Care Dependency and Nursing Care Problems in Nursing Home Residents with and without Dementia

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Declaration

I hereby declare that this thesis is my own original work and that I have fully acknowledged by name all of those individuals and organizations that have contributed to the research of this thesis. Due acknowledgement has been made in the text to all other material used. Throughout this thesis and in all related publications I followed the guidelines of “Good Scientific Practice”.

Graz, 27.08.2015 Sandra Schüssler, eh

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CONTENTS

LIST OF ABBRIVATIONS

ADI	Alzheimer's Disease International
CDS	Care Dependency Scale
CI	Confidence Interval
GDP	Gross domestic product
ICD-10	International Classification of Diseases, version 10
MDS	Minimum Data Set
MMSE-2	Mini-Mental State Examination 2
n	Number of subjects
OECD	Organisation for Economic Co-operation and Development
SD	Standard Deviation
WHO	World Health Organization

Chapter 1

General Introduction

GENERAL INTRODUCTION

Proportions of aging populations all over the world are increasingly rapidly. In 2050, around 2 billion people will be 60 years or older, with the fastest growing age group being 80+.[1,2] This development has led to a worldwide increase in chronic conditions like dementia.[3] Globally, around 35.6 million people are currently living with dementia.[4] In Austria, approximately 64 306 people have dementia.[5]

Dementia can be defined as "*a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain*".[6]

Dementia affects every person with this condition differently depending on the type of dementia (e.g. Alzheimer's or vascular dementia) and the ability of that person to deal it. Therefore, arising symptoms may differ between people with dementia and some progress faster and others more slowly over time,[2,5,7] but in general the progression of dementia can be classified into 3 stages (see Table 1).

Care dependency and nursing care problems

Dementia (irrespective of its different types) is, in comparison to other chronic diseases, like heart disease or stroke, the leading contributor to developing (care) dependency when a person is not able to self-care.[2]

According to Dijkstra et al.,[8] care dependency can be defined as a process in which a professional offers support to a person whose self-care abilities in basic physical (e.g. mobility, continence) and psychosocial (e.g. social contacts, learning ability) human needs have decreased and whose care demands make the person dependent to a certain degree. Basic human needs, which are universal for all humans[9] to stay healthy, were described in ancient Greece as light and air, food and drink, work and rest, sleep and wakefulness,

Table 1. Stages of dementia and their symptoms[2,7]

Stages of dementia	Symptoms
Mild dementia (first to second year of the disease)	• Forgetfulness arises • Communication difficulties may arise (e.g., finding the right words) • Losing track of time • Problems with instrumental activities of daily living (e.g. household, finances) • Mood and behavior changes (e.g. depression, anxiety, aggression, loss of interest in hobbies)
Moderate dementia (second to fourth or fifth year)	• Forgetfulness progresses (e.g. recent events, people names) • Communication problems progress • Difficulties with time and orientation • Problems in instrumental activities of daily living progress • Problems in activities of daily living (e.g. toileting, washing, dressing) arise • Unable to live alone safely • Behavior changes progress (e.g. wandering, hallucinations, aggression, disturbed sleeping)
Severe dementia (fifth year and longer)	• Unawareness of time, place and people • Problems in activities of daily living (e.g. eating problems, washing, toileting) progress • Mobility problems • Weight loss, problems swallowing • Behavior changes may escalate (e.g. aggression, agitation) • Urinary and fecal incontinence

excretions and secretions, stimulation of the mind and mental balance[10] and can be found in similar form in many researchers' theories, like Nightingale, Maslow, Henderson and Orem.[9,11-13] Defining care dependency as a process refers to the fact that it can increase, improve or remain stable.[2,8] In people with dementia, care dependency typically progresses over time, because of increasing cognitive (e.g. forgetfulness, increasing unawareness of time, place and people) -, behavioral and psychological (e.g. agitation, aggression, depression) and functional deterioration (e.g. mobility).[2,14] These deteriorations are also linked with the rise of various nursing care problems.[15-19]

Nursing care problems defined by Berger et al.[20] are impairments (e.g. malnutrition, incontinence) or risks related to health or interventions that the person cannot manage or resolve themselves and that restrict their independence. According to this definition, restraints can also be seen as a nursing care problem. Such interventions can be a health risk for residents, leading to negative consequences like falls, injuries, incontinence and care dependency, which nurses must try to avoid.[21-23]

The definitions of care dependency and nursing care problems are noticeably different, because care dependency in basic physical and psychosocial human needs reflects a person's degree of care dependency with regard to specific needs (like a high degree of care dependency in eating and drinking), but it does not address specific nursing care problems, like malnutrition. Therefore assessing the degree of care dependency in physical and psychosocial needs can help to identify areas where a potential nursing care problem may exist or arise.

Nursing care problems in people with dementia may be manifold, ranging from behavioral problems to falls to incontinence.[16,17,24] Such nursing care problems are closely related with the rise and increase in care dependency[23,25] and vice versa.[26,27]

Care dependency, nursing care problems and their monitoring in nursing homes

Internationally, most people with early-stage dementia get support at home from their family.[28] When dementia progresses and complex care needs arise due to increasing care dependency and nursing care problems, professional care becomes increasingly important and often necessitates nursing home

admission.[2,28-30] Andel et al.[31] pointed out that dementia is the strongest health predictor for increased risk of nursing home admission (by 54%) and they also discovered that people with dementia are admitted earlier into a nursing home than people without dementia. In nursing homes in developed countries, between 48 and 82% of the residents have dementia.[32-35] Annually performed prevalence studies in Austrian nursing homes show dementia's prevalence from 52.5 to 63.8%.[36-40]

Nursing homes play a key role in supporting the needs of older people with complex care needs like dementia,[2,30] and this setting is increasingly confronted with more and more dependent residents, which strain available resources in nursing homes like time, staff and health care costs.[5,41,42] Developed countries spend between 0.1% and 1.8% of their gross domestic product (GDP) on nursing home care, which is the most expensive sector in long-term care.[41] In Austria, 0.6% of GDP is spent on nursing home care.[41] The estimated costs of a nursing home stay per nursing home resident with dementia (including, e.g. nursing and medical care) in Austria is 35 000 Euro per year.[43]

The high pressure on nursing homes to decrease health care costs but continue to provide high quality care has caused many nursing homes in developed countries to collect and monitor data about the health status of residents with and without dementia.[28,30,44] The instruments they use vary in what they measure, because there is no gold standard, but most of them include the commonly occurring nursing care problems of pressure ulcers, incontinence, falls, malnutrition and restraints as well as limitations in activities of daily living or care dependency.[28, 44-46]

Collecting and monitoring such data in residents with and without dementia helps to identify potential areas of concern, including the extent of risks and unmet needs.[44] This knowledge helps to tailor care plans and prevent (e.g. pressure ulcers), improve or to stabilize care dependency and/or nursing care problems.[40,44] Particularly in residents with dementia, regular monitoring of care dependency and nursing care problems is essential,[2,28,47] because, unlike most other chronic conditions, people with dementia can develop care dependency in the early stage of the disease,[2] potentially causing the risks of related nursing care problems[23,48,50] to also arise very early. While people without dementia can often cope well and remain quite independent even with noticeable limitations on activities of daily living, increasing cognitive impair-

ment in people with dementia makes it difficult for them to manage self-care and communicate needs and problems.[2] Therefore, regular monitoring of care dependency and nursing care problems helps nursing professionals to recognize early (changing) needs and adapt care for dementia residents.[28,47]

Research gaps

Dementia is the leading condition treated in nursing homes,[50] but relatively less is known about the extent of care dependency and commonly occurring nursing care problems (pressure ulcers, incontinence, falls, malnutrition, restraints) in nursing home residents with dementia. Only a few international studies have focused on these aspects and no literature review was found that collected them. When summarizing existent knowledge about the extent of care dependency and nursing care problems, is important to provide deeper insight into these aspects of dementia in nursing home residents, which could in the long run improve dementia care. Achieving a broad overview is particularly crucial; one that includes information about care dependency and various nursing care problems together, because dementia is a complex condition requiring a great deal of diverse information in order to better understand it.[28]

It is also relevant to compare the extent of care dependency (in different needs) and nursing care problems (pressure ulcers, incontinence, falls, malnutrition, restraints) between residents with and without dementia, to highlight if and how they differ. Only a few international studies were found that compared residents with and without dementia.[51-54] Of these studies, only Luo et al.[52] compared care dependency and two nursing care problems (falls and restraints) between residents with and without dementia. The other three studies[51,53,54] compared just one nursing care problem or only care dependency. This lack of knowledge in the international literature emphasizes the importance of performing further comparison studies in this field, including information about care dependency (in different aspects) and various nursing care problems together. The differences discovered would help to better understand the needs of residents with dementia and would support the nursing care process of planning dementia-specific care.

Dementia can be classified into stages,[2] which makes it essential to compare the extent of care dependency and nursing care problems between stages of dementia. In the international literature only a few studies have been found that did this. All of them included only information about care dependency,[55-57]

whereby Wetzels et al.[55] did not focus on care dependency in different needs (like toileting and dressing) and only compared combined stages of dementia. In relation to the nursing care problems of pressure ulcers, incontinence, falls, malnutrition and restraints, no study was found comparing between stages. All studies identified focused only on the severe stage of dementia.[58-62] Comparing care dependency and nursing care problems between the stages of dementia is essential for understanding stage-appropriate dementia care.

Dementia is a progressive condition,[2] which makes it crucial to understand the changes in care dependency and nursing care problems over time. International, longitudinal studies examining changes of these aspects together, in nursing home residents with dementia, are lacking. This also applies to studies comparing residents with and without dementia. Published international research in this area only focused on all nursing home residents together[25, 63-65] or on residents with cognitive impairments (no formal medical diagnosis of dementia).[66,67] To explore changes in care dependency and nursing care problems in nursing home residents with dementia, it could help to examine to what extent residents with dementia change in care dependency and nursing care problems over time. It would further help to identify in which specific needs (e.g. *mobility, continence, getting (un)dressing*) care dependency most progresses and in which nursing care problems they increase the most. In comparisons between residents with and without dementia, it is also relevant to explore if they change differently in care dependency and common nursing care problems over time. This knowledge would help to identify where improvements in dementia care are necessary and to plan preventive actions (e.g. to avoid pressure ulcers).

These research gaps led to the overall aim of the doctoral thesis and the specific aims and research questions of studies 1 to 3 (part 1, part 2).

Aims and research questions

The overall aim of this doctoral thesis is to explore the extent and change of care dependency and nursing care problems in Austrian nursing home residents with and without dementia. Below, the aims and research questions of studies 1 to 3 (part 1, part 2) are listed.

Study 1

Aim: To provide an overview of the prevalence of care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in nursing home residents with dementia described in the international literature.

Research questions:

- How prevalent is care dependency in nursing home residents with dementia?
- How prevalent are the nursing care problems in nursing home residents with dementia?

Study 2

Aim: To compare the degree of care dependency and the prevalence of nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) between nursing home residents with and without dementia.

Research questions:

- How care dependent are nursing home residents with dementia compared to residents without dementia?
- How prevalent are the nursing care problems in nursing home residents with dementia compared to residents without dementia?

Study 3 (part 1)

Aim: To compare the degree of care dependency and the prevalence of nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) between residents with and without dementia and between the stages of dementia.

Research questions:

- What is the degree of care dependency among residents with versus without dementia and at different stages of dementia?
- What is the prevalence of nursing care problems among residents with versus without dementia and at different stages of dementia?

Study 3 (part 2)

Aim: To explore changes in care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in residents with and without dementia over time.

Research questions:

- How does care dependency (in various human needs) change in residents with and without dementia over two years and how does the change differ between these two groups?
- How do nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in residents with and without dementia change over two years and how does the change differ between these two groups?

Outline of the doctoral thesis

This doctoral thesis is divided into 7 chapters. Chapter 2 provides a brief overview of the methodological aspects of the studies conducted, including the design, sample, setting, data collection and data analysis. Chapters 3 to 6 present the published/submitted articles of studies 1 to 3 (part 1, part 2) in scientific peer reviewed journals. Finally, chapter 7 provides a discussion of the main findings and methodological aspects and gives recommendations for nursing practice and research.

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Chapter 2

Methods

METHODS

The following table provides an overview of the methodological aspects of studies 1 to 3 (part1, part 2).

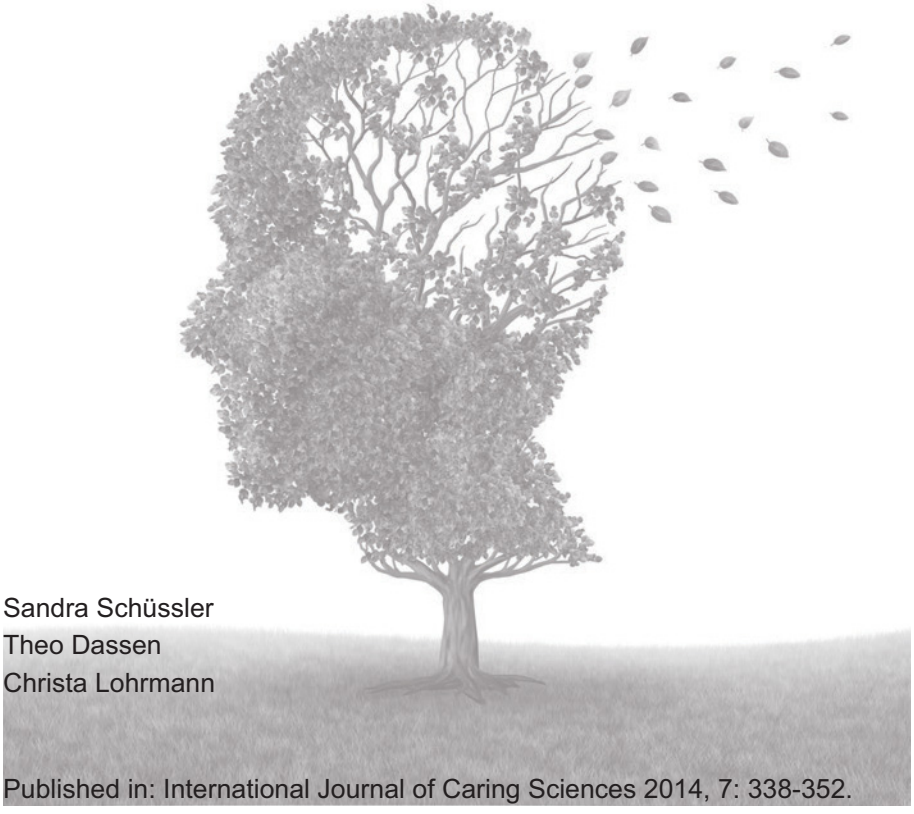
Table 1. Methodological overview of study 1 to 3 (part1, part 2)

	Study 1	Study 2
Aim	Provide an overview of the prevalence of care dependency and nursing care problems in nursing home residents with dementia	Compare the degree of care dependency and the prevalence of nursing care problems between residents with and without dementia
Design	Narrative literature review	Secondary data analysis of combined cross-sectional studies
Setting	Nursing- and residential homes, specialized dementia care facilities	24 Austrian nursing homes
Sample	20 articles with a focus on residents with dementia	2155 residents with dementia 1422 residents without dementia
Data collection	In spring 2013 including articles from 2003-2013 through search in PubMed, CINAHL, EMBASE via Ovid, EBM Reviews via Ovid and search in reference lists.	Yearly data collection (2009-2012) was performed by trained nursing professionals using the following instruments: • Austrian Prevalence Measurement of Care Problems questionnaire • Care Dependency Scale
Data analysis	Narrative synthesis	Descriptive statistics and statistical tests to explore differences between groups

Study 3 (part 1)	Study 3 (part 2)
Compare the degree of care dependency and the prevalence of nursing care problems between residents with and without dementia and between the stages of dementia	Explore changes in care dependency and nursing care problems in residents with and without dementia over time
Cross-sectional study as first measurement of a panel study	2-year panel study
9 Austrian nursing homes	
277 residents with dementia 249 residents without dementia	178 residents with dementia 80 residents without dementia
In April/May 2012 by trained nursing professionals using the following instruments:	Baseline measurement in April/May 2012 and 4 follow-ups in half-yearly intervals by trained nursing professionals using the following instruments:
• Austrian Prevalence Measurement of Care Problems questionnaire • Care Dependency Scale • Mini-Mental State Examination 2	• Austrian Prevalence Measurement of Care Problems questionnaire • Care Dependency Scale • Mini-Mental State Examination 2
Descriptive statistics and statistical tests to explore differences between groups	One- and two-factorial ANOVA with repeated measures to explore changes in care dependency Crosstabs and McNemar tests to explore changes in nursing care problems

Chapter 3

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.

Keywords: 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.[1] 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.[1] Dementia is one of the most common conditions treated in nursing homes.[2] More than 50% of nursing home residents are affected by this disorder.[3-5]

It is one of elderly people's greatest fears: living in a nursing home and being (care) dependent on others.[6] 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.[7] A decline in self-care abilities, and therefore a development and progression of care dependency, is a major component of the dementia syndrome.[8-10]

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.[11] If this is the case, professional nursing care is required to positively influence the person's health status.[11] 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[12-14] and they are important quality indicators in nursing homes.[3,15,16] Furthermore physical health is, in addition to behavioural problems, an important focus in dementia care.[1]

Nursing care problems and care dependency can influence each other negatively. This means that care dependency can lead to nursing care problems[17-19] and nursing care problems can lead to either care dependency or to an increase of care dependency.[3,20-22] Nursing care problems and care dependency in people with dementia are common grounds for nursing home admission.[16,23] Both reduce quality of life [3,24] and lead to enormous costs for health care institutions and systems.[3,25]

Care dependency can be reduced or stabilized and nursing care problems can be avoided, reduced or stabilized with adequate care.[3,26] 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.[3] Presently, knowledge and understanding about people with dementia in general is insufficient[1,16,27] as is knowledge pertaining to care dependency and nursing care problems. Consequently, nurses could have problems in dealing with this specific target group[16,27] 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[28]. 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.[28]

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 Fig. 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.[29] In total 20 studies were included in the narrative review (see Fig. 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.

