

# Patterns of and Reasons for Relocation in Dementia Care

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Because dementia is a progressive disease, the need for care in municipal shelter accommodations might change over time, raising the crucial question whether to relocate an individual. The aim of the study was to investigate the number of relocations between municipal dementia housing units and to examine the patterns and reasons for relocation, together with the various municipal prerequisites for carrying out relocation. Thirty-three managers of 101 dementia care units in 12 municipalities in Sweden were interviewed, and records of persons who had moved into or out of the dementia care units during the year 2002 were reviewed retrospectively. The results showed that turnover occurred in 35% of the 865 rooms during the year. Of those relocations, 78 (9%) were persons who moved to another accommodation—either into (59), between (13), or out of (6) a dementia care unit. This finding indicates that there are situations in which remaining in place was considered less appropriate than relocating a single individual with dementia to other accommodations with or without dementia specialization. The most common reason for relocation within the municipal shelters was an increased need for care. (*Geriatr Nurs* 2007;28:193-200)

**A** basic principle of caring for the elderly population in Sweden is that, as far as possible, care and support should be provided in their home, regardless of the type of disease an individual has. The right to a familiar and permanent dwelling thus also applies to persons with dementia who are in need of care and living in municipal shelters. However, the prerequisites for following this principle in a shelter varies between municipalities.<sup>1</sup>

A study in Sweden showed that “misplacement” among elderly persons in municipal shelters was most frequent among persons with cerebrovascular diseases and dementia.<sup>2</sup> Another Swedish study raises the question of whether the person should continue living in the same

unit irrespective of the degree of dementia.<sup>3</sup> Dementia-related illnesses are degenerative, resulting in progressive degrees of cognitive failure, deteriorating mobility, and behavioral symptoms.<sup>4</sup> However, some researchers believe that negative behaviors associated with dementia are reactions to inadequate treatment in an inappropriate environment rather than symptoms of the dementia.<sup>5</sup>

As the proportion of elderly people continues to rise in the coming decades, so will the number of people with dementia increase worldwide.<sup>6,7</sup> According to a Swedish estimate, the number of persons with moderate to severe dementia is expected to increase from 121,000 in 2000 to 154,000 by the year 2025.<sup>8</sup> Swedish local authorities provide special accommodation with staff available around the clock for persons with extensive medical and social needs. Persons with the late stages of dementia are often cared for in municipal shelter accommodations, a unit with around eight single rooms. Usually the units are categorized as group dwellings or nursing homes with or without specialized dementia care. In addition, some municipalities have units that specialize in caring for younger persons with dementia or demanding behavior.<sup>9</sup> The important idea with group dwellings is that persons with dementia maintain social activities in a homelike atmosphere and can stay there for the rest of their lives without having to relocate. In the late stages of dementia, it is possible that the care or the environment is insufficient to provide for the individual.<sup>10</sup> In this case, a common and crucial question is how the situation is handled within the municipal care unit; should the patient be relocated or not. An assessment of the person’s needs is carried out when he or she applies for a place in shelter. The decision to offer a person a place in shelter is taken by a social welfare case officer in accordance with the law.<sup>11</sup> However, when relocating within the shelter, a new appraisal is not necessarily undertaken because the type of assistance has already been approved. This situation also applies for persons

whose dementia gets worse or in whom another somatic disease sets in or deteriorates, changing their care needs considerably over a period of time. Rather little is known about quality of life of people with dementia in shelter accommodations and changes that occur as the dementia process progresses.<sup>12</sup>

Some studies related to the relocation of elderly persons may be found in the current literature. A review of resettlement studies over the past 40 years on the elderly population in need of care in the United States, England, and Canada shows conflicting results.<sup>13</sup> Studies report significant increases in mortality, whereas others found no difference in post-relocation mortality. Of the 65 studies reviewed, only 4 included persons with dementia.<sup>14-17</sup>

