### REVIEW PAPER

### **Prevalence of Care Dependency and Nursing Care Problems in Nursing** Home Residents with Dementia: A Literature Review

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#### **Abstract**

Background: Worldwide, around 35.6 million people live with dementia. This chronic condition is a risk factor in developing care dependency and nursing care problems, and often leads to nursing home admission.

Aim: The aim of this study was to conduct a literature review that provides an overview of the prevalence of care dependency and nursing care problems in nursing home residents with dementia, because such a review is missing from the international literature.

Methods: The type of narrative review was chosen and performed by doing an electronic search in PubMed, CINAHL and EMBASE and EBM Reviews via Ovid from 2003 to 2013. Furthermore, a manual search in reference lists was carried out. The literature was critically reviewed and results are presented as a narrative.

Results: The international literature indicates that 28% - 83% of residents with dementia are care dependent at the highest level. In view of the nursing care problems, the prevalence of malnutrition ranges from 14% - 56%; urinary incontinence from 39% - 59%; fecal incontinence from 43% - 87%; pressure ulcers from 7% - 47%; falls from 29% - 60%; and restraints from 10% - 60%.

Conclusions: The high prevalence of care dependency and nursing care problems in nursing home residents with dementia indicate that improvements in the management of these important quality indicators are still necessary. A suggestion for further nursing research would be to compare the prevalence of care dependency and different care problems between residents with and without dementia, and to undertake longitudinal studies to compare the development as well as the progression of the important quality indicators between residents with and without dementia, including the cognitive status of the residents.

Key words: dementia, care dependency, malnutrition, incontinence, falls, pressure ulcers, restraints, nursing homes

### Introduction

Worldwide, around 35.6 million people live with dementia, whereas current estimates assume that the number of people with dementia will more than triple by 2050 (WHO, 2012). For this large number of affected people, the worldwide costs amount to US\$604 billion per year, with the highest cost of care being particularly in nursing homes (WHO, 2012). Dementia is one of the most common conditions treated in nursing homes (Fulton, 2010). More than 50% of nursing home residents are affected by this disorder (Lohrmann, Schönherr & Mandl, 2012; Alzheimers's Association, 2013; Matthews et al., 2013).

It is one of elderly people's greatest fears: living in a nursing home and being (care) dependent on others (Baltes, 1996). Care dependency means that the self-care abilities of a person in terms of their basic physical and psychosocial human needs (e.g. eating and drinking, hygiene, social contacts) has decreased to such an extent that the person's care demands are, to some degree, dependent on professional support (Dijkstra, Buist & Dassen, 1998). A decline in self-care abilities, and therefore a development and progression of care dependency, is a major component of the dementia syndrome (Harwood, Sayer & Hirschfeld, 2004; Waldemar et al., 2007; Sousa et al., 2010).

In the course of dementia, people can develop, in addition to care dependency, various nursing care problems. Nursing care problems refer to an affected individual's actual impairments (stemming from the person themselves or from their environment), or risks associated with health or treatment which the individual cannot manage or resolve and which restrict his or her independence (Berger et al., 2012). If this is the case, professional nursing care is required to positively influence the person's health status (Berger et al., 2012). This review will focus on the nursing care problems of malnutrition, incontinence, pressure ulcers, falls and restraints; this is because people with dementia have a risk of acquiring these problems (Cotter, 2007; Alzheimer's Association, 2009; Alzheimer's Society, 2011) and they are important quality indicators in nursing homes (Nakrem et al., 2009;

Lohrmann, Schönherr & Mandl, 2012; Alzheimer's Disease International, 2013). Furthermore physical health is, in addition to behavioural problems, an important focus in dementia care (WHO, 2012).

Nursing care problems and care dependency can influence each other negatively. This means that care dependency can lead to nursing care problems (Nelson & Furner, 2005; Heinze, Halfens & Dassen, 2007; Lin, Watson & Wu, 2010) and nursing care problems can lead to either care dependency or to an increase of care dependency (Suominen et al., 2005; Amaral, et al., 2007; van der Steen et al., 2007; Lohrmann, Schönherr & Mandl, 2012). Nursing care problems and care dependency in people with dementia are common grounds for nursing home admission (Alzheimer's Association, 2012: Alzheimer's Disease International, 2013). Both reduce quality of life (Barca et al., 2011; Lohrmann, Schönherr & Mandl, 2012) and lead to enormous costs for health care institutions and systems (Gustavsson et al., 2011; Lohrmann, Schönherr & Mandl, 2012).