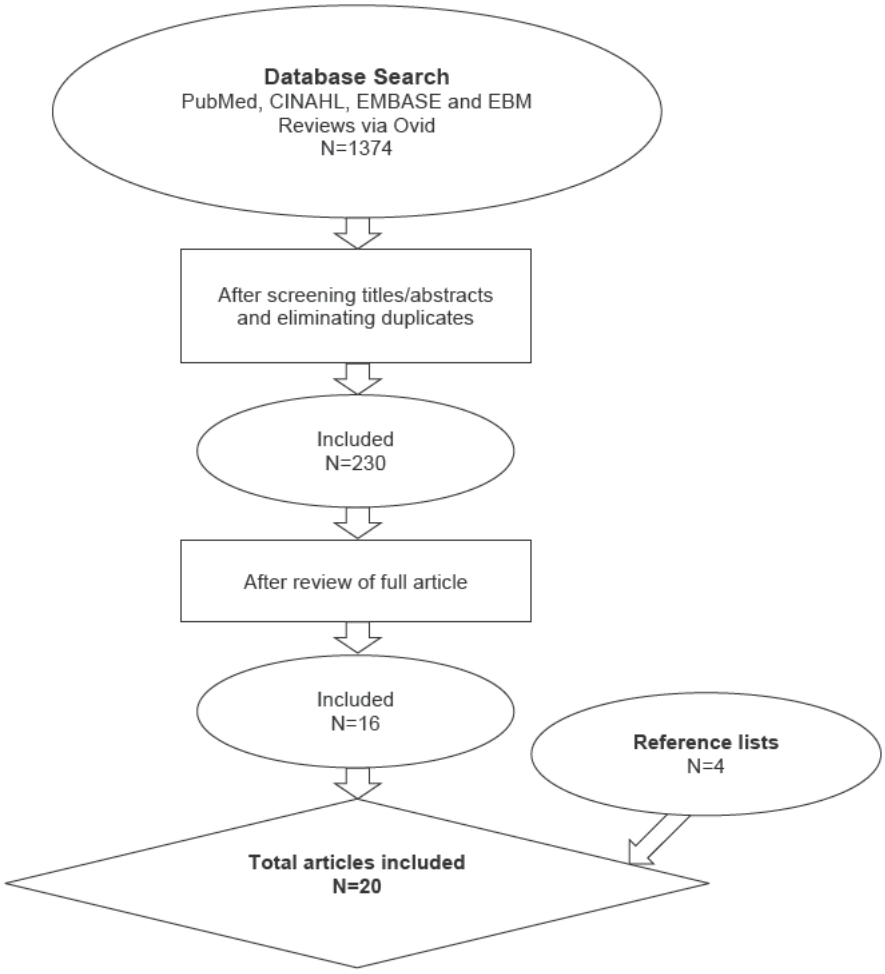

Fig. 1. Flowchart of paper selection

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[30] 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.[31] 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.[32] 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.[33] 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.[34] 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.[35] 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[19], in which 28% of the residents were care dependent at the highest level.

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..[36] 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.,[34] 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.[35] 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..[34] The study by Eriksson, Gustafson & Lundin-Olsson[37] 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..[38] 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.[39] 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..[40] 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[30] 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.[35] 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..[41] Observations by the residents showed that 59% of residents were affected by restraints. Luo, Lin & Castle[30] 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,[42] bed rails were the most used type of restraint.

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.[30]	USA	Cross-sectional	5057 (>180 days in nursing home)	1174 nursing homes	Medical records and other documentation Activities: transferring, eating, toileting, dressing, and bathing Level of dependency: 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.[31]	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.[32]	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. [33]	The Netherlands USA	Cross -sectional	175	1 nursing home	ADL Scale based on MDS (Minimum Data Set) and Bedford Alzheimer Nursing Severity Scale (BANS-S) Activities: 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. [34]	USA	Longitudinal, retrospective	222 405	Nursing homes	Baseline MDS Assessment Activities: - Level of dependency: Total dependence was defined as having a score of 28 on the scale.	totally dependent: 35.5%
Oliveria et al. [35]	USA	Longitudinal, retrospective	7728	Nursing homes	MDS Activities: dressing, eating, toilet use, bathing, locomotion, transfer, continence Level of dependency: 1-3 (mild dependent - dependent)	dependent: men: 28.7% women: 27.3%
Lin et al.[19]	Taiwan	Observational	477	Long-term care facilities, dementia special care units	100-point Barthel index Activities: 11 Items, not described Level of dependence: 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%

Table 2. Prevalence of nursing care problems in nursing home residents with dementia

Malnutrition

Author	Country	Design	Residents	Setting	Measurement	Prevalence
Jesus et al.[36]	France	Cross -sectional	223	26 nursing homes	BMI (Body Mass Index) < 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%
Bartholomey-c k et al.[46]	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%

Me jers et al.[47]	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[48]	China	Cross-sectional	93	5 nursing homes	BMI <18.5 (Weight and height were collected by reviewing medical charts)	19.4%
Lou et al.[49]	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.[34]	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.[35]	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%
Er ksson et al.[37]	Sweden	Longitudinal, prospective	186	4 nursing homes	Medical diagnosis (assessed by specialists in geriatric medicine based on previous knowledge and chart review)	Urinary incontinence: 38.8%
Mitchell et al.[34]	USA	Longitudinal, retrospective	222 405	Nursing homes	MDS (were selected from baseline MDS assessment)	Fecal incontinence: 87%

Pressure Ulcer

Author	Country	Design	Residents	Setting	Measurement	Prevalence
Di Giulio et al.[38]	Italy	Longitudinal, retrospective	141	7 LTC Institutions	Clinical records	47%
Mitchell et al.[34]	USA	Longitudinal, retrospective	222 405	Nursing homes	MDS (were selected from baseline MDS assessment)	14.7% (stage >2)
Pasman et al.[50]	The Netherlands	Observational	178	32 nursing homes	Physician questionnaire	10%
Luo et al.[39]	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.[40]	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.[39]	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.[30]	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.[35]	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.[41]	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.[38]	Italy	Longitudinal, retrospective	141	7 LTC facilities	Clinical records Restrain types: bed rails, abdominal-, upper limb- and lower limb restraints, other restraints	58% (restrained in the last 30 days of life)
Kirkevold et al.[42]	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.5[1]	Germany	3-arm cluster-randomized controlled trial	210	6 nursing homes	Nursing home`s documentation Restrain types: any kind of restr aints	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.[39]	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.[30]	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)

DISCUSSION

This review shows that 28% - 83% of the residents with dementia are care dependent at the highest level (see Table 1). 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 a result of differently 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.[15,43,44] 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.[30,31,36,37] 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.[45]

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 target-oriented 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 nursing 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 target group are still necessary. The 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 differenc-

es. 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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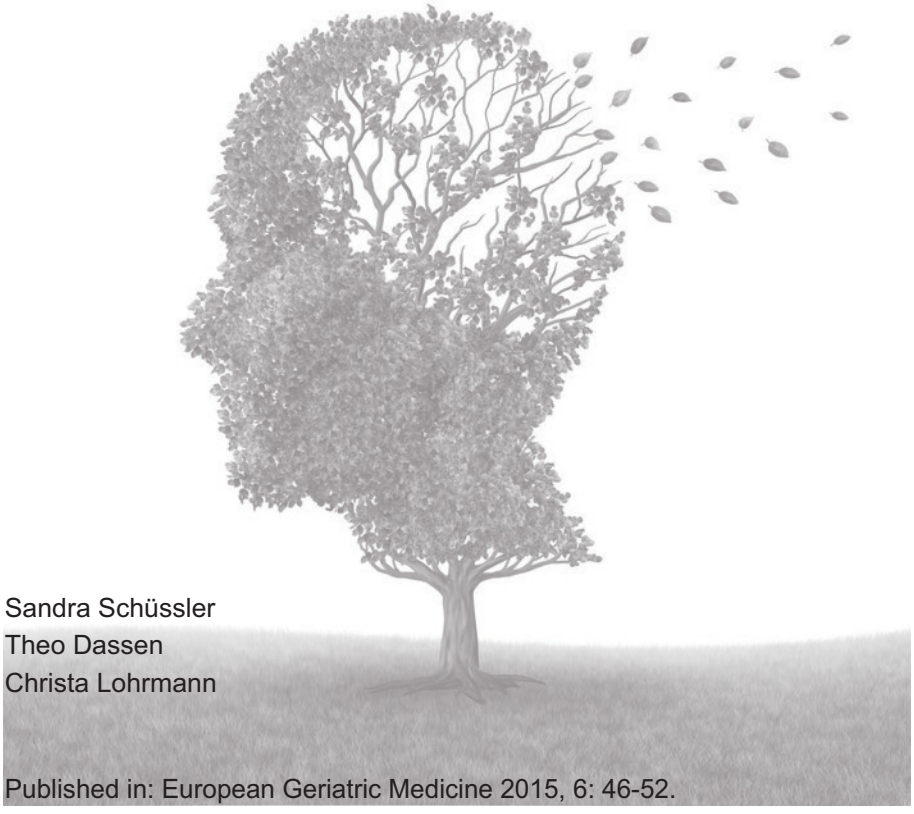
Chapter 4

Comparison of care dependency and related nursing care problems between Austrian nursing home residents with and without dementia



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ABSTRACT

Objective: Demographic developments have led to increased chronic diseases, such as dementia, which result in care dependency and nursing care problems like incontinence. This study aims to compare the degree of care dependency and the prevalence of nursing care problems between Austrian nursing home residents with and without dementia.

Methods: Since 2009 a cross-sectional study has been conducted annually in Austrian nursing homes. Data from the standardized questionnaire sampling 2,155 residents with and 1,422 residents without dementia between 2009 and 2012 have been analysed.

Results: 72% of residents with dementia compared to 45.5% of residents without dementia are completely or to a great extent care dependent, with the highest care dependency being in hygiene, continence, (un)dressing and avoiding danger. Residents with dementia have a significantly higher prevalence of urinary incontinence (87.9% vs. 69.5%), fecal incontinence (68.2% vs. 44.5%), double incontinence (64.8% vs. 36.1%), restraints (33.5% vs. 22.4%), malnutrition (27.9% vs. 18.4%) and falls (9.9% vs. 7.0%). No significant difference was found for pressure ulcers (5.2% vs. 6.5%).

Conclusion: Residents with dementia have a significantly higher degree of care dependency than residents without dementia and they also have, except for pressure ulcers, a significantly higher prevalence of nursing care problems. These results should increase awareness among health care professionals of areas requiring target-oriented dementia care. Further research should explore care dependency and nursing care problems in different stages of dementia and compare the development of care dependency and nursing care problems among residents with and without dementia.

Keywords: dementia · care dependency · quality indicators · prevalence · nursing homes

INTRODUCTION

Demographic developments and improved health care have led to an increasingly aging population.[1,2] By the year 2050, nearly 2 billion people worldwide will be 60 or older, with the fastest growing age group being 80+.[2] These developments will lead to a higher demand for long-term care, e.g. in nursing homes,[3-5] because (chronic) diseases, like dementia, increase with age.[1,6,7] In nursing homes internationally, more than 50% of residents suffer from dementia.[7,8,9]

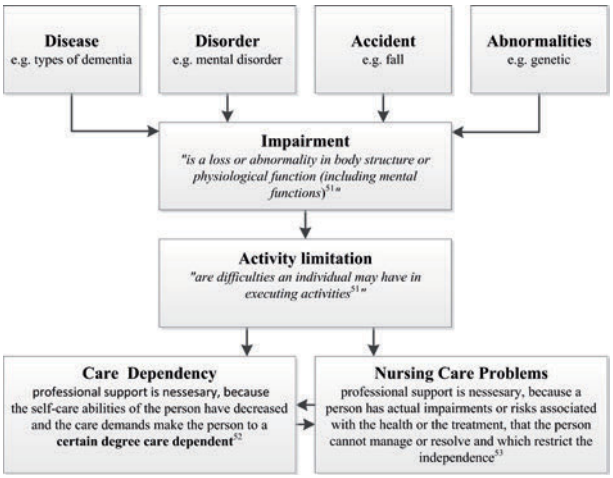

Fig. 1. Development of care dependency and nursing care problems (based on Eichhorn-Kissel[21])

Fig. 1 shows the development and definition of care dependency and nursing care problems. Besides care dependency, this study focuses on the nursing care problems of malnutrition, incontinence, pressure ulcers, falls and restraints, because people with dementia are at risk of developing these problems[10-12] and the problems themselves are important quality indicators for nursing homes.[8,13-15] Care dependency and nursing care problems can induce negative consequences like reduced quality of life, high health care costs and higher mortality.[8,16-19] Adequate care interventions can reduce, stabilize and perhaps even prevent (e.g. prevention of pressure ulcers in dementia residents) care dependency and/or nursing care problems.[8,20,21] This is why statistical data is integral to adequate care, as it provides institutions with an overview of the extent of care dependency and nursing care problems suffered

by their residents. These data help health care professionals to consciously introduce changes into their daily practice that will improve quality of care.[8,22]

In the international literature, (care) dependency remains a rarely studied and highly neglected topic.[15,23] From population-based studies we know that the worldwide prevalence of dependency (professional and/or non-professional care) in people over 60 is 13%[15] and from a few studies we know that the prevalence of care dependency in nursing home residents with dementia ranges from 28% - 83%.[24] However, we have very limited information regarding the comparison of the degree of care dependency between nursing home residents with and without dementia.[24] The same applies for studies comparing the prevalence of malnutrition, incontinence, pressure ulcers, falls and restraints between residents with and without dementia,[24] because most studies tend to take all nursing home residents into account.[14,25,26] This is why the results from the studies conducted only insinuate that care dependency and nursing care problems may be higher in residents with dementia.[24]

In general we know from the literature that dementia leads to a gradual cognitive, functional and behavioural decline[15,12] and that it is the strongest independent contributor to care dependency.[15] Therefore it could follow that residents with dementia are more care dependent than those without and that they may have a higher prevalence of nursing care problems; but it is not enough to assume this, it must be confirmed and visualised with data. It is important to compare care dependency and nursing care problems between residents with and without dementia in order to better understand residents with dementia.[24] Their improved care also requires demonstrating the extent of these differences and consequently exploring which nursing care problems and human needs (e.g. eating and drinking, social contact) are most important for them.[24] Such information can improve target-oriented care and priority identification for intervention studies.

The *International Prevalence Measurement of Care Problems* survey has the potential to provide insight into the quality of nursing care on national and international levels. It does so by measuring the degree of care dependency and the prevalence, prevention and treatment of nursing care problems (pressure ulcers, incontinence, malnutrition, intertrigo, falls, restraints) as well as by measuring the availability of structural quality indicators (e.g. guidelines) using a standardized and comprehensive questionnaire.[22] The survey is conducted

annually on one day in different healthcare settings (e.g. nursing homes, hospitals) in the Netherlands (since 1998), Austria, Germany, Switzerland and New Zealand.[22] The first survey in Austria was issued in 2009.

This study aims to show the results from the Austrian survey obtained by comparing the degree of care dependency and the prevalence of related nursing care problems between Austrian residents with and without dementia. The research questions are: 1.) How care dependent are Austrian nursing home residents with dementia compared to residents without dementia? 2.) How prevalent are the nursing care problems of pressure ulcers, incontinence, malnutrition, falls and restraints in Austrian nursing home residents with dementia compared to residents without dementia?

METHODS

Design

The Austrian Prevalence Measurement of Care Problems survey[8] as part of the International Prevalence Measurement of Care Problems survey is a cross-sectional, multi-centre point prevalence study conducted annually in Austria.[22] This study analysed the data from Austrian nursing homes between 2009 and 2012 (4 measurement points).

Setting and Sample

Of the 877 nursing homes in Austria, 467 have >50 beds.[27] A convenience sampling was performed for this study. Every year (2009-2012) all Austrian nursing homes with >50 beds were invited to participate by way of a flyer and additionally through an information meeting at the Medical University of Graz. Every nursing home had the opportunity to participate and choose the wards to be included. All nursing home residents present on the days of data collection were included in the study.

Ethical considerations

Ethical approval from the Medical University of Graz ethics committee was obtained. Written informed consent was acquired from each resident or their legal representatives.

Instrument

The *Austrian Prevalence Measurement of Care Problems* questionnaire was used to collect data.[8] The original Dutch questionnaire was translated into German by professional translators and was back translated and double-checked for nomenclature and cultural differences by the Austrian project group and experts in nursing care quality.[22] Based on expert feedback, small language changes were made which had no impact on questionnaire content. The questionnaire will be evaluated yearly in the international research group and updated if necessary (e.g. new evidence-based knowledge).[22]

This standardized questionnaire measures institutional- (43 questions), ward- (50 questions) and patient- (81 questions) level data.[22] At institution- and ward levels the questionnaire measure the type of institution/ward and the availability of structural indicators like guidelines or information brochures on nursing care problems.[22] At the patient level, questions solicit demographic data such as age and medical diagnosis (e.g. dementia)[22] based on the International Classification of Diseases, version 10 (ICD - 10). Questions on this level also include information about the prevalence, characteristics and treatment of the nursing care problems.[22] All questions are posed either dichotomously (yes/no) or with multiple answer possibilities.[22] Furthermore the questionnaire includes psychometrically-tested assessment scales, like the Care Dependency Scale (CDS),[22] to assess the degree of care dependency. The CDS was originally developed by Dijkstra et al.[28] in the Netherlands. The scale contains 15 items referring to basic physical and psychosocial human needs, assessed using a 5-point Likert scale ranging from completely care dependent (1 point) to almost care independent (5 points).[29] A CDS sum score of 15-24 points means *completely care dependent*, 25-44: *to a great extent care dependent*, 45-59: *partially care dependent*, 60-69: *to a limited extent care dependent*, 70-75: *almost independent*.[30] The German version of the CDS shows moderate to substantial observer agreement. Homogeneity by means of Cronbach's α coefficient is 0.94 and 0.98. Equivalence in terms of inter-rater and intra-rater reliability shows moderate to substantial Kappa values. Criterion-related validity (CDS with statutory care level and nursing personnel regulation) shows that a higher classification score is associated with increased care dependency.[29] The nurses gathered data with the standardized questionnaire at the patient level through various means, including resident interviews, observation/inspection, resident documentation (e.g. documented medical diagnosis

of dementia) and assessment with scales, like the CDS.[22] A more detailed description of the questionnaire can be found in van Nie-Visser et al..[22]

To answer our research questions, we analysed patient level data from the questionnaire, including the demographic data of age, gender and medical diagnosis of dementia and other disorders/diseases; the prevalence of nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints); as well as answers to the CDS.

Data collection

Data collection took place on one pre-determined day in April 2009, 2010, 2011 and 2012. In each participating nursing home, one internal coordinator was responsible for data collection. All coordinators were trained by the research team on co-ordinating the data collection process and correctly using the questionnaire. The coordinators trained the nurses who collected the data. In order to ensure objectivity, two nurses (one from the resident's ward and a second from another ward) assessed each resident. After data were collected, they were entered into an online programme.

