized here, while the full articles are to be found in the appendices. Note that between the years 2000-2005, the percentage of the population of Kalmar that is “elderly” (about 17.3% >65) is nearly the same as the percentage within the general population of Sweden (17.5% in Sweden) as can be seen in Table 4.

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | Mean |
|----------------------|---------------|---------------|---------------|---------------|---------------|---------------|-------------------------|
| Sweden (SD) | 8875038 | 8888496 | 8903540 | 8919814 | 8937156 | 8955422 | 8913244 (±24625) |
| ≥65 (SD) | 1530593 | 1531564 | 1534349 | 1540913 | 1550821 | 1559753 | 1541332 (±8394) |
| ≥75 (SD) | 790748 | 793730 | 794668 | 796602 | 795908 | 796799 | 794743 (±2289) |
| ≥80 (SD) | 453051 | 465267 | 472306 | 478638 | 483265 | 486847 | 473229 (±11877) |
| Proportion ≥ 65 | 17,2% | 17,2% | 17,2% | 17,3% | 17,4% | 17,4% | 17,3% |
| Proportion ≥75 | 8,9% | 8,9% | 8,9% | 8,9% | 8,9% | 8,9% | 8,9% |
| Proportion ≥80 | 5,1% | 5,2% | 5,3% | 5,4% | 5,4% | 5,4% | 5,3% |
| Proportion woman ≥65 | 58% | 58% | 57% | 57% | 57% | 57% | 57% |
| | | | | | | | |
| Kalmar (SD) | 59 308 | 59 787 | 60 066 | 60 415 | 60 649 | 60 924 | 60192 (±593) |
| ≥ 65 (SD) | 10 460 | 10 509 | 10 493 | 10 568 | 10 591 | 10 565 | 10531 (±51) |
| ≥75 (SD) | 5 483 | 5 498 | 5 492 | 5 536 | 5 521 | 5 530 | 5510 (±22) |
| ≥ 80 (SD) | 2 736 | 2 818 | 2 861 | 2 964 | 3 000 | 3 016 | 2899 (±112) |
| Proportion ≥ 65 | 17,6% | 17,6% | 17,5% | 17,5% | 17,5% | 17,3% | 17,3% |
| Proportion ≥75 | 9,2% | 9,2% | 9,1% | 9,2% | 9,1% | 9,1% | 9,1% |
| Proportion ≥80 | 4,6% | 4,7% | 4,8% | 4,9% | 4,9% | 5,0% | 5,0% |
| Proportion woman ≥65 | 59% | 59% | 59% | 59% | 59% | 59% | 59% |

Table 4. Population and proportionality (in percent) of elderly in Sweden as whole and Kalmar municipality.

5.1 PAPER I

5.1.1 Hypothesis

- The dementia management program is reliable to define most of the new patients per year.
- The dementia management program is at least cost neutral when applied in both county council and municipality.

5.1.2 Setting

The first study was based on yearly reports made by the DN, which were delivered to the dementia operational manager. Further, county council records were used to determine the situation that existed prior to introduction of the dementia management program. Subsequently, epidemiological data obtained on dementia in Sweden and Kalmar, was used for comparison.

5.1.3 Results

On average, 214 (range 160–257) patients were evaluated per year of which 127 individuals (range 113–157) obtained a dementia diagnosis at the primary care level (Table 5). Additionally, 22 patients per year were diagnosed at the local geriatric clinic. The number of patients registered locally in the PHC by the DN is in line with the central registry of diagnoses within the county council (Figure 11), a deference of less than 10%.

| | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | Mean |
|--|------|------|------|------|------|------|------|----------------------|
| Total (SD) | 206 | 160 | 192 | 240 | 257 | 203 | 242 | 214.3 (±33.9) |
| Proportion women (%) | 68 | 64 | 63 | 62 | 48 | 61 | 51 | 59.6 |
| Living alone (%) | – | – | 64 | 51 | 48 | 61 | 51 | 54.9 |
| Support from caregiver (%) | 39.8 | 51.3 | 42.7 | 34.2 | 31.9 | 40.4 | 33.9 | 39.2 |
| Mean age women | – | – | 81 | – | 80 | 82 | 80 | 80.8 |
| Mean age men | – | – | 79 | – | 79 | 78 | 77 | 78.3 |
| Diagnoses and referrals | | | | | | | | |
| No dementia (SD) | 56 | 33 | 32 | 40 | 53 | 49 | 82 | 49.3 (±17.2) |
| Suspected dementia (SD) | 28 | 14 | 42 | 43 | 59 | 33 | 44 | 37.6 (±14.2) |
| Referrals to specialist (SD) | 19 | 26 | 17 | 29 | 31 | 28 | 20 | 24.3 (±5.5) |
| Final diagnoses | | | | | | | | |
| Alzheimer's disease (SD) | 51 | 44 | 51 | 62 | 66 | 42 | 42 | 51.1 (±9.6) |
| Vascular dementia (SD) | 29 | 35 | 21 | 45 | 23 | 28 | 22 | 29.0 (±8.6) |
| Frontotemporal dementia(SD) | 3 | 3 | 5 | 3 | 5 | 1 | 1 | 3.0 (±1.6) |
| Levy Body dementia (SD) | 0 | 4 | 2 | 2 | 1 | 1 | 1 | 1.6 (±1.3) |
| Mixed dementia(SD) | 10 | 9 | 21 | 19 | 33 | 40 | 39 | 24.4 (±13.0) |
| Unspecified dementia (SD) | 29 | 18 | 18 | 26 | 17 | 9 | 11 | 18.3 (±7.3) |
| Total with a dementia diagnosis from PH (SD) | 122 | 113 | 118 | 157 | 145 | 121 | 116 | 127.4 (±16.7) |

Table 5. Registration from the PHC (Primary Health care centres) of patient referrals for dementia investigation during the introduction of the dementia programme in the Primary health care organization in Kalmar community from 1999 to 2005.

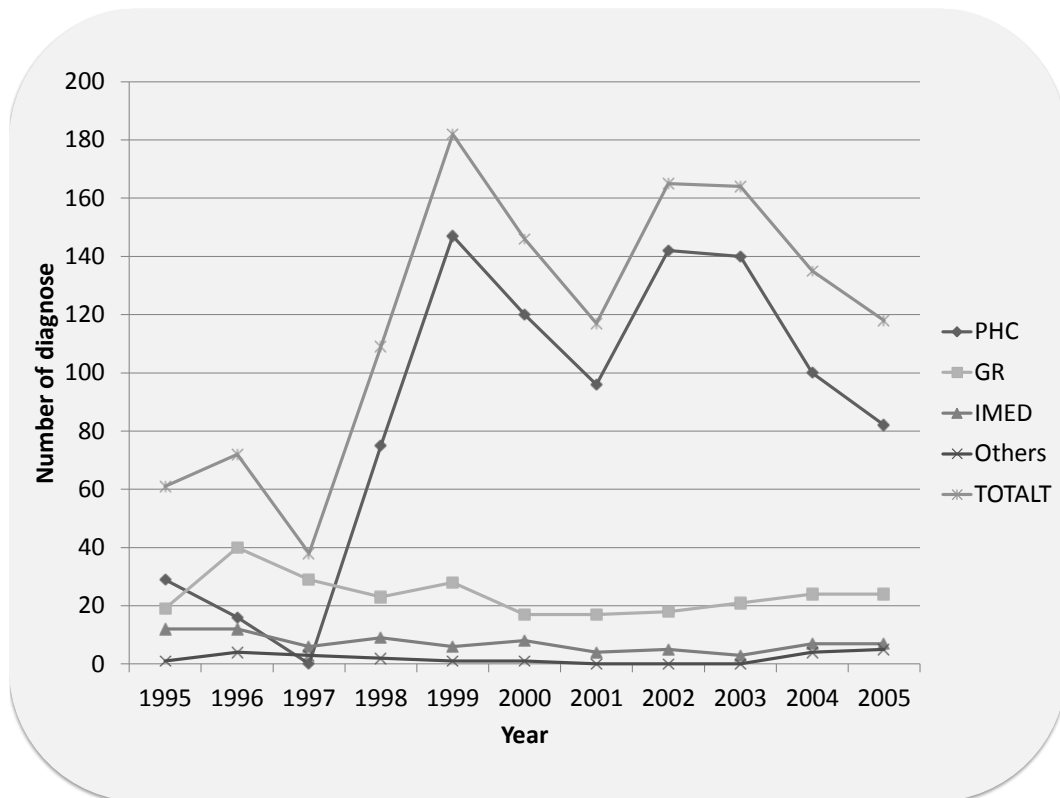


Figure 11. Registrations of diagnosed dementia patients from the County council (PHC=Primary Health care centre's, GR=Geriatric clinic, IMED=Internal medicine) and reporting from private physician in Kalmar community from 1995 to 2005. "Others" includes patients from other departments, such as infectious diseases, surgery and private physicians.

Most patients who entered the DMP began their diagnostic assessment after being referred by a physician and were followed by nurses within the primary care organisation. The municipality has introduced new patients with less numbers. The number of visits to a GP within the primary care organisation remained stable during the length of the observation period. The absence of comparative data before 2000 made an earlier comparison impossible.

5.1.4 Comments

The expected incidence and prevalence of dementia cases in Kalmar are approximately 153 and a prevalence of 889/949 (2000-2005 respectively). An important element in the program is that all patients with cognitive impairment are entered when whenever dementia is suspected. Thus, if it is assumed that only new dementia cases are entered into the "program," and that there are no false-positive or false-negative cases the detection rate of dementia in PHC was 129/153(84%). That number of patients, 129, when added to the patients diagnosed in the specialty clinics, is roughly equal to the expected annual incidence during the study years, or 153. Since the number of diagnosed patients is similar to the expected incidence, we may assume that the program is able to identify a major proportion of new cases. Furthermore, as the program continues, the dementia cases that are not diagnosed in one particular year

may be identified in subsequent years. Other studies have found that when GPs are trained in the diagnosis of dementia, the detection rate is acceptably accurate [136] but the distribution of the different types of dementia in Kalmar correlates with earlier studies, suggesting acceptable diagnosis [4, 167]. Improvement in diagnosis as a result of the dementia program maybe also reflected in corresponding decrease in the numbers of "unspecified dementia diagnoses". Finally, the 1997 inventory showed that 316 patients had a diagnosis of dementia (35%) of estimated prevalence. In 2005, 601 cases were identified in the inventory, corresponding to 63% of the estimated prevalence.