Care dependency can be reduced or stabilized and nursing care problems can be avoided. reduced or stabilized with adequate care (Eichhorn-Kissel, 2011; Lohrmann, Schönherr & Mandl, 2012). A prerequisite for adequate care is to have detailed information about the nursing home resident's prevalence of care dependency and nursing care problems, which can become reflected in daily clinical nursing practice as a means to stimulate positive changes, e.g. nursing interventions, (Lohrmann, Schönherr & Mandl, 2012). Presently, knowledge and understanding about people with dementia in general is insufficient (Alzheimer's Australia, 2003; WHO, 2012; Alzheimer's Disease International, 2013) as is knowledge pertaining to care dependency and nursing care problems. Consequently, nurses could have problems in dealing with this specific target group (Alzheimer's Australia, 2003, Alzheimer's Disease International, 2013) leading to inappropriate care. To our knowledge, in the international literature, no literature review exists which focuses on the prevalence of care dependency and nursing care problems in nursing home residents with dementia. For this reason,

the aim of this study was to conduct a literature review that asks following questions:

- How prevalent is care dependency in nursing home residents with dementia?
- How prevalent are the nursing care problems of pressure ulcers, falls, malnutrition, incontinence and restraints in nursing home residents with dementia?

### **Methods**

### Design

A narrative literature review was performed based on the guidelines by Green, Johnson & Adams (2006). This type of literature review is characterized by a comprehensive narrative synthesis of previously published literature and is fitting for presenting a broad perspective on a topic (Green, Johnson & Adams, 2006).

### Criteria for inclusion of studies

- Quantitative studies with information about the prevalence of care dependency and/or nursing care problems
- Literature written in English or German
- Literature published in databases from January 2003 January 2013
- Adults with dementia
- Nursing homes, residential homes and specialized dementia care facilities

### Search methods for identification of studies

A limited initial search in the PubMed database was conducted to identify the main keywords. This was followed by a comprehensive literature search in the databases PubMed, CINAHL, EMBASE via Ovid and EBM Reviews via Ovid using the following MESH terms/key words in combination with Boolean logics: dementia, cognitive impairment, cognitive defect, activities of daily living, daily life activity, dependency, dependent personality disorder, accidental falls, falling, pressure ulcers, decubitus, physical restraint, malnutrition, incontinence, urinary incontinence, fecal incontinence, residential facilities, residential home and nursing home. In addition, a manual search in the reference lists was carried out and one expert was contacted to discuss certain ambiguities in his article. The search process is shown in Figure 1.

### Selection and quality assessment of studies

All obtained references from the search were organized with Refworks, an online bibliographic management program, and duplicates were excluded. In the first critical appraisal performed by the researcher, the titles and abstracts were screened for content and relevance to the topic with focus on the inclusion criteria. After this first review, the full text was read and a quality appraisal was performed by the researcher using a checklist for quantitative studies by Burns and Grove (2011). In total 20 studies were included in the narrative review (see Figure 1).

### Data extraction and analysis

The essential data from each published study were extracted by the researcher into tables. Results are presented in a narrative form.

### Results

# Prevalence of care dependency in nursing home residents with dementia

Seven studies were found within the international literature that included information on the prevalence of care dependency in nursing home residents with dementia (see Table 1). The highest prevalence was found in the study by Luo, Lin & Castle (2011) which compared residents with (n=5057) and without dementia (n=4224). The results show that 83% of the residents with dementia, as opposed to 72% of residents without dementia, were care dependent at the highest level (The difference between these two groups was not significant (p > 0.05)). In comparison, the study conducted by Guo et al. (2012) explored differences in care dependency between residents with and without dementia. The results showed that more residents with dementia (n=97) were care dependent at the highest level than residents with mild cognitive impairment (MCI) (n=35) or residents without dementia or MCI (n=132) (67% vs. 31% vs. 22%, p<0.001). The study by Wetzels et al. (2010) explored care dependency between residents with very severe dementia and residents with moderate to severe dementia. The results showed that more residents in the very severe stage of dementia were care dependent at the highest level (56% vs. 5%, p<0.001). In the study by van der Steen et al., (2006), care dependency

was examined in a US and Dutch sample of residents. 56% of the Dutch residents and 43% of the US residents were care dependent at the highest level (p > 0.05). In the three assessed activities, namely eating, walking and dressing, both groups were most care dependent in dressing (Dutch: 61%, US: 58%). In a very big sample of 222,405 residents, Mitchell et al. (2010) found that 36% of the residents were care dependent at the highest level. A lower

prevalence of care dependency was found in the study by Oliveria et al. (2006) wherein the results showed that 29% of male residents and 27% of female residents were care dependent at the highest level. The lowest prevalence of care dependency was found in the study by Lin, Watson & Wu (2010), in which 28% of the residents were care dependent at the highest level.