Statistical analysis

All statistical analyses were performed using IBM® SPSS® Statistics, version 20.[31] Descriptive analyses were performed in order to describe the sample and statistical tests were run to explore differences between residents with and without dementia. The Crosstab subroutine was used for categorical variables (gender, disease, nursing care problems, degree of care dependency, restraint method, reason for restraint) and t-tests for metric variables (age, mean degree of care dependency in CDS items, mean care dependency sum score of residents suffering from nursing care problems).

RESULTS

From 2009 to 2012, 24 of the 467 Austrian nursing homes with 50+ beds took part in the Austrian Prevalence Measurement of Care Problems survey. All in all 3,577 (79.8%) residents participated in the study. 2,155 (60.2%) of these residents had a medical diagnosis of dementia.

Table 1. Comparison of characteristics between nursing home residents with and without dementia.

Characteristics	Residents with dementia (n=2155)	Residents without dementia (n=1422)
Age (years), mean ± SD***	84.8 ± 7.9	80.7 ± 12.9
Female gender, %	85.5	79.7
10 most assessed diseases/disorders, %		
Cardiovascular disease*	56.8	60.7
Motor disorder/disease	44.1	44.7
Disorder/Disease of kidney/urinary tract, sexual organs	25.1	24.9
Psychological disorder**	22.6	26.9
Disorder/disease of the digestive tract, including intestinal obstruction, peritonitis, hernia, liver, gal bladder, pancreas	22.0	23.8
Eye/ear disorder	20.5	20.0
Diabetes mellitus	18.0	18.6
Endocrine-nutritional or metabolic illness/disease*	17.2	14.6
Nervous system disorder, excluding CVA***	16.6	21.5
CVA/hemiparesis***	15.0	22.4

* Significant difference ($P < 0.05$)
** Significant difference ($P < 0.01$)
*** Significant difference ($P < 0.001$)

Table 1 shows the basic characteristics of the sample. Residents with dementia are older and they have more women in the sample than residents without dementia. The prevalence of endocrine-nutritional or metabolic diseases is higher in residents with dementia and the prevalence of cardiovascular diseases, psychological disorders, nervous system disorders (excluding stroke) and stroke/hemiparesis is higher in residents without dementia. The most prevalent diseases/disorders in both groups are cardiovascular diseases and motor disorders/diseases.

The comparison of the degree of care dependency, measured using the CDS, highlights that residents with dementia are significantly more care dependent than those without (Chi^2 test, $p<0.001$). More residents with dementia are completely- (37.4% vs. 15.8%) and to a great extent care dependent (34.6% vs. 29.7%), but fewer residents with dementia are partially care dependent (18.4% vs. 23.6%), to a limited extent care dependent (7.6% vs. 18.8%) or almost independent (2.1% vs. 12.1%) than residents without dementia.

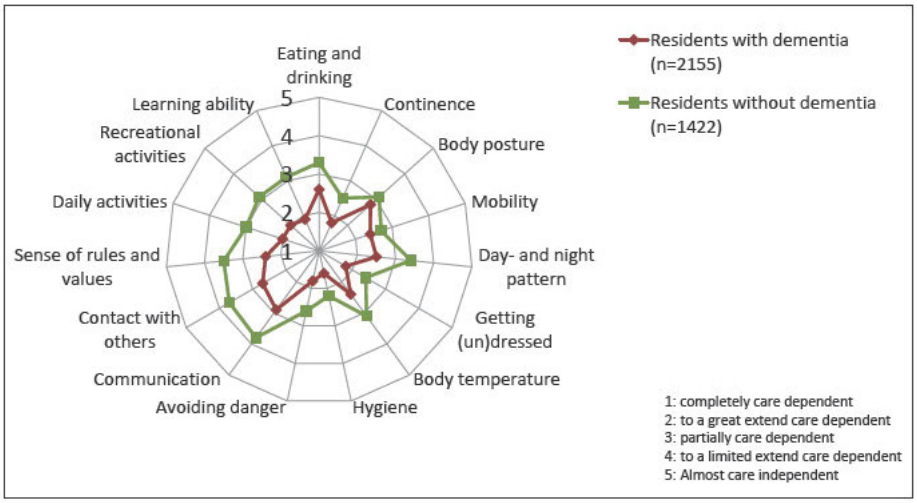

Fig. 2. Comparison of the mean degree of care dependency in CDS items between residents with and without dementia.

Fig. 2 shows that in every assessed CDS item, residents with dementia are significantly more care dependent than residents without dementia ($p<0.001$), but both groups are most care dependent in the areas of hygiene, continence, getting (un)dressed and avoiding danger.

Table 2. Comparison of the prevalence of nursing care problems in residents with and without dementia.

Nursing care problems	Residents with dementia (n = 2155) %	Residents without dementia (n = 1422) %
Urinary incontinence **	87.9	69.5
Fecal incontinence **	68.2	44.5
Double incontinence**	64.8	36.1
Restraints (last 7 days)**	33.5	22.4
Malnutrition**	27.9	18.4
Falls (last 30 days)*	9.9	7.0
Pressure ulcers (category 1 included)	5.2	6.5

* Significant difference (P < 0.01)
** Significant difference (P < 0.001)

Table 2 shows that residents with dementia vs. those without have no significant difference in the prevalence of pressure ulcers. All other nursing care problems are significantly higher in residents with dementia. The most prevalent nursing care problem in both groups is incontinence (urinary, fecal, double). Of the 1,778 residents with dementia and urinary incontinence and the 857 residents without dementia with urinary incontinence, the type of urinary incontinence is not known (36.2% vs. 42%), followed by total incontinence (33.7% vs. 21.5%), functional incontinence (10.8% vs. 13.3%), mixed incontinence-particularly urge incontinence (8.2% vs. 8.5%), urge incontinence (5% vs. 6%), mixed incontinence-particularly stress incontinence (3.3% vs. 4.7%), stress incontinence (2.1% vs. 3.3) and overflow incontinence (0.6% vs. 0.9%).

After incontinence (urinary, fecal, double), restraints are the second most frequent nursing care problem in residents with and without dementia. From the assessed restraint methods (bedrails, special blankets/sheets, Swedish belt in bed, lap restraint chair, table top, deep chair, isolation/separation, alarm monitoring, medication and individual monitoring), bedrails are most commonly used in residents with (n=723) and without dementia (n=319) (82.6 vs. 93.1%, p<0.001). The most frequently assessed reason for restraints (preventing falls, wandering, aggressive behaviour, easing medical treatment, sleep, other methods, unknown) is fall prevention (75.2% vs. 66.5%, p<0.001).

Table 3. Comparison of the mean care dependency sum score in residents with and without dementia suffering from various nursing care problems.

Nursing care problems	Care dependency in residents with dementia		Care dependency in residents without dementia	
	Mean sum score ± SD	n	Mean sum score ± SD	n
Urinary incontinence*	32.1 ± 14.9	1778	42.0 ± 16.4	857
Fecal incontinence*	26.9 ± 12.1	1469	32.4 ± 13.8	633
Double incontinence*	27.2 ± 12.2	1325	32.9 ± 13.4	464
Restraints in last 7 days*	25.0 ± 11.1	723	31.4 ± 14.0	319
Malnutrition*	29.1 ± 14.8	599	41.5 ± 19.0	261
Falls in last 30 days*	37.7 ± 15.1	214	49.1 ± 15.6	99
Pressure ulcers (category 1 included)*	24.1 ± 10.4	111	30.6 ± 13.0	92

* Significant difference ($P < 0.001$)

Table 3 shows that in both groups, residents with pressure ulcers, followed by restraints are most care dependent, but to a greater extent in residents with dementia.

DISCUSSION

This study conducted in Austrian nursing homes aimed to compare the degree of care dependency and the prevalence of related nursing care problems between residents with and without dementia. With respect to the first research question, results demonstrate that residents with dementia have a higher degree of care dependency than residents without dementia (more residents with dementia are completely care dependent: 37.4% vs. 15.8%), which confirmed study results by Guo et al.[32] and reported health care professionals' clinical experience in nursing homes. A higher degree of dependency in residents with dementia was expected because we know that the progressive decline in physical, behavioural and cognitive function caused by dementia is the strongest independent contributor to (care) dependency.[12,15] However, this study contributes to the visualisation of the extent of the difference. Furthermore it highlights the fact that both groups are most care dependent in the areas of hygiene, continence, getting (un)dressed and avoiding danger, but specifically residents with dementia show a higher degree of care de-

pendency in these areas. In addition, this study explores that in both groups, residents with pressure ulcers and restraints are most care dependent. This emphasises that they are very vulnerable groups.

Based on their high degree of care dependency, residents with dementia should be helped to maximize their independence as much as possible through, for example, person-centred care, which includes regular assessment and monitoring of their needs (to identify changes early on and adapt the care plan) and care tailored to their individual needs.[15,33,34] A prerequisite for adequate dementia care is education and training,[15,33,34] but we know from the literature that health care staff working in long-term care often are not or do not feel well trained enough to perform dementia care,[15,33,34] resulting in inappropriate care (e.g. too much-, to little-, incorrect care),[24,33] and thus promoting care dependency. The negative outcomes of a high degree of care dependency include being at risk for nursing care problems[35-37] and increased mortality.[16,17] Dijkstra et al.[16] explored that residents with dementia and a high degree of care dependency have a 20% higher mortality rate than residents with dementia and a low degree of care dependency.

Based on the second research question, the results show that in view of all nursing care problems, incontinence is the most prevalent problem in both groups, and is most prevalent in residents with dementia (urinary incontinence: 87.9% vs. 69.5%; fecal incontinence: 68.2% vs. 44.5%; double incontinence: 64.8% vs. 36.1%). This is in line with the results from Luo et al.[38] and Eriksson et al..[39] The higher prevalence of incontinence in this study in residents with dementia may be because they were significantly older, more care dependent and more often affected by restraints than residents without dementia. These aspects, in addition to progressive cognitive and functional decline, are described as risk factors for developing incontinence.[12,26,36] The very high prevalence of incontinence and the lack of knowledge of the resident's type of incontinence in both groups of this study indicate that improvements in incontinence care are necessary. Therefore, appropriate incontinence screening/assessment (e.g. type of incontinence, causes of incontinence, toileting skills) by health care professionals is suggested as a first step towards improving incontinence care.[34,40] Good incontinence management is important because incontinence can increase care dependency,[41] risk of pressure ulcers[42] and falls.[43,44]

The use of restraints is the most prevalent nursing care problem after incontinence in the participating residents with and without dementia, but more prevalent in residents with dementia (33.5% vs. 22.4%). This could be because residents with dementia fall more often and show a higher degree of care dependency in mobility, body posture, learning ability and avoiding danger, which along with agitation, behaviour problems and wandering, are common patient-oriented reasons for using restraints.[35,45,46] Restraints should be avoided where possible, because they are linked to negative outcomes like incontinence, pressure ulcers, functional decline, (care) dependency and falls.[46,47]

Malnutrition is a prevalent nursing care problem in both groups and definitively more prevalent in residents with dementia (27.9% vs. 18.4%). Jesus et al.[48] also explored the significantly higher prevalence of malnutrition in residents with dementia (56.1% vs. 46.4%), but both groups show a higher prevalence than in our study. This could be because they only included residents with eating difficulties. In terms of dementia, other international studies found malnutrition prevalence to be between 14.4% and 29.9%.[24] Malnutrition should be avoided, however, because it leads to many negative outcomes like increased mortality, reduced quality of life, (care) dependency or increasing (care) dependency, risk of falls and high health care costs.[8,37,49] The high prevalence of malnutrition among residents with dementia in our and other international studies may indicate that nutritional care should be improved. Therefore, the basis on which to provide optimal nutritional care is the use of nutritional screening and assessment tools for the early detection of malnutrition (risk).[11,50] A recent study performed in Austrian hospitals and nursing homes found that nutritional screening tools to detect malnutrition (risk) were used with just 28.9% of nursing home residents (n=1487).[50] Based on our study results, stabilizing care dependency, especially in eating/drinking, mobility and learning ability, should be emphasized in residents with dementia, because these risk factors for malnutrition[11,37] are significantly higher in residents with dementia.

Limitations of the study

In the annual Austrian study, only 24 nursing homes have participated since 2009, which limits in the generalizability of the results. Another bias could be that only nursing homes with a greater interest in improving quality of care participated in the study. Furthermore, not all nursing homes participated with all wards and some residents were able to be assessed more often. In addi-

tion, the degree of cognitive impairment was not explored, meaning that no information was available for different stages of dementia.

Strengths of the study

In this study, well-tested standardized instruments (*Austrian Prevalence Measurement of Care Problems* questionnaire*; Care Dependency Scale*) were used to collect data. Every resident was assessed by two health care professionals to ensure an objective assessment of care dependency and nursing care problems.

CONCLUSION

Residents with dementia are more care dependent than residents without dementia and they have, except for pressure ulcers, a higher prevalence of nursing care problems. The high degree of care dependency and prevalence of the assessed nursing care problems, especially in residents with dementia, depict the fact that these quality indicators are still important issues in nursing homes and that there is room for improvement. On the basis of the results, maximizing the independence of residents with dementia is recommended, especially in the areas of hygiene, continence, getting (un)dressed and avoiding danger, and focusing more strongly on residents suffering from pressure ulcers and incontinence, as they show the highest degree of care dependency. Furthermore, incontinence care should be improved particularly with regard to maximizing care independence and reducing the use of restraints. Further research should compare care dependency and nursing care problems in different stages of dementia to promote stage-appropriate dementia care in nursing homes. Additionally, longitudinal studies could be carried out that compare changes in care dependency and nursing care problems between residents with and without dementia.

DISCLOSURE OF INTEREST

The authors declare that they have no conflicts of interest concerning this article.

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ETHICAL STATEMENT

For this study ethical approval from the Medical University of Graz, Austria ethics committee was obtained. Written informed consent was acquired from each resident or their legal representatives. The authors guarantee that privacy has been strictly respected, and that no personal details are disclosed in the manuscript.

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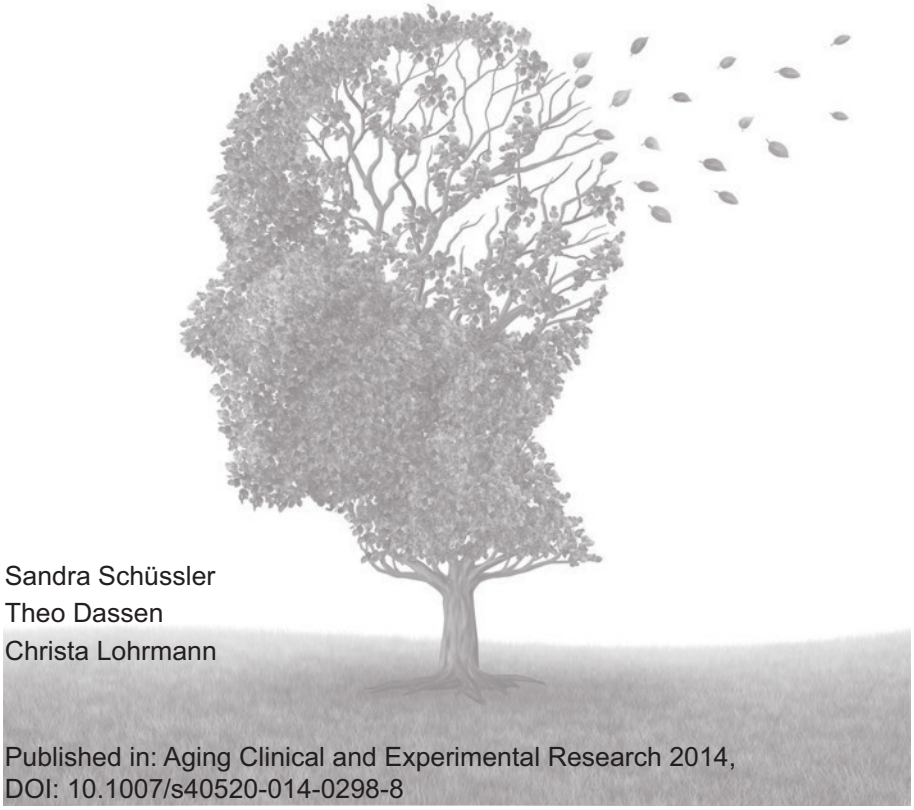
Chapter 5

Care dependency and nursing care problems in nursing home residents with and without dementia: a cross-sectional study



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ABSTRACT

Background and aim: Chronic diseases, like dementia, can lead to care dependency and nursing care problems. This study aims to compare the degree of care dependency and the prevalence of nursing care problems (pressure ulcer, incontinence, malnutrition, falls, restraints) between residents with and without dementia and between the stages of dementia.

Methods: A cross-sectional design was chosen and a total of 277 residents with and 249 residents without dementia from nine Austrian nursing homes were assessed by staff using standardized instruments.

Results: Significantly more residents with than without dementia are completely or to a great extent care dependent (54.5 vs. 16.9%). The comparison of care dependency between the stages of dementia indicates a large difference between moderate and severe dementia (completely care dependent: 9.3 vs. 44.3%). The comparison of the assessed nursing care problems between residents with and without dementia reveals a significant difference only with regard to incontinence (urinary: 84.2 vs. 53.2%, fecal: 50.9 vs. 17.7%, double: 49.1 vs. 14.9%). Urinary incontinence is high even in early dementia at 64%, reaching 94% in severe dementia. Fecal- and double incontinence are comparatively much lower in early dementia (both types 12%) and rise to more than 80% (both types) in severe dementia.

Conclusion: These results highlight areas in which dementia care needs further improvements. The authors suggest maximizing residents' independence to stabilize care dependency and improve incontinence care. Furthermore, longitudinal studies are recommended to deepen insight into the development of care dependency and nursing care problems in dementia residents.