At the time the program was introduced in Kalmar the number of visits to the GPs was an unchanged but a decreased in visits to the PHC nurses. No data are available to indicate the number of patient visits through the program in Kalmar. The turnover of PHC staff in Kalmar has been fairly unchanged during the observation period. No extra funding was needed and the number of staff somewhat unchanged.

5.1.5 Conclusions

- The study found that the dementia management program is probably capable of identifying the same number of individuals with suspected dementia as are expected according to epidemiological estimations of incidence. The dementia management program was able to achieve the objective above without requiring addition expenditure of money, though requiring reallocation of resources.

5.2 PAPER II

5.2.1 Hypothesis

- What is the (mean) cost of a complete assessment for dementia at the level of (specialist or PCU), and how does this compare with the total cost of dementia assessment, treatment, and care during the full course of disease?

5.2.2 Setting

This study was based on time and resource utilisations analysis of the process associated with dementia assessment in both primary care and specialist levels locally within Kalmar County.

5.2.3 Results

Where the dementia management program was utilized at the primary care level, dementia assessments took between two weeks and two months to arrive at diagnosis. The patients were seen on average three times per year by the GP and four times annually by the DN the year before diagnosis. The average length of time used for assessment of dementia was 1.45 hours for the GP and 4 hours the DN. The average cost for all included patients at GP level was 477 Euro (€) (Table 6). For those who

after evaluation received a dementia diagnosis by the GP, the mean cost was 654 €, while the corresponding costs for those referred to a specialist for further evaluation were 459 €. In addition to the average cost at GP level, the extra cost at specialist level was calculated to be 656 €. Thus, the total cost for the final diagnosis at specialist level was 1115 €. As some of the evaluated patients were not assigned a diagnosis of dementia, the total cost for cases diagnosed with dementia is the same as the cost for all dementia investigations divided by the number of definitive diagnoses.

| | Dementia diagnosis | Referral to Specialist and diagnosis | No Dementia | Others | Total | Mean |
|---|---------------------------|---|--------------------|---------------|--------------|---------------------------|
| PHC (n) | 13 | 5 | 10 | 2 | 30 | |
| Mean cost | 653.9 € | 459.1 € | 297.6 € | 274.2 € | | |
| Total cost (SD) | 8500.7 € | 2295.5 € | 2976.0 € | 548.4 € | 14320.6 € | 477.4 € (±275€) |
| Total cost no diagnosis (SD) | | | 2976.0 € | 548.4 € | 3524.4 € | 293.7 € (±185€) |
| Weight proportion diagnosis vs. remittent and diagnosed by specialist | 0.72 | 0.28 | | | | |
| Cost per positive diagnosis (true cases) by GP | 653.9+195.2=849.1 € | | | | | 849.1 € |
| Cost per positive diagnosis of those referred to a specialist | | 459.1+197.2=656.5 € | | | | |
| Specialist (n) | | 9 | 1 | - | 10 | |
| Mean cost (SD) | | 643.3 € (±206€) | 306.3 € | - | | |
| Cost per positive diagnosis (true cases) by specialist | | 1333.9 € | | | | 1333.9 € |

Table 6. The cost (€) per positive dementia diagnosis (true cases) in the Primary Healthcare Centre (PHC) diagnosed by General Practitioner (GP) and by specialist.

5.2.4 Comments

This study showed empirically what was actually done during the diagnostic process. Most of the costs came from the time used by the physicians and the DN but to some extent came from different technical diagnostic investigations such as MRI and SPECT. The costs at the specialist level were, as expected, higher than in primary care, as these cases are more complicated and require further investigation, such as lumbar puncture for analyzing biomarkers, such as, tau and beta-amyloid(Aβ). Cost of positive cases was higher than for negative cases, consistent with a targeted approach in which clinicians halted the process when appropriate.

Since the proportion of (what to what) are similar in Kalmar as in the whole of Sweden, extrapolation may be allowed, for example with regard to the number of confirmed dementia cases in Kalmar over the total Kalmar population, one could extrapolate the expected incidence in Sweden [168], In our study, 2 out of 3 cases had a confirmed

diagnosis while in the Kalmar five-year follow up study [168] about 50 % of patients with a suspected dementia had a confirmed diagnosis. Thus, we assume that the 50 % figure is more appropriate for the estimated national cost. We have estimated, therefore, that since there are about 24,000 new cases of confirmed diagnosis of dementia in Sweden annually [14], the number of needed diagnostic procedures (if we assume that the need corresponds to incident cases) would be expected to be double, or approximately 50,000 individuals to investigate.

Furthermore, if we assume that the proportion of referrals to a specialist is similar in all of Sweden as in Kalmar (1/3), our rough estimate would be 15,000 specialist diagnostic procedures per year. This is in line with the results from a Swedish study initiated by the SOS which showed approximately 13,200 cases [131]. Thus, the estimated yearly total cost for dementia diagnoses in Sweden is 13.4 million € ($4400 * 1334€ + 8800 * 849€$), which is similar to earlier estimations of 13.6 million € [131]. This is, however, a low estimation since the cost for dementia diagnoses in primary care for patients that are not referred to a specialist is unknown. Furthermore, if we assume that there is a need for approximately 50,000 diagnostic investigations, the costs under optimal conditions could be three fold, or in any case comparable to the estimated total societal costs of dementia in Sweden calculated at about 4.7-5 billion € [14].

5.2.5 Conclusions

The cost of the diagnostic procedure if this dementia management model is applied to the rest of Sweden is approximately 1 % of the total cost for dementia.

5.3 PAPER III

5.3.1 Hypothesis

- The dementia management program has additional influence on prescription patterns in the elderly population, to a more proper use of psychotropic, including sedatives, dementia drugs and drugs with anticholinergic properties.
- The dementia management program is at least cost neutral regarding the local use of target drugs.

5.3.2 Setting

The paper is based on drug utilization data provided by the Swedish drug delivery company (Apoteksbolaget AB), which at the time for this investigation had a monopoly on the drug market in Sweden.

5.3.3 Results

Results showed that patterns of prescription changed in a manner that appears to be associated with the dementia management programs. Examination of drug use, expressed as DDD per 1000 inhabitants aged 75 years and older (see the methods), showed that prescription patterns of dementia drugs increased more in Kalmar (289%) than nationally (142% in Sweden) between year 2000 to 2000. The proportion of dementia drugs prescribed by GPs increased from 42% to 86%, during which time the dementia management program was being implemented. In 2005 the use of dementia drugs in Kalmar was higher than in Sweden as a whole (204 %), probably due to patients initiated by the GP. However, during this same time prescription pattern of dementia drugs among specialists did not change. Antidepressant drugs on the other hand showed consistent prescription patterns in both local primary care program data as in the national data. Also both local and national data showed reduction in prescription pattern of older antidepressants (-26%), as well as with anticholinergic drugs. However, each of these drug types showed increases during the observation period. Selective serotonin-reuptake inhibitors (SSRI) showed similar elevation in prescription pattern in both local and national data. Prescription pattern of hypnotics was lowered in Kalmar (-22%), as was the use of benzodiazepines (-15%). Analysis of SPDR data showed proportions of users in agreement with the long term follow up analysis 2000 to 2005. In addition, neuroleptics, anxiolytics, sedatives and drugs with anticholinergic properties were used to a lower extent in Kalmar (Table 7). During the first three years after the introduction of the dementia program, we observed a more pronounced decrease in use of neuroleptics in Kalmar (local) compared to Sweden (national). In Sweden, there was a 13% decrease in use of neuroleptics from 2000 to 2005. However, in 2005, the use of neuroleptics by the elderly was 30% lower in Kalmar than in Sweden as a whole.

| | Kalmar (n=5036) | Sweden total (n=732230) | OR (95% CI) |
|--|------------------------|--------------------------------|-------------------------|
| Neuroleptics (N05A) | 148 (2.9%) | 33071 (4.5%) | 0.71 (0.60-0.84) |
| Benzodiazepines (N05B) | 384 (7.6%) | 68644 (9.4%) | 0.90 (0.81-1.01) |
| Sleeping agents (N05C) | 1032 (20.5%) | 167338 (22.9%) | 0.95 (0.88-1.02) |
| SSRI antidepressants (N06AB) | 577 (11.5%) | 82957 (11.3%) | 1.15 (1.05-1.26) |
| Dementia agents (N06D) | 271 (5.4%) | 20481 (2.8%) | 2.14 (1.89-2.43) |
| Drugs with anticholinergic properties | 270 (5.4%) | 42007 (5.7%) | 1.05 (0.92-1.19) |

Table 7. Number and proportion of persons (%) using neuroleptics, benzodiazepines, sleeping agents, SSRIs, dementia agents and drugs with anticholinergic properties among those 75 years and older in Kalmar and Sweden, 2005. The relationship between area, Kalmar community vs. Sweden, and usage is expressed as an odds ratio (OR) adjusted for differences in age and gender distribution. Data from the SPDR.

5.3.4 Comments

The relatively larger increase in prescription patterns of dementia drugs in Kalmar compared to the Swedish national figures may be a direct effect of the dementia program. However, this corresponds to approximately 40% of treatable patients with the indication, suggesting no excessive treatment. Guidelines put forward by SOS suggests that all patients with Alzheimer disease AD be offered dementia drug treatment [9]. In addition, SSRIs are recommended for depression, a condition frequently seen in elderly patients especially in combination with dementia [20]. Therefore, the somewhat higher use of SSRIs in Kalmar may be seen as positive, although this needs to be further explored. Drugs that may cause side effects in the elderly [64] include neuroleptics[68, 169], anxiolytics, sedatives and drugs with anticholinergic properties. In Kalmar, we observed reduced prescription patterns for all of these drugs compared to Sweden as a whole. Notably, the rate of decrease of neuroleptics was most prominent during the three first year of the dementia program and was observed to remain level in the years following.

The cost of dementia drugs in Sweden increased by 32% and the corresponding cost in Kalmar by 50%. Despite this the total cost of the targeted drugs, cost in Kalmar was unchanged while the cost at the same time increased with 26% in Sweden. In addition the dementia program was implemented without any extra resource allocations. Finally, it is notable that the cost for dementia drugs accounts for only 1% of the total cost for dementia care in Sweden [14].

During the dementia program (2000-2005), 1458 cognitively impaired individuals were initially identified in primary care [168]. All of these individuals were evaluated regarding their drug use.

