DEMENTIA CARE ALTERNATIVES
IN THE SUNDSVALL-REGION, SWEDEN

Studies on symptoms, costs and quality of life

by

Anders Wimo

University of Umeå
Umeå 1992
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IN THE SUNDSVALL-REGION, SWEDEN

Studies focusing on symptoms, costs and quality of life

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av

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ABSTRACT

The prevalence of dementia patients will increase in the forthcoming years as the number of so-called "elderly elderly" (people over 80 years of age) will grow. The social and economic consequences of this increase in demented people are considerable and new caring alternatives like Day Care and Group Living have been developed as a complement to institutions. The purpose of this thesis was to describe the dementia care in a Primary Health Care-organization from different aspects. The focus of the studies has been new caring options and routines and their effects on symptoms, costs and the well-being of patients, staff and relatives.

The effects of an Individual Care Plan (ICP) and mental activation were studied during 10 months in two psycho-geriatric wards and compared to two other psycho-geriatric wards where ICP was not performed. However, there were very few significant changes between the groups.

Factors predicting institutionalization of the demented were tested and a high score on the item "exhaustion of spouse" seemed to have the greatest value.

Day Care offers activation and supervision during part of the day. After the introduction of Day Care the situation of the relatives improved. The resources at home increased while the need for institutionalization decreased by 22%. After one year with Day Care, 24% of the patients were institutionalized compared to 44% in a control group.

Group Living was studied from an economic point of view and the use of resources and institutional care decreased clearly and significantly when Group Living was introduced. A Cost Utility Analysis was applied to Group Living, which turned out to be both cheaper and better in terms of Quality of life compared to the most likely control group.

The introduction of new caring alternatives for dementia patients has resulted in a more efficient and individualized care. The effects on Quality of life are positive for both patients and relatives, while there are few effects on the patient’s ADL- and cognitive functions. The new care also seems more cost-effective as institutionalization can be postponed.

The results of this thesis may be a contribution to priority discussions in the care of the elderly, but also an indication that there is a great need for methodological research concerning the concept of the Quality of life of dementia patients.

Key words: Dementia, costs, Quality of life, dementia symptoms, cost utility analysis, QALY, behaviour, institutionalization.
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To Christina, Maria and Erik
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ABSTRACT

The prevalence of dementia patients will increase in the forthcoming years as the number of so called "elderly elderly" (people over 80 years of age) will grow. The social and economic consequences of this increase in demented people are considerable and new caring alternatives like Day Care and Group Living have been developed as a complement to institutions.

The purpose of this thesis was to describe the dementia care in a Primary Health Care-organization from different aspects. The focus of the studies has been new caring options and routines and their effects on symptoms, costs and the well-being of patients, staff and relatives.

The effects of an Individual Care Plan (ICP) and mental activation were studied during 10 months in two psycho-geriatric wards and compared to two other psycho-geriatric wards where ICP was not performed. However, there were very few significant changes between the groups.

Factors predicting institutionalization of the demented were tested and a high score on the item "exhaustion of spouse" seemed to have the greatest value.

Day Care offers activation and supervision during part of the day. After the introduction of Day Care the situation of the relatives improved. The resources at home increased while the need for institutionalization decreased by 22%. After one year with Day Care, 24% of the patients were institutionalized compared to 44% in a control group.

Group Living was studied from an economic point of view and the use of resources and institutional care decreased clearly and significantly when Group Living was introduced. A Cost Utility Analysis was applied to Group Living, which turned out to be both cheaper and better in terms of Quality of life compared to the most likely control group.

The introduction of new caring alternatives for dementia patients has resulted in a more efficient and individualized care. The effects on Quality of life are positive for both patients and relatives, while there are few effects on the patient's ADL- and cognitive functions. The new care also seems more cost-effective as institutionalization can be postponed.

The results of this thesis may be a contribution to priority discussions in the care of the elderly, but also an indication that there is a great need for methodological research concerning the concept of the Quality of life of dementia patients.

Key words: Dementia, costs, Quality of life, dementia symptoms, cost utility analysis, QALY, behaviour, institutionalization.
SVENSK SAMMANFATTNING

Antalet demente personer i landet kommer att öka påtagligt under 1990-talet som en följd av att antalet så kallade "äldre-äldre" (personer 80 år och äldre) blir större. Ca 5-7% av gruppen 65 år och äldre samt ca 20% av gruppen 80 år och äldre är demente. Utifrån demografiska data kan man anta att det 1988 fanns ca 75 000 demente i Sverige och den siffan kommer att öka till ca 90-95 000 år 2000. De sociala och ekonomiska konsekvenserna av denna snabba ökning är påtagliga.


I Sverige har tre vårdnivåer för demente utvecklats:
1. Vård i hemmet med tillgång till hemtjänst, hemsjukvård, dagvård, dagcentraler m.m.  
2. Gruppboende.  
3. Institutionsvård på sjukhem, psyko-geriatriiska kliniker, geriatriiska kliniker och psykiatriska kliniker.

Genom ÄDEL-reformen tar kommunen över ansvaret för bl a gruppboende och sjukhemmen. I dagsläget är konsekvenserna av ÄDEL svåröverskådliga.

Syftet med föreliggande avhandling är att beskriva demensvård utifrån olika aspekter, bl a kostnader, symptomutveckling och livskvalitet och att försöka anlägga ett hälsoekonomiskt perspektiv på de nya vårdformerna dagvård och gruppboende för demente.

Sex arbeten ingår i avhandlingen.


II. I den andra artikeln studerades sambandet mellan å ena sidan ett antal faktorer som beskriver vårdtyngd, demensgrad och psyko-social situation omkring demente patienter i eget boende och å andra sidan institutionalisering. Det visade sig att påfrestningen på den medlevande anhörige var den faktor som bäst förutsade institutionalisering följt av tillsynsbehov och psykisk vårdtyngd. Dessa faktorer förutsade institutionalisering bättre än mått på själva demensgraden.

III. I detta arbete studerades dagvårdens effekter på kostnader, väbefinnande och
anhörigas situation. Perioden ett halvår innan start i dagvård jämfördes med första halvåret med dagvård. Behovet av insatser i hemmet ökade med ca 20% medan behovet av institutionsvård minskade med 22%. Totalt sett ökade kostnaderna från 199 till 269 kr per patient och dag. En förenklad form av s k Cost-Utility Analysis (CUA) gav en kostnad per "välbefinnandeår" på 48 076 kr beträffande patienterna och 43 391 kr beträffande de anhöriga.