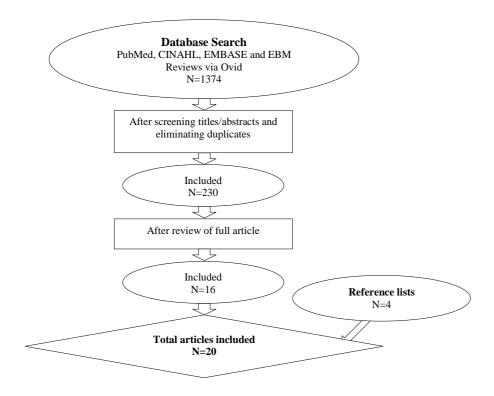


Figure 1: Flow chart of paper selection

# Prevalence of nursing care problems in nursing home residents with dementia

Thirteen studies were found in the international literature which included information on the prevalence of the nursing care problems of malnutrition, incontinence, pressure ulcers, falls and restraints in nursing home residents with dementia (see Table 2).

The highest prevalence of *malnutrition* in residents with dementia in nursing homes was found in the study by Jesus et al. (2012). In this

study malnutrition was compared between residents with and without dementia. The results showed that residents with dementia had a higher prevalence of malnutrition than residents without dementia (56% vs. 46%, p < 0.01). In the study from all licensed US nursing homes by Mitchell et al. (2010), malnutrition was examined in a very large sample of 222,405 residents with advanced dementia. These results showed the lowest prevalence of malnutrition (14%). Regarding **incontinence** (urinary and fecal) in residents with dementia, three studies were

found. The study by Oliveria et al. (2006) showed that 57% of male residents and 59% of female residents were affected by urinary incontinence and 49% of male residents and 42% of female residents were affected by fecal incontinence. The higher prevalence of fecal incontinence at 87% was examined in the study by Mitchell et al. (2010). The study by Eriksson, Gustafson & Lundin-Olsson (2008) assessed urinary incontinence in residents with and without dementia. The results showed that residents with dementia (n=103) have a higher prevalence of urinary incontinence than residents without dementia (n=83) (39% vs. 17%). Pressure ulcers were mostly found in studies which focused on residents in a very advanced stage of dementia, not long before death. The highest prevalence was found in the study by di Giulio et al. (2008). Pressure ulcers occurred in residents during their last 30 days of life with a prevalence rate of 47%. The lowest prevalence of pressure ulcers was found in the study by Luo et al. (2010) in which the prevalence of pressure ulcers was assessed in residents from three different types of nursing homes. The highest prevalence with 10% was found in a regular unit of a nursing home with a special care unit for residents with dementia, followed by 9% in a nursing home without a special care unit for residents with dementia and 7% inside the special care unit of a nursing home. The highest prevalence of falls in residents with dementia was found in the study by Fossey et al. (2006). The prevalence, including at least one fall in the past 12 months, was 58% in the control group and 60% in the intervention group. The study by Luo, Lin & Castle (2011) compared residents with and without dementia and explored the fact that residents with dementia had fallen more often (36.3% vs. 26.3%, p<0.001) in the past 180 days. Oliveria et al. (2006) examined the prevalence of falls in the previous 30 days of assessment. 31% of men and 29% of women fell during this time period. The highest prevalence of the use of restraints in residents with dementia was found in the study by Huizing et al. (2006). Observations by the residents showed that 59% of residents were affected by restraints. Luo, Lin & Castle 2011 demonstrated the prevalence of the use of restraints in two groups. 10% of the residents received trunk-, limb-, and chair restraints and 35% bedrail restraints. In all

included studies, except the study by Kirkevold & Engedal (2004), bed rails were the most used type of restraint.