5.3.5 Conclusions

- The prescription pattern for investigated drugs among elderly in Kalmar differs from Sweden as a whole:
 - Increased use of dementia drugs
 - Lower use of sedatives
 - Lower use of drugs with anti-cholinergic properties
 - Decreased use of neuroleptics in elderly after the introduction of the dementia managing program followed by a stabilization at a lower level.

5.4 PAPER IV

5.4.1 Hypothesis

- Implementation of dementia management programs does not increase cost burden of managing dementia for the municipality.
- The dementia management program is at least cost neutral when applied in both county council and municipality.

5.4.2 Setting

The paper is based on data provided by the municipalities of Kalmar and Älvsjö, as well as epidemiological and cost data from the whole of Sweden.

5.4.3 Results

5.4.3.1 Population

Local data was obtained from Kalmar and Älvsjö, and national data from Sweden. Demography is the proportionally in terms of age-groups, Kalmar is similar to Sweden as a whole, whereas Älvsjö has a younger population. Further has Älvsjö a larger proportion of individuals with higher education, followed by Kalmar, but both have a population that is somewhat better educated than in Sweden on average. Regarding income: has Älvsjö the highest level of income followed by Sweden and Kalmar. The standard number of long term care beds in Kalmar was lower in Kalmar Sweden as a whole.

5.4.3.2 Municipal dementia data for Kalmar

During the period January 2002 to June 2004, 576 patients with dementia were recorded. Most of these patients had received support in various ways, such as occasional hours of help at home, regular home help, day care centre 1-5 days per week, temporary or permanent resident in a nursing home. Based on epidemiological figures the estimated number of deaths amongst those with dementia was 150/year. Thus the records indicate that approximately ten percent of these individuals were living at home with home healthcare, care at a day centre or intermittent nursing home care at the time of death. Fifty percent died as nursing home residents and 40 % died without using any municipal resources.

5.4.3.3 Municipality data for Älvsjö

One hundred and eighty-nine patients with dementia were defined from January 2002 to December 2005. From the start of the study, the data were rather sparse but as a result of the study the authorities became more and more aware of the benefit of

reliable data and thus our data also became more and more robust. The estimated number of deaths amongst people with dementia in Älvsjö was 50 per year. Thus, at the time of death, ten percent were estimated to have home care, day centre care or temporary care in a nursing home whilst 59% were estimated to die as permanent nursing home residents. Finally, 31% died without using any municipality resources.

5.4.3.4 Cost

Municipal records obtained for the study period showed that the proportion of patients with a dementia diagnosis who also utilized resources was 61% (n=576 of estimated 949) in Kalmar and 63% (n=187 of estimated 298) in Älvsjö (Table 3). Assuming that all other demented persons not included in the cost model are not users of care, the yearly municipal cost-per-patient (based on the estimated total number of persons with dementia) in Kalmar was 14,206 € (in year 2003), which compares with 10,610 to 13,184 € in Älvsjö (in years 2003-2005). Using national figures for comparison the corresponding cost was 23,600 and 29,871€ in 2000 and 2005, respectively. However, based on the actual number of persons that are included in the cost model, the cost per person with dementia person in Kalmar 2003 was 26,334 €, 26,025 to 30,464 in Älvsjö and 27,594 and 36,459 in Sweden (Table 8).

| | Kalmar | | Älvsjö | | Älvsjö | | Älvsjö | | Sweden | | Sweden | |
|---|--------------------------------|-----------|--------------------------------|-----------|--------------------------------|-----------|-------------------------------|-----------|-----------------|-----------|-----------------|-----------|
| Year | 2003 | | 2003 | | 2004 | | 2005 | | 2000 | | 2005 | |
| Municipality costs (number) | € | % | € | % | € | % | € | % | €*1000 | % | €*1000 | % |
| Elderly care cost € | | | | | | | | | | | | |
| Home care | 13363238 | 40 | 4821846 | 40 | 5372023 | 43 | 5867157 | 43 | 1850070 | 27 | 1963714 | 27 |
| Day care | 879903 | 3 | 265777 | 2 | 303761 | 2 | 294384 | 2 | 121490 | 2 | 128952 | 2 |
| NH and Respite care | 19352667 | 58 | 6945782 | 58 | 6945782 | 55 | 7586729 | 55 | 4878488 | 71 | 5178095 | 71 |
| SUM | 33595808 | 100 | 12033405 | 100 | 12621566 | 100 | 13748270 | 100 | 6850048 | 100 | 7270762 | 100 |
| Dementia cost € | | | | | | | | | | | | |
| Home care | 2598858 | 19 | 156902 | 5 | 157149 | 5 | 341563 | 9 | 536000 | 17 | 860400 | 20 |
| Day care centres | 490573 | 3,6 | 44276 | 1,4 | 118555 | 3 | 150935 | 4 | 39000 | 1 | 41900 | 1 |
| Respite care | 645790 | 5 | 111282 | 4 | 67320 | 2 | 85759 | 2 | 943200 | 30 | 860900 | 20 |
| Permanent NH | 9746718 | 72 | 2849389 | 90 | 3071413 | 90 | 3350482 | 85 | 1620600 | 52 | 2484500 | 58 |
| SUM | 13481939 | 100 | 3161849 | 100 | 3414437 | 100 | 3928739 | 100 | 3138800 | 100 | 4247700 | 100 |
| Estimated number with dementia | 949 | | 298 | | 298 | | 298 | | 133000 | | 142200 | |
| Cost per patient vs. estimated | 14 206 € | | 10 610 € | | 11 458 € | | 13 184 € | | 23 600 € | | 29 871 € | |
| Dementia cost % | | 40 | | 26 | | 27 | | 29 | | 46 | | 58 |
| Number of patients in the model | 415 | | 76 | | 119 | | 127 | | 113750 | | 121105 | |
| Cost per patient in the model (SD) | 26 334 € (±15 955 €) | | 29 040 € (±18 845 €) | | 26 025 € (±18 956 €) | | 30 464€ (±18 585 €) | | 27 594 € | | 35 075 € | |

Table 8. Municipality costs in elderly related to dementia in 2003 in Kalmar, Älvsjö and the whole of Sweden. The cost from Kalmar and Älvsjö is derived from the municipality records. The elderly and dementia cost from Sweden 2005 and 2000 (calculated) is from two reports from publication by the National Board Of Health and Welfare [14, 170].

5.4.4 Comments

The municipalities in Sweden spent 3-4 billion € annually on dementia care during the years from 2000-2005 [14]. On the other hand, if the total cost figures (for example in Kalmar 13.5 million € in 2003, based on 415 persons) are assumed to represent all costs of the total dementia populations in the study areas (in Kalmar 949 persons), it is implicitly assumed that those not included (949-415 persons) are non users of care. This “hidden” subpopulation in the municipality records may include true non users, but also individuals with diagnoses receiving care from the dementia nurse and caregiver. Moreover, those not diagnosed with dementia (most of them probably with mild dementia) or those incorrectly- classified may utilize some resources, resulting in an underestimate of costs. Thus the cost figures per demented individual in Kalmar are 14,206 € (extrapolated to assumed whole dementia population) to 26,334€ (based on known study population) can be regarded as a min-max interval. Compared to the corresponding Swedish cost estimate for municipal care (29,871€ – 36,459€) the figures indicate, nevertheless, lower costs in Kalmar. This interpretation is supported by the lower standardized figure of long term care in Kalmar (53 beds per 1000 65+) as opposed to Sweden (71 beds per 1000 65+), since long term care is the major cost driver of formal care.

If we assume that the program in Kalmar reduces costs or at least is cost neutral, one may regard the program as successful. First, most patients were identified early in the disease which facilitated early intervention and supported care planning, caregiver support and training, drug review and symptomatic drug treatment. Secondly, the dementia nurse becomes a mentor along the whole course of the disease. The support the caregiver receives from the dementia nurse in ordinary, daily activities is the most valuable contribution. Thirdly, the social welfare officers become involved in the patient and caregivers’ situation early in the disease, facilitating support when home care or nursing home placement is required. Fourthly, caregivers can better cope with their situation when they know that support is available. Finally, if a problem arises the program provides easy accessibility, either to the dementia nurse or the physician. All of these benefits may positively influence the cost of care, but they also signify an improvement in the quality of care as a result of the program. In addition, less use of neuroleptics in the elderly and higher use of dementia drugs with a cost consequence approach, the program may be regarded as cost effective.

5.4.5 Conclusions

- The dementia management program was not associated with increased the cost of dementia for the municipality. Further, the cost of dementia per patient for Kalmar municipality suggest to be similar level per patient, but total cost at a lower level than the rest of Sweden.

6 DISCUSSION

6.1 SUMMARY OF MAIN FINDINGS

- The dementia management program in Kalmar identified and registered the expected number of new patients per year (incidence).
- The dementia management program was implemented without increasing cost
- Based on the actual cost of diagnosing dementia in the Kalmar and using this cost figure to estimate national cost, we project from this data that diagnosing dementia is but 1% of the total cost of dementia care in Sweden.
- The prescription pattern among elderly in Kalmar differs from the rest of Sweden:
 - Higher use of dementia drugs
 - Lower use of sedatives
 - Lower use of drugs with anticholinergic properties
 - Decreased use of neuroleptics
- The cost of dementia for the municipality did not increase during implementation of the dementia management program.
- The cost-of-dementia per patient with dementia for Kalmar municipality was lower than national cost-of-dementia in Sweden.

6.2 DISCUSSION OF THE MAIN FINDINGS

The main finding suggests that the dementia program in Kalmar is effective in identifying and diagnosing new patients. Patients and caregivers are hereafter followed during the course of the disease with collaboration with primary care and the municipality. The cost has not increased due to the program despite there being more patients with identified needs. Furthermore the findings suggest that the general drug treatment to elderly regarding psychotropic drugs is more optimal to the elderly issues compared to the whole of Sweden. Moreover, earlier presented findings related to elderly visiting emergency department in Kalmar suggest a decrease with 15% visits, during the introduction of the dementia program [171]. In view of using a triangulation model (se method) [160-162] analyzing these findings all together, it can be argued that the dementia management program in Kalmar works as intended. Moreover suggesting associated additional effects as long during the introduction of the DMP. Both in drug utilization in elderly and a lower frequency of acute incidences in elderly. Thus was this possible within available budget recourses, further suggesting to more optimal recourse

allocation than the rest of the country. Additional assessments are conducted during the period that the patient is being followed, including obtaining information regarding caregiver attitudes and needs. The education program was identified as the primary positive component by the caregiver (Gustavsson E. personal communication). Similar findings were supported from Ontario Dementia Care Networks [172]. Secondly, analyses have been performed identifying why some healthcare programs (chains of care) were successful and others were not [173]. Three major determinants of integrated health care development were identified: professional dedication, legitimacy and confidence [173]. The Kalmar dementia program was defined in the successful range.

