ASPECTS OF INSTITUTIONAL CARE OF PATIENTS WITH DEMENTIA

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ABSTRACT

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The aim of the present study was to investigate all long-term institutions in the county of Västerbotten, Northern Sweden, to give a detailed description of the institutionalized population with respect to motor functions, vision, hearing, speech, ADL-functions, prevalence of psychiatric symptoms and behavioral disturbances, staff work load, use of psychoactive drugs and prevalence of dementia. Another aim was to select some specific 'problem areas' in the nursing care of demented patients for further descriptive and interventional studies. For this reason, morning care procedure (hygiene, dressing), meal behavior (eating, communication), nutrition, constipation and relocation between institutions were selected.

The results of the study have been reported in six papers summarized below:

I. The study has shown that the proportion of demented patients is increasing in long-term institutions in Sweden. Furthermore, demented patients were shown to be more impaired in all rated functioning abilities and exhibited more psychiatric symptoms and behavioral symptoms. A high proportion of the demented probands were also prescribed psychoactive drugs, i.e. neuroleptics.

II. Five patients with Alzheimer-type dementia were monitored during morning care. A 12-step classification system was developed to be used as a guide to understand and determine abilities essential for performance of morning care for demented patients. The quantitative assessment showed that none of the patients were able to manage morning care independently, but there was a wide variation in their highest level of performance.

III. Five patients with Alzheimer-type dementia were observed (video taped) during their meals in a changed meal milieu and with new meal routines. When the patients ate without staff participation, the two least demented patients became 'caregivers'. When two mental nurses joined the group, first in civil clothes and then in white uniforms, the patients dropped their roles as helpers. The patients were able to compose complete meals in 0-79 per cent of the meals. The conversation during the meals could be characterized as incomplete, with short sentences and a lot of breaks. Sixty-three per cent of all utterances were about food and eating and almost all conversation concerned the present time.

IV. Thirty-three psychogeriatric patients, with severe constipation were given a high-bran bread instead of their accustomed laxatives. During the high-bran treatment period, the number of bowel evacuations and the volume of faeces increased. The total laxative consumption decreased by 93 per cent.

V. Nutritional status and dietary intake were studied in a sample of severely demented, institutionalized patients. Energy and/or protein malnutrition was found in 50 per cent of the patients. The mean energy intake was 2059 kcal. Malnourished patients had had four times as many infectious periods during their hospital stay as patients without malnutrition. Thirty-nine of 44 patients lost weight during their hospital stay.

VI. Thirty-three psychogeriatric patients were followed for 36 weeks after relocation from a mental hospital to two newly built nursing homes. An intensive pre-relocation program was performed. No negative effects of the relocation were found. On the contrary, the relocated group improved their ADL-functions after the transfer.

Based upon the above cited studies, a model for nursing care of demented patients is presented.

Key words: Dementia, institutional care, ADL, constipation, conversation, dietary intake, morning, care, relocation.
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Key words: Dementia, institutional care, ADL, constipation, conversation, dietary intake, morning, care, relocation.
The present thesis is based on the following studies:


The reports are presented in a logical rather than chronological order and in the following text the reports will be referred to by their Roman numerals.
INTRODUCTION

Population prognoses for the next 50 years, in the industrialized countries, show an increasing proportion of elderly. In Sweden, 13.8 per cent of the population were older than 65 years 1970. This had risen to 17.5 per cent by 1985 and is estimated to be about 20 per cent year 2025 (Figure 1) (Official Statistics of Sweden, 1986).

The prevalence of institutional care of the elderly in long-term institutions is high in Sweden (Adolfsson, 1980) compared to other countries in Europe and USA (Grundy and Arie, 1981). The prevalence of institutionalized older people increases with advancing age because of a higher incidence of chronic diseases. Some other factors predisposing to institutionalization are mental disorientation, use of ambulatory aids, living alone and the need of assistance to perform ADL-functions (Branch and Jette, 1982). Greenberg and Ginn (1979) found that those receiving institutional care were more often widowed or unmarried women and Nielsen et al, (1972) found, in a longitudinal study, that those who lived together with someone and had home care
services were less likely to become institutionalized. The progressive course of dementia can be seen as a continuum in which the patients will exhibit symptoms that successively involve more and more of their physical and psychological abilities which, in later stages, almost inevitably leads to institutional care. Organic brain disorders probably generate the heaviest demand for institutional care.

There are a number of different dementia diseases affecting the aged individual (Haase, 1977). The most prevalent dementia disorder is Alzheimer's disease/senile dementia of Alzheimer type (AD/SDAT) (ca 50%), followed by multi-infarct dementia (MID) (ca 20%) and a mixed form, i.e. AD/SDAT and MID coexisting (ca 12%) (Tomlinsson, 1980). According to the DSM-III classification (American Psychiatric Association, 1980), AD/SDAT is defined as a progressive disease leading to an intellectual reduction causing social or occupational impairment. The patients' memory functions, judgement, ability to concentrate and a variety of other higher cortical functions are affected. Neurologic signs such as aphasia, agnosia and apraxia are commonly seen and, in later stages, desorientation, psychiatric symptoms and behavioral disturbances and impairments in ADL performances will characterize the clinical picture. Hence, the demented patient will find it increasingly difficult to manage his life independently.