Keywords: dependency · incontinence · quality indicators · prevalence · stages of dementia

INTRODUCTION

Demographic and epidemiological transitions are characterized by increasing life expectancy, population aging, and chronic diseases, like ischemic heart diseases and dementia.[1] Consequences of such chronic diseases may result in care dependency and/or various nursing care problems (see Fig. 1),[2] which could lead to nursing home admission[1, 3, 4] when in-home care is no longer possible. In nursing homes, the nursing care problems of pressure ulcers, incontinence, malnutrition, falls and restraints are common indicators that assess quality of care[1, 5, 6] and these problems are topics of interest for research on nursing homes.[7]

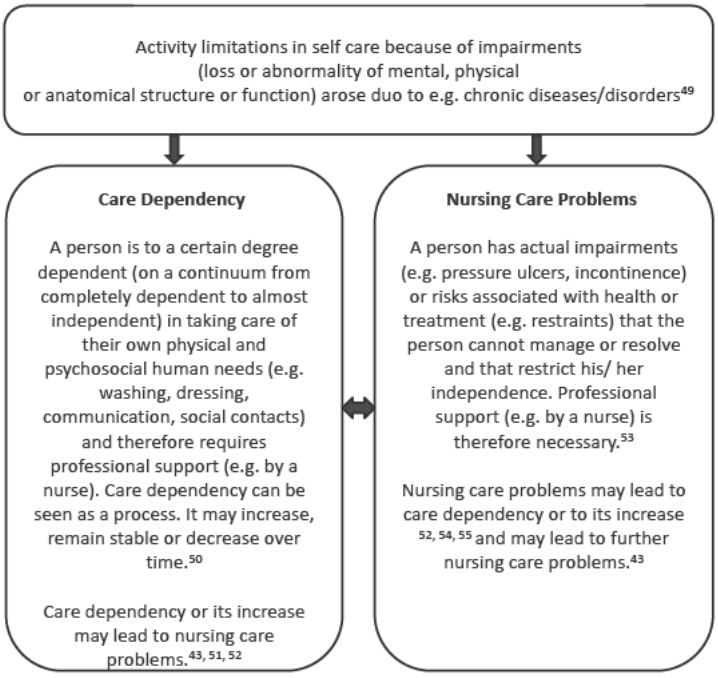

Fig. 1. Development and definition of care dependency and nursing care problems (based on Eichhorn-Kissel[17])

In nursing homes in developed countries, between 48 and 82% of the residents have dementia.[8–11] A recently performed Austrian prevalence study with 1,397 participating nursing home residents showed a dementia prevalence of 52.5%.[12] Dementia can generally be classified into mild-, moderate- and se-

vere dementia, but the course of dementia may vary from person to person.[1, 13] (Care) dependency/increase of (care) dependency and nursing care problems can occur in a very early stage of dementia and worsen over time.[1, 13] Both can result in many negative outcomes, like a reduced quality of life, high health care costs and increased risk of mortality.[12, 14–17] Therefore adequate nursing care interventions for residents are necessary to prevent (e.g. pressure ulcers are preventable in many cases), reduce or stabilize care dependency and nursing care problems.[12, 18, 19] A prerequisite for adequate nursing care is the critical reflection and evaluation of daily nursing care practice, e.g. nursing interventions.[12, 20] Prevalence values support critical refection by highlighting the extent of care dependency and nursing care problems in institutions/persons and help to indicate whether nursing care in this area needs to be improved.[12, 20]

A literature review by Schüssler et al.[2] highlighted that only a few international studies from the past 10 years included information about the prevalence of care dependency and/or nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints) in residents with dementia, and that only four of the included 20 articles focused on differences between residents with and without dementia. These studies can therefore only infer that the prevalence of care dependency and nursing care problems may be higher in residents with dementia.[2] Due to health care professionals' clinical experience, it can be presumed that residents with dementia are more care dependent and have a higher prevalence of nursing care problems. However, this should be corroborated and visualized with statistical data to show professionals the extent of the differences between residents with and without dementia and to illustrate which specific needs residents with dementia have compared to other residents. This kind of deeper understanding of residents with dementia may help to reach the goal of providing high quality care (e.g. target-oriented care according to the needs of a person/group) for residents with dementia.[1,2,21] Besides knowledge about the differences between residents with and without dementia, high quality dementia care furthermore requires in-depth knowledge about care dependency and nursing care problems at different stages of dementia.[2] It is generally known from the international literature the stages of dementia during which care dependency in different areas and various nursing care problems develop,[1, 13] but awareness of their extent in different stages is very limited. In a cross-sectional study in the Netherlands, Wetzels et al.[22] compared care dependency with the InterRai Long-Term Care

Facility scale using 207 residents with mild to moderately severe dementia and 81 residents with severe dementia [stages of dementia were assessed with the Global Deterioration Scale (GDS)]. The results showed significant differences between these two groups. Only 4.8% of the residents with mild to moderately severe dementia were totally care dependent compared to 55.6% of the residents with severe dementia. Other studies focused only on the severe stage of dementia and included no information about other stages. They found that 35.5 - 55.8% of the residents are completely care dependent; [23, 24] 7 - 47% had pressure ulcers;[23, 25, 26] 87% had fecal incontinence;[23] 14% were malnourished;[23] 58 - 60% had fallen[27] and 58% were restrained.[25]

The identified lack of knowledge in the international literature about differences in the extent of care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) as they relate to residents with and without dementia, as well as in different stages of dementia demands that the following research questions be asked:

1. What is the degree of care dependency among residents with versus without dementia and at different stages of dementia?
2. What is the prevalence of nursing care problems among residents with versus without dementia and at different stages of dementia?

METHODS

Design

A multicentre cross-sectional study, the first measurement in a longitudinal study, was conducted in 2012.

Setting and sample

Austria has nine federal states with 8.5 million people, of whom 18% are 65 years and older and 8% are 75 years and older[28]. About 4% of people aged ≥ 65 and 18% of people aged ≥ 85 are receiving institutional long-term care.[29] Austria has 890 public and private nursing homes with approximately 70,000 beds, ranging between ones with just four to approximately 400 beds[30]. Most of the Austrian nursing homes provide both nursing care and residential places. Because of this, residents will have different (care) needs.[29]

For this study the two Austrian federal states (Vienna, Styria) with the biggest cities were chosen. These two federal states contain 295 nursing homes, of which 175 have a capacity of ≥ 50 beds.[30] In this convenience sampling, all proprietors and nursing directors of these nursing homes were invited to participate through an information flyer sent via post and e-mail. Eleven interested nursing homes were visited and the staff was informed about the study by the first author. In total, nine nursing homes (29 wards) participated in the study. The nursing homes provide a mix of residential and nursing care places. Eight of the nine nursing homes are private institutions in urban areas. The average number of beds per nursing home is 97.3 ± 47.6 and the average number of beds per ward is 30.2 ± 10.7. At the time of data collection, 876 residents lived in these homes, of which 815 fulfilled participating criteria (not terminal, not comatose/too sick, not in short term care). Of these eligible residents, only those who had given informed consent, were present at the time of data collection and could understand German were included.

Ethical considerations

Approval from the Medical University of Graz ethics committee was obtained. Written informed consent was acquired from every resident or their legal representative by the nursing homes.

Instruments

Demographic data and prevalence of nursing care problems

The demographic data age, gender, medical diagnoses (based on ICD-10), length of nursing home stay and the prevalence of nursing care problems (definition see Fig. 1) including incontinence, malnutrition, restraints, pressure ulcers and falls were collected with the Austrian version of the International Prevalence Measurement of Care Problems questionnaire.[12] This questionnaire is a standardized and tested instrument, with dichotomous and multiple answer possibilities, which was developed by Maastricht University.[20] The original Dutch questionnaire was translated (forward and backward) and double-checked for nomenclature and cultural differences by researchers and experts in quality of nursing care.[20] A comprehensive description of the questionnaire with a detailed definition of every nursing care problem can be found in van Nie-Visser et al..[20] As an example, restraints are interventions including

bed rails, bed-straps, nursing blankets, deep chairs and chair tables, which are used to prevent dangerous or risky situations.[20]

Care dependency

To assess care dependency (definition see Fig. 1), the German version of the Care Dependency Scale (CDS)[31] was used, which is included in the Austrian version of the International Prevalence Measurement of Care Problems questionnaire. The CDS was developed in the Netherlands to asses care dependency in residents with dementia and intellectual disabilities in long-term care institutions (e.g. nursing homes) by Dijkstra et al..[32] The instrument has been comprehensively tested regarding its psychometric properties.[15, 31] The CDS contains 15 items referring to physical and psychosocial needs which are assessed by means of a 5-point Likert scale ranging from completely care dependent (1) to almost care independent (5).[31] In accordance to Dijkstra et al.,[33] residents with sum scores of 15 - 24 were classified as 1: *completely care dependent* (no independence, support and/or guidance is always necessary); 25 - 44 as 2: *to a great extent care dependent* (severely restricted independence, support and/or guidance is frequently required to a great extent); 45 - 59 as 3: *partially care dependent* (restricted independence, support and/ or guidance is necessary); 60 - 69 as 4: *to a limited extent care dependent* (independence with little support and/or guidance); and 70 - 75 as 5: *almost care independent* (everything is done independently).

Medical diagnosis of dementia and stages of dementia

Medical diagnoses of dementia documented in patient records (based on ICD-10) were also collected using the Austrian version of the International Prevalence Measurement of Care Problems questionnaire (dichotomous answer: dementia yes or no). Furthermore in residents with the medical diagnosis of dementia the stages of dementia were determined with the German version of the Mini- Mental State Examination-2 (MMSE-2).[34] Based on the dementia guideline by DEGAM,[35] dementia residents with sum scores of 30 - 5 points were classified as having *early dementia with no visible cognitive impairment* at MMSE-2; 24 - 20 points as *mild dementia*; 19 - 10 as *moderate dementia*; and scores below 10 points were classified as *severe dementia*. A sum score of up to 30 points is possible for persons with diagnosed dementia because the MMSE is not particularly sensitive to determining mild dementia in individ-

uals.[36] Because of this, residents with diagnosed dementia and a sum score between 25 and 30 were not excluded from the dementia group.

Data collection

Data collection by nursing professionals took place from April to May 2012. Within this timeframe, all 29 participating wards from the nine nursing homes had 1 week's time to conduct data collection. Each resident was assessed once. The first author trained all nursing professionals on the correct use of the standardized instruments. To obtain objective data, each resident was assessed by two health care professionals (one of whom was involved in their daily care and a second who was not). The first author visited all of the nursing home wards on the first day of data collection to check that it was being done correctly and to discuss any ambiguities. After data collection the questionnaires were sent from the nursing homes to the researcher for data analysis.

Statistical analysis

Statistical analysis was performed using IBM® SPSS® Statistics, version 20.[37] Descriptive analysis was conducted to describe the sample and statistical tests were run to explore differences between residents with and without dementia and between residents at different stages of dementia. Crosstabs were performed for categorical variables (gender, diseases, degree of care dependency, nursing care problems) and Pearson's Chi-squared test or Fisher's exacter tests were used to explore differences between groups. No differences were explored for the degree of care dependency in different stages of dementia because certain prerequisites were lacking (5 x 4 table with values too small or no value in seven cells) for Pearson's Chi-square test or Fisher's exact test.[38] For metric variables (age, mean length of nursing home stay, mean degree of care dependency in CDS items), means and standard deviations [standard deviations are not shown for mean degree of care dependency in CDS items (Fig. 2, 3)] were calculated and differences were explored using the t test or Kruskal – Wallis test. In all analyses, p values of ≤ 0.05 were considered significant.

RESULTS

Sample characteristics

At the time of data collection, 815 residents for potential inclusion lived in the 29 participating wards of the nine nursing homes. Of these residents, 65% (n = 527) took part in the study. Reasons for non-participation included resident refusal (29.7%), unavailability at the time of data collection (2.7%) and other unspecified reasons (2.9%). One resident with dementia was excluded from data analysis of this study because of missing MMSE-2, resulting in a sample of 277 residents with and 249 residents without dementia.

A comparison of the basic characteristics of residents with and without dementia reveals that residents with dementia are significantly older (mean age: 85.1 ± 6.6 [SD] vs. 82.9 ± 9.8 [SD], $p < 0.05$) and had lived longer in the nursing home (mean length of stay, in months: 33.8 ± 30.9 [SD] vs. 42.8 ± 42.3 [SD]; $p < 0.05$). No significant differences were found regarding gender between these two groups (female: 81.2% [95% CI, 76.6 - 85.9] vs. 79.1% [95% CI, 74.1 - 84.0], $p > 0.05$) or diseases. The five most prevalent diseases in residents with and without dementia were cardiovascular diseases (57.6% [95% CI, 51.8 - 63.3] vs. 60.2% [95% CI, 53.7 - 66.1], $p > 0.05$), motor diseases (35.9% [95% CI, 29.9 - 41.7] vs. 37.8% [95% CI, 31.5 - 43.5], $p > 0.05$), diabetes mellitus (27.5% [95% CI, 22.4 - 32.9] vs. 24.1% [95% CI, 18.6 - 29.7], $p > 0.05$), depression (26.1% [95% CI, 20.9 - 31.7] vs. 27.3% [95% CI, 22.0 - 32.6], $p > 0.05$) and diseases of the kidney/urinary tract or sexual organs (22.1% [95% CI, 17.3 - 27.0] vs. 20.5% [95% CI, 15.4 - 25.5], $p > 0.05$). These diseases showed furthermore no significant differences between the stages of dementia.

Care dependency

The comparison of the degree of care dependency between residents with and without dementia (Table 1) shows that residents with dementia have a significantly higher degree of care dependency than residents without dementia. 54.5% of the residents with dementia compared to 16.9% of the residents without dementia are completely or to a great extent care dependent.

Table 1. Comparison of the degree of care dependency between residents with and without dementia

Degree of care dependency	Residents with dementia[a] (n = 277)		Residents without dementia (n = 249)	
	%	95% CI	%	95% CI
Completely dependent	20.6	15.9-25.3	2.8	0.8-5.1
To a great extent dependent	33.9	28.5-39.7	14.1	10.0-18.0
Partially dependent	27.1	21.7-32.1	28.9	23.5-34.9
To a limited extent dependent	14.1	10.1-18.4	26.5	21.0-32.1
Almost independent	4.3	2.2-6.9	27.7	22.0-33.1

[a] Significant difference between residents with and without dementia, Chi-square test, $p < 0.001$

Table 2. Degree of care dependency in residents with dementia at different stages

Degree of care dependency	Severe Dementia (n = 106)		Moderate dementia (n = 97)		Mild dementia (n = 49)		Early dementia (n = 25)	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Completely dependent	44.3	35.0-54.2	9.3	3.9-15.8	2.0	0.0-7.0	0.0	-
To a great extent dependent	45.3	35.5-55.4	39.2	28.7-49.5	16.3	6.5-27.0	0.0	-
Partially dependent	8.5	3.6-13.9	36.1	26.2-46.3	40.8	28.1-54.8	44.0	24.2-63.6
To a limited extent dependent	0.9	0.0-3.0	13.4	6.8-20.7	30.6	17.3-44.6	40.0	21.7-60.9
Almost independent	0.9	0.0-2.9	2.1	0.0-5.3	10.2	2.0-19.6	16.0	3.4-32.1

[a] Lacking prerequisites for Chi-square test/ Fisher's exact test to compare degree of care dependency between the stages of dementia

The analysis of the degree of care dependency at different stages of dementia (Table 2) indicates that residents with severe dementia are most care dependent; 89.6% of them are completely or to a great extent care dependent. Residents with moderate dementia demonstrate a markedly lower degree of care dependency; 48.5% of them are completely or to a great extent care dependent.

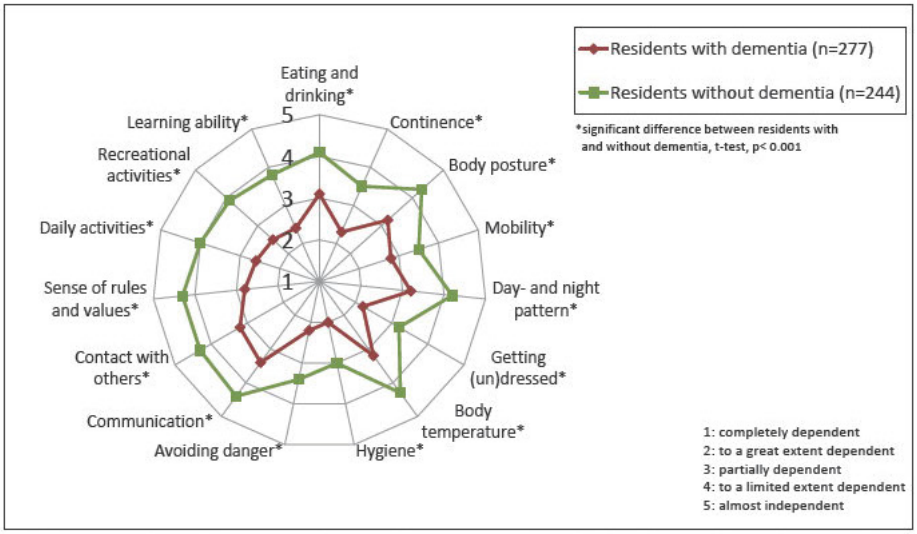

Fig. 2. Comparison of the mean degree of care dependency in the 15 care dependency scale items between residents with and without dementia

On the item level in the CDS, Fig. 2 shows that residents with dementia compared to residents without dementia are in every item significantly more care dependent, but both groups are most care dependent in hygiene, getting (un) dressed, avoiding danger and continence.

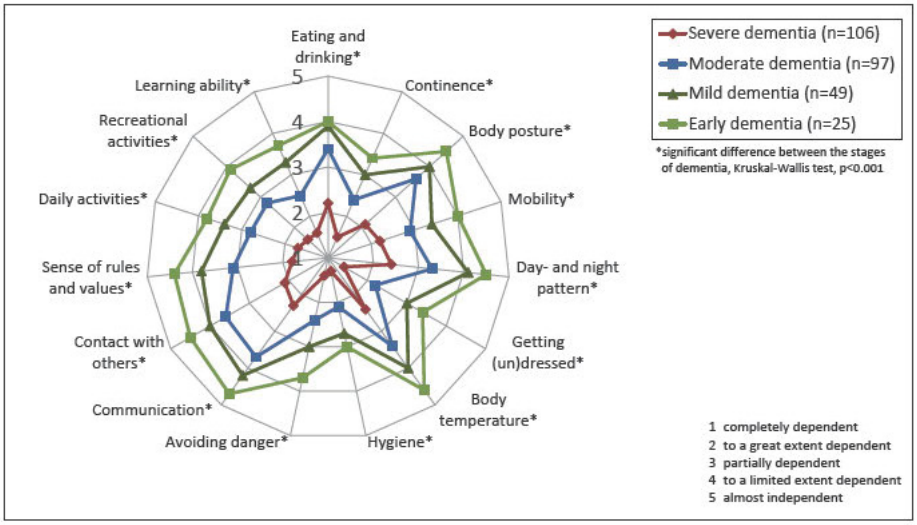

Fig. 3. Comparison of the mean degree of care dependency in the 15 care dependency scale items between residents with dementia at different stages

The in-depth picture of residents at different stages of dementia (Fig. 3) reveals significant differences between the groups. The most care dependent residents are those with severe dementia according to every item of the CDS.

