

# **Agitation and use of restraint in nursing home residents with dementia**

**Prevalence, correlates and the effects of care staff training**

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Dissertation for the degree philosophiae doctor (PhD)  
at the University of Bergen

2009

# Agitation and use of restraint in nursing home residents with dementia

Prevalence, correlates and the effects of care staff training



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The Norwegian  
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Disorders

Stavanger, Norway, 2009

## **Scientific environment**

This thesis was conducted during the years 2003 to 2009 under supervision of the Department of Psychiatry, Stavanger University Hospital, Stavanger, Norway and in co-operation with Stokka Teaching Nursing Home, Stavanger, Norway and the Norwegian Centre for Movement Disorders, Stavanger, Norway.

## Acknowledgements

First of all, I want to thank all the participants in this study. Without you, this would not have been possible.

A very special thanks to my supervisor Dag Aarsland, for inspiring me to go into the field of research in the first place. Thank you for all your encouragement, enthusiasm and patience in guiding and supervising me throughout this process. I am very grateful for your willingness to teach and for always being accessible, answering and giving feed back, no matter small or large issues.

Also a special thanks to Anne Margrethe Kinn Aasland, who has been my colleague and partner in the development and implementation of the intervention. Thank you for numerous inspiring discussions, for sharing your knowledge and for all your support, contribution and participation throughout this work.

A sincere thanks to Hilde Rydland Marianayagam for doing such an important work in collecting all the data for the second study and to Allan Øvereng for the first study.

A special thanks to all my co-authors for their contribution to this work and specially Stefanie Auer and Clive Ballard, for your encouragement and for willingly sharing your knowledge throughout this work process, Mary Mittelman, for hosting me as a visitor scholar at the University of New York, Jane Fossey, Yvonne Donabauer and to Aslaug Mikkelsen, for your knowledgeable contribution and support, Kolbjørn Brønnick, for always being willing to offer solutions on statistic questions, and technical computer issues.

And a great thanks to all my colleagues at Norwegian Centre of Movement Disorder, for a stimulating and supporting scientific environment. A special thanks to Jan Petter Larsen, Kirsten Lode and Ingrid Leiknes and a very special thanks to Karen Rinden Simonsen, for your continuous support, your abilities to offer solutions and follow through in all issues possible.

Also a sincere thanks to the Division of Psychiatry, SUS which has been my main working place through most of this work. A special thanks to Jan Olav Johannessen, for the scientific environment you have provided for years and to all my colleagues. Also a great thanks to the scientific environment at SUS, with a special thanks to Stein Tore Nilsen and Målfrid Meling for the support of this thesis and to the PhD group for great encouragement and support.

A sincere thanks to all my colleagues at Stokka Teaching Nursing home and to Stavanger municipality, for inspiration and support to continue this work.

And there are also many dear colleagues and friends that I wish to thank for great support and encouragement throughout this process: Målfrid Meling, you have been a wonderful leader teaching me to step one stone at a time, Kari Vevatne, for bringing the education of nursing science to Stavanger, you have always been inspiring and a great support, Arnfinn Fiskå, for numerous conversations on the ethics of caring and for sharing your knowledge and wisdom, Karin Smedvig and Vigdis Vagle, for always offering encouragement and support. Also a great thanks to my biking, hiking and travelling friends for encouragement and lots of fun and a special thanks to my always faithful friend Ingvild Hjelle Sanne and to Connie Norup for all your support.

Last but not least, to my children Joakim and Maiken, you are both amazing individuals and I am proud and honoured to be your mom. Thank you for being who you are and for all the great adventures and experiences we have had through out this process and otherwise. Nothing is more important than that! And finally, a very grateful thanks to my parents, sis and brother, for all your loving support, for all the practical help and for always believing in me.

This thesis was supported by Norwegian Research Council, the Leiv Erikson Mobility Program and Stavanger University Hospital.

## Introduction

“In the past, most people didn’t age – they died”, states Dychtwald<sup>1</sup> in his reflections on how the 21<sup>st</sup> century, will be ruled by the old. Today, elderly have grown in numbers with a higher concentration than any other age group, the United Nations<sup>2</sup> expects that there will be nearly two billion people in the world 60 years and older, by the year 2050. Today 1 of every 10 persons living is age 60 or older, by 2050 that ratio will double to 1 to 5, and the oldest old (80 years and older) is the fastest growing segment of the older population.<sup>2</sup> Dementia is one of the most prevalent syndromes in the elderly population, and has become one of the major challenges to public health and elderly care systems, due to the universal aging of the population. Worldwide, there are 4.6 million of new cases every year, and the number of people with dementia in 2001 was 24 million, which will almost double every 20 years to 42 million by 2020 and 81 million by 2040, providing no changes in mortality and no effective prevention strategies or curative treatment are provided.<sup>3,4</sup> The cost of dementia can be considerable. While most people with dementia are retired and do not suffer income losses from their disease, the cost of care is often enormous. Financial burdens include lost wages for family caregivers, medical supplies and drugs, home modifications to ensure safety and institutionalisation. The psychological cost is not as easily quantifiable but can be even more profound. The person with dementia loses control of many of the essential features of his life and personality, also affecting loved ones, as they continue to cope with the burdens of increasing dependence and unpredictability.