Studies on relocating elderly persons with dementia mainly concerned relocating from older buildings to a new facility.<sup>14,17-19</sup> There were few or no adverse effects on persons with dementia when residents and staff moved as a unit.<sup>15</sup> In addition, most relocation studies relate to relocation between different institutional settings, such as mental hospitals to group-living accommodation.<sup>14,17-21</sup> The modern environment of a new facility, adjusted for dementia care, may partially explain the lack of negative impact on relocated resident. Results from a study in a new dementia care unit showed that 6 of 10 persons had a maximum length of stay in the unit of 4 months, suggesting that the placement was inappropriate because of aggressive behavior and depression.<sup>22</sup> Higher rates of depression and mortality were identified following an individual relocation compared with a group relocation.<sup>14,15,17</sup>

Some conclusions can be drawn from the existing studies concerning the relocation of elderly persons with or without dementia. First, there were conflicting results; some reported no increased mortality, and other reported significant changes in mortality. Second, only 2 of the studies<sup>17,22</sup> were about relocating a single person with dementia within the sheltered accommodation. Third, neither the frequency nor the pattern of relocation into or out of municipal dementia care units was found in the literature.

The aim of this study is to describe the relocation within the municipal shelter (dementia care units) in terms of pattern and reasons and, in addition, to describe the prerequisites to accomplish relocation. In this study, relocation is

defined as a permanent change of environment for an elderly person within municipal shelter dementia care units. The relocation was to be permanent and not of a temporary nature, such as a hospital stay or short-term care in a municipal housing unit.

## Method

This descriptive study was conducted in a Swedish county with a population of approximately 275,000 people in 12 municipalities, varying in size from 5400 to 125,000 inhabitants.<sup>23</sup> Three types of shelter accommodations for persons with dementia were included in this study, group dwelling, nursing home, and special unit, as reported by the medically responsible nurses at the social authorities in each municipality. A research ethics committee at a university hospital has approved the study (Dnr: 134/03). In addition, permission for the study was obtained from the social director of each municipality.

## Data Collection and Analysis

Data collection was conducted in 2 stages. In the first stage, 33 managers at the 101 dementia care units were interviewed regarding the accommodations. Questions regarding issues such as the number of units in the building, the number of rooms in each unit, the type of unit, and staff and organizational changes during the year 2002 were asked. The manager also identified persons who had been relocated during 2002.

In the second stage, records were reviewed for persons who had moved into or out of the dementia care units during the year. The review was undertaken at the unit or at the local social service office by the first author. The records comprised notes from the unit kept by nurses or other care staff or from the social welfare case officers. Two checklists were developed for reviewing the records: 1 for those who moved in to the shelter unit and 1 for those moving out. These checklists were similar, highly structured, and contained information about the relocated person's age, gender, municipality, the type of units involved in the relocation, and the documented reason for relocation. The checklists were created for this study and tested in a pilot study in 2 dementia care units. The pilot study resulted in a number of minor adjustments, and the checklists were assessed as useful instruments.

**Table 1.**  
**Subcategories, Categories, and Content Areas of Documented Reasons for Relocation**

Subcategories	Categories	Content Area
Increased need of care because of dementia	Increased need of care	Strongly connected to the person's disease(s)
Increased need of care because of (another) somatic disease	Increased need of care	Strongly connected to the person's disease(s)
Unspecified increased need of care	Increased need of care	Strongly connected to the person's disease(s)
Aggressive behavior toward other residents	Demanding behavior	Strongly connected to the person's disease(s)
Aggressive behavior toward staff	Demanding behavior	Strongly connected to the person's disease(s)
Aggressive behavior—unspecified	Demanding behavior	Strongly connected to the person's disease(s)
Anxiety	Demanding behavior	Strongly connected to the person's disease(s)
Other disruptive behavior patterns	Demanding behavior	Strongly connected to the person's disease(s)
Husband/wife moved to another unit	Social changes	Loosely or not connected to the person's disease(s)
Move closer to relatives	Social changes	Loosely or not connected to the person's disease(s)
Closure of the unit	Organizational changes	Loosely or not connected to the person's disease(s)

The documented reasons for relocation in the checklist were analyzed into categories according to manifest content analysis.<sup>24</sup> The exact wordings were divided into codes. The various codes were sorted into 4 categories and 11 subcategories. The tentative categories were discussed by the authors and revised. Content areas, categories, and subcategories are presented in Table 1. In addition, descriptive statistics of the numbers of and reasons for relocation, unit characteristics, and municipal prerequisites were undertaken.