Nursing care problems

The comparison of the assessed nursing care problems between residents with and without dementia shows significant differences between these two groups regarding incontinence. Residents with dementia have a higher prevalence of all three types of incontinence with the highest prevalence being for urinary incontinence. The other nursing care problems do not differ significantly between the groups (Table 3).

Table 3. Comparison of the prevalence of nursing care problems between residents with and without dementia

Nursing care problems	Residents with dementia (n = 277)		Residents without dementia (n = 249)	
	%	95% CI	%	95% CI
Urinary incontinence[a]	84.2	80.2-89.1	53.2	46.9-59.9
Fecal incontinence[a]	50.9	44.3-56.6	17.7	11.4-20.8
Double incontinence[a]	49.1	43.2-55.5	14.9	10.4-19.3
Malnutrition	14.7	9.5-17.9	12.2	8.9-17.5
Falls in last 30 days (at least one fall in the last 30 days)	12.3	8.5-16.7	11.3	7.7-16.4
Restraints in last 7 days (at least one use in last 7 days)	7.6	4.7-11.2	4.4	2.2-7.8
Pressure ulcers (category 1 included)	5.1	2.3-7.3	2.8	0.9-4.7

[a] Significant difference between residents with and without dementia, Chi-square test, $p < 0.001$

In view of the different stages of dementia, Table 4 demonstrates significant differences in all three types of incontinence between the groups. Urinary incontinence is most prevalent with severe dementia, but it is already highly prevalent in early dementia. In comparison to this result, fecal- and double incontinence is likewise most prevalent in severe dementia, but is definitively less prevalent in earlier stages of dementia. The other nursing care problems do not differ significantly between the stages of dementia.

Table 4. Comparison of the prevalence of nursing care problems between residents with different stages of dementia

Nursing care problems	Severe Dementia (n = 106)		Moderate dementia (n = 97)		Mild dementia (n = 49)		Early dementia (n = 25)	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI
Urinary incontinence[a]	94.0	88.9-98.1	85.1	77.1-91.7	71.7	58.6-85.7	64.0	42.9-83.3
Fecal incontinence[b]	84.0	76.2-90.7	39.2	30.2-49.5	22.4	11.1-34.0	12.0	0.0-27.3
Double incontinence[b]	81.0	72.9-88.3	37.2	27.0-48.4	23.9	11.8-38.1	12.0	0.0-27.6
Malnutrition	19.4	12.0-27.5	13.5	6.7-21.6	10.2	2.4-19.6	8.3	0.0-21.1
Falls (at least one fall in the last 30 days)	13.2	6.9-19.8	15.5	8.3-22.5	8.2	2.0-16.4	4.0	0.0-13.6
Restraints (at least one use in last 7 days)	12.3	6.4-19.2	7.2	2.6-12.9	2.0	0.0-6.7	0.0	-
Pressure ulcers (category 1 included)	5.7	1.9-10.5	7.2	2.4-13.1	2.0	0.0-6.8	0.0	-

[a] Significant difference between the stages of dementia, Chi-square test, $p < 0.001$
[b] Significant difference between the stages of dementia, Fisher's exact test, $p < 0.001$

DISCUSSION

Care dependency

This study compared the degree of care dependency between residents with and without dementia and between the stages of dementia. The results show that residents with dementia have a significantly higher degree of care dependency than those without dementia (54.5% vs. 16.9% are completely or to a great extent care dependent). A similar result was found in the study by Guo et al.,[39] but in contrast, we additionally explored the degree of care in different areas (15 items of the CDS). The results highlight that residents with and without dementia are most care dependent in the same needs [hygiene, getting (un)dressed, avoiding danger and continence], but to a significantly higher degree in residents with dementia.

This higher degree of care dependency is not surprising because it is known from the literature that dementia is the strongest independent contributor to (care) dependency.[1] On the basis of the results, the higher degree of care dependency in residents with dementia may also be a result of the findings that most of the residents with dementia were in the severe stage. This stage is characterized by increasing behavioral, physical and mental problems leading to them being completely care dependent on others.[1, 13, 40] In our study 8% (n = 9) of the residents with severe dementia were only partially dependent. One reason for this may be that these residents were at the beginning of the severe stage of dementia or that they were measured during a good phase/ on a good day, because it is known from the literature that stages of dementia may overlap and symptoms can occur earlier or later in the course of illness.[13] 44.3% of the residents with severe dementia are completely care dependent. Three other studies also found a high prevalence in 35.5 - 55.8% of residents at this stage,[22–24] but in contrast to these studies we explored the degree of care dependency for all stages of dementia and highlighted a large difference in care dependency between severe and moderate dementia (44.3 vs. 9.3%). This result indicates that promoting independence (e.g. helping the resident to perform activities as much as possible without or with minimal support) may be very important particularly at the moderate stage of dementia to prevent an unnecessarily accelerated progression of care dependency.

Nursing care problems

Along with the degree of care dependency, this study compared the prevalence of pressure ulcers, incontinence, malnutrition, falls and restraints between residents with and without dementia and between the stages of dementia. The results show that among all of the assessed nursing care problems, incontinence is most prevalent in both groups, but significantly more in residents with dementia (urinary incontinence: 84.2 vs. 53.2%; fecal incontinence: 50.9 vs. 17.7%; double incontinence: 49.1 vs. 14.9%). Luo et al.[41] found a prevalence of 82.2% in residents with and 66% in those without dementia, but they didn't differentiate between urinary- and fecal incontinence. The study by Eriksson et al.[42] focused only on urinary incontinence and indicated a higher prevalence in residents with dementia (38.8 vs. 16.9%).

The higher prevalence of all incontinence types in residents with dementia in our study may be because residents with dementia are significantly older

than those without dementia, are far more care dependent in general, and also in different areas [e.g. in mobility, continence, body posture, learning ability, (un)dressing], which are described in the international literature as risk factors for developing incontinence.[40, 43, 44] The results additionally show that the prevalence of urinary incontinence is high in all stages of dementia; it affects 64% of people in the early stage of dementia, and reaches 94% in the severe stage. Compared to urinary incontinence, the prevalence of fecal- and double incontinence is low in the early stage (both types 12%) and high in the severe stage (fecal 84%; double 81%). According to the literature, incontinence generally arises in residents with moderate dementia and increases to a loss of bladder and bowl control in severe dementia.[1, 13, 26, 45, 46] A common reason is the progressive cognitive (e.g. forgetting to go or not finding the toilet) and physical (e.g. mobility, communication, fine motor skills, diabetes) decline as well as mental disorders (e.g. depression) and medication side effects.[40, 47] The very high prevalence of incontinence in just early or mild dementia in this study might have been because residents in these stages were already highly care dependent (early dementia: 44% were partially care dependent; mild dementia: 57.1% were partially or to a great extent care dependent), especially in continence, getting (un)dressed, hygiene and learning ability, which is a main risk factors for incontinence.[43, 44] The high degree of care dependency in residents with early and mild dementia may indicate that independence in self-care is not adequately promoted by nursing professionals. This assumption must be investigated in a later study.

In contrast to incontinence, the prevalence of malnutrition, falls, restraints and pressure ulcers is not significantly different between residents with and without dementia; there only tends to be a slightly higher prevalence in residents with dementia. The studies by Jesus et al.[48] and Luo et al.,[41] however, revealed a significantly higher prevalence of malnutrition, falls and restraints in residents with dementia. This could be because both studies had a higher sample size of either residents and/or nursing homes than our study (13,335 residents from 1,174 nursing homes in the study by Luo et al.;[41] 346 residents from 26 nursing homes in the study by Jesus et al.).[48]

This study does have some limitations. The small sample size of Austrian nursing homes provides just a glimpse into the differences in the extent of care dependency and nursing care problems in residents with and without dementia. The participation of the nursing homes was voluntary and the re-

searchers were not privy to the reasoning behind a nursing home's decision to participate or not, which could constitute a selection bias. Furthermore, the specific type of dementia was not collected with the questionnaire, which should be included in further studies to provide a more detailed description of care dependency and nursing care problems for different types of dementia.

On the basis of these results, we recommend that health care staff in nursing homes focus on consciously maximizing the independence of residents with dementia (e.g. through person-centred care) in particular the areas of hygiene, getting (un)dressed, avoiding danger and continence as much as possible at all stages, but especially for patients with moderate dementia, to prevent an unnecessary acceleration of care dependency. In view of the nursing care problems, the authors suggest continuing to improve continence care particularly for residents with even early stage dementia. Special attention should be paid to assessing exploring the resident's degree of care dependency in the area of continence based on their individual needs, followed by maximizing independence in continence at every stage of dementia.

Further research should aim to repeat our study with larger sample sizes, because at the moment, international prevalence values on care dependency and nursing care problems are lacking. Furthermore, longitudinal studies should be performed to compare the progression of care dependency and the development of nursing care problems between residents with and without dementia, over a longer period of time, to gain deeper insight into the needs of residents with dementia and promote dementia (stage)- appropriate care in nursing homes.

Conflict of interest

The authors declare no conflict of interest.

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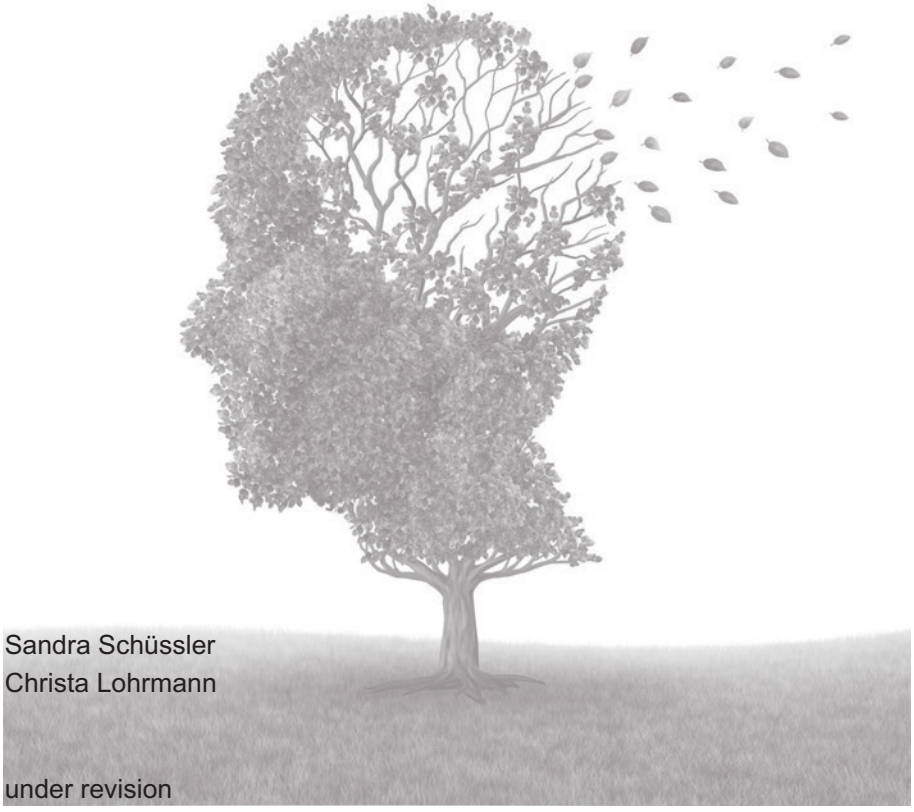
Chapter 6

Change in care dependency and nursing care problems in nursing home residents with and without dementia: a 2-year panel study



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under revision

ABSTRACT

Background: Over time, chronic conditions like dementia can lead to care dependency and nursing care problems, often necessitating nursing home admission. This study aims to explore changes in care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints) in residents with and without dementia over time.

Methods: Nine Austrian nursing homes participated in a panel study (2012-2014), with 258 residents (178 with, 80 without dementia) completing all five measurements. Data were collected with the International Prevalence Measurement of Care Problems questionnaire, the Care Dependency Scale and the Mini-Mental State Examination-2. Repeated measures ANOVA and crosstabs were used to analyse changes.

Results: Care dependency in dementia residents increased significantly for all 15 items of the Care Dependency Scale, with the highest increase being residents' day-/night pattern, contact with others, sense of rules/values and communication. In contrast, care dependency in residents without dementia increased for four of the 15 items, with the highest increase being for continence, followed by getting (un)dressed. With respect to the assessed nursing care problems, residents with dementia and those without only differed significantly in terms of an increase in urinary- (12.3% vs. 14.2%), fecal- (17.4% vs. 10%), and double incontinence (16.7% vs. 11.9%).

Conclusion: Results indicated that residents with dementia experienced increased care dependency in different areas than residents without dementia. Furthermore, residents with dementia experienced a lower increase in urinary incontinence but a higher increase in fecal- and double incontinence. These results help professionals to identify areas for improvement in dementia care.

INTRODUCTION

Worldwide, the aging population is growing and people are now living longer than ever before.[1] This transition is related with an increase in chronic conditions like cancer and dementia.[1] As these conditions progress, care dependency and nursing care problems like malnutrition may occur and increase because of declines in physical-, social- and mental abilities.[1-3] Dementia sufferers may be especially affected early in their illness.[1]

This study defines care dependency as a process in which an individual's care demands require professional nursing support because of their decreased ability to provide self-care for physical and psychosocial human needs, like eating and drinking, dressing, communication and social contacts.[4] Nursing care problems include impairments (e.g. malnutrition, incontinence, falls) and risks related to health or treatment (e.g. restraints) that nursing home residents are not able to address themselves.[5]

Care dependency, its progression and consequential nursing care problems are identified as common reasons that people relocate to a nursing home.[1,6] In this setting, frequent problems include pressure ulcers, incontinence, falls, malnutrition and restraints.[1,7-9] Therefore many nursing homes today monitor their quality of care[7,8] to stabilize or improve care dependency and/or nursing care problems for residents[7,10,11] and to avoid negative consequences like reduced quality of life, high health care costs and mortality.[7,11-13]

Few international studies explore changes in care dependency (in various human needs) and/or nursing care problems over time. Most have only examined changes in residents as a group,[14-17] or in residents with/without cognitive impairments.[18-20] Research exploring changes in care dependency (in various human needs) and nursing care problems in residents with diagnosed dementia compared to those without is, to our knowledge, missing in the international literature, as are studies that explore changes in care dependency and various nursing care problems together. This research would be important, because it could help to identify differences in the change of care dependency (in different human needs) and nursing care problems between residents with and without dementia. This knowledge would help to tailor care better to the specific needs and nursing care problems of nursing home residents with dementia.

Our study explores changes in care dependency and common nursing care problems in nursing home residents with and without dementia over time using the following research questions: 1) How does care dependency (in various human needs) change in residents with and without dementia over two years and how does the change differ between these two groups? 2) How do nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in residents with and without dementia change over two years and how does the change differ between these two groups?

METHODS

Design

A panel study was conducted from April 2012 - April 2014 with five measurement points (baseline assessment [T0] and follow-ups after six- [T1], 12- [T2], 18- [T3] and 24 months [T4]).

Setting and Sample

A convenience sampling was performed. An Austrian governmental database[21] was used to identify 175 nursing homes with ≥50 beds in two federal states. These nursing homes were invited to participate via post and e-mail, of which nine agreed to participate. All residents from said nursing homes (29 wards) were included in the study if they were present at T0 and could understand German. Comatose and dying residents were excluded as were residents in short-term care. The approval of the Medical University of Graz ethics committee (EK: 23-520 ex10/11) was obtained and written informed consent was acquired from each participating resident or their legal representative.

Instruments

The following instruments were used by trained nursing staff at all measurement points.

Demographic data and prevalence of nursing care problems

Age, gender, medically diagnosed dementia and other diseases (based on ICD-10), length of stay in nursing home and prevalence of nursing care problems (incontinence, malnutrition, restraints, pressure ulcers and falls) were collected using the Austrian version of the International Prevalence Meas-

urement of Care Problems questionnaire.[9,11] This standardized questionnaire originally developed at the Maastricht University had both dichotomous (yes/no) and multiple answer options and included assessment instruments (e.g. Care Dependency Scale).[9] The Dutch questionnaire was forward and backward translated and double-checked for nomenclature and cultural differences by researchers and experts in the field of quality nursing care. An in-depth description of the questionnaire can be found in van Nie-Visser et al.[9] Additionally, the type of dementia and the diagnosing physician were collected by nursing staff using medical records.

Care dependency

Care dependency was assessed using the German version of the Care Dependency Scale (CDS),[22] originally developed in the Netherlands to assess care dependency in residents with dementia.[10] The psychometric properties of the CDS have been well-tested.[10,22] The CDS contains 15 items (physical and psychosocial human needs) that are assessed by a 5-point Likert scale. A resident can be assigned between 15 and 75 points.[10,22] According to Dijkstra et al.[23], residents with sum scores of 15-24 are classified as *completely care dependent*, 25-44 as t*o a great extent care dependent*, 45-59 as *partially care dependent*, 60-69 as *to a limited extent care dependent* and 70-75 as *almost care independent*.

Cognitive impairment

Cognitive impairment in residents with and without dementia was assessed using the German version of the Mini-Mental State Examination 2 (MMSE-2).[24] This version has the same structure and scoring as the original MMSE. Small changes were made to improve items (e.g. words added for repetition exercises include *milk*, *sensible* and *before*) as a means to standardize translation into other languages and cultures. The English version of the MMSE-2 was forward- and backward translated by professional translators. The 30 items (every item 0 or 1 point) of the MMSE-2 include questions on registration; orientation in time and place; recollection; attention and calculation; naming; repetition; comprehension; reading; writing; and drawing. Lower scores on the MMSE-2 indicate higher cognitive impairment.[24]

Data collection

Data were collected in each nursing home at T0 and during four follow-ups (see design part) with a one month period for each data collection. The first author trained all nursing professionals who performed data collection. To ensure objectivity, each resident was assessed by two internal nursing professionals (one involved in the resident's daily care and a second who was not). If there were disagreements, the second one made the final decision. The first author visited all nursing home wards on the first day of T0 to ensure data were collected properly and clarify any ambiguities. After each data collection, the nursing homes sent questionnaires to the researchers.