Koch et. al. defined three main factors that enhance the capability for primary care to identify, diagnose, treat and follow up patients with dementia [174], including: First are skills together with education, secondly is financial and economical, and final is organization and multi disciplinary approach. In scope of this is the Kalmar dementia program involved in at least organization and skills. Thus the economical part is included not as an incentive, but as suggesting to be better resource utilization.

This study identified in the Kalmar dementia program some significant attributes. Collaboration was demonstrated both horizontally and vertically. Callahan et. al. suggested that collaboration in a primary care setting has been suggested to be beneficial improving the quality of care, lowering BPSD without increasing neuroleptics and sedatives [95]. Collaboration has been described at different levels, such as in the local organization, in and between organizations, and between stakeholders. Such collaboration can help overcome challenges faced within different organisations, such as the county councils and municipalities. Organizations having such programs in place remain intact with one budget, maintain local resources and existing framework, and thus present no conflict with other agency resources. Such programs benefit from having been set up locally and shareholders have been involved in planning and development the process promoting factors for success. Finally the program has been approved by the different operators in the system, such as local politicians, regional stakeholders, etc. [173] and therefore supported by them.

6.3 METHODOLOGICAL ISSUES, LIMITATIONS AND GENERALIZABILITY

This thesis reports on the evaluation of the Kalmar dementia management program. A major focus in this study was on primary care. Evaluating the full scope of the program was problematic due to the disease complexity and the sheer number of professionals and organizations involved. We selected a quasi-experimental cost-of-illness method and used national figures for comparison. However this method has some limitations. We did not compare Kalmar with any other community. Although a direct comparison might have been useful, finding another community for exact comparison is unreasonable. First, doing so would have outstripped the capacity of this study to address ethical and strategic issues regarding how patients with dementia are treated. Second, it is nearly impossible not to interfere with ongoing measurement in a controlled area without interfering.

A limitation of the studies represented in this thesis is the absence of QOL evaluative information from the perspective of patients and caregivers. Also, “indirect costs and other additional costs” are not defined and incorporated in the overall study.

Information regarding validation of diagnoses of dementia does not describe what effort was made to compare against a “gold standard.”. However, the validation of clinical diagnoses was considered outside the scope of this thesis. Neither was there investigation of possible impacts on other departments at the hospital beside some minor analyses in emergency department. In order to compare the findings we have not used a controlled area similar to Kalmar. Instead we used the total of Sweden as comparison (Paper I-IV) and Älvsjö as comparison area in (paper IV).

6.3.1 Population

Distribution of age in the Kalmar sample was not obviously dissimilar from national figures in Sweden, and thus, this did not dissuade our using these for comparison in papers I, III and IV and paper II in the calculation of the total cost of dementia investigations in Sweden as a whole. Some minor differences in gender, income distribution and educational levels can almost be ignored in this respect. Furthermore, the proportionality in the population suggests generalizability to population’s comparisons to the rest of Sweden.

6.3.2 Organization

The analyzed dementia program fulfils most of the criteria to be a disease management program. First, there is coordination of the healthcare between different stakeholders. Secondly, there is a clear definition and responsibility of who is doing what in this collaboration. Thirdly, there is a part (run by the DN) taking care of education and support to the patient and caregiver, supporting better self-care efforts. Fourth, there is an

intention to be as cost neutral as possible, in spite of that no regular total cost evaluation where done. Finally the continually caring of patients with dementia might serve as a model for a “chain of care”. This concept is suitable in a logistic framework in order to illustrate the need of a cross functional operational management working in a Lean Production environment such as in the dementia management program in Kalmar.

The Kalmar program was chosen for this study because it offered unique advantages, such as having local support to build it from the earliest planning stage. Further the dementia program in Kalmar is specific for that region. The program is built up from the ground locally. Further, the program is based on already established organizations, mainly primary care, specialist in geriatric and the elderly organization within the municipality which is standard all around Sweden. Moreover the program works within the general laws and recommendations from the authorities in Sweden. In this respect the tradition of local government within the Nordic countries [133] might be of help to new programs.

Another problematic limitation with this study is that local traditions and regulations regarding the support of the demented patients provided by the municipalities changed during the study, and could affect the results? Further, if new regulation and laws were implemented during the investigation period further focusing on the care of the demented? In order to address this question we analyzed locally significant confounders such as changes of organization, new standards etc. that might interfere during the period from 2000 to 2005. However, no such major local confounders were identified.

6.3.3 Establishing of the diagnose

We found 153 cases per year during the observation period, which was almost the number expected [4]. This concordance might, however, be a coincidence. We did not account for potentially missed diagnosis by the GP. Additionally, diagnoses may simply be inaccurate. There was no “gold standard.” Also, some cases may have come to be diagnosed later, and effectively missed in incidence figures for a given year. However, the rather high (within the mild dementia range) MMSE scores support the hypothesis that mostly new cases are diagnosed. Fourth, at the beginning of the program, prevalence estimates indicated that approximately 400 cases were not yet identified prior to introduction of the program. During the study period 755 new patients were diagnosed. Thus, the doubling of known cases from 1997 (31%) to 2005 (63%) suggests diagnostic improvement. The pertinent question could be raised why not 100% of all patients are identified? Hypothetical some milder cases has not yet been identified. Further with multiple diseases with cognitive problem where the other diseases is more in focus. Furthermore patients who not want to know what caregivers still supporting the needs. Finally, we have used the same geographical area as its own comparison. A control area could be an option, but such an approach is also problematic. However as the program continues all patients will soon or later be incorporated in the program.

The patients in our sample were a little older than in samples from some earlier publications [175, 176]. It might be argued that the patients were somewhat older than those newly diagnosed dementia patients generally presented in studies performed at specialist clinics. On the other hand that the average age is only three years older in the primary care population than that found in this area in a previous study [168]. We believe that the reason for the younger population at specialist clinics is due to preselection, where there is a tendency of seeing more patients who are still working age since such would be the case with patients having early onset of AD [175]. The patients diagnosed with dementia (positive cases) do not necessarily represent the “true cases”. The diagnosis is a result of a diagnostic process performed by the clinician after an individual evaluation. Furthermore, it is not possible to say that an investigation on the primary care level is “better” or “more cost effective” than on a specialist level. In order to analyze the cost effectiveness of a dementia diagnostic process, another study design is needed. Another problem is that ideally, the diagnostic investigation should be initiated early in new cases (incident cases) but is often delayed due to the complex and vague early symptoms.

6.3.4 **Drugs utilization in elderly**

A pertinent question is whether the dementia program had an influence on prescription practices, and if so, in what way? Clearly, one part of the program focuses on optimizing pharmacological treatment, even if this is not the main goal in the dementia investigation and the diagnose process. In addition we have seen interest among general practitioners for understanding the aging brain and its vulnerability for drugs. Thus, it is reasonable to assume that this may have had a positive influence on the drug use in the elderly in Kalmar. However, to our knowledge, up until now there are no dementia or elderly management programs in the literature that also suggest changes in prescribing for long term [71].

As a result of the dementia program (2000-2005) 1294 cognitively-impaired patients were identified in primary care [75] (corresponding to over 10% of 65 year and near 15% of 75 year olds in the municipality). All of these patients were evaluated regarding their drug use. The demographic characteristics of the elderly population in the Kalmar municipality are comparable to that of Sweden. Thus, suggest generalizability of the finding in this thesis to the rest of the country.

6.3.5 **Economical issues and resource utilization**

This thesis was not designed to analyze cost-effectiveness, since no comparison group was included from the beginning. Thus no statement of cost-effectiveness can be made. From a pragmatic cost-consequence viewpoint, there are indications that the program improves the quality of dementia diagnoses (the outcome) without increasing the costs.

6.3.5.1 *Primary care*

There are some drawbacks with this study that should be further investigated. Since this project partly focuses on the diagnostic procedure, the proportion of patients undergoing an investigation in primary care is probably higher in Kalmar than in other parts of Sweden. It is therefore difficult to apply the cost to the rest of Sweden, as dementia programs are not yet implemented in many areas. The unit costs may also vary in different parts of Sweden depending upon available resources (specialists, neuropsychologists etc). The sample in Study 2 was rather small, which makes it difficult to draw general conclusions. We have identified differences in costs between primary and specialist care with a specific distribution of costs in each group. It would therefore, however, be interesting to expand the project to other areas for a greater sample size. There are some limitations in this study regarding generalization of the cost for dementia investigation in Kalmar compared to the rest of Sweden. Recently presentation shows a higher cost for dementia investigating in a specialist setting from the SveDem database [177]. Most driven by investigations at the specialist level such a neuropsychological tests, lumbar puncture and brain images. From an international perspective, and to the best of our knowledge, there are no earlier publications that describe the cost of a dementia investigation. There is, however, a presentation of calculated international costs of diagnostic procedures [132]. This analysis shows a high variability of procedures used, and thus different costs, in the dementia diagnostic process between countries. No increase of budget was allocated for introducing the dementia disease management program in Kalmar, and no extra cost can be identified retrospectively. Thus the implementation was done within already existing resources. We could not argue that this was the optimal use of allocated resources. On the other hand we know that patients with dementia in early stages used primary care resources to a higher extent [136, 144] Further we did not identify an increase use of the resources in the primary care in our studies in this thesis. Thus the economical part is included not as an incentive, but as suggesting to be better resource utilization.

6.3.5.2 *Municipality*

The municipal costs were studied in a “bottom up” model (the real cost for dementia in the municipality). The comparison to the rest of Sweden is therefore somewhat problematic as these costs were not analyzed in a similar way. In spite of this it is positive to see that the cost appear similar. This suggests that a careful comparison is possible and therefore supports the idea that the cost for dementia in Kalmar with the

DMP is not higher than the cost in the rest of Sweden. If a difference may be seen it is a lower cost in Kalmar than the rest of the country, suggesting better resource utilization. Finally it is uncertain if all patients with dementia using municipal resources are identified in this “bottom up” model, as compared to the estimated cost for the whole of Sweden. For Kalmar there are probably patients missing due to the long period of the running of the dementia program. In addition, if there are missing patients they are using resources probably due to other reasons than dementia. Otherwise, dementia would be a main problem they would probably be included in the dementia program. Further studies should have a more prospective approach when including a control area even though this also will create problems due to difficulties of identification and diagnosis which may contaminate the control area. The conclusion is that even with its limitations we find that the implementation of the dementia program are suggesting a lower cost for dementia in the municipality. The decreasing of the costs for the municipality will spill over with a higher cost in the primary care system may be a crucial risk. However, the dementia program was implemented within an unchanged budget via reallocation of the resources.