## Results

All 12 municipalities had dementia care units with or without specialization. There were a total of 51 buildings, containing 101 dementia care units with 865 rooms. The largest type of unit was group dwellings (57%) followed by nursing homes (40%). The number of specialist units was limited (3%). All municipalities had multiprofessional competence available for the care of demented persons and their problems. The staff nurses and nursing assistants, in the

shelter units were supported by a multiprofessional team (general practitioner, occupational therapist, and nurse) or nurses specializing in dementia care.

Some organizational changes were identified during the yearlong study period. Of the total 101 units, 2 were closed and 3 changed their specialization, resulting in organizational changes in 5% of the units. Of the 865 rooms used for dementia care in the county, turnover occurred in 304 rooms (35%), either because of death or relocation between different municipal shelter units. The majority of the relocations into dementia care units were persons with dementia moving from their own home (226 persons). Seventy-eight persons were relocated within the municipal dementia units. This number of relocation equals 9% of the total number of rooms in the dementia care units. The 78 relocated persons were a median of 82 years old (range 67-91 years), and 56% were women.

Of the 12 municipalities, 4 had 1 type of dementia care unit (either group dwelling or nursing home). Seven of the municipalities had 2

types of dementia care accommodation (group dwelling and nursing home). Only 1 municipality had all 3 types of dementia care accommodation (group dwelling, nursing home, and special unit) (Table 2). To have 2 or 3 types of dementia care units in the same building was uncommon, occurring in 4 municipalities. In addition, having more than 1 of the same type of dementia care unit in the same building occurred in 11 of the 12 municipalities (Table 2). Thus, the municipalities had varying abilities to accomplish relocation among persons with dementia.

Three types of relocation were found: into, between, and out of dementia care units. The most common relocation, 59 of 78 (76%), was relocating from nonspecialized group dwellings into a dementia care unit. This type of relocation occurred in 10 municipalities. Thirteen (17%) relocations occurred in 4 municipalities between dementia care units. Those municipalities were able to relocate nearby, within the same building, and between different types of dementia care units. Six (8%) relocations in 5 municipalities were from a dementia care unit to a unit not specializing in dementia care (Table 2).

In summary, persons with dementia were relocated in 10 municipalities during 2002. The 2 municipalities where no relocation occurred during the year had just 1 type of accommodation for dementia care. However, in 2 other municipalities with just 1 type of dementia care, accommodation relocation occurred during the year. Relocations into and out of units occurred in municipalities with 2 types of dementia care accommodation in different buildings. When 2 to 3 types of dementia care accommodation and different types existed in the same building, all patterns of relocation—into, between, and out of—were seen.

Different reasons for relocation were identified (Table 3). Fifty-five (70%) of the documented reasons related to increased need for care or aggressive behavior. Fourteen (18%) were connected to organizational changes in the municipality or to social factors. In 9 records (12%), the reasons for relocation were not clearly documented.

## Discussion

This study focused on the relocation of persons with dementia—how and why they were

relocated within municipal shelter accommodations. The results of this study show that relocation occurred in 3 ways: into, between, and out of dementia care units. Seventy-eight relocations were undertaken in the municipal shelters during the year. This number comprises 9% of the total available rooms in the municipal dementia care accommodations. The structure of dementia care units varied between municipalities, which resulted in different prerequisites for relocation. The main reason for relocation within municipal housing was an increase in an individual's need for medical or social care.