Today, there are no possibilities to cure dementia. Psychiatric symptoms and behavioral disturbances are traditionally treated with psychoactive drugs, but the effects of such treatment are controversial (Helms, 1985). Other, non-pharmacological alternatives are, for example, reality orientation, reminiscence groups and life review therapy. The effects of these treatment strategies on cognition (e.g. memory) has however given ambiguous results (Ivan, 1982; Åkerlund and Norberg, 1986).
There is a pronounced need for more knowledge about how to take care of demented patients (Adolfsson et al, 1982). New methods must be developed which will give the staff possibilities to provide more specific care for patients with dementia and, thereby, increase the quality of life although the dementia disease is uncurable.

The aim of the study

The principal aim of the present work was to investigate all long-term institutions in the county of Västerbotten in the Northern part of Sweden, in order to give a detailed description of the institutionalized population with respect to motor functions, vision, hearing, speech, ADL-functions, prevalence of psychiatric symptoms and behavioral disturbances, staff work load, use of psychoactive drugs and prevalence of dementia. Another aim of the investigation was to select some specific 'problem' areas in the nursing care of demented patients for further descriptive or interventional studies. For this reason, morning care procedure (hygiene, dressing), meal behavior (eating, speech), nutrition, constipation and relocation between institutions were selected for further research.
MATERIAL AND METHODS

Epidemiological study (I)

The investigation was a period prevalence study 1982 in the county of Västerbotten with a total population of 244 789 of whom 37 767 (15,4%) were older than 65 years. During two weeks in May 1982, all institutions in the county (36 homes for the aged, 23 nursing homes, 3 somatic long-stay clinics, 9 psychiatric long-stay units and 9 psychogeriatric units) were inventoried. A rating scale was distributed to all institutions to be filled out by the staff. Of 3910 patients, 3607 were rated (92%). Nursing homes had the lowest response rate (86%). For other institutions the response rate varied between 94 and 97 per cent.

Two instruments were used in the study. The occurrence of dementia was measured with the subscale, II, (see Appendix I in paper 1) (Gottfries and Gottfries 1968; in: Adolfsson et al, 1981). The scale consists of 27 questions (yes/no) on orientation and general information. If a proband is rated to have less than 24 points, i.e. more than three "no" answers, he is considered demented. The II scale has been validated against the 'Mini-Mental-State-Examination' (MMSE) (Folstein et al, 1975) in a geriatric and a psychogeriatric clientele (n=52). The sensitivity of the II scale was measured to 90 per cent and the specificity to 91 per cent.

The second scale used (Multi-Dimensional Dementia Assessment Scale; see Appendix 2, paper I), measures motor functions, vision, hearing, speech, ADL-functions, behavioral disturbances, psychiatric symptoms and staff work load (see Appendix 2 in paper I). The scale allows a construction of three subsets of scores, i.e. scores for orientation, psychiatric symptoms and behavioral disturbances. A group of forty-four and another of 55 patients, with different organic brain disorders, at a psychogeriatric clinic in a mental hospital were rated to describe the intra-rater and inter-rater
reliability. Scores for exact agreement (= ea%) (Bartko and Carpenter, 1976) and Cramer's Phi (Howell, 1982) measuring the correlation between the different ratings were calculated.

**Morning care (II)**

Five patients (2 men, 3 women; 54-76 years old), representing different stages of Alzheimer-type dementia, were included in the study. The patients' level of functioning were assessed with the Multi-Dimensional Dementia Assessment Scale (see paper I). All patients were to a varying degree dependent upon the staff for managing their activities of daily living (ADL). None of the patients were orientated to time and place but four of them were orientated to their own person and all could recognize their relatives.

The patients were monitored by unstructured direct observations by four observers during morning care procedure, on six occasions for each patient. For each occasion, two independent observations were performed simultaneously. Observations were performed and notes were taken during the observation period so that observing and taking notes alternated in an unsystematic way.

The observation notes were analyzed qualitatively line by line according to a method developed by Strauss and Glaser (Glaser, 1978). The data were also analyzed quantitatively to measure the help provided by the staff. The patients' abilities to perform two aspects of morning care, i.e. washing and dressing, were analyzed on four levels of dependence: complete independence, need of instructions/suggestions, need of initiation, and total dependence on the staff. The percentage of exact agreement for the quantitative assessment between two independent observers was 88 per cent.
Meal behavior  (III)

Five patients with Alzheimer-type dementia (2 men, 3 women; 63-80 years old) were selected for the study. The duration of illness was 3-10 years and the time for hospital stay 2-6 months. Two patients were severely and three moderately impaired according to the MMSE test (range 0-24 p). Three patients had symptoms of aphasia, two of agnosia and one of apraxia. Four of them could not recognize taste and smell. All were prescribed different types of psychoactive drugs.

For the five patients, a small room was fitted out as a dining room in order to create a positive meal milieu. The table was laid with a set of china, tableware, flowers and napkins and the patients could serve themselves from dishes and deep dishes. The study was performed during a three-week period, with one week of training (period 1), one week when the patients ate totally independent of the staff (period 2) and a third week when two mental nurses participated in the meals dressed in civil clothes (period 3) and then in white uniforms (period 4). They were instructed not to initiate conversations or offer the patients any help if the patients did not request for it. The same mental nurses participated in all meals.