IV. I den fjärde artikeln undersöktes under ett år effekterna på demenssymptom och institutionsvård hos patienter i dagvård och jämfördes med en kontrollgrupp. Det visade sig att bågge grupperna försämrades i kognitiva funktioner och ADL-förmåga under året. Försämringen i förmågan att klä sig gick långsammare i dagvårdsgruppen. Nytjandet av institutionsvård var klart mindre i dagvårdsgruppen (73 dagar jämfört med 131 dagar per patient och år i kontrollgruppen). Efter ett år var 24% av dagvårdsgruppens patienter och 44% av kontrollgruppens patienter institutionaliserade. Den institutionsvårds förebyggande effekten berodde sannolikt till stor del på att anhöriga fick vila.


VI. En CUA, där kostnaden per QALY (Quality Adjusted Life Year) beräknades, utfördes på patienter i gruppboende, som jämfördes med olika kontrollgrupper, dels demente som var hemma vid studiens början (CH) och dels demente på institution (CI). Mätperioden var ett år och sedan gjordes en modell för en förväntad återstående livslängd på åtta år (inkusive mätåret). Tre alternativ för utfallet av gruppboende-patienterna (GL1-3) jämfördes med tre kontrollgruppsalternativ (CH, CI, CH+CI). Som bästa jämförelsealternativ ("best guess") bedömdes GL2 (dvs 50% av patienterna i gruppboende bedömdes bli institutionaliserade när de nådde den allvarligaste demensnivån) och CH+CI (dvs en blandning av kontrollpatienter från hemmet och institution). I detta jämförelsealternativ bedömdes gruppboende vara både bättre och billigare dvs kostnaden per QALY <0. Om GL2 jämfördes med enbart CH blev kostnaden per QALY ca 171 000 kr.

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


<table>
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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AN</td>
<td>Assistant Nurse</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Life</td>
</tr>
<tr>
<td>CBA</td>
<td>Cost Benefit Analysis</td>
</tr>
<tr>
<td>CC</td>
<td>County Council</td>
</tr>
<tr>
<td>CEA</td>
<td>Cost Effectiveness Analysis</td>
</tr>
<tr>
<td>CPG</td>
<td>Care Planning Group</td>
</tr>
<tr>
<td>CUA</td>
<td>Cost Utility Analysis</td>
</tr>
<tr>
<td>DC</td>
<td>Day Care</td>
</tr>
<tr>
<td>GL</td>
<td>Group Living</td>
</tr>
<tr>
<td>GNP</td>
<td>Gross National Product</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HA</td>
<td>Home Aid</td>
</tr>
<tr>
<td>HNC</td>
<td>Home Nursing Care</td>
</tr>
<tr>
<td>HSO</td>
<td>Home Service Officer</td>
</tr>
<tr>
<td>IWB</td>
<td>Index of Well Being</td>
</tr>
<tr>
<td>MDDAS</td>
<td>Multi Dimensional Dementia Assessment Scale</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>PHCC</td>
<td>Primary Health Care Centre</td>
</tr>
<tr>
<td>QALY</td>
<td>Quality Adjusted Life Year</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>RDN</td>
<td>Registered District Nurse</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>RNT</td>
<td>Registered Nurse Teacher</td>
</tr>
<tr>
<td>RO</td>
<td>Reality Orientation</td>
</tr>
<tr>
<td>SPRI</td>
<td>Sjukvårdens Planerings och Rationaliserings Institut</td>
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INTRODUCTION

The scenario; epidemiology, costs and organization of care

Two main tendencies prevail when the development of dementia care during the 1980s is illuminated: the increase in the number of demented people and the financial burden of the public health system. As a consequence of the increasing number of the so called "elderly elderly" population (people over 80 years of age) [1], the prevalence of dementia is increasing. About 5-7% of the population over 65 years of age [2,3] and about 20% of those over 80 [4] suffer from dementia symptoms, causing severe problems in their daily living. The incidence of dementia is more difficult to calculate and most results are based on earlier studies[5]. From the epidemiological figures and well-known and prognosticated national population statistics [1,6], the prevalence of dementia in Sweden can be estimated at about 35 000 in 1950, about 75 000 in 1988 and to be about 90 000-95 000 in the year of 2000. The social and economic consequences of this rapid increase in demented people are considerable.

Health Care in Sweden, which is largely administrated by County Councils, uses about 9% of the Gross National Product (GNP) [1,7], resulting in a total cost of about SEK 100 000 000 000 in 1989 [1]. About 5% of the GNP is used by the care of the elderly [8], which is administrated by both municipalities and County Councils. The total cost of the care of the elderly has grown rapidly during the 1980s. In 1982, the total costs were estimated at about SEK 20 000 000 000 [9]. In 1985 this figure had risen to SEK 46 000 000 000 - 52 000 000 000, and about 65% of the costs were covered by County Councils with the organization of care at that time [8,10]. The figure had grown to about SEK 74 000 000 000 in 1989 [11]. To these figures should also be added the cost of the informal support from family members in the patients' homes, which is difficult to quantify. Johansson has estimated that this informal support is about twice as extensive as the formal support in home care [12].

The tendency is that the number of demented patients is increasing at all caring levels. The fraction of demented patients at long-term care institutions (nursing homes, psycho-geriatric wards, mental hospitals, home for the aged) in the County of Västerbotten, Sweden, increased from 35% in 1975 to 40% in 1982 [13] and to 63% in 1988 [14]. Wimo et al found that in 1976 39% of the patients at Sundsvall's Nursing home in Sundsvall, the County of Västernorrland in Sweden, had dementia or cerebrovascular disorders, to be compared to 64% in 1988 [15]. In Kungälv, the County of Bohuslän, Sweden, 41% of a nursing home population and 26% of a Home Nursing Care population were classified as demented [16]. Ineichen reports in a review article that there is a dementia prevalence of about 50% in Great Britain at residential homes [17]. In a Norwegian survey of waiting-list patients for nursing homes, 84% had mental disturbances, where dementia was the main reason for this condition [18]. As a consequence of the growing dementia population at institutions, the nursing load grows [19]. The demented patients' part of the institutionalized population depends to a great extent on the increase in the "elderly-elderly"-population. Whether mortality among dementia patients is low is controversial. The main opinion is that dementia shortens expected life length [20], but in a Norwegian study of institutionalized patients [21], the demented patients survived longer than the non-demented, causing a larger number of demented people at institutions.