Statistical analysis

Statistical analyses were performed using IBM® SPSS® Statistics, version 22 (IBM Corporation, NY). Only residents who had completed all measurement points were included in the analysis. Sample characteristics were analyzed using means and standard deviations for age, length of stay and MMSE-2 as metric variables. Differences between residents with and without dementia at T0 were explored using unpaired t-tests. Gender, medical diseases/disorders were analyzed as categorical variables using crosstabs; differences between the groups at T0 were explored using chi-squared tests. The change of the MMSE-2 sum score, the overall CDS-sum score and the individual 15 CDS items were first analyzed for residents with and without dementia using one-factorial ANOVA with repeated measures and then between residents with and without dementia using a two-factorial ANOVA with repeated measures on one factor. The changes in medical diseases/disorders and nursing care problems were analyzed using crosstabs and differences (T0-T4) within and between the groups were explored using McNemar tests. In all analyses, p-values ≤ .05 were considered significant.

RESULTS

Sample characteristics

From a total of 815 residents, 527 (65%) participated in the study at T0. Of these residents, 258 completed all measurements points. The response rate (T1, T2, T3, T4) was between 79.6% - 88.5%. The most common reason for non-participation (T1-T4) was either that residents had died (63.7%) or refused further participation (14.4%).

Overall, 69% (178 of 258) of the residents had dementia, of which 52% had Alzheimer's, 15.8% vascular dementia, 19.2% other types of dementia and 13% no specific type of dementia. Diagnoses were mainly made by a neurologist (86.4%).

Table1 shows significant differences between residents with and without dementia at T0. Residents with dementia had shorter nursing home stays and were less often afflicted by motor diseases and cancer. Cognitive impairment (MMSE-2) was higher in residents with dementia. The other characteristics did not significantly differ between the two groups.

Table 1. Sample characteristics of residents with and without dementia at baseline

Sample characteristics	T0	T0	
	Dementia (n=178)	No Dementia (n=80)	P-value
Age (in years), mean ± SD	83.5 ± 7.6	82.0 ± 10.4	.277
Length of stay in nursing home (in years), mean ± SD	2.5 ± 2.8	3.5 ± 3.4	.017
Female, %	83.1	78.8	.397
Medical diseases/disorders, %			
Cardio vascular disease	56.5	53.8	.681
Motor disorder/disease	29.4	42.5	.039
Diabetes mellitus	25.4	17.5	.162
Depression	22.6	26.3	.524
Eye/ear disorder	16.9	23.8	.199
Disorder/disease of the digestive tract, including intestinal obstruction, peritonitis, hernia, liver, gallbladder, pancreas	21.5	12.5	.088
Disorder/Disease of kidney/urinary tract, sexual organs	20.9	12.5	.107
CVA/hemiparesis	16.4	12.5	.422
Endocrine-nutritional or metabolic illness/ disease	13.0	15.0	.664
Cancer	2.8	11.3	.014
Nervous system disorder, excluding CVA	11.9	8.8	.458
Respiratory disorder/disease, including nose and tonsils	6.2	1.3	.111
Disease of blood or blood related organs	1.7	2.5	.648
MMSE-2, mean sumscore ± SD	16.5 ± 9.2	25.9 ± 4.6	<.001

Over two years, residents with dementia compared to residents without experienced a significant greater increase in motor diseases (15.8% vs. 5%; P= <.001) and cognitive impairment assessed with the MMSE-2 (-3.8 points vs. -0.9 points; P=.001). The change of other medical diseases/disorders did not significantly differ between the two groups.

Change in care dependency

Over two years, care dependency increased significantly in residents with (P<.001) and without dementia (P=.04). A comparison of these two groups revealed that the increase in care dependency was significantly higher in residents with dementia (-8.8 vs. -3.5 points; p<.001) (Fig. 1).

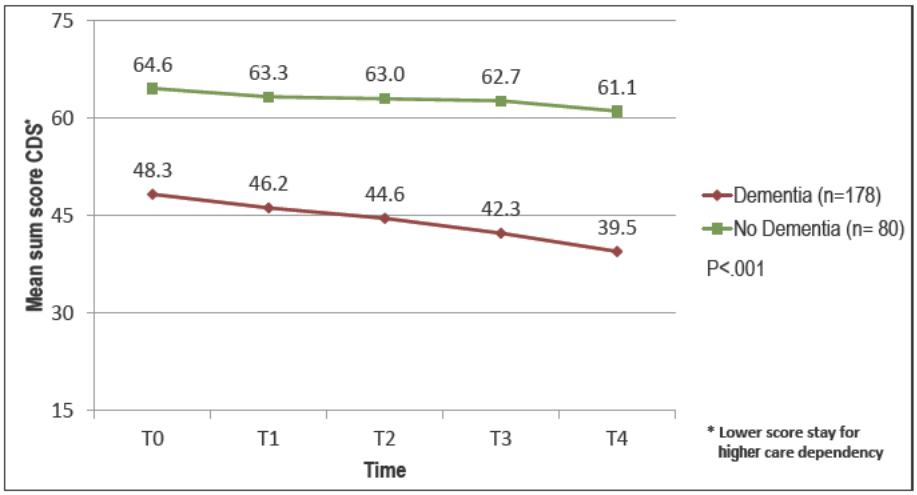

Fig. 1. Change in care dependency in residents with and without dementia over time

Fig. 2 highlights that over two years, care dependency for all 15 CDS items increased significantly in residents with dementia. Residents without dementia became increasingly care dependent for 4 of the 15 items.

The comparison of the 15 CDS items between residents with and without dementia showed that over two years, residents with dementia experienced a significantly higher increase in care dependency for the items day-/night pattern, body temperature, communication, contact with others, sense of rules and values and learning ability. The other items did not differ significantly between the groups (Table 2).

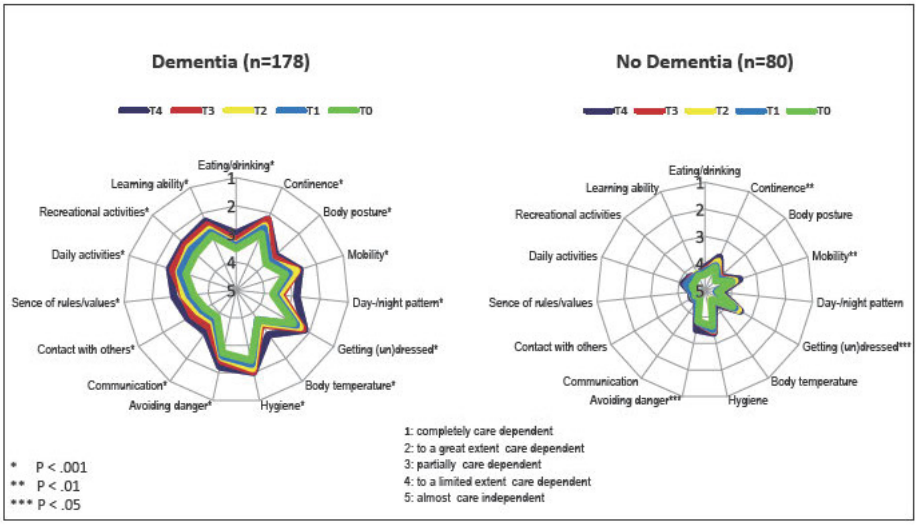

Fig. 2. Change in care dependency on an item level in residents with and without dementia over time

Table 2. Mean differences in the change of care dependency on an item level between residents with and without dementia

15 CDS Items	T0 to T4 Dementia (n=178) Mean Difference ± SD	T0 to T4 No Dementia (n=80) Mean Difference ± SD	P-value
Eating/drinking Ability to eat and drink/ prepare food/beverages	-0.54 ± 1.08	-0.24 ± 1.02	.074
Continence Ability to voluntarily control the discharge of urine/bowel movements and to take appropriate measures in response	-0.56 ± 1.21	-0.41 ± 1.22	.193
Body posture Ability to adopt appropriate activity-dependent positions	-0.45 ± 1.24	-0.23 ± 1.01	.462
Mobility Ability to move independently and without assistance	-0.54 ± 1.27	-0.31 ± 1.00	.064

Day-/night pattern Ability to independently maintain an appropriate day/night cycle	-0.85 ± 1.28	-0.13 ± 0.99	<.001
Getting (un)dressed Ability to get (un)dressed without assistance	-0.46 ± 1.08	-0.33 ± 1.08	.470
Body temperature Ability to maintain body temperature despite external influences	-0.65 ± 1.37	-0.16 ± 1.15	.028
Hygiene Ability to maintain personal hygiene and grooming	-0.43 ± 1.02	-0.26 ± 0.95	.254
Avoiding danger Ability to recognize danger and ensure safety	-0.52 ± 1.15	-0.30 ± 1.26	.346
Communication Ability to communicate with others (verbally and non-verbally)	-0.67 ± 1.23	-0.16 ± 0.65	<.001
Contact with others Ability to make, maintain and end social contact	-0.70 ± 1.24	-0.16 ± 0.97	.001
Sense of rules/values Ability to observe rules and values and assert the protection of privacy	-0.70 ± 1.23	-0.16 ± 0.68	.002
Daily activities Ability to manage/structure/perform daily activities unaided (e.g. household, shopping, money, appointments)	-0.61 ± 1.27	-0.34 ± 1.07	.095
Recreational activities Ability to make sensible use of free time/participate in leisure activities unaided	-0.58 ± 1.22	-0.26 ± 0.99	.148
Learning ability Ability to acquire knowledge/skills and/or to retain knowledge/skills learned in the past	-0.55 ± 1.28	-0.05 ± 1.10	.003

Change in nursing care problems

Fig. 3 indicates that over two years, the number of residents with dementia who experienced fecal incontinence increased by 17.4% (from 34.8% - 52.2%), followed by double incontinence with 16.7% (from 32.7% - 49.4%),

urinary incontinence with 12.3% (from 73.1% - 85.4%) and pressure ulcers with 4% (from 1.1% - 5.1%). In residents without dementia, urinary incontinence increased by 14.2% (from 33.8% - 48.0%), followed by double incontinence with 11.9% (from 3.9% - 15.8%) and fecal incontinence with 10% (from 7.5% - 17.5%). No other nursing care problems changed significantly for residents with and without dementia.

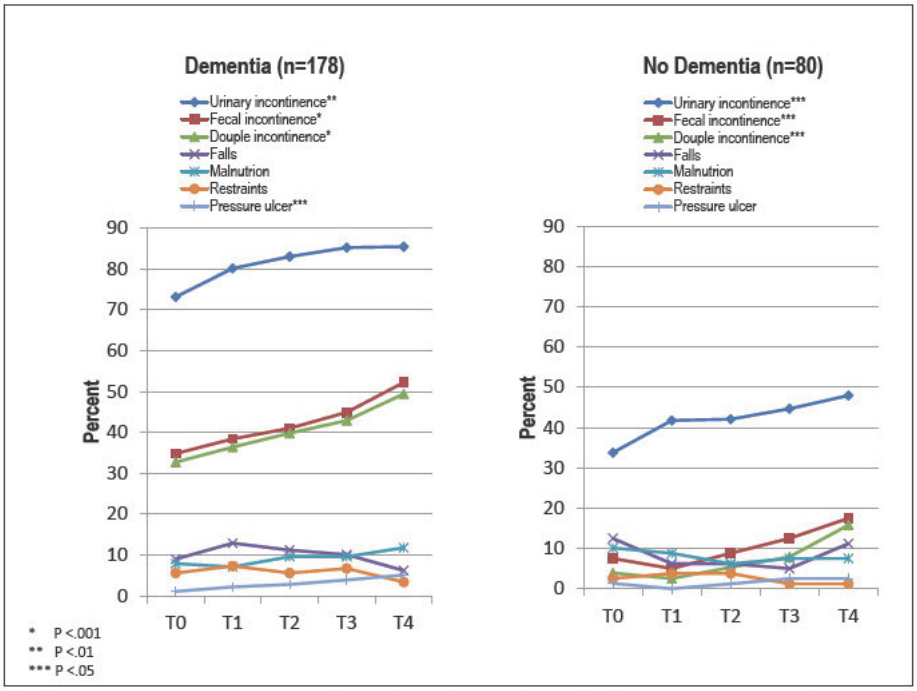

Fig. 3. Change in nursing care problems in residents with and without dementia over time

The comparison of nursing care problems between residents with and without dementia revealed that over two years, residents with dementia experienced a significant lower increase in urinary incontinence (12.3% vs. 14.2%, $P < .001$), but a significant higher increase in fecal- and double incontinence (fecal: 17.4% vs 10%, $P < .001$; double: 16.7% vs. 11.9, $P < .001$). The changes in all other nursing care problems did not differ significantly between residents with and without dementia.

DISCUSSION

Care dependency

Results showed that care dependency in residents with and without dementia increased significantly over two years, but for residents with dementia, it increased significantly more than in residents without dementia.

The fact that both groups changed significantly confirmed the understanding that once dependency in older people with chronic diseases takes hold, it tends to become chronic and progressive.[1] In our study, both groups were already care dependent at baseline, but more so for residents with dementia. Despite this fact, they experienced significantly higher care dependency over time. This may be because dementia is known to be the greatest independent contributor to care dependency based on its association with early physical, mental and behavioral decline.[1] In our study, residents with dementia were in a moderate stage of their illness at baseline (MMSE-2: sum score 16.5).

Dijkstra et al.[10] used the CDS scale to explore changes in care dependency in residents with Alzheimer's after two years and found a higher increase of care dependency (-11.37 points) than in our study, despite the fact that their residents were, at baseline, more care dependent. The higher increase of care dependency may be because they only included residents with Alzheimer's, which is characterized by its gradual progression. Other types of dementia, like vascular dementia, can progress differently.[25]

Our results highlighted that care dependency in all 15 items of the CDS significantly increased for residents with dementia; especially in day-/night pattern, contact with others, sense of rules and values and communication. Dijkstra et al.[10] also identified, with the exception of mobility, a significant increase in care dependency in the individual CDS items. Furthermore, they highlighted that dependency, specifically in terms of contact with others and communication, as well as the degree of care dependency, is a strong predictor that residents with dementia will become increasingly care dependent over time. In the present study, care dependency in residents without dementia only increased significantly in the areas of continence, mobility, getting (un)dressed and avoiding danger. This indicates that care dependency in residents without dementia only increased in physical areas in contrast to residents with dementia who experienced great increases in care dependency in psychosocial areas.

Nursing care problems

This study highlights that over two years, residents with and without dementia experienced significantly more incontinence. Urinary incontinence increased more in residents without dementia, while fecal- and double incontinence increased more in residents with dementia. The other nursing care problems, except for pressure ulcers, did not change significantly within and between the two groups; the prevalence of other problems was definitively lower compared to incontinence.

The significant increase of incontinence in residents with and without dementia may be related to a general increase in care dependency, which is an important risk factor in older people developing urinary or fecal incontinence.[16,26-28]

The literature shows that impairment of toilet use is one of the highest risk factors for urinary- and fecal incontinence in nursing home residents (odds ratio: 5.6 and 7.4, respectively).[27,29] In accordance with our results, care dependency in residents with and without dementia increased significantly in the area of continence. For this CDS item, residents without dementia experienced the highest increase in care dependency over time compared to the other 14 items.

The literature identifies further risk factors in specific areas of care dependency as eating, dressing, hygiene and mobility.[27,29] In the present study, care dependency in these risk factors increased significantly in residents with dementia, but it is possible that additional areas of care dependency (e.g. learning ability, communication) influenced the increase of incontinence in dementia residents. Such psychosocial areas are often not included in instruments (e.g. Katz Index, Barthel Index) that measure care dependency. The increase of incontinence in residents without dementia may also be influenced by increasing care dependency in mobility, getting (un)dressed and avoiding danger. Dependency in the ability to avoid danger (e.g. falls) might be connected with mobility problems and could necessitate bathroom accompaniment; should this not be executed in a timely way, incontinence could be reinforced. Care dependency in eating/drinking and hygiene did not increase significantly in residents without dementia and may have had a weaker influence on the increase of incontinence than the other areas in our study.

Besides care dependency, the international literature describes many other risk factors for incontinence. These include aging-related anatomic and physi-

ologic changes in the anorectal area and/or in the lower urinary tract, diabetes, cognitive impairment, stroke, depression, pressure ulcers and physical restraints.[27-30] With respect to the medical diseases/disorders assessed as well as cognition and nursing care problems, only residents with dementia displayed significant changes over time, specifically in terms of increases in cognitive impairment, motor disorders/diseases and pressure ulcers. These areas, in addition to care dependency, may influence increasing incontinence in dementia residents.

The fact that residents with dementia experienced a significantly lower increase in urinary incontinence may be explained by their higher prevalence of urinary incontinence (73.1% vs. 33.8%) at baseline. This may be, besides the other described risk factors, a reason why residents with dementia exhibited a greater increase of double incontinence than those without dementia, because urinary incontinence is a risk factor for developing fecal incontinence.[26,28]

Our study does have some limitations. The participation of nine nursing homes provides only a glimpse into changes in care dependency and nursing care problems in residents with and without dementia in Austria. Nursing home participation was voluntary. The reasons behind their participation/non-participation were not known by the researchers, leaving open the possibility of a selection bias. This study provided further no information about behavioral problems, pain and psychotropic medications, which are also relevant in nursing homes. Furthermore data for different types and stages of dementia were not analyzed, which would be important to better understand when developing type- and stage appropriate dementia care.

CONCLUSION

Residents with dementia experience a significantly greater increase in care dependency than other residents, primarily in day-/night patterns and psychosocial areas. Care dependency in residents without dementia only increased significantly in physical areas, with the highest increase being in continence. With regard to nursing care problems, the residents with and without dementia only differed significantly in terms of changes in incontinence (urinary, fecal, double).

Because of the high prevalence and increase of incontinence, particularly in residents with dementia, the authors suggest that clinical practice increase its focus on continence care in nursing homes. A priority should be the training and support of residents in managing their continence according to their needs. Further research should examine changes in care dependency and nursing care problems throughout different stages and types of dementia to gain further knowledge about dementia-specific care in nursing homes.

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Chapter 7

General Discussion

GENERAL DISCUSSION

Summary of the results

Study 1 provided an overview of the prevalence of care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in nursing home residents with dementia, which were described in the international literature. The results revealed that 28% - 83% of residents with dementia showed the highest degree of care dependency. Concerning the prevalence of nursing care problems, malnutrition ranged 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 105% - 60%.

Study 2 compared the degree of care dependency and the prevalence of nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints) between nursing home residents with and without dementia. The results showed that 72% of the residents with dementia, compared to 45.5% of residents without dementia, were completely or to a great extent care dependent. The highest care dependency was found in *hygiene, continence, getting (un)dressing* and *avoiding danger*. According to the nursing care problems, residents with dementia had a significantly higher prevalence of urinary incontinence (87.9% vs. 69.5%), fecal incontinence (68.2% vs. 44.5%), double incontinence (64.8% vs. 36.1%), restraints (33.5% vs. 22.4%), malnutrition (27.9% vs. 18.4%) and falls (9.9% vs. 7.0%). No significant difference was found for the nursing care problem pressure ulcers (5.2% vs. 6.5%).