All meals during periods 2-4 (10 breakfasts, 10 lunches, 10 coffee meals and 10 suppers) were videotaped with a fixed video camera in the dining room. A microphone on the table recorded the patients' conversation. Four meals were not possible to analyze due to technical errors.

The videotapes were analyzed qualitatively in order to describe the meal behavior for each patient, and the interaction in the group. A quantitative analysis was performed to estimate the time the patient spent in the dining room for all the 36 meals. Breakfasts and supper meals (19 meals) were selected for a quantitative analysis of
the patients' abilities to compose complete meals and to determine on whose initiative and by whom the patients were served the different components of the meal.

Nineteen meals (4 breakfasts, 6 lunches, 4 coffee meals and 5 suppers; total 6.5 hours) were selected for an analysis of the patients' communication. Each utterance was coded for 'direction', 'content' and 'tense'. The content of the communication was further analyzed into five categories:

1. Food and eating
2. Relations
3. Remaining
4. Incomplete sentences
5. Incomprehensible

The categories 'food and eating' and 'remaining' were further analyzed with respect to themes.

**Treatment of constipation (IV)**

To investigate whether it was possible to replace traditional laxatives with a high-bran diet, all patients receiving laxatives at a psychogeriatric clinic (109 of 166 patients; 65%) were studied. Those among them who could manage their toilet visits independently were excluded. Another eleven patients dropped out during the trial due to somatic deterioration (5), relocation (3), abdominal pains (1) and refusal (2). The final group consisted of 33 patients (15 men, 18 women; mean age 74.9 years) with diagnoses of multi-infarct dementia (20) and Alzheimer-type dementia (13). All patients were up and about during the day. Twenty-four patients were served food that had been finely chopped into a more easily chewable consistency. Six of the patients were without teeth.
The study was designed with an experimental period (5 weeks) and a control period (5 weeks). A special high-bran bread, Wasa Fiber (Wasa-Bröd AB), was given to the patients throughout the experimental period instead of their laxatives. The bread was prepared from whole rye meal and wheat bran and had a fibre content of 22 per cent (according to Weinstock and Benham, modified by Thomas, 1975). The bread was given as an open sandwich or broken up and mixed with milk, six pieces per day throughout the experimental period. During both periods the bowel habits and the laxative consumption were recorded. At the end of both periods the patients metabolic status (week 5, n=33) was measured. For a randomly selected group of 20 patients, the glucose metabolism (week 4, n=17) and dietary intake (week 5, n=18) were recorded. The nutritive content was calculated with the aid of a nutritional computer (NutriData) where the Swedish Food Tables were used for the data base (Food Composition Tables, 1978).

**Nutritional status and dietary intake** (V)

Forty-four patients in a psychogeriatric clinic (mean age 77.6 years; with a diagnosis of AD/SDAT (18) or MID (26) (DSM-III classification) were included in the study. The mean duration of illness calculated from the onset of amnesia was 66 months and the mean length of hospital stay 25 months. The patients were rated as severely demented, e.g. scoring between 4 and 5 on Berger's 6-step scale (Berger, 1980). Forty-five per cent of the patients were dependent on the staff for their feeding and all patients could eat at least finely chopped food. None of the patients were totally bedridden. The patients were initially chosen for the high-bran bread trial (see paper IV). Out of those, 20 patients were randomly selected for determination of dietary intake and nutritional status. Two refused to participate, so the final group consisted of 18 patients (8 men, 10 women; mean age 73 years) with a diagnoses of AD/SDAT (10) and MID (8). The group was determined to be representative for the total group
in respect of age, duration of illness, length of hospital stay, motor functions, ability to eat and degree of dementia.

For all patients, weight for height index, weight change, an extensive laboratory screening (including albumin, pre-albumin and transferrin) were determined and mortality recorded. The dietary intake was determined on two occasions, during five consecutive days, five weeks apart. The nutritive content (energy, proteins carbohydrates, fat, water, minerals and vitamins) was calculated with the aid of a nutritional computer (NutriData). Furthermore, the patients' energy needs were calculated (Hessov, 1980; Calloway, 1980). Finally the nutritional status of the group was determined according to energy and/or protein malnutrition (for definitions and reference values, see paper V). Antibiotic treated infectious periods and the time on antipsychotic medications during the hospital stay were also recorded.

**Relocation (VI)**

Forty-six patients from a psychogeriatric clinic were prepared for relocation to two newly built nursing homes, some 150 km distant. Eleven of them were not transferred for different reasons, so the relocated group comprised finally of 33 patients (16 men, 17 women; mean age 75 years). Fifteen of the patients were diagnosed as AD/SDAT, four as MID and 14 as having chronic schizophrenia with residual symptoms. Mean length of hospital stay was 34 months for the demented patients and 218 months for those with schizophrenia. A majority of the patients were dependent upon the staff to manage their ADL except for eating. A majority had normal vision and hearing but nine of them could not walk unaided.

Another 33 patients were selected as a control group from the remaining population at the mental hospital. The most important criteria for the selection of the control patients were the patients' ability to orientate to person, time and room. Secondly diagnosis,
sex, age and length of hospital stay were matched as close as possible to the relocated group. When comparing the groups according to these background variables, no significant difference was found.

The relocation was extremely well-prepared. Prior to the relocation the physicians from the 'new' nursing homes assessed the patients. Furthermore, those among the nursing home staff who were lacking psychiatric training were educated theoretically and spent thereafter two weeks at the mental hospital to become familiar with the patients. A detailed telephone report to the new department and an accompanying staff-member from the mental hospital completed the pre-relocation preparation program.