### **Discussion**

This review shows that 28% - 83% of the residents with dementia are care dependent at the highest level (see Table1). 14% - 56% of the residents with dementia suffer from malnutrition, 39% - 59% have urinary incontinence, 43% -87% have fecal incontinence, 7% - 47% have pressure ulcers, 29% - 60% experienced falls and 10% - 60% were restrained (see Table 2). The large variances of these prevalence values may be differently result of defined terms. measurement methods and sample sizes in the studies. Nevertheless the results overall show a high prevalence of care dependency and nursing care problems in residents with dementia, despite the fact that in recent years many countries have implemented quality systems, like the Minimum Data Set (MDS), to monitor the quality of care in nursing homes (Wiener, Freiman & Brown, 2007; Nakrem et al. 2009; Du Moulin, van Haastregt & Hamers 2010). In most of the included studies, either care dependency or nursing care problems were examined in residents with dementia and when the focus was on nursing care problems, often only one nursing care problem was explored. In few studies were care dependency and/or nursing care problems the main focus of the research. It would be important for future studies to focus on more than one of these quality indicators, as it could help to reveal which indicators are most prevalent in residents with dementia and therefore require special attention.

Only four of the 20 included studies compared residents with and without dementia (Eriksson, Gustafson & Lundin-Olsson, 2008; Luo, Lin & Castle, 2011; Guo et al., 2012; Jesus et al., 2012). Therefore these studies only insinuate that care dependency and/or the nursing care problems of malnutrition, incontinence, falls, and the use of restraints may be higher in residents with dementia. More comparative studies should be carried out in order to investigate this in greater detail. Furthermore, such studies may help to find out which nursing care problems are specific to residents with dementia; in which physical and psychosocial human needs (e.g. eating and

drinking, social contacts, communication) residents with dementia are most care dependent and if they are in respect to other needs more care dependent than residents without dementia.

In studies assessing care dependency, instruments were most often used (e.g. the Katz index of ADL or Barthel index) to measure only physical human needs, such as toileting, hygiene and mobility, and did not include psycho-social aspects. To measure the needs and abilities of a person, a comprehensive assessment should also include psychological and social aspects (Harwood, 2003).

Studies which included information on the prevalence of urinary incontinence gave no information about the prevalence of different types of urinary incontinence (e.g. stress incontinence, functional incontinence). This information would be very important for targetoriented incontinence care, but it is clear that it is not always possible to assess the specific type in residents with dementia, especially if the person is at a very advanced stage of the disorder. Most of the studies which assessed the prevalence of pressure ulcers only included residents in advanced stage of dementia, shortly before death. The reason could be that these residents have a greater risk of developing pressure ulcers because of their advanced cognitive and functional decline. In the future it would be important to include residents in all stages of the disorder and to explore the prevalence in the different stages of dementia in order to have better insight into this nursing care problem.

### Limitations of the literature review

This review is limited to literature written in English and German found in data bases and reference lists.

### Strengths of the literature review

This is, as far as we know, the first literature review which includes the prevalence of care dependency and different nursing care problems of residents with dementia in one review. Therefore the review provides a broad overview of the subject area.

### **Conclusion and recommendations**

There are only few published studies in the international literature which provide information

about the prevalence of care dependency and the care problems of malnutrition. incontinence, pressure ulcers, falls and restraints in nursing home residents with dementia. The prevalence may vary, but even the lowest values indicate that improvements in the care for this group are still necessary. recommendation would be regular monitoring of care dependency and nursing care problems with well tested instruments in order to explore the effectiveness of used interventions in residents with dementia. Further nursing research should compare the prevalence of care dependency and nursing care problems between nursing home residents with and without dementia using tested standardized measurement tools to explore differences. It would also be important to assess the prevalence of care dependency and nursing care problems in different stages of dementia and to undertake longitudinal studies to compare the progression of care dependency and the development of different nursing care problems between nursing home residents with and without dementia in order to gain better insight into residents with dementia.