6.3.6 **Generalizability overall**

In summary we find it possible to generalize the effects of the dementia management program of dementia in Kalmar to at least to the rest of Sweden. Moreover, suggesting the results in this thesis a carefully generalizability of the findings in this thesis to the Nordic countries [133] in general with local adaptation due to regional differences and traditions.

7 CONCLUSIONS AND FURTHER PERSPECTIVES

7.1 CONCLUSIONS

All suggested hypotheses in this project were confirmed or pending to be confirmed:

- The dementia management program is reliable to defined most of the new patients per year. (Paper I)
 - Confirmed
- What is the (mean) cost of a complete assessment for dementia at the level of (specialist or PCU), and how does this compare with the total cost of dementia assessment, treatment, and care during the full course of disease? (Paper II)
 - Confirmed
- The dementia management program has additional influence on prescription patterns in the elderly population, to a more proper use of psychotropic, including sedatives, dementia drugs and drugs with anticholinergic properties. (Paper III)
 - Confirmed
- Implementation of dementia management programs does not increase cost burden of managing dementia for the municipality. (Paper IV)
 - Confirmed
- The dementia management program is at least cost neutral when applied in both county council and municipality. (Paper I, III and IV)
 - Pending to be confirmed

7.2 FUTURE PERSPECTIVES

To confirm the results from this thesis a setting with controlled data and analyses of the cost and the consequences should a controlled setting be appropriate to use. After the presentation of the new Swedish dementia guidelines in 2010 [32] would this be complicated to perform in Sweden.

In this study we excluded QOL both from a patient and a caregiver perspective. In a broader perspective, analyzing a dementia program could utilize QOL data. Further to investigate is, if and how the QOL for the patients and the caregivers is changing during the years as long as the disease progress.

Moreover the quality of the diagnose in a primary care setting and specialist is of interest to analyze. In respect to has it is performed in a dementia program such as this.

Cognitive deficits are an important area for further evaluation by a range of healthcare providers, such as in the emergency department, medicine, as well as care provided by surgical, orthopaedic, and psychiatric units.

The economical aspect of dementia is of further interest for in view of the anticipated increase in the incidence in coming years. Thus if we aim to maintain a high quality level, or improve the dementia care in the future we have to have better knowledge of the economical perspective in dementia. The different economical steering instruments are of interest to investigate in order to fulfill the intentions of dementia care. The program in Kalmar started without economical steering. But if similar program follows the intentions of the new Swedish guidelines shall be implemented in general, the effects of economical steering instrument is of interests to investigate. Instruments such as knowledge, economical and process steering, together with a similar program. Further, if or what type steering activity will have the most preferable influence. Example of this can be changing the economical input to the GP to be a “Gate Opener” rather than a “Gate Keeper” when a patient with early cognitive problems is presented.

Regulations, laws and governmental steering are ongoing processes. The tradition in the Nordic countries is a decentralized process. The regional differences in treatment of AD can be associated to that patients with cognitive problems have difficulties to be visualized. Thus, when patients and caregivers’ voice is not enough there is a risk that those persons are marginalized within the system while all the resources are used elsewhere. Perhaps a more centralized process is to be advocated in order to protect the equity geographically, social and economical, between genders and between diagnostic groups. How to address this in the best way has to be further analyzed.

Finally, with visualization, identification, diagnosing and targeted treatment in a structural dementia management program, we suggest a better care of patient with dementia in an early phase and as the disease progress. All this is taking place together and suggests more optimal resource utilization for the benefit of the patients and their caregivers. With future treatment may offer possibilities to modify disease and new techniques and innovations will rephrase the questions that shall be offered this, what parameter shall be prioritized to this treatment and who shall diagnose and initiate this treatment. Thus have we already today start to prepare for these issues.

8 EPILOGUE

During the work with this thesis about the Kalmar dementia program, the question of visibility of the dementia disease has often been discussed. The question of what will happen with this project is also being asked. Will it survive in the new era of the right to choose the provider “vårdvalet” (addressing the cognitive problem for the patients to choose the best for themselves), new organization, new treatments, new regulations and when devoted people how will leave the “ship”. Certainly economical steering [174] can have an effect to the future. If we introduce a system supporting the process in a disease instead of rather than just a simple cost model like to be “paid per appointment”.

Operations Management in charge of the implementation of the new guidelines could be a framework to solve resistance to implementation and stimulates horizontal and more functional driven activities. Moreover the lane-production organization is a method considers helping improve the process that focus on patients and caregivers (customers). Its attributes could be a solution who is coping with the need of patients with chronic disease and who are particularly vulnerable due to cognitive impairment.

Regarding the Nordic and Swedish tradition of local governance it can be argued that if this would not be the case none of this would have happened. Further in the future with new possibilities to treat dementia and Alzheimer’s disease in particular, the need for a functional organization targeting the diagnose process will be of most interest for the patients and the society as a whole, all in a frame of reasonable and justified costs.

9 ACKNOWLEDGEMENTS

First, I would like to thank all **patients** and **caregivers** within Kalmar and Älvsjö communities.

Niels Andreasen my supervisor, always positive, supporting, enthusiastic, challenging, encouraging, available, listening etc., in other world a perfect supervisor! But most of all a good friend for many years.

Co-supervisors; first **Bengt Winblad**, the main conductor in dementia, in all categories totally outstanding.

Secondly, **Anders Wimo**, hard working, always supportive and positive but also keeping the reins tightly.

Finally, **Johan Fastbom**, thanks for excellent guidance in the elderly brain sensitivity all along this journey.

Jan Strömqvist, as co-author as well as a friend along from the start of this project, without whom this project would never have been possible in this context. Thank you for all the help and positive support along all the years.

Kristina Johnell, Linus Jönsson and Ulrika Winblad, as co-authors and for great support in the manuscripts but also in the final stages of the Thesis.

The staff of the primary care units in Kalmar, specialist unit and the Municipality of Kalmar, a special thank to **Anneli Adolfsson, Marianne Jakobsson, Helen Holmström, Ann-Christin Arvidsson, Katarina Jervelind, Janet Mosén, Monica Svanäs, Philip Johansson, Maud Löfström, Margareta Johansson, Thomas Johansson, Anders Haglund, Arne Sjöberg** and last but not least **Gunvor Adolfsson**. Älvsjö municipality; **Anette Ekegren, Johan Stavrot and Anders Håkansson**. Haninge municipality; **Elisabeth Hane**

Special support and guidance by, **Kurt Svärdsudd, Mona Khilgren, Stellan Båtsman, Miia Kivipelto, Agneta Nordberg, Marie Eriksdotter-Jönhagen, Helle Wijk, Anna-Karin Edberg, Fredrik Tjulander, Matti Viitanen, Lennart Minthon, Elisabeth Londos, Kaj Blennow, PO Sandman, Barbro Beck Friis, Yvonne Freund-Levi, Karin Lindgren, Ulla-Britt Hjelmblink, Eva Holmgaard and Gunilla Johansson**.

Thanks for all support from all **Student colleges in the NVS-department**, all members in the **Swedish Dementia Network** arranging the yearly “Swedish Dementia Days” and the small but increasingly **Swedish Network for Dementia Managing Operators**.

Roberta Boson, Paul Passant, Mary Njurfor and Kevin Grimes for linguistic support and guidance.

Carina Wattmo, Per-Åke Aronsson, Fredrik Hjärthag and Gunnar Edman for statistical support and advice. **Kristian Aranas** at the Apoteket AB for drug sales figures. **Krister Westerlund** at the Swedish Alzheimer association and **Stina-Klara Hjulström** at the Dementia Association in Sweden.

Thanks to **Christina Sjödin, Anki TysénBäckström, Mari Lärksäter Ulrika Akine and Ulla Maache** for all the support and good advice.

All colleges at Janssen for all the support and understanding, especially to **Bo “Bosse” Eriksson** who passed away from us so suddenly, who confirmed his believed in this project with his extraordinary support and positivism.

A warm thanks to the **Swedish Alzheimer foundation, The foundation for the memory of Ragnhild and Einar Lundström**, the **Swedish brain power** program, **Kalmar county council** and finally but not least **Janssen** for the support during all the years and especially for all time to finalizing and processing of the thesis.

Thanks to all my all supporting and fantastic friends, no one mentioned but everyone in my mind, together with my family members especially my mother **Erika** and father who passed away from us suddenly. Many years ago **Gunnar** (the first one who thought this was possible for me to achieved). Further my two brothers **Olof** and **Fredrik** with their families. Further also **Bengt, Gunilla, Christine** and **Max**. All of whom I've had in my mind during my journey with this thesis.

To **SJ** (Statens Järnvägar) for all the time to study and write all along the railways of Sweden.

To my closest family, Catharina, Anna, Arthur and Oscar for the understanding and patients with my introvert and special behavior, especially in the final stages of finalizing this thesis. Helping me along, sometimes simply by asking me nicely or with pushy questions as “should you not doing your writing now !?”.