The relocated patients and the controls were followed for nine months with a baseline rating and ratings at 1, 3, 12 and 36 weeks. Ratings were performed with the Multi-Dimensional Dementia Assessment Scale (see paper I). To simplify the comparisons, four scores were constructed, i.e. a score for ADL-functions, orientation, behavioral and psychiatric symptoms (for details, see paper I). The same staff rated the same patient upon each occasion after relocation. Interviews were performed with the staff at the mental hospital and at the nursing homes and with the closest relative to the patient to complete the information about the outcome of the relocation.

Statistics

Statistical methods are described in papers I-VI
RESULTS

Epidemiological study (I)

During the period 1975-1982 the population older than 65 years had increased by 11.6 per cent in the county of Västerbotten. The increase was most marked in the ages above 80 years (Figure 2)

![Graph showing increase in population by age group]

Figure 2. Per cent increase in the population older than 65 years during the period 1975-1982, in the county of Västerbotten.

Out of the total population in Västerbotten, 9.2 per cent of those older than 65 years were institutionalized. The mean age of all institutionalized was 79.6 years, the highest mean age being found in homes for the aged (82 years). With increasing age, a higher proportion was institutionalized (Figure 3).
The mean time for hospital stay varied between 2.7 years (somatic long-stay clinics) and 14.3 years (psychiatric long-stay wards). A higher proportion of women was found in all types of institutions with the exception of psychiatric long-stay wards.

About forty per cent of all probands were demented. The highest proportion was found in psychogeriatric clinics (90.6%) and the lowest in homes for the aged (18.8%). Sixty-eight per cent of all the demented were women. As can be seen in Figure 4, the proportion institutionalized demented in proportion to the whole population increased with increasing age as did the share of demented probands in different age groups.
In comparison to the results of the 1975-year survey, it was found that the proportion demented in the population had increased in nursing homes (6.3%), in somatic long-stay clinics (4.0%) and in homes for the aged (1.7%). There was also a displacement towards older patients with a longer time of hospital stay but, the sex distribution remained unchanged.

Fifty-five per cent of the probands could walk unaided. Other impaired functions were seen in vision (20%), hearing (32%). Nine per cent of the probands were reported to have such severe speech disturbances that their talk could not be understood. Total dependency or need for assistance from the staff to manage primary ADL-functions was a common finding (Figure 5).
The most common, daily occurring behavioral disturbances were wandering back and forth in the corridors (9.3%) and resistance when being dressed and undressed (6.3%). The most common, daily occurring psychiatric symptoms were 'seeks help' (15%) and 'disturbed and restless' (12.2%).

Compared to probands in other institutions, the probands in nursing homes and somatic long-stay clinics were rated to represent the highest physical staff work load. These institutions also had the highest proportion of probands with symptoms of paralysis and the lowest proportion with normal ability to walk. According to ADL-functions, lower proportions of probands managing their ADL independently were found in nursing homes and somatic long-stay clinics (Figure 6).
Furthermore, use of indwelling catheters (CAD) and bowel incontinence were most prevalent in nursing homes and somatic long-stay clinics.

Behavioral disturbances and psychiatric symptoms were most prevalent in psychogeriatric clinics and psychogeriatric long-stay wards. The psychiatric work load was rated high in these institutions. Furthermore, the use of psychoactive drugs was most frequent in psychogeriatric clinics and psychogeriatric long-stay wards.

When comparing demented and non-demented probands marked differences were observed with respect to all ADL-functions (Figure 7).
More demented probands also had impaired vision, hearing speech and motor functions. Behavioral disturbances, psychiatric symptoms and disorientation were also more prevalent in the demented population. Demented probands were also rated to have the highest physical and psychiatric work load on the staff. They were also more frequently prescribed psychoactive drugs, e.g. neuroleptics, than non-demented.
Morning care of demented patients (II)

A classification system was developed based upon the qualitative analysis of the morning care behavior. This classification system is composed of 12 abilities necessary for performance of morning care (Table 1).

1. Be motivated to participate and to perform the actions
2. Recognize and understand one's own body
3. Have the sensory-motor functions required for performing the actions, e.g. hearing, strength
4. Understand the purpose of each sub-system, e.g. that the hands should be clean and dry
5. Recognize and understand the objects used during morning care, e.g. soap, towel
6. Be able to perform the actions necessary, e.g. perform movements for washing oneself
7. Be able to combine different actions into a logical goal-directed sequence of actions, e.g. wet, rub, rinse, and dry
8. Be able to combine the separate subsystems, e.g. wash, dress and comb, into a logical whole
9. To have an adequate perception of time and how much time to use for each subsystem
10. To understand quality, e.g. judge if the hands are clean enough

If the patient is dependent upon a nurse:

11. Be able to communicate
12. Recognize and understand the function of the nurse

Table 1. Classification system. Abilities necessary for performance of morning care.

For a detailed description of the patients' self-care capabilities analyzed on the basis of the classification system, see paper II, Table 2.