Study 3 (part 1) compared the degree of care dependency and the prevalence of nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints) between residents with and without dementia and between the stages of dementia. The results showed that significantly more residents with than without dementia were completely or to a great extent care dependent (54.5% vs. 16.9%). The comparison of the stages of dementia indicated a large difference in completely care dependent residents with moderate to severe dementia (9.3% vs. 44.3%). With regard to nursing care problems, only incontinence differed significantly between residents with and without dementia (urinary: 84.2% vs. 53%; fecal: 50.9% vs. 17.7%; double: 49.1% vs. 14.9%). According to the stages of dementia, urinary incontinence was high even in early dementia with 64%, reaching 94% in severe dementia. Fecal-

and double incontinence was comparatively much lower in early dementia (both show a prevalence of 12%) and rose to more than 80% (both types) in severe dementia.

Study 3 (part 2) explored the changes in care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls and restraints) in residents with and without dementia over 2 years. The results highlighted that care dependency in residents with dementia increased significantly in all 15 physical- and psychosocial needs measured with the Care Dependency Scale, with the highest increase in residents' *day-/night pattern, contact with others, sense of rules/values* and *communication*. In contrast, care dependency in residents without dementia increased in four of the 15 physical- and psychosocial needs with the highest increase being for *continence*, followed by *getting (un)dressed*, *mobility* and *avoiding danger*. With regard to the nursing care problems assessed, residents with dementia compared to residents without differed significantly in terms of an increase in urinary- (12.3 vs. 14.2%), fecal- (17.4 vs. 10%), and double incontinence (16.7 vs. 11.9%). The other nursing care problems showed no change between the two groups over time.

Discussion of the main results

Extent of care dependency and nursing care problems in residents with dementia

The results of the narrative review in study 1 illustrated a large variance of the prevalence values of care dependency and the nursing care problems of pressure ulcers, malnutrition, incontinence, falls and restraints in nursing home residents with dementia. These large variances can be explained by the different definitions of care dependency and nursing care problems used in the studies included, the use of various measurement instruments and the different stages of dementia included. Additionally, the variances may be influenced by the differing sample sizes (care dependency: between 175 and 222 405 residents; nursing care problems: between 55 and 222 405 residents). In most of the studies, either the extent of care dependency or nursing care problems were examined, but not both aspects together. If the studies focused on nursing care problems, often only one nursing care problem was investigated. To get a comprehensive overview of the needs and nursing care problems of residents with dementia, it is crucial to determine the extent of care depend-

ency and various nursing care problems together.[1] This will help to identify the areas in which residents with dementia require special attention.

In the studies included that assessed the extent of care dependency, often only instruments like the Katz Index of ADL were used which included only physical needs (e.g. mobility, continence) to identify care dependency in residents with dementia. The drawback of including only physical needs is that a comprehensive overview of care dependency of persons with chronic diseases, like dementia, is excluded, because such persons also have psychosocial needs in addition to physical needs.[2,3] Therefore using instruments that include psychosocial needs (e.g. social contacts, communication) is particularly necessary.[4]

Comparing the extent and change in care dependency and the nursing care problem of incontinence between residents with and without dementia

Care dependency

The results of studies 2 and 3 (part1) showed that residents with dementia were significantly more care dependent than residents without dementia. This is in line with results from Burdick et al.,[5] Samus et al.[6] and Guo et al.[7]. In contrast, the study by Luo et al.[8] found no difference in the extent of care dependency between residents with and without dementia. This could be because they did not use a standardized instrument to assess care dependency. They instead extracted 5 needs from patient documentation and categorized them into 3 degrees of care dependency. The dementia residents' higher degree of care dependency in the studies of the doctoral thesis may be because most of them were in the moderate or severe stage of illness, which is characterized by the (increased) presence of various behavioral, physical and mental problems.[9-11]

With regard to the 15 physical and psychosocial needs assessed, the findings from studies 2 and 3 (part 1, part 2) highlighted the fact that residents with and without dementia were most care dependent in the same needs, but dementia residents to a greater extent. These were in the needs *hygiene, continence* and *getting (un)dressed*. According to Maslow's Hierarchy of Needs,[12] such physical needs are the most basic and occur for people with chronic conditions early in their course of illness, which is when care dependency can

arise.[13-15] This may be the reason why both groups were most care dependent in *hygiene*, *continence* and *getting (un)dressed*. Dementia residents' higher extent of care dependency in these needs may be because of their cognitive impairment and higher degree of care dependency in the need *learning ability* (require support in acquiring knowledge/skills and retaining knowledge/skills learned in the past) compared to residents without dementia. After *hygiene, continence* and *getting (un)dressed*, residents with and without dementia were most care dependent in the need *avoiding danger*, but for residents with dementia to a greater extent. It may be that both groups were more care dependent in this need because, like the other needs, *avoiding danger* is a very fundamental human need.[12] In the hierarchy of Maslow's model, the higher basic human needs are psychosocial ones (e.g. social contacts).[12]

The results of study 3 (part 2) showed that care dependency in the 15 physical and psychosocial needs assessed progressed differently for residents with and without dementia. Care dependency in residents with dementia significantly increased in all 15 physical and psychosocial needs, but primarily in the needs *day-/night pattern, contact with others, sense of rules/values* and *communication*. In comparison, care dependency in residents without dementia only increased significantly in 4 needs, namely in *continence*, followed by *getting (un)dressed, mobility* and *avoiding danger*. These results show that care dependency in residents with dementia, contrary to residents without dementia, increased mainly in psychosocial aspects. This can be explained by the fact that residents with dementia compared to residents without dementia experienced a significant increase in cognitive impairment, which makes it generally difficult for people with dementia to, for example, communicate with others and maintain social contacts.[16,17] Therefore a nursing home's ability to identify and meet psychosocial needs in residents with dementia is important to improve resident's quality of life[18] and avoid psychological problems like anxiety, depression and a sense of isolation.[19,20]

Incontinence

Of all the nursing care problems assessed in studies 2 and 3 (part 1, part 2), incontinence (urinary-, fecal-, double incontinence) was found to be the main nursing care problem with the highest prevalence and greatest increase in residents with and without dementia. The high increase of incontinence in both groups may be related to their care dependency level at baseline,

because care dependency is one of the main risk factors for developing incontinence.[21-24] In view of the individual needs of care dependency, the limitation of self-care in terms of continence (e.g. using the toilet) and related care dependency in the needs eating, dressing, hygiene/bathing and mobility/transfer are closely connected with the development of incontinence.[22,25] Care dependency in residents with dementia increased significantly in all the stated needs, but it may be possible that additional needs influenced the increase of incontinence in the studies performed, like *communication* (e.g. problems communicating that help with continence is required), *learning ability* (e.g. not recognizing the need to go to the toilet), *day-/night pattern* (e.g. problems finding the toilet at night) and *avoiding danger* (e.g. the person does not reach the toilet in time, because of a fear of falling, walking too slowly or not receiving support early enough to reach the toilet in time). Residents with dementia increased significantly in these needs and they are listed in the literature as possible reasons for incontinence.[26,27] The increase of incontinence in residents without dementia may be connected with the significant increase of care dependency in *continence*, *getting (un)dressed*, *mobility* and *avoiding danger*. Care dependency in *eating and drinking* as well as in *hygiene* did not increase significantly and may have had a weaker influence on the increase of incontinence than the other stated needs.

Aside from care dependency, many other risk factors for incontinence are described in the international literature, including age-related anatomic and physiological changes in the anorectal area and/or in the lower urinary tract; diabetes mellitus; cognitive impairment; stroke; depression; pressure ulcers; and restraints.[22,24,25,28] With respect to the medical diseases/disorders assessed, cognitive impairment and nursing care problems in the studies conducted, only residents with dementia displayed significant changes over time with increases in cognitive impairment, motor diseases/disorders and pressure ulcers. It is possible that these risk factors, alongside care dependency, influenced the increase of incontinence in the studies conducted here.

With regard to the different types of incontinence, the results have shown that residents with dementia had a significantly lower increase in urinary incontinence than residents without dementia over time. This can be explained by their already higher prevalence of urinary incontinence (73.1% vs. 33.8%) at baseline. This high prevalence of urinary incontinence may be one reason why residents with dementia experienced a greater increase over time in dou-

ble incontinence than residents without dementia, because urinary incontinence is a risk factor for developing fecal incontinence.[23,24]

In view of the stages of dementia, the results of study 3 (part 1) showed that urinary incontinence was high even in early (64%) and mild dementia (71.7%) and reached the highest prevalence in severe dementia (94%). The prevalence of fecal- and double incontinence was, in comparison to urinary incontinence, low in early- (both types 12%) and high in severe stage dementia (fecal: 84%, double: 81%). The international literature describes that incontinence tends to arise in a moderate to severe stage of dementia.[27] The high prevalence of urinary incontinence in the current study may be related to the already high degree of care dependency in early and mild dementia (early dementia: 44% were partially care dependent; mild dementia: 57.1% were partially or to a great extent care dependent), which is a main risk factor for incontinence.[22,29] It may also be that continence management was not adequately performed according to the needs of dementia residents in nursing homes. Research by Hancock et al.[19] showed that 24% of residents with dementia had unmet needs with regard to continence/incontinence. Since incontinence can foster care dependency[30-32] and vice versa[21-24], and incontinence could lead to further nursing care problems like pressure ulcers and falls,[33-35] continence management is essential in nursing homes.

Methodological reflections

In **study 1**, a narrative review was chosen to answer the research questions. This design was appropriate because it is very well suited to present a broad topic.[36] A systematic review however would not have been appropriate, because it is more appropriate in dealing with very narrow focused (clinical) questions on topics like effectiveness of interventions.[36,37] A narrative review is often seen as too subjective and unsystematic. For that reason the review was performed based on the guideline for narrative reviews by Green et al.[36] to strengthen objectivity and systematic procedure in the review.

Study 2 used a secondary data analysis of combined data from cross- sectional studies. This design allowed access to a large data set of Austrian nursing home residents with and without dementia, saving resources like time, personnel and costs. Primary research would have strained resources to get access and perform research with a comparatively large sample of nursing home residents. A further benefit of secondary data analysis was that the

knowledge gained was used to prepare a panel study. The preparation included modifying the International Prevalence Measurement of Care Problems questionnaire and selecting an instrument to assess cognitive impairment over time. A limitation of this secondary data analysis was that the original study was done for another purpose and therefore available data were limited (e.g. no data was available regarding the stages of dementia).

The panel design of **study 3 (part 1 and part 2)** was suitable for exploring changes in care dependency and nursing care problems in the same residents over time. A trend analysis however, could only have given information about overall changes and overlooked resident's individual changes. Therefore a panel study was more convincing. A further strength of the panel study was the ability to collect dementia diagnoses according to the ICD 10[38] with additional application of the MMSE-2 assessment[39] to explore the stage of dementia. Other longitudinal studies mostly only use instruments like the MMSE to determine whether dementia is present, but such instruments only suggest the possibility of dementia, because they are screening instruments and a formal diagnosis must be established with further tests (e.g. examination by an neurologist, computed tomography, magnetic resonance). A limitation of the study was that the responsiveness of the Care Dependency Scale was not verified for the Austrian nursing home setting; research in an other setting in Austria and research using the original scale in the Netherlands have shown that the Care Dependency Scale is able to explore changes over time.[40-43] Although the responsiveness of the Care Dependency Scale was not tested in the panel study conducted, the scale did show changes over time in that it identified that residents with a significantly higher increase of cognitive impairment also showed a significantly higher increase in care dependency. This increase can also be found in the international literature.[44-46] A further limitation of the study was the convenience sampling of nine out of 175 nursing homes in 2 out of 9 Austrian federal states. Therefore the results are not generalizable for Austria, but they do provide initial insight into the changes in care dependency and nursing care problems in Austrian nursing homes over time.

Study 2 used the *International Prevalence Measurement of Care Problems* questionnaire and the *Care Dependency Scale (CDS)* and **study 3 (part 1, part 2)** used, in addition to these instruments, the *Mini-Mental State Examination-2 (MMSE-2)*.

The *International Prevalence Measurement of Care Problems* questionnaire is a standardized instrument which has the potential to provide insight into the quality of nursing care on national and international levels by assessing quality indicators that include the prevalence of nursing care problems. This questionnaire is used annually in *the International Prevalence Measurement of Care Problems* survey in different health care settings (e.g. nursing homes, hospitals) in the Netherlands (since 1998), Germany, Switzerland, New Zealand and Austria (since 2009). The original Dutch questionnaire is tested regarding its face validity and interrater reliability, which has been shown to be good. Furthermore the questionnaire includes tested instruments (e.g. Braden Scale, CDS). The Dutch questionnaire was translated into German by professional translators and then back translated and double-checked for nomenclature and cultural differences by the Austrian project group and experts in nursing care quality. Based on expert feedback, small language changes were made that had no impact on questionnaire content.[47] The choice of the *International Prevalence Measurement of Care Problems* questionnaire was appropriate because in comparison with other instruments, like the oft used RAI-MDS (Resident Assessment Instrument – Minimum Data Set), it is a more comprehensive instrument; besides questions on the prevalence of nursing care problems and patient characteristics, it also addresses prevention and treatment of nursing care problems.[47] The psychometric properties of this instrument are not tested for in the German version, but the use of this instrument did not likely lead to a measurement bias because, for one reason, all studies found that incontinence, in comparison to other nursing care problems, is the nursing care problem with the highest prevalence. This result can also be found in other studies in Austria and in the Netherlands using the same questionnaire[48-50] and in a study from Germany using a modified version of the instrument.[51] Studies using other instruments (e.g. MDS) also found that incontinence has a higher prevalence than other nursing care problems in nursing homes.[52,53]

The *CDS* is a standardized instrument to assess a person`s degree of and changes in care dependency. The instrument was originally developed by Dijkstra et al.[54] in the Netherlands and is well tested for its psychometric properties.[55-58] The German version of the CDS, which was used in the studies included in this thesis, shows moderate to substantial observer agreement. Homogeneity by means of Cronbach's α coefficient is 0.94 and 0.98. Equivalence in terms of inter-rater and intra-rater reliability shows moderate to sub-

stantial Kappa values. Results of the Criterion-related validity also showed satisfactory results.[59] The use of the *CDS* was appropriate for the studies conducted because the scale is well tested for its psychometric properties; was originally developed for nursing home residents with dementia; originates from the nursing perspective based on the theory of nursing scientist Virginia Henderson; and comprehensively includes psychosocial needs.[54,60] Other instruments (e.g. Katz Index, Barthel index) are lacking in that they are most often not comprehensive (include only physical needs), they are frequently developed by disciplines other than nursing (e.g. medicine) and are developed for settings other than nursing homes.[61,62] Therefore the use of the very well tested and comprehensive *CDS* has strengthened the internal validity of the studies presented in this doctoral thesis.

The *MMSE-2*[39] is the new version of the MMSE, developed by Folstein et al..[63] It was developed in the USA, and is internationally the most well-known, widely used and well-tested way to assess a person's cognitive impairment and changes therein.[64-66] In this doctoral study, the German version of the *MMSE-2*[39] was used. This version has the same structure and scoring as the original MMSE. Only small changes were made to improve certain items (e.g. words added for repetition exercises include milk, sensible and before) as a means to standardize translation into other languages and cultures. The English version of the *MMSE-2* was forward- and backward translated by professional translators.[39] The new German version was not tested for its psychometric properties in the studies at hand because of the marginal changes in the new version. Most of the nurses in the participating nursing homes had already used the MMSE in their institution and had no problems with the new version. The measurements with this instrument did not likely lead to a measurement bias reducing internal validity of the study because the results of the studies showed, for example, that residents without a formal diagnosis of dementia registered on average no cognitive impairment with the *MMSE-2* and residents with a formal diagnosis of dementia showed different levels of cognitive impairment. Most were in a moderate or severe stage of dementia, which is typical for the nursing home setting[67,68] because residents with mild dementia are most often cared for at home by their family.[1]

To guarantee good data monitoring of the manually entered data in SPSS, data from every data collection was entered into the software program by the same person. The literature suggests that for minimum quality, all data should

be scanned for values that do not belong to identify errors (e.g. does a 4 appear in the data file where the maximum is 3?).[69] This was done in the panel study, but to increase the accuracy of the data, sample checks for errors by a second person were also performed. This is described in the literature as a very good method for identifying errors in data.[69,70] Furthermore, all implausible data identified during each data entry were discussed with the nursing homes and corrected (e.g. unrealistic height of a person). Moreover, after each data entry, the new data (e.g. second measurement) were compared with the old (e.g. first measurement) and implausible data (e.g. a person had a hip prosthesis at the first measurement and at the second measurement did not) were corrected after consultation with the nursing homes. Based on these measures, the quality of the entered data was ensured.

Recommendations for nursing practice and research

Practice

Care dependency

Based on the results of this doctoral thesis, it is recommended that nursing professionals regularly monitor degrees of care dependency in dementia residents in order to identify early changing needs and adapt nursing care accordingly. Each intervention should support residents with dementia in remaining as independent as possible, based on their stage of dementia and their individual abilities. This will help to avoid an unnecessarily fast rise in care dependency due to inadequate care (too much-, wrong-, lacking support) and would help to identify risks for nursing care problems.

It is highly recommended to support dementia residents particularly with their needs surrounding *continence* (e.g. help with using the toilet, and avoiding toilet accidents), *hygiene* (e.g. washing, bathing), *getting (un)dressed, avoiding danger* (e.g. falls) and *learning abilities* (help with cognition), because residents with dementia are most care dependent in these areas and lack of support may foster the development of nursing care problems, like incontinence. It is also suggested to support dementia residents with *day-/night pattern* (e.g. help with changing sleep schedule, like wandering at night and day time sleeping), *contact with others* (e.g. problems maintaining contact with friends, other residents), *sense of rules/values* (e.g. help to remember nursing home rules) and *communication* (e.g. help with verbal and nonverbal communica-

tion), because residents with dementia showed the highest care dependency increase in these needs over time. Therefore, it is recommended to regularly assess the care dependency of residents with dementia with instruments, like the Care Dependency Scale. Other than only physical items, it includes psychosocial items in order to achieve a comprehensive overview of the needs of residents with dementia and to guide nursing interventions in these needs.