Sweden had one of the highest institutional rates (including homes for the aged) in
the world in 1980; 8.7-10.5% of those who were 65 or older lived in institutions [22].
In the official statistics [1], the total number of beds (homes for the aged not included)
was 117 038 (14.1 beds per 1000 inhabitants) in 1980 (i.a. 44 859 in long-time care and
26 962 in psychiatric care). In the 1980s, however, there was a shift from conventional
institutional care to non-, and semi-institutional caring alternatives [23] and in 1989, the
total number of beds was just 101 809 (11.9 beds per 1000 inhabitants) [1], yet the
number of people 80 or older had increased from 260 000 in 1980 to 370 000 in 1990
[1].

The correct figure of the number of demented patients in institutions in Sweden in
the 1980s is difficult to estimate. The official number of patients in long-time care with
"psychiatric disorders caused by age" was 15 346 [1] in 1988 but the number of beds in
long-time care occupied by demented patients can be estimated at about 33 000 (about
3 500 demented patients in psychiatric care), and 60% of the patients at nursing homes
(of 33 319 beds in 1988 [1]) and at geriatric clinics (of 15 720 beds in 1988 [1]). From
another source, the figure 31 500 institutionalized demented patients has been presented
[24].

It is hazardous to estimate the annual cost of dementia care in Sweden, but roughly,
the cost can be calculated on the 1989-level with the assumptions and cost-figures
presented in Table I.

Table I. Estimated annual costs (SEK) of dementia care in Sweden in 1989, based on
the estimates of different sources [1,6,24-28].

<table>
<thead>
<tr>
<th></th>
<th>Number of demented</th>
<th>Per item cost</th>
<th>Per item unit</th>
<th>Quantity</th>
<th>Annual cost SEK 1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing home</td>
<td>21 000</td>
<td>324 000</td>
<td>year</td>
<td></td>
<td>6 804 000</td>
</tr>
<tr>
<td>Geriatric clinic</td>
<td>8 000</td>
<td>1 100</td>
<td>day</td>
<td></td>
<td>3 212 000</td>
</tr>
<tr>
<td>Psychiatric clinic</td>
<td>3 500</td>
<td>100</td>
<td>day</td>
<td></td>
<td>1 405 250</td>
</tr>
<tr>
<td>Group Living</td>
<td>1 000</td>
<td>229 500</td>
<td>year</td>
<td></td>
<td>229 500</td>
</tr>
<tr>
<td>Home for the aged</td>
<td>20 000</td>
<td>162 100</td>
<td>year</td>
<td></td>
<td>3 242 000</td>
</tr>
<tr>
<td>Day Care</td>
<td>4 000</td>
<td>300</td>
<td>day 2 visits/week</td>
<td></td>
<td>124 800</td>
</tr>
<tr>
<td>Social Service</td>
<td>20 000</td>
<td>145</td>
<td>hour 8 hours/week</td>
<td></td>
<td>1 206 400</td>
</tr>
<tr>
<td>and HNC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16 223 950</td>
</tr>
</tbody>
</table>

The per item cost figures have been received from Kommunförbundet [25], except
for the cost (and figures of visits) of Day Care, which come from Sundsvall [26 and
Paper III]. The number of patients in GL in 1989 has been calculated on the trend
between 1988 and 1990 [24,27]. The number of patients in DC is an estimate based on
the number of DC-units in Sweden in 1989 (319) [28], The number of demented
patients in different long time care institutions run by County Councils (i.e. nursing
homes 34 944 beds and geriatric clinics 12 972 beds [1]) in 1989 is estimated at about
60% and at 50% on home for the aged. The figure of Social Service and HNC (8
hours/week) come from Sundsvall [26, Papers III and V].
All in all these assumptions result in direct costs of about SEK 16 200 000 000. This figure is probably too low if an estimate of the overall cost of the consequences of dementia care is aimed at. The following expenses must be added: the cost of care at emergency clinics, visits to municipal day centers, travelling costs, the cost of informal support from family members, and the loss in production of family members. In a SPRI-report [24], a total cost of SEK 15 582 000 000 was calculated for 1985 and the prognosis for the year of 2000 was about SEK 20 000 000 000.

As the proportion of the demented is increasing, there is also, in despite of the humanitarian and caring aspects, an interest for the nation from a financial point of view, to consider the economic aspects of this increasing number of patients. Therefore, the organization of care is of great importance.

In dementia care in Sweden, three levels of care have been developed:

1. At home: support from the municipal Social Service, the County Council's Home Nursing Care (HNC) with Registered District Nurses (RDN) and Assistant Nurses (AN). Family members paid and unpaid efforts. Day Centers and Day Care (DC) for dementia patients.
2. Group Living (GL).
3. Institutional care at nursing homes, psycho-geriatric clinics, geriatric clinics and psychiatric clinics.

The responsibility for care varies in Sweden (1991). GL is administrated by the County Councils in some regions, by the municipalities in some and by both in other areas. In the County Councils, the responsibility for GL falls under the PHC or the geriatric or the psycho-geriatric clinics. The responsibility for HNC also varies; in some regions, like in Sundsvall, the Primary Health Care (PHC) has the responsibility, (until 1992) in other regions the geriatric clinics.

As a consequence of the new reform called ÄDEL [11], municipalities will have the main responsibility for the care of the elderly from 1992. The consequences for dementia care are difficult to overlook. All over the country DC and GL will probably be administrated by municipalities. So will also dementia care at nursing homes. The care at geriatric clinics, psycho-geriatric clinics and psychiatric clinics will probably be administrated by the County Councils, with the exception of Malmö, Gothenburg and Gotland (which has no County Council). There were a great many discussions before the ÄDEL-reform came into effect [29-31], and these discussions included also the future of the whole PHC [31,32].