The five Alzheimer patients observed could be characterized in the following way:

Patient 1 was well motivated, showing good insight in his situation and seemed to understand the function of the nurses. He had severe problems to perform his morning care procedure due to apraxia, agnosia and aphasia. Characteristic was his inability to plan his actions and proceed from one action to another. He also
demonstrated a disturbed body image but, however, it seemed to be easier for him to perform actions related to his body than to objects. His symptom of apraxia was affected by the emotional climate between him and his nurses, e.g. he could more easily perform actions in an automatic way in a warm and friendly atmosphere.

*Patient 2* was not motivated and did not seem to understand either the situation or the function of the nurses. He often reacted with aggression or resistance and the nurses often failed to complete his morning care due to his lack of cooperation.

*Patient 3* was well motivated and understood the morning care situation and the function of the nurses. She seemed to be more dependent on the nurses than would seem to have been necessary, as she sometimes showed a surprisingly good ability to perform morning care independently.

*Patient 4* was not motivated to cooperate in her morning care. She was quite passive during the whole process and the nurses performed all actions. The patient seemed to be annoyed with the situation and the nurses.

*Patient 5* was chair and bedridden and totally dependent upon the nurses for her morning care. She was not able to communicate with her nurses verbally but could express reactions non-verbally by crying, smiling or grimacing.

No patient could manage his/her morning care fully independently and two of them (4 and 5) were totally dependent on help from the nurses on all occasions. For patients 1-3, the highest level of performance varied from day to day according to washing and dressing (Figure 8).
It was obvious that it was more easy for the patients to perform washing than dressing. Fifty-five per cent (mean) of all actions of washing were performed by the patient after suggestions or instructions from the staff. The corresponding figure for dressing was 22 per cent.

**Meal behavior (III)**

The patients spent about 1.5 to 2 hours a day in the dining room. They showed pronounced difficulties to compose their meals. A minority of all meals could be characterized as complete meals (0-42%). However, most often the patients had eaten the main dish (74-100%). The most demented patients (C-E) ate less complete meals. They could for example eat only potatoes without fish or meat or solely porridge without milk. All patients ate more complete meals when the mental nurses participated in their meals during periods 3 and 4.
During period 2, 82 per cent of all meal components were served by the patient him/her self and on his/her own initiative in 74 per cent. During period 3 and 4 the proportion meal components served by the patient him/her self remained unchanged while initiative to serve from other patients decreased to 14 per cent.

The conversation in the group could be characterized as sporadic and scanty (5 utterances per minute) with a lot of breaks and short and incomplete sentences with few utterances and a lot of unanswered statements between the patients. A majority of the conversation concerned the actual situation, e.g. food and eating (63% of the comprehensible speech). Almost all conversations were classified as concerning present tense. When comparing period 2 and periods 3+4 it was evident that the pattern in the group was changed when the mental nurses participated. This was most obvious for patient A who decreased her utterances from 21 per cent to 5 per cent.

Patient A and B had no problem to perform the meals in a proper way. During period 2 they developed a responsibility for the other patients and became more aware of their problems. They could for example serve food, instruct or even spoon feed other patients. Patient C had in general no problems to manage the eating procedure. Sometimes when he was confused he did not eat at all. Patient D had the most pronounced problems due to apraxia and aphasia. He could not handle a fork and knife correctly and had to be served by the other patients to get any food on his plate. Sometimes he ate directly from the deep dishes. However, he was aware of his disabilities and tried to explain to the other patients that his problems were caused by his disease. Patient E showed an 'anorexic' behavior. She often talked about the food and tried to give the other patients an impression of that she had been eating, although she sometimes did not eat at all. When comparing the two periods according to the patients' behavior, patient A and B lost their 'staff-function' when the mental nurses participated in the meals (period 3 and 4), that is, they decreased their help to the other
patients. The most impaired patients did not change their behavior from period 2 to periods 3 and 4. They did not seem to be aware of the mental nurses.

**Treatment of constipation (IV)**

The patients consumed an average of 5 pieces of the crisp bread per day during the high-bran period. When comparing both periods it was found that the total number of bowel evacuations increased (+42%) and the frequency of diarrhea decreased (-48%). The total number of doses of laxatives given decreased by 93 per cent while the number of enemas given remained unchanged (Table 2).

<table>
<thead>
<tr>
<th></th>
<th>Control period</th>
<th>High-bran bread period</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Total number of stool evacuations per patient</td>
<td>12,2</td>
<td>4,3</td>
</tr>
<tr>
<td>Number of enemas given per patient</td>
<td>1,0</td>
<td>1,4</td>
</tr>
<tr>
<td>Total number of doses of laxative per patient</td>
<td>27,4</td>
<td>13,0</td>
</tr>
</tbody>
</table>

Table 2. Comparison of observation period and high-bran period with reference to bowel function and consequent changes in laxative consumption (n=33) (Student's t test ** P< 0,01, *** P< 0,001).

The patients had had a water intake of some two liters per day during both periods. A slightly increased energy intake was found for the high-bran period. The oral glucose-tolerance test showed that the seven patients with the largest area beneath their tolerance curve during the control period decreased their area during the high-bran period. Furthermore, blood glucose values between 90 and 150 minutes were significantly lower during the high-bran period. No metabolic side-effects were found as a consequence of the higher bran intake.
Nutritional status and dietary intake (V)

The patients in the total group (n=44) had a mean weight of 60 kg at admission. Thirty-nine of them lost weight during their hospital stay (mean loss 12%). Patients with AD/SDAT had lost significantly more weight than MID patients. No correlation was found between weight change and time of hospital stay.