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Table 1: Prevalence of care dependency in nursing home residents with dementia

Care Dependency						
Author	Country	Design	Residents	Setting	Measurement	Prevalence (Highest level of care dependency)
Luo et al. (2011)	USA	Cross-sectional	5057 (>180 days in nursing home)	1174 nursing homes	Medical records and other documentation <u>Activities:</u> transferring, eating, toileting, dressing, and bathing <u>Level of dependency:</u> minimal (impairment in 0-1 ADL (Activities of daily living)), moderate (impairment in 2-3 ADLs), and dependent (impairment in 4-5 ADLs)	dependent: 82.9%
Guo et al. (2012)	China	Cross-sectional	264	4 nursing homes and 2 veteran care homes	Edited ADL Scale based on Katz Index of ADL and Lawton and Brody's IADL (Instrumental activities of daily living) Scale Activities: - Level of dependency: Normal - severely dependent	severely dependent: 67%

Wetzels et al. (2010)	The Netherlands	Cross-sectional	288	9 nursing homes (special care units)	InterRai Long-Term Care Facility scale, Section G Activities: - Level of dependency: 1-7 (Totally dependent-independent)	Very severe dementia: totally dependent: 55.6% Moderate to severe dementia: totally dependent: 4.8%
Van der Steen et al. (2006)	The Nether-lands/ USA	Cross-sectional	175	1 nursing home	ADL Scale based on MDS (Minimum Data Set) and Bedford Alzheimer Nursing Severity Scale (BANS-S) <u>Activities:</u> eating, walking, dressing Level of dependency: 0-2 (0 means independent and 2 mean fully dependent.	at least one full dependency in dressing, walking, or eating, and need for assistance in the two other activities: US: 42.7% Dutch: 55.8%;
Mitchell et al. (2010)	USA	Longitudinal, retrospective	222 405	Nursing homes	Baseline MDS Assessment <u>Activities</u> : - <u>Level of dependency:</u> Total dependence was defined as having a score of 28 on the scale.	totally dependent: 35.5%
Oliveria et al. (2006)	USA	Longitudinal, retrospective	7728	Nursing homes	MDS <u>Activities:</u> dressing, eating, toilet use, bathing, locomotion, transfer, continence <u>Level of dependency:</u> 1-3 (mild dependent - dependent)	dependent: men: 28.7% women: 27.3%

Lin et al. (2010)	Taiwan	Observational	477	Long-term care facilities, dementia special care units	100-point Barthel index <u>Activities</u> : 11 Items, not described <u>Level of dependence</u> : 100 Points mean totally independent, 91-99 mean mildly dependent, 61-90 means moderately dependent, 21-60 means severely dependent and 0-20 mean totally dependent	totally dependent: 27.9%
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Table 2: Prevalence of nursing care problems in nursing home residents with dementia

Malnutrition								
Author	Country	Design	Residents	Setting	Measurement	Prevalence		
Jesus et al. (2012)	France	Cross sectional	223	26 nursing homes	BMI (Body Mass Index) $\leq$ 24 (Weight was determined by an electronic scale (sitting or standing) and height by a ruler or by calculating the knee height with Chumlea's formula) or MNA (Mini Nutritional Assessment) $<$ 17.	56.1%		
Bartholomeycik et al. (2010)	Germany	Cross- sectional	1252	32 nursing homes	BMI < 18.5 kg/m2 in subjects 18 to 64 years old or a BMI < 20 kg/m2 in those older than 64 years, unintentional weight loss (>6 kg in the previous 6 months or >3 kg in the previous months), and/or no nutritional intake for 3 days or a decreased intake for more than a week combined with a BMI from 18.5 to 20 kg/m2 in subjects 18 to 64 years old or 20 to 23.9 kg/m2 in those older than 64 years. Weight and height was collected with a standardized questionnaire.	29.9%		

Meijers et al. (2009)	The Netherlands	Cross- sectional	1262	39 nursing homes	BMI < 18.5 kg/m2 in subjects 18 to 64 years old or a BMI < 20 kg/m2 in those older than 64 years, unintentional weight loss (>6 kg in the previous 6 months or >3 kg in the previous months), and/or no nutritional intake for 3 days or a decreased intake for more than a week combined with a BMI from 18.5 to 20 kg/m2 in subjects 18 to 64 years old or 20 to 23.9 kg/m2 in those older than 64 years. Weight and height were collected with a standardized questionnaire.	22.1%
Chang (2012)	China	Cross- sectional	93	5 nursing homes	BMI < 18.5 (Weight and height were collected by reviewing medical charts)	19.4%
Lou et al. (2007)	Taiwan	Cross- sectional	55	2 long term care (LTC) settings	BMI < 18.5 (Weight was measured using a portable or mechanical chair scale, height was measured using a standing upright scale, or the prone length if residents could not stand)	18.2%
Mitchell et al. (2010)	USA	Longitudinal, retrospective	222 405	Nursing homes	BMI < 18.5 (was selected from baseline MDS (Minimum Data Set ) assessment)	14%