DC for dementia patients was developed in Great Britain in the 1950s [33] and in Sweden in the late 1970s [34]. The organization of DC varies; DC-units are located both as day hospitals close to nursing homes or geriatric/psycho-geriatric clinics and, as in Sundsvall [26], in flats or houses with no connection with institutions. The DC-concept includes activation, supervision and participation in small groups during part of the day.

GL for dementia patients is a Swedish phenomenon [35-37]. The first unit was established more than ten years ago, Råbyhemmet in Upplands Bro [36], but the real expansion began in 1983-84 at different places (i. a. Karlstad, Malmö, Sundsvall, Motala etc.) [38-42]. The GL-concept consists of small units in flats or houses, sometimes in one part of a home for the aged or in a nursing home [43], staffed around the clock, where 6-9 patients live together. The main purpose is to offer a sense of community, supervision and a natural situation without institutional characteristics. GL
Dementia: classification and research

Alzheimer's disease (AD) [47,48] is the most common type of dementia (50-70% of a dementia population), followed by vascular dementia (17-34%), frontal lobe dementias (10%) and mixed types (10%) [2-4,49-51]. There has been a considerable increase in dementia research during the 1980s, regarding both the basic nature of the different types of dementia [3,52-56], the classification and diagnostics [56-59], epidemiology [60,61], treatment [62-64] and caring [65-70], but still there are no methods available to cure the different types of dementia.

The care of the elderly in Sundsvall during the 1980s

Sundsvall is an industrial city in the middle of Sweden with about 93 000 inhabitants (Figure 1). About 15 700 of the people in Sundsvall were 65 years old or more and about 3 400 were older more than 80 in 1989 [71].

Figure 1. The city of SUNDSVALL, Sweden

During the whole study-period of the thesis, 1984-1991, i.e. before the ÄDEL-reform, the PHC had the main responsibility for the medical care of the elderly living in their own homes (HNC), at homes for the aged, in GL and at nursing homes. There were close relations between the PHC and the municipal Social Service, which organised the social support with home aides in the homes and in the home for the aged. In the Care Planning Group (CPG) the municipal Home Service Officer (HSO) and the RDN from the PHC planned and administered the care (Figure 2), always in cooperation with GPs, assistant nurses, home aides, physiotherapists and occupational therapists.
Figure 2. Organization of the care for the elderly in Sundsvall during the 1980s and until 1992 (when the ÄDEL-reform was introduced).

The patients were referred to the CPGs from the Social Service, emergency clinics, nursing homes, the Psychiatric Clinic and The Geriatric Clinic. The Geriatric Clinic performed rehabilitation, diagnoses and training of staff in the care of the elderly. The Geriatric Clinic also had some nursing home responsibility in areas where nursing home capacity was limited.

The care of the elderly in Sundsvall expanded notably during the 1980s, regarding the care offered by the municipality as well as that offered by the County Council. This expansion has been documented in various ways. Thus changes over time [15,72-74] and in organization [23,75-80] have been described as well as nursing home care [15,81-82], the situation for the very old [83,84] and those retired recently [85], the elderly and their families [86-88]. Development of dementia care [26-27,67,87,89-90], the everyday situation in social service and confidence [91,92], methodological aspects [93-95] and the future organization of the care of the elderly [96] have also been illuminated. This thesis is another contribution to the evaluation of the care of the elderly in Sundsvall.
AIMS OF THE THESIS

The origin of the respondents interest in dementia care was the experiences of the insufficient situation for the demented patients at all caring levels in the beginning of the 1980s. The purpose of this thesis is to describe dementia care in the PHC-organization from different aspects.

The focus of the studies has been new caring alternatives and routines and their effects on symptoms, costs and on the well-being of patients, staff and relatives. The following questions are illuminated:
1. Do new ward routines affect the progress of the disease among in-patients? (Paper I)
2. Can institutionalization be predicted by the use of rating scales? (Paper II)
3. How do families and staff look at Day Care (DC) as a new caring alternative? (Paper III)
4. Does DC have any impact on symptoms and institutionalization? (Paper III, IV)
5. Are DC and Group Living (GL) economically favourable alternatives? (Paper III, V, VI)
6. What are the effects of GL on the relation between marginal costs and quality of life compared to other caring alternatives (Paper VI)
MATERIAL AND METHODS

1. Patients
The effects of an Individual Care Plan (ICP) [97] and mental activation were studied in Paper I during 10 months at two psycho-geriatric wards (n=44) and compared to two other psycho-geriatric wards (n=41) where ICP was not performed. The ICP consisted of a number of activation moments and environmental changes on the wards. The predictive validity [98] of a form describing the psycho-social-, cognitive- and nursing situation of 69 non-institutionalized (at inclusion) patients with psycho-geriatric disorders was studied during one year (Paper II). In Paper III the effects on the use of resources, costs and well-being during 6 months on 47 participants in psycho-geriatric DC were studied with the patients as their own controls (the 6-month period prior to DC). Cognitive function, ADL-capacity and behaviour were studied every third month during one year (Paper IV) on fifty-five demented patients in DC and compared to a control group (n=44) with no access to DC. Twenty-four demented patients were analysed in Paper V regarding the use of resources and costs [99] during the first six months in GL and compared to the six-month period prior to GL. 46 demented patients in GL (GL-group), 39 patients who lived at home at the inclusion in the study (CH-group) and 23 permanently institutionalized patients (CI-group) were studied in a prospective open non-randomized concurrent control study and a Cost Utility Analysis were performed (Paper VI).

2. Localities.
In Paper I, patients at psycho-geriatric wards in Sundsvall’s Nursing home were analysed. The first three DC units in Sundsvall were established in 1984; in Stöde (about 50 km west of the central area of Sundsvall), at Riddargatan in Skönsberg (central Sundsvall) and in Finsta (about 8 km north of the central area) and Papers III and IV concern patients at these DC-units. Two GL-units, which are concerning patients in Paper V, were established in 1984, one in Bergsåker (named "Gnistan"), about 5 km west of the central area and a second unit in Finsta. Paper VI also includes patients from "Gnistan" and Finsta and from three other GL-units, "Lyran" in Bredsand about 7 km south of the central area, "Lyktan" in Ljustadalen about 7 km north of the central area and Bergebo in the municipality of Timrå, about 25 km north of Sundsvall. Patients in the different control groups and in Paper II were recruited from and analysed at different caring levels in the whole of Sundsvall.