The municipalities do not maintain a central register where relocation in the specific units is recorded. This means that the only source of information regarding relocation is the managers of the respective units. The problem with recall bias among the managers could not be entirely dismissed but is considered to be small because the units keep their own register of residents. The personal contact with the medically responsible nurse ensured that no dwellings were missed because of organizational changes. The retrospective structure resulted in some difficulties with incomplete record notes, combined with organizational changes in 5% of units, which meant that some of the managers interviewed were not the one(s) responsible during 2002. The advantage of the retrospective design was that considerations relating to relocation were not affected by the awareness of an ongoing study.

The documents studied were notes made at the unit, together with the assessment decision. Other studies of municipal nurses' documentation have found shortcomings,<sup>25,26</sup> and these limitations also apply to this study. Owing to weaknesses in the existing documentation in the unit, the social welfare officer documentation was also studied. However, in 9 (12%) cases, the documentation was missing. A limitation in this study is that staff members were not asked about undocumented information about the relocation that could have been a contributing factor and perhaps further clarify the reason for relocation. A contributing explanation for the missing data could be that nursing assistants, who do the main part of the care, have not been obliged to take part in the documentation process, neither by law nor by the organization. However, the records review was performed by

**Table 2.**  
**Characteristics of Municipal Dementia Care Units and Accomplished Relocations in 2002**

Municipality	No. Dementia Care Units	Types of Dementia Care Units	No. Rooms in Dementia Care	No. Buildings With Dementia Care	Different Types of Dementia Care in the Same Building	Relocation Into Dementia Care	Relocation Between Dementia Care	Relocation From Dementia Care
A	2	1	16	1	No			
B	2	1	16	1	No			
C	2	1	17	2	No	1		
D	2	2	18	1	Yes	2	6	2
E	3	1	23	1	No	5		
F	5	2	35	3	No	12		
G	5	2	42	3	No	4		1
H	5	2	48	3	Yes	2	2	
I	7	2	55	2	Yes	6	3	
J	8	2	65	3	No	4		1
K	12	2	97	8	No	5		1
L	48	3	433	23	Yes	18	2	1
All	101		865	51		59	13	6

**Table 3.**  
**Documented Reasons (N = 78) for Relocation**

		Into Unit With Specialized Dementia Care	Between Specialized Dementia Care Units	Out of Unit Specialized in Dementia Care	
Strongly connected to the person's disease(s)	Increased need of care	31	6	2	39
	Demanding behavior	11	2	3	16
Loosely or not connected to the person's disease(s)	Social or organizational changes	9	4	1	14
		Missing	8	1	
All		59	13	6	78

a researcher who is an experienced nurse and who is familiar with the specific languages of both the medical and elderly care culture and their documentation habits.

The extent of and the reason for relocating from a person's own home to a municipal shelter within the municipal housing forms have been mapped in a Swedish town over a 20-year period.<sup>27,28</sup> However, in that study, it was not possible to identify relocation for persons with dementia relocating within the municipal shelter accommodation, which was the focus in our study.

The most common reason given for relocation was an increased need for care. It was not always possible to distinguish from the record notes what was meant by "increased need for care." It could be another somatic illness, dementia, or a combination. A worsening of another somatic illness could be the primary care need, and the dementia secondary. Earlier studies<sup>29-31</sup> reported other external explanations for increased care requirements, such as environment, interaction, and staff competence explanations that were not identified in this study. Some studies of quality of life for persons with dementia in shelter accommodations found differences between ratings of staff and persons with dementia.<sup>12,32</sup> Levels of dependency and behavior problems influenced staff ratings, whereas subject ratings were associated with symptoms of anxiety and depression.<sup>12</sup> A study of the records directly connected with the relocation combined with staff interviews, including quality-of-life rating, would have provided in-

creased possibility for a more modulated and complete picture of the reasons for the relocation in this study. This approach requires a prospective design instead of the retrospective design used in our study.