10 REFERENCES

1. WHO. *Executive summary, mental and neurological disorders* 1997 [cited; Available from: http://www.who.int/whr/1997/media_centre/executive_summary1/en/index14.html].
2. Wimo, A., B. Winblad, and L. Jonsson, *The worldwide societal costs of dementia: Estimates for 2009*. *Alzheimers Dement*. **6**(2): p. 98-103.
3. Ferri, C.P., et al., *Global prevalence of dementia: a Delphi consensus study*. *Lancet*, 2005. **366**(9503): p. 2112-7.
4. Andreasen, N., et al., *Prevalence and incidence of clinically diagnosed memory impairments in a geographically defined general population in Sweden. The Pitea Dementia Project*. *Neuroepidemiology*, 1999. **18**(3): p. 144-55.
5. Fratiglioni, L., et al., *Prevalence of Alzheimer's disease and other dementias in an elderly urban population: relationship with age, sex, and education*. *Neurology*, 1991. **41**(12): p. 1886-92.
6. Arvidson, B., et al., *Farmakologisk behandling av kognitiv störning vid Alzheimers sjukdom*. 2002, Medical Produkts Agency. p. 1-14.
7. Wallström, M., *Proposition 1996/97:60 Prioriteringar inom hälso- och sjukvård*, T.S. Parlament, Editor. 1997, The Swedish Parliament.
8. SBU, *Dementia diseases*, A. Norlund, Editor. 2008, SBU-The Swedish Council on Technology Assessment in Health Care: Stockholm.
9. SOS, T.N.B.o.H.a.W., *Nationella riktlinjer för vård och omsorg vid demenssjukdom*. 2010.
10. Doody, R.S., et al., *Practice parameter: management of dementia (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology*. *Neurology*, 2001. **56**(9): p. 1154-66.
11. Dening, T., *Prescribing policy with dementia drugs: the UK NICE experience*. *Maturitas*, 2009. **64**(2): p. 59-60.
12. Hunt, N., *New strategy for improving dementia care in the UK*. *Br J Nurs*, 2009. **18**(5): p. 276.
13. Wimo, A., L. Jönsson, and L. Johansson, *Äldreuppsdraget*, T.N.B.o.H.a. Welfare, Editor. 2000, The National Board of Health and Welfare.
14. Wimo, A., L. Jonsson, and L. Johansson, *Demenssjukdomarnas samhällskostnader och antalet dementa i Sverige 2005*, M.-L. Sjogren, Editor. 2007, The National Board of Health and Welfare: Stockholm. p. 1-47.
15. Grossberg, G.T., *The ABC of Alzheimer's disease: behavioral symptoms and their treatment*. *Int Psychogeriatr*, 2002. **14 Suppl 1**: p. 27-49.
16. Jost, B.C. and G.T. Grossberg, *The natural history of Alzheimer's disease: a brain bank study*. *J Am Geriatr Soc*, 1995. **43**(11): p. 1248-55.
17. Visser, P.J., et al., *Distinction between preclinical Alzheimer's disease and depression*. *J Am Geriatr Soc*, 2000. **48**(5): p. 479-84.
18. Carpenter, G.I., et al., *RUG-III and resource allocation: comparing the relationship of direct care time with patient characteristics in five countries*. *Age Ageing*, 1997. **26 Suppl 2**: p. 61-5.
19. Beerli, M.S., et al., *The cost of behavioral and psychological symptoms of dementia (BPSD) in community dwelling Alzheimer's disease patients*. *Int J Geriatr Psychiatry*, 2002. **17**(5): p. 403-8.
20. Jost, B.C. and G.T. Grossberg, *The evolution of psychiatric symptoms in Alzheimer's disease: a natural history study*. *J Am Geriatr Soc*, 1996. **44**(9): p. 1078-81.
21. MPA. 2008.
22. Jellinger, K.A., *Influence of Alzheimer pathology on clinical diagnostic accuracy in dementia with Lewy bodies*. *Neurology*, 2004. **62**(1): p. 160; author reply 160.

23. Jellinger, K.A., *Morphologic diagnosis of "vascular dementia" - a critical update*. J Neurol Sci, 2008. **270**(1-2): p. 1-12.
24. WHO, *WHO international classifications, ICD 10*. 2008, WHO.
25. McKhann, G., et al., *Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease*. Neurology, 1984. **34**(7): p. 939-44.
26. Dubois, B., et al., *Research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS-ADRDA criteria*. Lancet Neurol, 2007. **6**(8): p. 734-46.
27. Blennow, K., et al., *Cerebrospinal fluid and plasma biomarkers in Alzheimer disease*. Nat Rev Neurol. **6**(3): p. 131-44.
28. Andreasen, N. and K. Blennow, *CSF biomarkers for mild cognitive impairment and early Alzheimer's disease*. Clin Neurol Neurosurg, 2005. **107**(3): p. 165-73.
29. Folstein, M., et al., *The meaning of cognitive impairment in the elderly*. J Am Geriatr Soc, 1985. **33**(4): p. 228-235.
30. Olafsdottir, M. and J. Marcusson, *Diagnosis of dementia at the primary care level*. Acta Neurol Scand Suppl, 1996. **165**: p. 58-62.
31. Cahill, S., et al., *Dementia in primary care: the first survey of Irish general practitioners*. Int J Geriatr Psychiatry, 2006. **21**(4): p. 319-24.
32. Socialstyrelsen. *Nationella riktlinjer för vård och omsorg vid demenssjukdom (prel vers)*. 2010 [cited 2010; Available from: <http://www.socialstyrelsen.se/riktlinjer/nationellariktlinjer/demens>].
33. Chung, J.C., et al., *Snoezelen for dementia*. Cochrane Database Syst Rev, 2002(4): p. CD003152.
34. Hope, K.W., *The effects of multisensory environments on older people with dementia*. J Psychiatr Ment Health Nurs, 1998. **5**(5): p. 377-85.
35. Luijpen, M.W., et al., *Non-pharmacological interventions in cognitively impaired and demented patients--a comparison with cholinesterase inhibitors*. Rev Neurosci, 2003. **14**(4): p. 343-68.
36. Andren, S. and S. Elmstahl, *Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five-year follow-up study*. Int Psychogeriatr, 2008: p. 1-16.
37. Brodaty, H. and A. Cumming, *Dementia services in Australia*. Int J Geriatr Psychiatry. **25**(9): p. 887-995.
38. Giacobini, E., *Cholinesterase inhibitors stabilize Alzheimer's disease*. Ann N Y Acad Sci, 2000. **920**: p. 321-7.
39. Nordberg, A. and A.L. Svensson, *Cholinesterase inhibitors in the treatment of Alzheimer's disease: a comparison of tolerability and pharmacology*. Drug Saf, 1998. **19**(6): p. 465-80.
40. Raskind, M.A., et al., *Galantamine in AD: A 6-month randomized, placebo-controlled trial with a 6-month extension. The Galantamine USA-1 Study Group*. Neurology, 2000. **54**(12): p. 2261-8.
41. Winblad, B., et al., *Donepezil treatment in severe Alzheimer's disease: a pooled analysis of three clinical trials*. Curr Med Res Opin, 2009. **25**(11): p. 2577-87.
42. Winblad, B., et al., *Memantine in moderate to severe Alzheimer's disease: a meta-analysis of randomised clinical trials*. Dement Geriatr Cogn Disord, 2007. **24**(1): p. 20-7.
43. Giacobini, E. and R.E. Becker, *One hundred years after the discovery of Alzheimer's disease. A turning point for therapy?* J Alzheimers Dis, 2007. **12**(1): p. 37-52.
44. Wimo, A., B. Winblad, and L. Jonsson, *An estimate of the total worldwide societal costs of dementia in 2005*. Alzheimers Dement, 2007. **3**(2): p. 81-91.
45. Garfield, F.B., et al., *Assessment of Health Economics in Alzheimer's Disease (AHEAD): treatment with galantamine in Sweden*. Pharmacoeconomics, 2002. **20**(9): p. 629-37.
46. Holmes, C., *AD2000: design and conclusions*. The lancet, 2004. **364**(9441): p. 1213-4.

47. Fillit, H. and J. Hill, *The economic benefits of acetylcholinesterase inhibitors for patients with Alzheimer disease and associated dementias*. Alzheimer Dis Assoc Disord, 2004. **18 Suppl 1**: p. S24-9.
48. Haider, S.I., et al., *Trends in polypharmacy and potential drug-drug interactions across educational groups in elderly patients in Sweden for the period 1992 - 2002*. Int J Clin Pharmacol Ther, 2007. **45**(12): p. 643-53.
49. Haider, S.I., et al., *The influence of educational level on polypharmacy and inappropriate drug use: a register-based study of more than 600,000 older people*. J Am Geriatr Soc, 2009. **57**(1): p. 62-9.
50. Johnell, K. and J. Fastbom, *Concomitant use of gastroprotective drugs among elderly NSAID/COX-2 selective inhibitor users: a nationwide register-based study*. Clin Drug Investig, 2008. **28**(11): p. 687-95.
51. Johnell, K. and J. Fastbom, *Concurrent use of anticholinergic drugs and cholinesterase inhibitors: register-based study of over 700,000 elderly patients*. Drugs Aging, 2008. **25**(10): p. 871-7.
52. Johnell, K. and J. Fastbom, *The association between use of cardiovascular drugs and antidepressants: a nationwide register-based study*. Eur J Clin Pharmacol, 2008. **64**(11): p. 1119-24.
53. Johnell, K. and J. Fastbom, *The use of benzodiazepines and related drugs amongst older people in Sweden: associated factors and concomitant use of other psychotropics*. Int J Geriatr Psychiatry, 2009. **24**(7): p. 731-8.
54. Johnell, K., G.R. Weitoft, and J. Fastbom, *Education and use of dementia drugs: a register-based study of over 600,000 older people*. Dement Geriatr Cogn Disord, 2008. **25**(1): p. 54-9.
55. Johnell, K., G.R. Weitoft, and J. Fastbom, *Sex differences in inappropriate drug use: a register-based study of over 600,000 older people*. Ann Pharmacother, 2009. **43**(7): p. 1233-8.
56. Hajjar, E.R., et al., *Adverse drug reaction risk factors in older outpatients*. Am J Geriatr Pharmacother, 2003. **1**(2): p. 82-9.
57. Hanlon, J.T., et al., *Update on drug-related problems in the elderly*. Am J Geriatr Pharmacother, 2003. **1**(1): p. 38-43.
58. Woolcott, J.C., et al., *Meta-analysis of the impact of 9 medication classes on falls in elderly persons*. Arch Intern Med, 2009. **169**(21): p. 1952-60.
59. Gales, B.J. and S.M. Menard, *Relationship between the administration of selected medications and falls in hospitalized elderly patients*. Ann Pharmacother, 1995. **29**(4): p. 354-8.
60. Turnheim, K., *Drug therapy in the elderly*. Exp Gerontol, 2004. **39**(11-12): p. 1731-8.
61. Sweden, S.S., *Population statistics 2000-5. Description of the population in Sweden*. 2010, SCB. Statistiks Sweden.
62. Pehrsson, Å., et al., *Läkemedelsgenombgångar på Kungsholmen och Norrmalm*. 2002, Norra Stockholms läkemedelskommité: Stockholm. p. 1-27.
63. WHO. *WHO Collaborating Centre for Drug Statistics Methodology*. 2008 [cited 2007; Available from: <http://www.whocc.no/atcddd/>].
64. Björkman, I.K., et al., *Pharmaceutical Care of the Elderly in Europe Research (PEER) Group, Drug-drug interactions in the elderly*. Annals of Pharmacotherapy, 2002. **36**(11): p. 1675-1681.
65. Barnett, S.R., *Polypharmacy and perioperative medications in the elderly*. Anesthesiol Clin, 2009. **27**(3): p. 377-89, table of contents.
66. Ritter, C.A., *[How to identify and prevent pharmacokinetically relevant drug-drug interactions]*. Med Monatsschr Pharm, 2009. **32**(10): p. 364-74; quiz 375-6.
67. Giron, M.S., et al., *Psychotropic drug use in elderly people with and without dementia*. Int J Geriatr Psychiatry, 2001. **16**(9): p. 900-6.
68. Raivio, M.M., et al., *Neither Atypical Nor Conventional Antipsychotics Increase Mortality or Hospital Admissions Among Elderly Patients With Dementia: A Two-Year Prospective Study*. Am J Geriatr Psychiatry, 2007.
69. Hosia-Randell, H.M., S.M. Muurinen, and K.H. Pitkala, *Exposure to potentially inappropriate drugs and drug-drug interactions in elderly nursing home*