## **Incontinence (Urinary and Fecal)**

Author	Country	Design	Residents	Setting	Measurement	Prevalence
Oliveria et al. (2006)	USA	Longitudinal, retrospective	7728	Nursing homes	ICD-9 (International Classification of Diseases, Ninth Revision) codes and MDS	Urinary incontinence: Men: 57.2% Women: 58.6% Fecal incontinence Men: 48.5% Women: 42.7%
Eriksson et al. (2008)	Sweden	Longitudinal, prospective	186	4 nursing homes	Medical diagnosis (assessed by specialists in geriatric medicine based on previous knowledge and chart review)	<u>Urinary</u> <u>incontinence</u> 38.8%

Mitchell et al. (2010)	USA	Longitudinal, retrospective	222 405	Nursing homes	MDS (were selected from baseline MDS assessment)	Fecal incontinence: 87%
Pressure ulcer						
Author	Country	Design	Residents	Setting		Prevalence
Di Giulio et al. (2008)	Italy	Longitudinal, retrospective	141	7 LTC Institutions	Clinical records	47%
Mitchell et al. (2010)	USA	Longitudinal, retrospective	222 405	Nursing homes	MDS (were selected from baseline MDS assessment)	14.7% (stage $\ge$ 2)
Pasman et al. (2006)	The Netherlands	Observational	178	32 nursing homes	Physician questionnaire	10%
Luo et al. (2010)	USA	Cross- sectional	6234	1174 nursing homes	Medical records and other documentation	7%-10.3%; according to residence type
Falls						
Author	Country	Design	Residents	Setting	Measurement	Prevalence
Fossey et al. (2006)	UK	Cluster randomised controlled trial	349	12 specialist nursing homes for dementia	Documentation of falls	58%-60%; according to intervention- and control nursing home (at least 1 fall in the past 12 months)
Luo et al. (2010)	USA	Cross- sectional	6234	1174 nursing homes	Medical records and other documentation	35.1%-43.3%; according to residence type (a fall in past 180 days)

Luo et al. (2011)	USA	Cross- sectional	5057 (>180 days in nursing home)	1174 nursing homes	Medical records and other documentation	36.3% (a fall in past 180 days)
Oliveria et al. (2006)	USA	Longitudinal, retrospective	7728	Nursing homes	ICD-9 codes + MDS	Men: 31.3% Women: 28.7% (fall in the past 30 days)

### Restraints

Author	Country	Design	Residents	Setting	Measurement	Prevalence
Huizing et al. (2006)	The Netherlands	Cluster randomised trial	167	1 nursing home	Observation Restrain types: bed rails, sleep suit, belts in bed/chair, chair with table/board, special sheet, deep/overturned chair, infrared system, safe seat, vest with belt, bedroom door locked	59% (observed restrained at any time during a 24-hour period)
Di Giulio et al. (2008)	Italy	Longitudinal, retrospective	141	7 LTC facilities	Clinical records <a href="Restrain types">Restrain types</a> : bed rails, abdominal-, upper limb- and lower limb restraints, other restraints	58% (restrained in the last 30 days of life)
Kirkevold et al. (2004)	Norway	Cross- sectional	444	Nursing homes, special care units for dementia	Structured interview Restrain types: bed rails, belts in bed/chair, locked in a room, physical retention, electronic surveillance, force or pressure in medical examination or treatment, force or pressure in ADL and other restraints	45% (use of any restrain in the last 7 days)

Kuske et al. (2009)	Germany	3-arm cluster- randomized controlled trial	210	6 Nursing homes	Nursing home`s documentation Restrain types: any kind of restraints	30.9%-41.2%, according to the resident groups (restrained during 4 weeks prior to a fixed cut-off date of each assessment period)
Luo et al. (2010)	USA	Cross- sectional	6234	1174 nursing homes	Medical records and other documentation Restrain types: trunk-, limb-, chair restraints and bed rails	9.8%-10.5% (trunk-, limb-, chair restraints), according to residence type; 18.9%-39.2% (bedrails), according to residence type
Luo et al. (2011)	USA	Cross- sectional	6576	1174 nursing homes	Medical records and other documentation Restrain types: trunk-, limb-, chair restraints and bed rails	9.9% (trunk-, limb-, chair restraints) 35% (bedrails)