During the research year, 2002, sweeping economic changes or radical organizational changes occurred in only 5 units (5%). This finding makes it more credible that relocation was carried out primarily because of the person's need for medical and social care based on his or her illness or social situation and not on organizational conditions. The study was a complete investigation carried out in a well-defined county with municipalities of differing size (<10,000-125,000 inhabitants) representing varying resources relating to number and type of dementia care units and specialization or area of interest. The ability to generalize the results must be regarded as acceptable for dementia care in Sweden.

In Sweden, the right for individuals to remain in their place of residence is a principle, but it is not one that all are forced to follow. The lack of empirical research on this principle, either in ordinary or special dwellings, has been noted nationally.<sup>33</sup> It should be kept in mind that the ability of the municipalities to staff their dementia care units might vary. During the interview about the units, some managers mentioned different ways to handle the difficulties with the care of demented persons. In practice, one model is to relocate staff with special competence in dementia care between units according to existing or varying care needs among the residents.

Another model is to increase the competence level in the ordinary staff group. A third model is to relocate the elderly to another, more appropriate unit.

If the principle of remaining in place is strictly applied, none of the three forms of relocation identified in this study should occur. Sometimes it may be reasonable for a person who has lived in a particular unit that lacks dementia competence and who later suffers from dementia to be relocated to a specialized dementia care unit. A move from a dementia care unit may occur when dementia is not judged to be the primary illness. Moves between dementia care units were more unexpected. It is not possible to disregard the difficulties in offering care and support to people with dementia in their existing dwelling when the care needs change or increase over time.<sup>10</sup> The principle of remaining in place must be considered against the requirement for adequate and safe care while satisfying the individual's need for care and support. Providing the same resources for everyone cannot solve this dilemma; doing the same thing for everyone does not equate to fairness. In the eyes of the staff, a move to another dwelling is an attempt to improve conditions and is an example of how the ethical principle of beneficence, of doing good, may be applied.<sup>34</sup> However, individual needs can come into conflict with the organizational, social, and economic requirements to structure the world as rationally as possible.

Different perspectives of dementia care and ethical issues have been discussed, such as ethics and day care, different treatments, terminal care, and nursing home residents.<sup>35-38</sup> The studies raise the dilemma of how ethical questions in daily care can be met by adequate medical action and a professional attitude. Some of the ethical reasoning regarding whether to relocate when dementia illness worsens has not been discussed. Albinsson<sup>3</sup> found that misplacement was not an unusual problem among those persons with dementia in a care unit. It is often difficult for people with dementia to express their needs, which results in care personnel sometimes acting as interpreter and being the patients' proxy. There is some research concerning staff members and their ability to assess health and quality of care on behalf of their patients/clients. A review of studies about proxy assessment showed a fairly good agreement between subjects and proxies when assessing

functioning, physical health, and cognitive status.<sup>39</sup> Similar assessments of quality of care were made by subjects, themselves primary family caregivers, proxy caregivers who knew the subject well, according to some Swedish studies.<sup>40,41</sup> This implies that the perceived misplacement (increased need of care) that causes relocation is reasonably in line with the individual's situation. However, the effect of the relocation on the individual's continued care, support, and quality of life is unknown and needs to be further addressed. Another issue that deserves attention is the link between staff attitudes and quality of life for elderly demented residents. Spector and Orrell<sup>32</sup> found that there may be a link between low staff hope and lower resident quality of life, pointing to possible advantages of training and support for care staff.

## Conclusions

Data show that when the municipal prerequisites to relocate persons with dementia exist, relocation occurs, not only into but also between and out of dementia care accommodations. The most common reason for relocation within the municipal shelter accommodation was an increased need for care. This finding indicates that there are situations in which remaining in place is considered less appropriate than relocating a single individual with dementia to other accommodations with or without dementia specialization.<sup>9,11,13-24</sup>

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