- residents in Helsinki, Finland: a cross-sectional study.* *Drugs Aging*, 2008. **25**(8): p. 683-92.
70. Pitkala, K.H., et al., *Behavioral symptoms and the administration of psychotropic drugs to aged patients with dementia in nursing homes and in acute geriatric wards.* *Int Psychogeriatr*, 2004. **16**(1): p. 61-74.
 71. Pitkala, K.H., T.E. Strandberg, and R.S. Tilvis, *Is it possible to reduce polypharmacy in the elderly? A randomised, controlled trial.* *Drugs Aging*, 2001. **18**(2): p. 143-9.
 72. Pitkala, K.H., T.E. Strandberg, and R.S. Tilvis, *Inappropriate drug prescribing in home-dwelling, elderly patients: a population-based survey.* *Arch Intern Med*, 2002. **162**(15): p. 1707-12.
 73. Raivio, M.M., et al., *Use of inappropriate medications and their prognostic significance among in-hospital and nursing home patients with and without dementia in Finland.* *Drugs Aging*, 2006. **23**(4): p. 333-43.
 74. Giron, M.S., et al., *The appropriateness of drug use in an older nondemented and demented population.* *J Am Geriatr Soc*, 2001. **49**(3): p. 277-83.
 75. Jedenius, E., et al., *A Swedish programme for dementia diagnostics in primary healthcare.* *Scand J Prim Health Care*, 2008. **26**(4): p. 235-40.
 76. Jönsson, L., et al., *Costs of Mini Mental State Examination-related cognitive impairment.* *Pharmacoeconomics*, 1999. **16**(4): p. 409-16.
 77. Brodaty, H., A. Green, and A. Koschera, *Meta-analysis of psychosocial interventions for caregivers of people with dementia.* *J Am Geriatr Soc*, 2003. **51**(5): p. 657-64.
 78. Brodaty, H. and M. Gresham, *Effect of a training programme to reduce stress in carers of patients with dementia.* *Bmj*, 1989. **299**(6712): p. 1375-9.
 79. Brodaty, H., et al., *Time until institutionalization and death in patients with dementia. Role of caregiver training and risk factors.* *Arch Neurol*, 1993. **50**(6): p. 643-50.
 80. Cherry, D.L., et al., *Interventions to improve quality of care: the Kaiser Permanente-alzheimer's Association Dementia Care Project.* *Am J Manag Care*, 2004. **10**(8): p. 553-60.
 81. Fortinsky, R.H., K. Kercher, and C.J. Burant, *Measurement and correlates of family caregiver self-efficacy for managing dementia.* *Aging Ment Health*, 2002. **6**(2): p. 153-60.
 82. Gifford, D.R., et al., *Improving adherence to dementia guidelines through education and opinion leaders. A randomized, controlled trial.* *Ann Intern Med*, 1999. **131**(4): p. 237-46.
 83. Vickrey, B.G., et al., *The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial.* *Ann Intern Med*, 2006. **145**(10): p. 713-26.
 84. Lemieux-Charles, L., *Understanding the conditions that lead to effective health services delivery networks.* *Healthc Pap*, 2006. **7**(2): p. 40-5; discussion 68-75.
 85. Kreitner, S., et al., *Assessing the competencies and training needs for public health professionals managing chronic disease prevention programs.* *J Public Health Manag Pract*, 2003. **9**(4): p. 284-90.
 86. Graff, M.J., et al., *Community occupational therapy for older patients with dementia and their care givers: cost effectiveness study.* *Bmj*, 2008. **336**(7636): p. 134-8.
 87. Melis, R.J., et al., *Cost-effectiveness of a multidisciplinary intervention model for community-dwelling frail older people.* *J Gerontol A Biol Sci Med Sci*, 2008. **63**(3): p. 275-82.
 88. Iliffe, S., et al., *Evidence Based Interventions in Dementia.* 2010, EVIDEM.
 89. Iliffe, S., et al., *Evidence-based interventions in dementia: A pragmatic cluster-randomised trial of an educational intervention to promote earlier recognition and response to dementia in primary care (EVIDEM-ED).* *Trials*. **11**: p. 13.
 90. Powell, J., T. Chiu, and G. Eysenbach, *A systematic review of networked technologies supporting carers of people with dementia.* *J Telemed Telecare*, 2008. **14**(3): p. 154-6.

91. Andren, S. and S. Elmstahl, *The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia*. J Clin Nurs, 2008. **17**(6): p. 790-9.
92. Brodaty, H., M. Gresham, and G. Luscombe, *The Prince Henry Hospital dementia caregivers' training programme*. Int J Geriatr Psychiatry, 1997. **12**(2): p. 183-92.
93. Brodaty, H. and K.E. Peters, *Cost effectiveness of a training program for dementia carers*. Int Psychogeriatr, 1991. **3**(1): p. 11-22.
94. Burns, R., et al., *Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study*. Gerontologist, 2003. **43**(4): p. 547-55.
95. Callahan, C.M., et al., *Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial*. Jama, 2006. **295**(18): p. 2148-57.
96. Chiverton, P. and E.D. Caine, *Education to assist spouses in coping with Alzheimer's disease. A controlled trial*. J Am Geriatr Soc, 1989. **37**(7): p. 593-8.
97. Drummond, M.F., et al., *Economic evaluation of a support program for caregivers of demented elderly*. Int J Technol Assess Health Care, 1991. **7**(2): p. 209-19.
98. Eloniemi-Sulkava, U., et al., *Effects of supporting community-living demented patients and their caregivers: a randomized trial*. J Am Geriatr Soc, 2001. **49**(10): p. 1282-7.
99. Fisher, L. and M.A. Lieberman, *A longitudinal study of predictors of nursing home placement for patients with dementia: the contribution of family characteristics*. Gerontologist, 1999. **39**(6): p. 677-86.
100. Gaugler, J.E., et al., *Respite for dementia caregivers: the effects of adult day service use on caregiving hours and care demands*. Int Psychogeriatr, 2003. **15**(1): p. 37-58.
101. Gaugler, J.E., et al., *Adult day service use and reductions in caregiving hours: effects on stress and psychological well-being for dementia caregivers*. Int J Geriatr Psychiatry, 2003. **18**(1): p. 55-62.
102. Gaugler, J.E., et al., *Caregiving and institutionalization of cognitively impaired older people: utilizing dynamic predictors of change*. Gerontologist, 2003. **43**(2): p. 219-29.
103. Gilley, D.W., et al., *Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease*. Psychol Med, 2004. **34**(6): p. 1129-35.
104. Hebert, R., et al., *Efficacy of a support group programme for care-givers of demented patients in the community: a randomized controlled trial*. Arch Gerontol Geriatr, 1994. **18**(1): p. 1-14.
105. Lawton, M.P., E.M. Brody, and A.R. Saperstein, *A controlled study of respite service for caregivers of Alzheimer's patients*. Gerontologist, 1989. **29**(1): p. 8-16.
106. Martikainen, J., H. Valtonen, and T. Pirttila, *Potential cost-effectiveness of a family-based program in mild Alzheimer's disease patients*. Eur J Health Econ, 2004. **5**(2): p. 136-42.
107. Meeuwssen, E.J., et al., *Cost-effectiveness of post-diagnosis treatment in dementia coordinated by multidisciplinary memory clinics in comparison to treatment coordinated by general practitioners: an example of a pragmatic trial*. J Nutr Health Aging, 2009. **13**(3): p. 242-8.
108. Mittelman, M.S., et al., *A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial*. Jama, 1996. **276**(21): p. 1725-31.
109. Mittelman, M.S., et al., *An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers*. Gerontologist, 1993. **33**(6): p. 730-40.
110. Mohide, E.A., et al., *A randomized trial of family caregiver support in the home management of dementia*. J Am Geriatr Soc, 1990. **38**(4): p. 446-54.
111. Wimo, A., et al., *Dementia day care and its effects on symptoms and institutionalization--a controlled Swedish study*. Scand J Prim Health Care, 1993. **11**(2): p. 117-23.