3. Scales
In the first paper outcome was measured with four scales: The Hultén-scale measured work load [100], the Robinson-Crichton scale [101] measured work load and behaviour, the SCAG-S scale measured aspects of well-being [102,103] and the Kahn’s test measured orientation [104]. ICP-performance and the staff’s opinion about dementia care were studied with a questionnaire handed out to the staff. When the predictive validity in Paper II was tested, a new form measuring the psycho-social-, cognitive- and nursing situation was constructed. The form included both well established scales like the Mini Mental State Examination (MMSE) [105] and the Y-scale [93] as well as new items describing the need for supervision and activation and
also exhaustion among family members, staff and neighbours. In Paper III the effects on well-being were studied with interviews with staff and families, and the interview results were converted into a discrete scale. In the assessments of the patients of Paper IV, two scales were used: cognitive function was measured with MMSE while the Multi Dimensional Dementia Assessment Scale (MDDAS) [13] was used to study ADL and behaviour. For the utility-analysis in Paper VI, a scale developed by Kaplan and Busch [99], the Index of well-being (IWB), was used. The IWB-figures were calculated by computerized If-transformations [106] from the Global Deterioration Scale (GDS) [107].

4. Statistics
When rating scales were used (Papers I, II, III, IV, VI), statistics were analysed with the non-parametric method Mann-Whitney’s U-test [108], while T-test was used when costs and other parametric variables were tested (Paper I-VI).

5. Use of resources and costs
In Papers III, V and VI the use of resources was defined as use of Social Service, living at a home for the aged, HNC and institutional care offered by the County Council. The use of DC and GL was also included. The use of resources was calculated in variable costs by the multiplication of the cost of each activity and overhead costs were added. In Papers II and IV the outcome measurements consisted of the total number of institutional days during one year and in Paper II the caring level after one year (institutionalized or not) was also included.

In Paper III, a Cost Utility Analysis (CUA) [109] was applied, based on the cost analysis and the interview results, while the CUA of Paper VI was performed by a comparison between the GL-costs and the GL effects on the Quality of life of the patients. To calculate the cost per gained QALY (Quality Adjusted Life Year) [109], the quotient of the cost figures and the IWB-figures as a utility-indicator [110] was used. Different comparison alternatives of the GL-outcome and the control-groups were tested by using a model of an expected life-length of 8 years.
PAPER I. Can changes in ward routines affect the severity of dementia? A controlled Swedish prospective study.
There were few significant changes between the groups after 10 months. The variables "restlessness" and "orientation" with the Robinson-Crichton scale and the variable "eating" with the Hultén scale deteriorated significantly at the ICP-wards. No significant effects on mood were seen. The questionnaire showed that the goals had been partly attained.

PAPER II. Predictive validity of factors influencing the institutionalization of elderly people with psycho-geriatric disorders
A high score correlated significantly with a greater use of institutional care than a low score in all items. A high score in the item "exhaustion of spouse" had the highest predictability of all items (p<0.001). The items "supervision need among the demented living alone" and "mental nursing load" were also highly significant as institutionalization predictors (p<0.001).

PAPER III. Impact of Day Care on dementia patients-costs, well-being and relatives' views.
The use of resources at home increased by 20% while the need for institutional care decreased by 22%. The cost analysis showed that the costs increased from SEK 199/day and patient to SEK 269/day after the introduction of DC. The CUA showed that the cost for a Well-Year was SEK 48 076 for the patients and SEK 43 931 for the families.

PAPER IV. Dementia Day Care and its effects on symptoms and institutionalization - a controlled Swedish study.
DC-patients and patients in the control group deteriorated during the 12-month period. There were few significant changes. Dressing capacity was better preserved in the DC-group (p<0.05). The use of institutional care was significantly less (p<0.01) in the DC-group (73 days/year) compared to the C-group (131 days). After one year, 24% of the patients in the DC-group and 44% of the C-groups were institutionalized. The postponement of institutionalization was probably an effect of less exhaustion among families and less need for supervision.

PAPER V. Group Living, an alternative for dementia patients. A Cost analysis.
The use of resources at home and in institutional care decreased very clearly and significantly (p<0.001) when GL was introduced. The total cost of the GL-period was £42/day and patient (about SEK 470), compared with £49/day (about SEK 550) for the 6-month period prior to GL (NS) (cost level of 1985). If there is no GL and the only alternative was institutionalization, the alternative cost would be £68 (about SEK 760) (p<0.05).

PAPER VI. Cost-Utility Analysis of Group Living in dementia care.
The IWB deteriorated in all the study groups during an expected life length period of 8 years. The comparison between Group Living alternative 2 (GL2 i.e. 50% of the GL-patients who reached GDS stage 7 would be institutionalized) and the CH+CI
alternative (i.e. the control group was a mixture of patients from both homes and institutions) was considered to be the "best guess". In this case, the cost per gained QALY was <USD 0 i.e. GL was both cheaper in marginal cost terms and better in marginal IWB-terms. In the comparison between GL2 and CH (i.e. only patients in homes at the inclusion were used as comparison group) the cost for a QALY was USD 28,560 (about SEK 171,360). If all GL-patients who reached GDS stage 7 would be institutionalized, the cost per gained QALY in comparison with the CH-group would be USD 1,830,571.
GENERAL DISCUSSION

The relation between the increasing number of dementia patients and the financial burden in the public health system is a real challenge for dementia research. This thesis focuses on the effects of two new caring alternatives in dementia care, DC and GL, which were established in Sundsvall in 1984. At that time, research experiences concerning these caring alternatives were limited and there were hopes that the effects on both costs and well-being would be very positive. Initial preliminary reports also confirmed this view, but naturally, it is of vital importance to test these hypotheses. Since the most impaired demented patients were cared for at institutions, it was also interesting to study the effects of DC and GL on institutionalization and to focus on the caring of the demented patients who had already been institutionalized.

1. Do ICP, DC and GL improve dementia symptoms and behaviour? (Paper I, IV)?

In our studies no positive effects on cognitive capacity were found (Papers I, IV). Only slight effects on ADL-capacity were noticed (Paper I, IV). The better preserved dressing ability (Paper IV) was the most obvious effect. The changes in behaviour were not the ones that had been expected in the sense that activated patients seemed to be more disturbed (Paper I, IV) than those who were not subject to the new caring methods.