By definition (see paper V, Table 2 and 3), six of 16 patients in the study group showed energy malnutrition, one patient showed chronic protein malnutrition and one patient both protein and energy malnutrition.

The patients in the study group had a mean dietary intake of 2059 kcal, which, for 16 of the 18 patients, was significantly higher than their calculated needs. Patients who were fed by the staff had a higher energy intake than those who ate independently (2146 kcal compared to 1922 kcal). Most of the patients had an intake of energy, carbohydrates, fat, proteins, minerals and vitamins well above recommendations from the Swedish National Food Administration (1981). There was no difference in energy intake when comparing AD/SDAT and MID patients or patients with or without malnutrition. However, patients with malnutrition had had four times as many antibiotic treated infectious periods during their hospital stay compared to those without malnutrition.

Relocation (VI)

Of the 33 relocated patients, two died and three were transferred again during the observation period while four of the control patients died and three were transferred.

The relocated group and the control group were comparable on the basis of ADL-, orientation- and behavior scores before relocation while the control group had a
significantly higher score for psychiatric symptoms. After relocation, the relocated group showed an improvement in ADL-score 1, 3, 12 and 36 weeks after relocation when compared to baseline ratings (Figure 9). This improvement was not seen in the control group.

The improvement was significant for patients with schizophrenia 3, 12 and 36 weeks after relocation but for patients with dementia only at 3 weeks.

Orientation and psychiatric scores were unchanged when comparing baseline and post-relocation scores for both control and relocated patients. Scores for behavioral disturbances tended to be higher 1 and 3 weeks after relocation in the relocated group (Figure 9).

Most of the relatives were positive to the transfer 3 months after the relocation, mainly because it facilitated their visits to the patients. However, a majority of the relatives
stated that they felt an increasing demand to make more frequent visits, and there was actually an increase in visits.
GENERAL DISCUSSION AND CONCLUSIONS

The present study of individuals living in long-term care institutions has shown that demented patients, to a considerable degree differ from the non-demented. Demented patients were found to be more impaired in ability to walk, vision, hearing and speech. Furthermore, they were rated to be less capable in their ADL-functions and showed more psychiatric symptoms and behavioral disturbances. An unexpectedly high proportion were prescribed psychoactive drugs. The reason why the proportion demented patients had increased in some institutions, when comparing data from 1975 and 1982, might be a reflection of the current health care system which provides especially for non-demented persons increasing possibilities to be cared for at home. These results were not unexpected when considering the profound differences between demented and non-demented. The burden for relatives, caring for demented individuals at home has often been described as overwhelming (Hirschfeld, 1981; Rabins et al, 1982; Sandman et al, 1986).

The increasing number of older people and, hence, the increasing number of demented, in the industrialized countries will imply heavy demands on the health care organization as represented by traditional institutional care. There is an obvious need to develop and extend new ways to manage this. Home care with different kinds of support to relatives and/or in combination with day care is one alternative. Another is the kind of living arrangements where the patients live together with staff in ordinary apartments (Asplund et al, 1986) One interesting fact emerging from this living arrangement was that for long periods the patients were not in need of the expertise of a physician or a registered nurse. Furthermore, this kind of living offered the patients a natural and homelike milieu to live in, unlike the traditional institutional care. However, being aware of the risks of becoming institutionalized, with negative effects on the patients psychological and physical well-being, should, in the future, lead to strong demands that new forms of care for the demented will be developed.
Another common situation, often affecting the elderly patients' well-being, is relocation within or between institutions. Studies of relocation of elderly persons have reported adverse effects, such as an increased mortality or a reduced physical, social or psychological level of functioning (Liebermann, 1961; Aldrich and Mendkoff, 1963; Killian, 1970). In this study we could not find any negative effects of the relocation. On the contrary, the relocated group improved their ADL-functions after the transfer. The intensive pre-relocation preparation, which provided the new staff with detailed knowledge about the patients and an opportunity to develop a relationship to the patient prior to the relocation, seems to be a plausible explanation for the positive outcome. The importance of a pre-relocation program has also been shown in other investigations (Zweig and Csank, 1975; Dube, 1982; Amenta et al, 1984), although many of these programs described were not adjusted to the needs and impairments of demented patients.

Relocation between institutions is necessary if there is an ambition to differentiate the care, i.e. take care of demented and non-demented patients as well as patients with various degree of dementia in different wards. This issue is controversial. Some argue that if you are housing demented and non-demented together, the demented patients might be positively influenced by the non-demented and, consequently, improve their level of functioning. There is, however, no support for this in the literature. On the contrary, based on clinical experience, there are advantages with separating demented and non-demented patients. One problem with this kind of differentiation is that few staff are interested to work exclusively with demented patients (Sandman et al, 1983).