112. Wimo, A., et al., *Cost-effectiveness analysis of day care for patients with dementia disorders*. Health Econ, 1994. **3**(6): p. 395-404.
113. Wolfs, C.A., et al., *Integrated multidisciplinary diagnostic approach for dementia care: randomised controlled trial*. Br J Psychiatry, 2008. **192**(4): p. 300-5.
114. Jonsson, L. and A. Wimo, *The cost of dementia in Europe: a review of the evidence, and methodological considerations*. Pharmacoeconomics, 2009. **27**(5): p. 391-403.
115. Getsios, D., et al., *Assessment of health economics in Alzheimer's disease (AHEAD): galantamine treatment in Canada*. Neurology, 2001. **57**(6): p. 972-8.
116. Wimo, A., et al., *An economic evaluation of donepezil in mild to moderate Alzheimer's disease: results of a 1-year, double-blind, randomized trial*. Dement Geriatr Cogn Disord, 2003. **15**(1): p. 44-54.
117. Bostrom, F., et al., *Patients with Lewy body dementia use more resources than those with Alzheimer's disease*. Int J Geriatr Psychiatry, 2007. **22**(8): p. 713-9.
118. Fillit, H. and J. Hill, *The costs of vascular dementia: a comparison with Alzheimer's disease*. J Neurol Sci, 2002. **203-204**: p. 35-9.
119. Charlesworth, G., et al., *Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial*. Health Technol Assess, 2008. **12**(4): p. iii, v-ix, 1-78.
120. Wimo, A., *Cost effectiveness of cholinesterase inhibitors in the treatment of Alzheimer's disease: a review with methodological considerations*. Drugs Aging, 2004. **21**(5): p. 279-95.
121. Wimo, A., et al., *Patients with dementia in group living: experiences 4 years after admission*. Int Psychogeriatr, 1995. **7**(1): p. 123-7.
122. Jönsson, L., et al., *Patient- and proxy-reported utility in Alzheimer disease using the EuroQoL*. Alzheimer Disease and Associated Disorders, 2006. **20**(1): p. 49-55.
123. Haberstroh, J., H. Hampel, and J. Pantel, *Optimal management of Alzheimer's disease patients: Clinical guidelines and family advice*. Neuropsychiatr Dis Treat. **6**: p. 243-53.
124. Grafström, M. and B. Winblad, *Family burden in the care of the demented and nondemented elderly--a longitudinal study*. Alzheimer Dis Assoc Disord, 1995. **9**(2): p. 78-86.
125. Wimo, A., L. Jonsson, and B. Winblad, *An estimate of the worldwide prevalence and direct costs of dementia in 2003*. Dement Geriatr Cogn Disord, 2006. **21**(3): p. 175-81.
126. Wimo, A. and M. Prince, *Alzheimer's Disease International World Alzheimer Report 2010*. 2010, Alzheimer's Disease International (ADI): London UK.
127. Raivio, M., et al., *How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease?* Am J Alzheimers Dis Other Dement, 2007. **22**(5): p. 360-8.
128. Ringsby, A., *Resan genom vårdkedjan*. 2010, Svenskt demens centrum.
129. Olafsdottir, M., I. Skoog, and J. Marcusson, *Detection of dementia in primary care: the Linköping study*. Dement Geriatr Cogn Disord, 2000. **11**(4): p. 223-9.
130. Jönsson, L., et al., *Determinants of costs of care for patients with Alzheimer's disease*. Int J Geriatr Psychiatry, 2006. **21**(5): p. 449-59.
131. Sjöberg, M., *På väg mot en god demensvård. Samhällets insatser för personer med demenssjukdomar och deras anhöriga*, in T.N.B.o.H.a. Welfare, Editor. 2003, Fritzes. p. 48-49.
132. Wimo, A., et al., *Health Economics of Dementia*. A. Wimo, ed. 1998, Chichester,: John Wiley & Sons Ltd., 576.
133. Magnussen, J., K. Vrangbaek, and R. Saltman, *Nordic Health Care System, Recent Reforms and Current Policy Challenges*. 1 ed. 2009, Maidenhead: Open University Press. 339.
134. Simpson, J. and E. Weiner, *Official Oxford English Dictionart*. 1989, Oxford: Oxford University. 22000.
135. Plsek, P.E. and T. Greenhalgh, *Complexity science: The challenge of complexity in health care*. Bmj, 2001. **323**(7313): p. 625-8.

136. Olafsdottir, M., M. Foldevi, and J. Marcusson, *Dementia in primary care: why the low detection rate?* Scand J Prim Health Care, 2001. **19**(3): p. 194-8.
137. Coughin, J.F., *Old age, new technology, and future innovations in disease management and home health care.* Home Health Care Management & Practice, 2006. **3**(18): p. p. 196-207.
138. Holtz-Eakin, D., *An analysis of the literature on disease management programs*, in *C.B. Office*. 2004, Douglas Holtz-Eakin, Director.
139. Norman, G., *DMAA: The Care Continuum Alliance* 2010.
140. Folland, S., A.C. Goodman, and M. Stano, *The Economics of Health and Health Care*. 4 ed, ed. B. R. Vol. 1. 2004, New Jearsy: Paerson Prenticer Hall. 618.
141. Lemieux-Charles, L., et al., *Evaluating the effectiveness of community-based dementia care networks: the Dementia Care Networks' Study.* Gerontologist, 2005. **45**(4): p. 456-64.
142. Helgesson, C.-F. and H. Winberg, *Detta borde vården handla om.* 2008, Stockholm: Stockholm School of Economics, EFI:the economic Research Institute.
143. Koch, T., S. Iliffe, and F.T. Project, *Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review.* BMC Fam Pract. **11**(1): p. 52.
144. Olafsdottir, M., J. Marcusson, and I. Skoog, *Mental disorders among elderly people in primary care: the Linköping study.* Acta Psychiatr Scand, 2001. **104**(1): p. 12-8.
145. Downs, M., et al., *Effectivness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study.* BMJ, 2006. **332**: p. 692-696.
146. Dalsgaard, T., H. Kallerup, and M. Rosendal, *Outreach visits to improve dementia care in general practice: a qualitative study.* Int J Qual Health Care, 2007. **19**(5): p. 267-73.
147. Waldorff, F.B., et al., *Implementation of a clinical dementia guideline. A controlled study on the effect of a multifaceted strategy.* Scand J Prim Health Care, 2003. **21**(3): p. 142-7.
148. Hancock, K., L. Chenoweth, and E. Chang, *Challenges in conducting research with acutely ill hospitalized older patients.* Nurs Health Sci, 2003. **5**(4): p. 253-9.
149. Hansagi, H., et al., *Frequent use of the hospital emergency department is indicative of high use of other health care services.* Ann Emerg Med, 2001. **37**(6): p. 561-7.
150. Onen, F., et al., *Emergency hospitalization in the elderly in a French university hospital: medical and social conditions and crisis factors precipitating admissions and outcome at discharge.* Aging (Milano), 2001. **13**(6): p. 421-9.
151. Stathers, G.M., V. Delpuch, and J.R. Raftos, *Factors influencing the presentation and care of elderly people in the emergency department.* Med J Aust, 1992. **156**(3): p. 197-200.
152. Kihlgren, A.L., et al., *Older patients awaiting emergency department treatment.* Scand J Caring Sci, 2004. **18**(2): p. 169-76.
153. Bellelli, G., et al., *Dementia, delirium, and depression in patients with hip fracture: 1+1 doesn't always make 2.* J Am Geriatr Soc, 2009. **57**(1): p. 179-80.
154. Beloosesky, Y., et al., *Dementia does not significantly affect complications and functional gain in elderly patients operated on for intracapsular hip fracture.* Arch Orthop Trauma Surg, 2001. **121**(5): p. 257-60.
155. Hedman, A.M. and M. Grafstrom, *Conditions for rehabilitation of older patients with dementia and hip fracture--the perspective of their next of kin.* Scand J Caring Sci, 2001. **15**(2): p. 151-8.
156. Strömqvist, J. *Riktlinjer för demensutredning inom primärvården i Kalmar länVårdprogram demens i Kalmar län.* 2007 01-04-2006 [cited; Available from: http://www.ltkalmar.se/documents/Hälsa%20&%20Vård/Vårdguide%20A-Ö/vårdprogram/Demensutredning_06.pdf.

157. Schubert, C.C., et al., *Comorbidity profile of dementia patients in primary care: are they sicker?* J Am Geriatr Soc, 2006. **54**(1): p. 104-9.
158. Altman, D.G., *Practical statistics for medical research*. 1997.
159. Sweden, S.S., *Population statistics 2000-5. Description of the population in Sweden*. 2008, SCB. Statistics Sweden.
160. Duffy, M.E., *Methodological triangulation: a vehicle for merging quantitative and qualitative research methods*. Image J Nurs Sch, 1987. **19**(3): p. 130-3.
161. Dunkelberg, S. and H. van den Bussche, [*Triangulation or how different research methods may lead to different results*]. Z Arztl Fortbild Qualitatssich, 2004. **98**(6): p. 519-25.
162. Williamson, G.R., *Illustrating triangulation in mixed-methods nursing research*. Nurse Res, 2005. **12**(4): p. 7-18.
163. Johnell, K., et al., *Inappropriate drug use in the elderly: a nationwide register-based study*. Ann Pharmacother, 2007. **41**(7): p. 1243-8.
164. Fastbom, J., [*Increased consumption of drugs among the elderly results in greater risk of problems*]. Lakartidningen, 2001. **98**(14): p. 1674-9.
165. Wettermark, B., U. Bergman, and I. Krakau, *Using aggregate data on dispensed drugs to evaluate the quality of prescribing in urban primary health care in Sweden*. Public Health, 2006. **120**(5): p. 451-61.
166. Lau, H.S., et al., *Validation of pharmacy records in drug exposure assessment*. J Clin Epidemiol, 1997. **50**(5): p. 619-25.
167. Snowdon, D.A., *Healthy aging and dementia: findings from the Nun Study*. Ann Intern Med, 2003. **139**(5 Pt 2): p. 450-4.
168. Jedenius, E., et al., *A Swedish programme for dementia diagnostics in primary healthcare*. Scand J Prim Health Care, 2008: p. 1-6.
169. Klarin, I., J. Fastbom, and A. Wimo, *A population-based study of drug use in the very old living in a rural district of Sweden, with focus on cardiovascular drug consumption: comparison with an urban cohort*. Pharmacoepidemiol Drug Saf, 2003. **12**(8): p. 669-78.
170. Sweden, N.B.O.H.a.W., *Vård och omsorg om Äldre, lägesrapporter 2007*, N.B.O.H.a.W. Sweden, Editor. 2008, National Board Of Health and Welfare p. 1-85.
171. Jedenius, E., et al., *Can a dementia program in primary care affect the acute ward at the local Hospital?*, in *Alzheimer's Disease International*. 2005: Stockholm.
172. Colantonio, A., et al., *What support do caregivers of elderly want? Results from the Canadian Study of Health and Aging*. Can J Public Health, 2001. **92**(5): p. 376-9.
173. Ahgren, B. and R. Axelsson, *Determinants of integrated health care development: chains of care in Sweden*. Int J Health Plann Manage, 2007. **22**(2): p. 145-57.
174. Koch, T. and S. Iliffe, *The role of primary care in the recognition of and response to dementia*. J Nutr Health Aging. **14**(2): p. 107-9.
175. Ostberg, P., et al., *Impaired verb fluency: a sign of mild cognitive impairment*. Brain Lang, 2005. **95**(2): p. 273-9.
176. Wallin, A.K., et al., *Five-year outcome of cholinergic treatment of Alzheimer's disease: early response predicts prolonged time until nursing home placement, but does not alter life expectancy*. Dement Geriatr Cogn Disord, 2004. **18**(2): p. 197-206.
177. Religa, D., et al., *Cost of dementia diagnosis depends on gender and age*, in *Springfield*. 2010: Geneve.