Cognitive function was more or less unaffected by the activation practiced in DC and GL or by the use of ICP at institutions. The decline in cognitive function in dementia is probably directly related to the loss of neurons [3, 111]. According to most authors this process is unavoidable in social programs like Reality Orientation (RO) [112-116] even if there are opposite opinions [117].

The small positive effects on ADL-capacity might reflect the fact that this ability has a potential to change more than the effects on cognitive function. Even if impaired ADL-capacity largely depends on apraxia, which is also a manifestation of the loss of neurons [118], there seems to be a space for training and activation (Paper V), shown also by Bråne [119], and Svensson [120].

The behavioural changes are more difficult to interpret. Behavioural disturbances are by no means linearly related to the progression of the dementia [111], but the mental derangement correlates logically to what people around the patient regard as a "behavioural disturbance" [121]. Kleban et al found that an individualized treatment approach reduced aggressiveness among non-institutionalized women [122]. Reisberg et al stated that in the middle stages of dementia, level 5-6 on the Global Deterioration Scale (GDS) [107], behavioural disturbances are frequent and cause great problems. In the late stages, (GDS 7 with substages) however, the disturbances are less frequent, as the patients are badly impaired by the disease [123].

Scales measuring behaviour, for instance the MDDAS [13], often focus on disturbances in behaviour, which might increase after activation (Paper I and [120]). The positive effects of the increased activation are difficult to score. It seems as if other approaches (interviews, for instance Paper III and [87]) have other possibilities to document these different aspects of higher activation. Changes in behaviour also relate to attitudes in the caring situation and to external stress, and are difficult to measure in quantitative terms. Dementia patients' capacity to tolerate changes, like travelling to DC, is reduced and it may be difficult to reach a balance between the patients need for
stability on the one hand and their need for activation on the other.

2. What are the effects on the Quality of life (Papers I, III, VI)?
It seems as if the effects on the QoL are positive. This cautious interpretation is based on the slower deterioration of variables measuring QoL-aspects (Paper VI and a tendency in Paper I) and interviews (Paper III). The common feature of ICP, DC and GL is the focus on the individual, the communion and security in small groups or units. Early reports on GL also focus on the positive QoL-effects as the most prominent result of the new caring alternative [35-38, 42, 87, 89, 124]. On the other hand may loneliness, insecurity and understimulation occur both in homes and in institutions [125-128]. The QoL-concept is, however, difficult to use and estimate among dementia patients (see methodological considerations).

3. Do DC and GL offer better use of resources and lower costs? (Papers III, IV, V, VI)?
DC and GL very clearly reduced the need for institutional care the first 6-12 months after admission (Papers III, IV, V, VI). A cost analysis including the DC/GL costs and overhead costs (see Table II) does, however, create a more controversial and complicated situation. The monetary benefits of the reduction of institutional care are largely consumed by the very DC/GL costs. If the costs for informal and unpaid efforts made by family members are included, the cost analysis becomes more intricate, as the degree of their work varies and is difficult to quantify [129]. Johansson [12, 130-131] has estimated that the degree of informal support is at least twice as extensive as the formal support in home care, and this figure may increase if the financial problems of the public health system continues. If the institutionalization of severely impaired patients is delayed by DC, the need for families’ support will probably extend in time. Apparently this prolonged period at home will be assisted by the daily caring in DC. CUA on the families of demented patients are rarely accomplished. Drummond et al [132] evaluated a support program to families and calculated that the cost per gained QALY was about Canadian $20 000 in 1988 (about SEK 100 000), to be compared to the SEK 43 000 per gained QALY of the families of the demented patients in DC of our studies (Paper III).

Evaluation studies on DC are controversial and methods and quality of analysis vary [26, 133-136]. Even if the DC-costs themselves and costs for extra HNC, Social Service and episodes of institutional care are added, DC is probably a cheaper alternative for dementia patients than institutional care. Such a comparison is, however, not quite accurate as the average DC-patient is less demented than his counterpart in an institution. Nevertheless, if comparisons with institutional care are made, it must be supposed that the alternative to DC must be immediate institutionalization. DC reduced institutionalization compared to controls at home (Paper IV), and the total DC-costs were also lower.

In an other study (Paper III), DC seemed to be more expensive, but the patient was his own control during a 6-month period prior to DC and the progression of the dementia probably misfavoured the DC-period. It seems as if an important explanation for the ability of DC to prevent institutionalization is the relief that this caring form offers the care-givers. Most spouses (Paper III) have expressed feelings of gratitude and relief in this situation and the application in Paper IV of the psycho-social form
evaluated in Paper II also indicates that the relief of spouses is of great importance. It has also recently been commented on [137], but otherwise has seldom been described in the literature.

Most reports on GL are based on rather short experiences, about 6-12 months. In these studies the GL-costs, analysed with different methods, are about 40-80% of the costs of conventional institutional care [24, 138-140]. Longitudinal studies over longer periods are rare yet, however. Asplund and Wimo [90] found that 8 of the 16 patients who entered GL in 1984-85 were alive four years after admission. Four of these 8 patients still lived in GL. The main reasons for a shift in caring level from GL to institution were behavioural disturbances such as aggression and screaming. Behavioural disturbances among dementia patients in different care settings have been scarcely studied. Hallberg [68] has, however, focused on and described the screaming patterns of the institutionalized demented.

There is a discussion whether severely deteriorated demented patients, either physically impaired or with aggressive and screaming behaviour, are best cared for in an institution or in GL with extra staff and technical support [24]. If the patients live in GL until they die, the costs for the care in GL will probably increase, as this presupposes more HNC-resources.

4. Methodological considerations


Rating scales are widely used in dementia care, both in practice research and as instruments in care planning. Most scales describe nursing load from different aspects. Even if there are objections per se against scales as for their pseudo-parametric appearances, validity and reliability, the instruments are, bearing these disadvantages in mind, incorporated in dementia research. For the statistical analysis of the ratings, non-parametric methods are necessary [108].