A positive environment in the care of demented patients is crucial. In the relocation study the patients were relocated to an environment which could be characterized as more positive than the environment at the mental hospital, i.e. new facilities, a
well-educated and well motivated staff and being able to live closer to relatives. The outcome with an improvement in ADL-functions could be interpreted out of Lawton's theory (Lawton, 1980) in which behavior is described as a function of the individuals' competence and the environment. An environment not adapted to the patients' abilities can lead to the patient's optimal capacities not being used. In an environment adapted to the patient's individual competence, an increase of the individual's manifest capacity can be expected. The same theory can be used to interpret the results from the investigation of meal behavior, where a positive, natural and more homelike meal environment adapted to the patients' abilities, meant that the patients could function at an unexpected high level, independently of the staff. This was most obvious for the two patients with the highest level of performance, who became 'caregivers' in the group. Their 'caregiver' behavior was changed when the mental nurses participated in the group, e.g. they took less responsibility for more impaired fellow patients. Positive outcome of a changed meal environment has previously been reported (Davies and Snaith; 1980; Melin and Götestam, 1981; Elmståhl et al, 1985). Other changes of the environment in institutions have also given positive effects. Svensson (1984) reported improved ability to orientate in a group of psychogeriatric patients after introducing signposts. The results are supported by other investigations (Gilleard et al, 1981; Hanley, 1981). Other types of environmental changes, which have been reported to have a positive influence on the behavior in psychogeriatric or geriatric patients were reached by modifying various features of the settings in which behavior occurs, giving the patients recreational material or by occupational therapy sessions (Jenkins et al, 1977; McClannahan and Risley, 1975; Miller, 1977; Burton, 1980).

In the epidemiological study, some specific 'problem areas' separating demented and non-demented groups were identified. Out of the ADL-ratings it could be seen that a very high proportion of the probands were dependent on the staff to manage their hygiene (55%) and dressing (55%). Only 10 per cent of the demented but 61 per cent
of the non-demented could perform dressing independently. Corresponding figures for hygiene were 17 per cent and 67 per cent, respectively. Furthermore, the combined measure of workload, i.e. the number of staff needed to perform morning care (washing, dressing), showed that 63 per cent of the demented probands needed help of one, and 31 per cent of two attendants to manage their morning care procedure. Corresponding figures for the non-demented probands were 46 and seven per cent, respectively. These figures clearly demonstrate a specific 'problem area' in the care of demented patients.

Direct observations of five patients with Alzheimer-type dementia during their morning care procedure provided even better insight into the demented patients' problems of dependency. The analysis of morning care, based on the 12 steps in the classification system, has provided substantial information about the complexity of the situation. None of the patients in the study could perform morning care independently, but it turned out that it was possible to determine which abilities were missing with aid of the classification system. From the observations, apraxia seems to be the crucial factor in the morning care. The striking fact was not the patients' inability to identify the objects but to use them in a certain sequence of actions and to understand what they should be used for. Another factor related to the ability to perform morning care was lack of motivation. This is in accordance with observations made by Weintraub et al (1982). Interestingly, the patients' level of performance varied from day to day, to a certain extent influenced by several patient-nurse related factors, e.g. the way the nurse initiated an action or the emotional climate.

Other problem areas in the care of demented patients is eating, communication and nutrition. In the epidemiological study it was shown that 28 per cent of the demented compared to 2 per cent of the non-demented patients were dependent on the staff to manage their eating. Eating problems are a rather late symptom in the natural course of progressive dementia. It was a challenge to find that even severely demented
patients ate almost independently and could identify, and serve, themselves the main
dish. Furthermore, it was remarkable to see how the interaction between the patients
developed in the group. It was obvious that the less demented patients felt responsible
for those with the most pronounced eating problems. It has previously been reported
that geriatric patients increased their social interaction when seating arrangements
were altered and the patients were given more choice over the way the meals were
served (Davies and Snaith, 1980).

A majority of the comprehensible conversation during the meals concerned food,
eating and the meal situation. Almost all conversation concerned present time. The
conversation pattern changed when the mental nurses participated in the group, i.e.
one of the patients dropped her role as a helper and almost completely ceased
conversing with the other patients.

Three of the patients in the meal study were assessed to have symptoms of aphasia
that influenced their possibilities to communicate with the other patients and the
mental nurses. The epidemiological study showed that only 64 per cent of the
demented probands were rated to have a normal ability for speech. The corresponding
figure for the non-demented probands was 90 per cent. Communication problems,
such as difficulties in object naming, use of indefinite terms and uncompleted
sentences and difficulties to understand the meaning of words (for review, see
Norberg and Athlin, in press), are impairments that contribute to make the eating
situation, and most of all other nursing situations, even more difficult for a severely
demented patient.

A weight-loss is often observed in demented, institutionalized patients. The reason for
this is obscure. It could be a consequence of the neuropsychiatric manifestations of
the diseases, e.g. memory loss, disorientation, apraxia, restlessness, co-existent
anxiety leading to a reduced dietary intake and changes in physical activity. The meal
environment, the lack of time for the staff to feed the patients, the short time between meals and the high number of staff responsible for each patient could be other contributing factors (Bäckström et al, in press). In our study, 50 per cent of the patients were classified as malnourished. This figure is in accordance with findings in other studies of inpatients (Bistrian et al, 1976; Asplund et al, 1981; Albiin et al, 1982). The mean energy intake in our sample was 2059 kcal, which was in accordance with recommendations of the Swedish National Food Administration (1981) and on a level with Swedish pensionaries living at home (Steen, 1976; Nordström et al, 1986). The intake was surprisingly high compared to other studies of elderly inpatients (Warnhold et al, 1978; Stiedemann et al, 1978; Vincent and Gibson, 1982; Stähelin et al, 1983). The high caloric intake could be explained by the fact that the clinic is specialized to care for patients with dementia and has a high personnel/patient ratio, which enables the personnel to allow each patient sufficient time for eating. A well-developed team nursing system, where each patient is cared by two or three nurses, could be another factor contributing to the high dietary intake.