Incontinence

Of the nursing care problems collected in the studies concerned, all three types of incontinence (urinary-, fecal- and double incontinence) showed the highest prevalence and increase in residents with and without dementia over time. Therefore it is suggested to strongly focus on this nursing care problem in all nursing home residents, but particularly with residents with dementia, because they showed a significantly higher prevalence of incontinence and a significantly higher increase in 2 of the 3 types of incontinence than residents without dementia. A primary focus should be support with *continence* (e.g. help to use the toilet, avoiding toilet accidents, help finding the toilet) because care dependency in *continence* is closely connected to the development of incontinence[22] and vice versa.[31] Regular monitoring of care dependency, particularly in *continence*, can help to identify arising or increasing needs in *continence*. A multidisciplinary team should be used to clarify every detected change in the continence status and adapt interventions according to the specific needs of the resident in question. These needs can be very individual, because the causes of incontinence in persons with dementia are multiple and therefore the management of incontinence must be multifaceted.[71] Nursing-, medical- and surgical interventions may be necessary. Based on the results of this doctoral thesis, a strong focus on support with *getting (un)dressed* (e.g. help with removing clothes), *hygiene* (e.g. help with personal hygiene after using the toilet) and *learning abilities* (e.g. to reminding the resident to go to the toilet) is recommended, because they are risk factors for self-care limitations in continence and consequential incontinence. Adequate support may help to avoid this unnecessary decline.

With respect to the different types of incontinence, the management of urinary incontinence should start early in the dementia journey in order to slow the development of urinary incontinence and related fecal incontinence. To adequately manage urinary incontinence, the type of urinary incontinence should

be discovered through early cooperation with a urologist/gynecologist and a continence nurse advisor. This would help to adapt nursing and medical interventions to the specific type of incontinence, which may improve continence management in the long run.

Research

For further longitudinal studies, changes in care dependency (in different aspects) and nursing care problems between the stages and types of dementia over time should be compared in order to identify the main increasing needs in the different stages and types of dementia and thus to better understand type- and stage-appropriate dementia care.

It is also important to perform intervention studies in the area of continence (urinary-,fecal- and double incontinence), because the studies conducted here showed a very high prevalence and increase of incontinence. Such intervention studies could help to explore effective interventions for nursing home residents (with dementia) to prevent an unnecessarily early increase of incontinence and to adequately manage existing incontinence.

Care dependency (in different human needs) and nursing care problems can influence each other, therefore more research is necessary to explore the relationship between the 15 measured physical- and psychosocial needs with the Care Dependency Scale and the nursing care problems of incontinence, pressure ulcers, malnutrition, falls and restraints to identify which physical- and psychosocial needs most influence the rise and increase of each collected nursing care problem and vise versa.

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Chapter 8

Summary

SUMMARY

The overall aim of this doctoral thesis is to determine the extent and change of care dependency and nursing care problems in Austrian nursing home residents with and without dementia.

Chapter 1 is a general introduction, presenting an overview of dementia, care dependency and nursing care problems. Afterwards the research gaps, the overall aim of the doctoral thesis as well as the specific research aims and -questions of the conducted studies are laid out. The chapter ends with an outline of the content of the doctoral thesis.

Chapter 2 is a brief overview of the methods (design, setting, sample, data collection, data analysis) used in studies 1 to 3 (part 1, part 2).

Chapter 3 provides an overview of the prevalence of care dependency and nursing care problems (pressure ulcers, malnutrition, incontinence, falls, and restraints) in nursing home residents with dementia. Within the scope of a narrative review, a literature search was conducted in the databases PubMed, CINAHL, EMBASE via Ovid, EBM Reviews via Ovid and reference lists in the period from 2003-2013. After critical appraisal of the articles identified, 20 were included in the final review. A narrative synthesis revealed that 28% - 83% of residents with dementia showed the highest degree of care dependency. Concerning the prevalence of nursing care problems, malnutrition ranged 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%. The high prevalence of care dependency and nursing care problems in residents with dementia indicates that improvements in their management are necessary in nursing homes.

In **chapter 4** the degree of care dependency and the prevalence of nursing care problems were compared between nursing home residents with (n=2155) and without (n=1422) dementia from 24 nursing homes. A secondary data analysis of combined cross-sectional studies from 2009-2012 was performed. Data collections were performed by nursing professionals using standardized instruments. The results highlighted that more residents with dementia were completely, or to a great extent, care dependent than residents without dementia. Both groups were most care dependent in the needs *hygiene, continence, getting (un)dressed* and *avoiding danger*, but residents with dementia

to a higher extent. Regarding the nursing care problems, residents with dementia compared to residents without had a significantly higher prevalence of urinary-, fecal- and double incontinence as well as restraints use, malnutrition and falls. No significant difference was found for the nursing care problem of pressure ulcers. Concerning the high degree of care dependency and prevalence of the collected nursing care problems, especially in residents with dementia, stabilizing care dependency, particularly in the needs *hygiene, continence, getting (un)dressed* and *avoiding danger* is recommended. Furthermore, an intensified focus should be set on the management of all collected nursing care problems with special attention on continence management.

Chapter 5 compares the degree of care dependency and prevalence of nursing care problems between residents with and without dementia and between the stages of dementia. In a cross-sectional study (first measurement of a panel study) with 24 participating nursing homes, data from 277 residents with and 249 residents without dementia were collected with standardized instruments by nursing professionals. The results showed that significantly more residents with than without dementia were completely or to a great extent care dependent. The highest care dependency was in the needs *hygiene, getting (un)dressed, avoiding danger* and *continence*. The comparison of the stages of dementia indicated a large difference in completely care dependent residents between moderate and severe dementia (9.3 vs. 44.3%). Regarding the collected nursing care problems, only incontinence (urinary-, fecal-, double incontinence) differed significantly between residents with and without dementia, whereby residents with dementia were more often affected by incontinence. In total, 64% of the residents with early dementia had urinary incontinence and in severe dementia the number reached 94%. Fecal- and double incontinence were comparatively much lower in early dementia (both show a prevalence of 12%) and rose to more than 80% (both types) in severe dementia. Considering the high degree of care dependency and prevalence of incontinence in residents with dementia, it is recommended for all stages of dementia, but particular for the moderate stage, to stabilize care dependency. In addition, it is necessary to improve continence care and place a stronger focus on residents in the early stage of dementia.

Chapter 6 shows the changes in care dependency and nursing care problems (pressure ulcers, incontinence, malnutrition, falls, restraints) in residents with and without dementia in a period of two years. A panel study (2012-2014)

with 5 measurement points in nine Austrian nursing homes was conducted. In total, 178 residents with and 80 residents without dementia completed all measurements. Data were collected by nursing professionals using standardized instruments. The results showed that care dependency in residents with dementia increased significantly in all 15 physical- and psychosocial needs measured with the Care Dependency Scale. The highest increase was identified in the needs *day-/night pattern, contact with others, sense of rules/ values* and *communication*. In contrast, care dependency in residents without dementia increased in four of the 15 physical- and psychosocial needs. The highest increase was in the needs continence, followed by *getting (un) dressed, mobility* and *avoiding danger*. In view to the nursing care problems, residents with dementia compared to residents without experienced a lower increase in urinary incontinence, but a higher increase in fecal- and double incontinence. The other nursing care problems showed no significant differences between the groups. The present results highlight that residents with dementia experience increased care dependency in other needs than residents without dementia. With regard to the nursing care problems, only the increase of incontinence differed significantly between the two groups. In light of these results, the improvement of continence management as well as stabilized care dependency of residents with dementia are recommended, particularly in the needs *day-/night pattern*, *contact with others*, *sense of rules/ values* and *communication*.

Chapter 7 briefly summarizes the results of the doctoral thesis and the main results and methodological aspects discussed. Finally recommendations for nursing practice and research are given.

Chapter 9

Zusammenfassung

ZUSAMMENFASSUNG

Das übergeordnete Ziel dieser Doktorarbeit ist es, das Ausmaß und die Veränderung der Pflegeabhängigkeit und der Pflegeprobleme bei österreichischen PflegeheimbewohnerInnen mit und ohne Demenz zu bestimmen.

Kapitel 1 beginnt mit der allgemeinen Einleitung, in der ein Überblick über die Demenz, Pflegeabhängigkeit und Pflegeprobleme gegeben wird. Danach werden die Forschungslücken, das übergeordnete Ziel der Doktorarbeit, sowie die spezifischen Forschungsziele und -fragen der durchgeführten Studien dargestellt. Das Kapitel endet mit der Gliederung des Inhaltes der Doktorarbeit.

Kapitel 2 gibt einen Kurzüberblick über die verwendeten Methoden der Studien 1 bis 3 (Teil 1, Teil 2).

Kapitel 3 liefert einen Überblick über die Prävalenz der Pflegeabhängigkeit und der Pflegeprobleme (Dekubitus, Mangelernährung, Inkontinenz, Sturz, Freiheitsbeschränkungen) von PflegeheimbewohnerInnen mit Demenz. Im Rahmen eines narrativen Reviews erfolgte eine Literaturrecherche in den Datenbanken PubMed, CINAHL, EMBASE via Ovid, EBM Reviews via Ovid und in Referenzlisten im Zeitraum von 2003 - 2013. Nach einer kritischen Bewertung der gesichteten Artikel wurden 20 Artikel in das Review inkludiert. Eine narrative Synthese ergab, dass 28% - 83% der BewohnerInnen mit Demenz den höchsten Grad der Pflegeabhängigkeit aufwiesen. Hinsichtlich der Prävalenz von Pflegeproblemen reichte diese bei Mangelernährung von 14% - 56%, Urininkontinenz von 39% - 59%, Stuhlinkontinenz von 43% - 87%, Dekubitus von 7% - 47%, Sturz von 29% - 60% und bei den Freiheitsbeschränkungen von 10% - 60%. Die hohe Prävalenz der Pflegeabhängigkeit und der Pflegeprobleme bei den BewohnerInnen mit Demenz weist darauf hin, dass in Pflegeheimen Verbesserungsmaßnahmen in diesen Bereichen notwendig sind.

In **Kapitel 4** wird der Grad der Pflegeabhängigkeit und die Prävalenz der Pflegeprobleme zwischen BewohnerInnen mit (n=2155) und ohne (n=1422) Demenz aus 24 Pflegeheimen verglichen. Eine sekundäre Datenanalyse von zusammengeführten Querschnittstudien der Jahre 2009 - 2012 wurde durchgeführt. Die Datenerhebungen erfolgten durch Pflegepersonen mittels standardisierter Instrumente. Die Ergebnisse zeigten, dass mehr BewohnerInnen

mit Demenz vollständig- oder überwiegend pflegeabhängig waren, als BewohnerInnen ohne Demenz. Beide Gruppen wiesen die höchste Pflegeabhängigkeit bei den Bedürfnissen *Hygiene, Kontinenz, An- und Auskleiden* und *Vermeiden von Gefahren* auf, aber Personen mit Demenz in höherem Ausmaß. Bezüglich der Pflegeprobleme hatten BewohnerInnen mit Demenz, im Vergleich zu den BewohnerInnen ohne Demenz, eine signifikant höhere Prävalenz von Urin-, Stuhl- und Doppelinkontinenz, sowie von Freiheitsbeschränkungen, Mangelernährung und Sturz. Kein signifikanter Unterschied wurde für das Pflegeproblem Dekubitus gefunden. Aufgrund des hohen Grades der Pflegeabhängigkeit und der hohen Prävalenz der erhobenen Pflegeprobleme, besonders bei BewohnerInnen mit Demenz, wird eine Stabilisierung der Pflegeabhängigkeit, insbesondere bei den Bedürfnissen *Hygiene, Kontinenz, An- und Auskleiden* und *Vermeiden von Gefahren,* empfohlen. Des Weiteren sollte eine verstärkte Fokussierung auf das Management aller erhobenen Pflegeprobleme gerichtet werden, mit Hauptaugenmerk auf das Kontinenzmanagement.

In **Kapitel 5** werden der Grad der Pflegeabhängigkeit und die Prävalenz der Pflegeprobleme zwischen BewohnerInnen mit und ohne Demenz und zwischen den Stadien der Demenz verglichen. In einer Querschnittstudie (erster Messzeitpunkt einer Panelstudie) an der 9 Pflegeheime teilnahmen, erfolgte die Datenerhebung bei insgesamt 277 BewohnerInnen mit und 249 BewohnerInnen ohne Demenz mit standardisierten Instrumenten durch geschulte Pflegepersonen. Die Ergebnisse zeigten, dass signifikant mehr BewohnerInnen mit Demenzerkrankung vollständig- oder überwiegend pflegeabhängig waren, als BewohnerInnen ohne Demenz. Die höchste Pflegeabhängigkeit war bei den Bedürfnissen *Hygiene, An- und Auskleiden, Vermeiden von Gefahren* und *Kontinenz* ersichtlich. Der Vergleich der Stadien der Demenz zeigte einen großen Unterschied von vollständig pflegeabhängigen BewohnerInnen zwischen dem mittleren und schweren Demenzstadium (9,3% vs. 44,3%). Bezüglich der erhobenen Pflegeprobleme, unterschied sich nur die Inkontinenz (Urin-, Stuhl-, Doppelinkontinenz) signifikant zwischen den BewohnerInnen mit und ohne Demenz, wobei BewohnerInnen mit Demenz häufiger von Inkontinenz betroffen waren. Insgesamt wiesen 64% der BewohnerInnen im frühen Stadium der Demenz eine Urininkontinenz auf, im schweren Stadium waren es 94%. Im Vergleich dazu war die Prävalenz der Stuhl- und Doppelinkontinenz bei den BewohnerInnen im frühen Stadium der Demenz geringer (beide Typen zeigten eine Prävalenz von 12%) und stieg auf

über 80% (beide Typen) bei den BewohnerInnen im Stadium der schweren Demenz an. Angesichts des hohen Grades der Pflegeabhängigkeit und der Prävalenz der Inkontinenz bei den BewohnerInnen mit Demenz wird für alle Stadien der Demenz, aber besonders für das mittlere Stadium, eine Stabilisierung der Pflegeabhängigkeit empfohlen. Zudem wird eine Verbesserung des Kontinenzmanagements mit verstärktem Fokus auf BewohnerInnen im frühen Stadium der Demenz vorgeschlagen.

Kapitel 6 zeigt die Veränderung der Pflegeabhängigkeit und der Pflegeprobleme (Dekubitus, Inkontinenz, Mangelernährung, Sturz, Freiheitsbeschränkungen) bei BewohnerInnen mit und ohne Demenz im Zeitraum von 2 Jahren. Eine Panelstudie (2012 - 2014) mit 5 Messzeitpunkten wurde in neun österreichischen Pflegeheimen durchgeführt. Insgesamt haben 178 BewohnerInnen mit und 80 BewohnerInnen ohne Demenz bei allen Messzeitpunkten teilgenommen. Die Datenerhebung erfolgte mit standardisierten Instrumenten durch geschulte Pflegepersonen. Die Ergebnisse zeigten, dass sich die Pflegeabhängigkeit der BewohnerInnen mit Demenz in allen 15 physischen- und psychosozialen Bedürfnissen, erhoben mit der Pflegeabhängigkeitsskala, erhöhte. Der höchste Anstieg wurde bei den Bedürfnissen *Tages- und Nachtrhythmus, Kontakt mit Anderen, Sinn für Regeln/Werte* und *Kommunikation* identifiziert. Im Vergleich dazu stieg die Pflegeabhängigkeit der BewohnerInnen ohne Demenz bei 4 der 15 physischen- und psychosozialen Bedürfnissen an. Am höchsten war der Anstieg bei den Bedürfnissen *Kontinenz*, gefolgt von *An- und Auskleiden, Mobilität* und *Vermeiden von Gefahren*. In Hinblick auf die Pflegeprobleme zeigten BewohnerInnen mit Demenz, im Vergleich zu den BewohnerInnen ohne Demenz, einen geringeren Anstieg der Harninkontinenz, aber dafür einen höheren Anstieg der Stuhl- und Doppelinkontinenz. Bei allen anderen Pflegeproblemen gab es keinen signifikanten Unterschied zwischen den beiden Gruppen. Die vorliegenden Ergebnisse zeigen, dass BewohnerInnen mit Demenz in anderen Items der Pflegeabhängigkeitsskala eine Zunahme der Pflegeabhängigkeit aufweisen, als BewohnerInnen ohne Demenz. In Hinblick auf die Pflegeprobleme zeigt nur die Zunahme der Urininkontinenz einen signifikanten Unterschied zwischen den beiden Gruppen. Angesichts dieser Resultate wird bei den BewohnerInnen mit Demenz eine Verbesserung des Kontinenzmanagements empfohlen sowie eine Stabilisierung der Pflegeabhängigkeit, besonders bei den Bedürfnissen *Tages- und Nachtrhythmus*, *Kontakt mit Anderen, Sinn für Regeln/Werte* und *Kommunikation.*

In K**apitel 7** werden die Ergebnisse der Doktorarbeit kurz zusammengefasst und die Hauptresultate, sowie die methodischen Aspekte diskutiert. Abschließend werden Empfehlungen für die Pflegepraxis und Forschung gegeben.

Chapter 10

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Chapter 11

Curriculum vitae

CURRICULUM VITAE

Sandra Schüssler performed her training as a psychiatric mental health nurse at the nursing school of the mental clinic Sigmund Freud in Graz, Austria. Afterwards she worked as a nurse in (psychiatric) hospitals and nursing homes and as the manager in a nursing home for people with dementia.

From 2004 to 2007 she completed the Bachelor programme in Health and Nursing Science at the Medical University of Graz, Austria and from 2007-2009 the Master programme in Health and Nursing Science at the same university.

In 2010 she was offered a position as researcher at the Ludwig Boltzmann Institute of Health Promotion Research in Vienna, Austria. She worked on the preparation of a project to promote health in nursing home residents. In the same year she started her work as a lecturer and researcher at the Institute of Nursing Science, Medical University of Graz, Austria and is still working there as a Senior Scientist.

In 2010 she also started her doctoral studies and was enrolled in the doctoral program in Nursing Science at the Medical University of Graz (Austria), the Maastricht University (The Netherlands) and the Charité-Universitätsmedizin Berlin (Germany).

Sandra Schüssler has been on the scientific council for the Albert Schweizer Institute of Geriatrics and Gerontology since 2014, gave training courses for the Care Dependency Scale in various health care institutions and is author and reviewer in several national and international journals. She has also been frequently involved in organizing the European Doctoral Conference in Nursing Science (EDCNS) in Graz, Austria.

Chapter 12

List of publications and presentations

LIST OF PUBLICATIONS AND PRESENTATIONS

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