Ratings can be obtained either by direct observation or by interviews with staff. To obtain reliable data regarding for instance behaviour or ADL-functions, it is necessary to make observations during a substantial period of time (days, weeks). Observations made by external non-biased raters are unpractical unless they are combined with interviews with staff or families. If the staff is responsible for the ratings, the daily observations are long enough, but there are problems concerning bias and reliability [141]. In the studies of this thesis, short-time observations made by external observers have been combined with interviews with the staff and families of the patients.

4.2. Statistical problems

Rating scales often consist of many items, involving a risk of the "multiple significance effect" [142]. If several items are tested at significance level $p<0.05$, five out of a hundred items are expected to show significant results by mere chance. The significant results of Paper I might be a result of this effect. Statistics also require sufficiently large patient samples. When complex caring programs, like those in the care of the elderly, are performed and evaluated, it is difficult in single-centre studies to organize samples of hundreds of persons or more. Multi-centre studies are often used in pharmacological surveys. However, as in this case when there is a psycho-socially complex situation, a multi-centre design has disadvantages due to the big variation of different centres. We have analysed one area and discussed the problems of this
particular area and thus reduced the immediate possibility of generalization. With this single-centre approach, there is also a risk of type II-errors [143,144] as the samples of Papers I and V are small.

When change is analysed with scales, there is a tendency that patients with initially high values change less than patients with initial low values (if the change points towards increase in the rating results[145]). The populations studied in this thesis are heavily impaired by dementia disorders and the base-line figures are "bad" with a limited space for change.

4.3. The measurement of health-related quality of life?
Some of the papers focus on health related quality of life (particularly Papers III and VI). This concept is difficult to judge and the question of validity is essential in the evaluation of different instruments [99]. The question arises whether it is possible to explain quality of life in an index between 0 and 1? If a CUA is aimed at, it is necessary to use an index, but some QoL-researchers argue that an index is not possible to create. They prefer a multi-dimensional profile instead[146,147].

The concept of health related QoL is usually defined by means of a multi-dimensional approach including i.a. functional/physical, cognitive, psychological and social aspects and also the respondent's own view of his situation and well-being [98,109,148-156]. The validity of the functional and cognitive dimension is possible to analyse with conventional methods (see 4.1) and the social network can be described in quantitative terms [157]. The psychological dimension and the well-being is more difficult to objectify. By interviewing healthy or sick people and by confronting them with certain hypothetical life-situations an apprehension of the psychological aspects can be obtained. QoL scales are then constructed as a weighted synthesis of the different dimensions. The major weakness is of course the validity and generalisability of the psychological dimensions of the well-being of the QoL-figures, especially when the QoL-concept is practised on dementia patients. The generalisability includes at least two problems: Firstly, the representativity of the answers from a few hundred non demented respondents can be questioned. Apart from the dimensions mentioned earlier, QoL also relates to family bonds [158], friends, economic capacity, staff-patient relations and burn-out [70] etc. Among the families of demented patients, the QoL-concept is also a multidimensional task, influenced by factors like burden [159], coping [160], stress [161], social network [162] and depression [163]. The other problem associated with generalisability is the difficult task of comparing different conditions. For example, how does a QoL-figure of 0.44 of a man of 55 years of age who has undergone a coronary by-pass surgery compare to another QoL figure of 0.44 of a demented woman of 80 years of age staying in a GL-unit?

When demented people are analysed, it is very difficult or impossible to obtain an apprehension of the respondents' own views of QoL. It is necessary to use the views of external observers, in accordance with De Jong et al in their work to construct a QoL-scale for patients suffering from cognitive decline [164]. In Paper VI, the IWB-figures are a result of the conversion from dementia-profiled scales to the general IWB-scale. Another approach, used for patients with severe-profiled scales, is to analyse the expressions of the small face muscles, which relate to expressions of mood [67, 165]. QoL-scales can be either generic or specific for different diagnostic entities [166]. Generic scales permit comparisons with other diseases, which is aimed at in priority...
discussions. The interpretation of data might however be too vague, offering unsatisfactory validity [167].

Specific scales can be generated in order to make possible the comparison of the caring results of a target population, but they have little to add in comparisons with other diseases. There are also "semi-specific" scales, focusing on the elderly (i.e. they are not diagnose-specific), [168,169]. A semi-structured approach is sometimes used [170,171], and the information is then more substantial but comparisons with other studies are more difficult to perform.

Scales are often aimed at describing symptoms, and focus on the negative aspects of the patient, families or staff. Positive effects, like joy and happiness are seldom included in the instruments. The different steps of the scales are also rather rough and the small changes, which for the patient, families or staff may be regarded as an important variation, are easily lost in the documentation. Emotions, relations and attitudes, which are of vital importance to the QoL, are difficult to describe both in positive and negative terms by using quantitative methods.

In the accomplishment of CUA, an operationalization and a quantification of the health-related QoL is needed. It is, however, obvious that substantial information of the QoL in wider terms can be lost. As a complement, the use and the development of qualitative methods are vitally important [170].

4.4. Cost calculations (Papers III,V,VI).
In general, when a new method is introduced it has been tested and compared with some kind of established standard method (convergent validity [172]). One of the problems of cost analysis in Health Economy is the difficulties in defining established standards. Comparisons between countries, for instance, are difficult to make since different methods of both financing and organizing care are at hand [109]. If the methods used are presented in detail it might be possible to analyse and interpret the results even if some uncertainty remains. The lack of consensus on the nomenclature of costs in health economy is another obstacle to the efforts to make valid comparisons. Concepts like direct costs, indirect costs, shared costs, variable costs and fixed costs include different properties. In this thesis, the nomenclature is used in accordance with that of Drummond et al [109], and the costs are thus divided into three categories (Table II).
4.5.3. The papers presented in this thesis lack blindness and randomization and sometimes the control of drop-ins is insufficient. The design can be said to be quasi-experimental [145,177]. This design is often used in geriatric research [178], though rarely classified as such.

Campell and Stanley [145] have classified scientific studies and divided research designs into 16 different types. Only three types were truly experimental and had random designs. In their analysis they defined eight criteria of the internal validity and four criteria of external validity that characterized scientific studies. Internal validity concerns the actual study and its results, while external validity encompasses the more difficult questions regarding relevance, representativeness and generalisability [179]. Double-blind random studies fulfill all criteria of internal validity, but such a design does not guarantee proper external validity. Non randomized-, and quasi-experimental studies may also have qualities and advantages according to the validity criteria.