One basic problem in all institutional care of the elderly is constipation. An indication of this, even if not extensively studied, was that 45 per cent of the demented probands in the epidemiological study were rated not to be able to control their bowel. It could be hypothesized, even if not investigated, that the main reason for this is constipation. Among elderly, long-term patients in institutions, laxatives are one of the most commonly prescribed drugs (Lamy et al, 1978; Pollman et al, 1978) although the risk of side-effects of traditional laxatives are well known (Cummings, 1976; Pietrusko, 1977). Bran has been put forward as an alternative to traditional laxatives but its use has been restricted because of difficulties of administrating it. In this study it was possible to supplement the diet with large amounts of bran in the form of a crispbread, which was included in a natural way in the hospital diet. Furthermore, it was astonishing to see that 93 per cent of all laxatives could be replaced during the
bran period. It appeared that the high-bran diet had a normalizing effect on the patients bowel habits.

On the basis of the above-cited studies, a model for nursing care was constructed (Figure 10). According to the model, nursing care has to be planned with respect to three dimensions:

1. Methods: compensation versus taking over
2. Means: natural versus artificial
3. End: quality of life versus survival

Figure 10. Schematic illustration of a model for nursing care of demented patients
1 Compensation versus taking over

Nursing care should be based on a systematic assessment of the patient's abilities and disabilities and the interventions should aim at helping the patient to use his abilities. The role of the nurse is to structure the environment so that the patient's actions are facilitated. She should only carefully compensate for his deficiencies - a compensation for a lack of the patient's self-care capabilities (Orem, 1980). Nursing care could also be delivered in a routine fashion without any individualized assessment of the patient's abilities and disabilities - the nurse does for the patient what he would be able to do for himself. The experiment with an improved meal milieu showed, e.g. that the five demented patients indeed had abilities which were not used in the routine care. It was also suggested that the patients' communicative behaviors might have been improved with a more supportive conversation from the mental nurses.

2 Natural versus artificial

Long-term care has for years been guided by norms derived from acute care (Gustafsson, 1978; Gardell and Gustafsson, 1979). This has made the care quite artificial and poorly adapted to the needs of demented patients. However, during the last decade there have been attempts to make the care of demented patients more natural and to conform better to their special needs and demands. Demented patients are, for example, treated in home-like environments (Asplund et al, 1986), cared for in facilities located closer to their previous home settings (see paper VI), less frequently treated with tube feeding (Michaelsson et al, in press), and urinary catheters (Hollo, personal communication). The use of psychoactive drugs in the care of demented patients has also been questioned (Helms, 1985; Barnes et al, 1985) which could be interpreted as another example of an ambition to make the care of demented patients more natural. Even in the small details of care, artificial treatment could be replaced for more natural treatments. In paper IV, for example, it is described how laxatives were successfully replaced by high-bran bread. There is a
search for more natural means to improve the patients physical and psychological environment.

3 Quality of life versus survival

The use of more compensatory and natural treatments are closely linked to a stress on quality of life as a goal in dementia care, whereas the use of taking over by artificial treatments is connected with the patient's survival as the primary goal of care. When quality of life is stressed in care it seems logical to stress that the patients' meals should not only aim at satisfying his nutritional needs but also aim at satisfying his psychological, social and cultural needs (c.f. paper III).

The model described results in eight main types of care;
- compensatory / natural / quality of life
- compensatory / natural / survival
- taking over / artificial / quality of life
- taking over / artificial / survival, and so on.

No variant of care is wrong per se. Care must be chosen according to the patient's needs. It seems evident that there even in dementia care might be situations when care of type 'taking over' / 'artificial' and 'survival' is appropriate, e.g. during an acute illness in a non-terminal, demented patient.

The model can be used in all stages of the disease. A severely demented patient who is bedridden, curled up like a fetus, mute and unable to perform activities by herself, to some degree needs care of the 'taking over' type, although the goal also for this patient has to be to give as compensatory care as possible. However, this does not imply that she also needs an artificial care. Even this care could aim at the patient's quality of life. In this stage of the disease quality of life is probably very much equal to comfort.
A compensatory care presupposes that the caregiver is able to make a precise and individualized assessment of the patient's abilities and disabilities in order to base nursing interventions on specific nursing diagnosis (Carnevali and Patrick, 1986). Providing a compensatory and natural nursing interventions also presupposes an assessment of the patient's present and past environment. A 'home-like' environment is home-like only in relation to the patient's perception of what his/her home is like.

The patient's quality of life as a goal for care is connected to the value system of the society he lives in (Norberg and Hirschfeld, in press). Increasing the patient's quality of life presupposes that his quality of life is assessed (Michaelsson et al, in press). The evaluation of the patient's quality of life must be performed from the patient's own value system (Veatch, 1984). To know the patient's value system the caregiver either must have the opportunity to work with the same patient throughout his disease from that period when he can express his values to his last period or, when the patient no longer can express his will, work in close contact with the severely demented patient's relatives and friends.

A compensatory, natural care aiming at the demented patient's quality of life presupposes an organization that makes it possible for the caregiver to give individualized care. Nursing education should provide the knowledge and skills necessary for such nursing care.
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