Boruch et al [180] also advocated the quasi-experimental design in this type of scientific work and focused on the practical problems that arise when the evaluation of social programs adapts to demands of scientific designs suitable for pharmacological studies or experimental studies in laboratories. The same difficulty of applying "laboratory" concepts in "field" work may also occur when surgical interventions are evaluated. Buxton [181] studied and described the selection of patients in a cardiac transplantation program, which was evaluated by means of a complex decision tree in a quasi-experimental design of the benefits of the program. At five decision points where patients were selected for the study no random procedure occurred. Even if a random selection had been practiced at the final point (transplantation or not), selection bias could already have occurred at earlier stages.

4.6. Diagnostic problems (Papers I,II,III,IV,V,VI)

One of the major problems of the comparisons of the studies of dementia care over time is the scarce diagnostics of older studies. Characteristics of dementia disorders and differential diagnostics have earlier been relatively unknown which does not disqualify older studies; the value of a longitudinal approach is important. A study frequently referred to is the Lundby-study, which started in the 1940s [182].

The classification and terminology have also changed over time ("age psychosis" and "organic brain syndrome" are seldom used nowadays) and the impact of the concept "presenile dementia" has altered over the years. Today, research work in the field of classification of different types of dementia is intensive [51] and differential diagnostic problems between dementia on the one hand and acute confusional states [183] and depression [184] on the other are of great interest.

The main diagnostic procedure of this thesis has been to differentiate between "dementia" and "no dementia". In Papers II,IV,VI, the diagnostic procedure included a clinical judgement made by the project manager (AW) and a dementia-profiled geriatrician (AN). A diagnostic schedule used by the Geriatric Clinic was also utilized. The diagnostics of these studies, regarding both the differentiation between "dementia" and "no dementia" and the typing of separate forms of dementia must be regarded as sufficient.

In Paper I, the diagnoses were based on the diagnoses of medical records and a clinical examination made by the project manager and one of the co-authors (AN). In Papers III and V, some of the patients have been judged by dementia-profiled
physicians (geriatricians and gero-psychiatrists). Diagnostic procedures according to the schedule of Papers II, IV, VI were, however, never used in Papers III and V, as the schedule was not at hand when these studies started. The typing of the dementia of these studies ought to be questioned to some extent. However, as the patients in Papers I, III, V (as well as the patients in Papers II, IV, VI) have been observed during the whole study period, and the cause of the disease over time, i.e. progression, is one of the most important diagnostic factors, the reliability of the diagnostic labelling can be regarded as satisfactory enough.

5. Health economy

In health economy, the analysis focuses on the relation between the costs and the effects of care and so basic data for priorities can be obtained. Health economy aspects were studied before the 1980’s, but the financial burden of the public health system during the last decades has focused on the research in this field. Even if the fundamental principles of an analysis are quite simple; i.e. the costs and the effects to perform CBA, CEA and CUA [109] are defined, there are problems to interpret the data. If the target is to compare the results of different diagnostic groups, certain problems arise. The QALY-concept [99, 185, 186] has been introduced to facilitate comparisons and it has been used worldwide and the number of studies in this field is increasing. Most reports focus on rather easily defined effects, for instance results of surgery [187, 188] or pharmacological treatment [189]. It is, however, more uncommon to analyse the long-time perspective of the daily care of chronic, progressive and untreatable diseases among the elderly, like dementia (Paper VI) [190].

To discount future costs to a now-value [191] has often been used since there is a tendency for costs and benefits to be valued higher today than tomorrow or in five or ten years ahead. A discount rate between 2 and 10% is often used, depending on the estimated inflation among other things during the period [109], which for the demented patients covers the estimated period of survival (usually between 7 and 10 years [2, 192]). The discount rate chosen often influences on the results, and this effect is reflected in Paper VI.

The use of QALYs has been discussed, for instance its ethical implications [193], the risk of misfavouring old and very sick patients [194], and also regarding the preferences in time. Does one QALY have the same value when you are 18 years old as when you are 70 [195]?

Health economic principles are of vital importance in a cut economy. Today’s tendency is to question whether principles of market economy are applicable to Health Care. In Oregon, U.S.A, a concept based on the IWB among other things is supposed to be used to make health care priorities [196]. Concerning dementia care, a provocative question could be expressed as follows:

"Is it possible to use the cost per gained QALY as a price-indicator on the market of the health-related quality of life for the demented?"

This question is difficult to answer for several reasons. There are some well-known objections against a strict use of market principles in health care, for example the unclear and unequal part situation [190, 197], problems for the price mechanism to work, difficulties to formulate business agreements, the tendency of the market to lead to inequality [190, 198, 199] and the fact that an increase in
productivity might misfavour the effectiveness and quality of care [7]. Furthermore, there is also some methodological insecurity in the CUA, with regard to both the cost calculations and the different QoL-indexes. If the cost per QALY is to serve as a support for the making of priorities, the demands on validity and reliability must be high and the span for potential results (for instance confidence intervals) must be narrow. However, CUA is worth improving.

The "old" system with centralized health care planned in detail, had many disadvantages causing inefficiency, waiting lists and bureaucracy, and the introduction of effectiveness discussions has been a vital injection, but like John L Appleby stated in the BMJ [200], "....Cost effectiveness analysis should not be seen as having the power of veto, but rather as providing one part of the information (in addition to political, social, medical, and philosophical criteria) necessary to achieve a truly informed decision about using the society's resources."
CONCLUDING REMARKS

The introduction of new caring alternatives for dementia patients, i.e. DC and GL and the interpretation of the principles of ICP and mental activation, have resulted in a more efficient caring organization where patients can be offered more individualized care.

The effects on the QoL regarding both the patients and their families are positive. However, the effects on ADL-functions and cognitive functions are poor if any, while the effects on behaviour are difficult to evaluate. With a differentiated caring organization, the care also becomes more cost-effective, as institutionalization can be postponed. The CUA also shows that for many dementia patients GL offers better care to a lower cost than institutionalization.

The results of this thesis may be a contribution to the priority discussions in the care of the elderly, but also an indication of the great need for methodological research concerning the QoL-concept of dementia patients which may lead to improved CUA application.
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