Over half of the persons with dementia in Norway live in long-term care homes, and 80% of residents in nursing homes have dementia, the majority with severe functional impairments and complex needs including associated behavioural changes, with severe consequences for their functioning and quality of life.<sup>5</sup> In addition, recent research has demonstrated that there are still important challenges in order to improve quality of life for residents. The proportion with psychiatric symptoms is very high,

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and approximately two-thirds of residents in Norwegian nursing homes experienced at least one psychiatric symptom during the last month prior to assessment,<sup>5</sup> and the use of restraints is high.<sup>6</sup> Residents with dementia experience behavioural changes, including apathy,<sup>7</sup> agitated and aggressive behaviour,<sup>5</sup> which affect the quality of life of the resident himself, their family and care staff. In a large nursing home study conducted in Norway,<sup>6</sup> degree of dementia, and the presence of aggressive or agitated behaviour, were highly associated with use of restraint, which is potentially harmful. To preserve the personal control, dignity and quality of life of these vulnerable individuals, as long as possible, is an important goal of our society. Caring for people with dementia requires specific skills and knowledge of the cognitive, functional and emotional changes accompanying dementia, well trained care staff that can provide comprehensive, individualized and person centred care and high quality physical and social living conditions. Dementia is the most common reason for institutionalization,<sup>8</sup> and the increased number of residents with dementia will lead to a marked increase in the need for qualified care staff in nursing homes. The question if we have enough care staff to carry out health care in our welfare system, is becoming a more acutely question to attend to, as the number of elderly and the demand of sufficient health care is increasing. By year 2020, the shortage of registered nurses in general is forecasted to be 20% below the projected requirements,<sup>9</sup> work environment and job stress has been implicated in the nursing shortage.<sup>10</sup> A shortage of 40000 health care workers towards year 2030 is forecasted in Norway as well.<sup>11</sup> Health and well-being in care staff in nursing homes is an important issue, as well as organizational and psychosocial factors, in achieving the goal of personal control, dignity and quality of life in residents with dementia. Therefore, the objective of this thesis was to study the relationship between agitation, use of restraint, carer burden, organizational and psychosocial factors, and whether agitation and use of restraint could be reduced by means of a novel care staff training.

# **Abstract**

## **Background**

Dementia is one of the most prevalent syndromes in the elderly population, and over half of people with dementia live in long-term care homes. 80% of residents in nursing homes have dementia, the majority with severe functional impairments and complex needs. Agitation and other behavioural changes are common, with severe consequences for their functioning and quality of life, including use of restraint and use of psychotropic drugs. To preserve the personal control, dignity and quality of life of these vulnerable individuals, as long as possible, is an important goal of our society. Few studies have explored the relationship between agitation and factors such as stress in care staff and working conditions, and there is little evidence whether education and guidance in care staff can improve agitation and reduce use of restraint and psychotropic drugs.

## **Objective**

The objective of this thesis was to study the relationship between agitation and use of restraint, carer burden, organizational and psychosocial factors and whether agitation and use of restraint could be reduced by means of a novel care staff training.

## **Methods**

Descriptive, cross-sectional surveys were conducted to analyse the prevalence of agitation in nursing home residents, and to study correlates of health and well-being in care staff. Residents and care staff from four nursing homes in Rogaland County were included. In addition, data from nursing homes in England and Austria were used. Two cluster-randomized controlled trials were conducted to study the effect of a novel care staff training program; Relation Related Care (RRC). Data on agitation and use of restraint and antipsychotics were collected immediately before and after the 6-month intervention period by a research nurse, blinded for study hypothesis. In the



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second study, an additional follow-up assessment was conducted 6 months after completion of the intervention.

Standardized measures were used: Clinical Dementia rating Scale (CDR), Functional Assessment rating Scale (FAST) and the Global Deterioration Scale (GDS) were used to rate severity of dementia. Two rating scales were used to score agitation; Brief Agitation Rating Scale (BARS) and Cohen-Mansfield Agitation Inventory (CMAI). Frequency of use of restraint was determined by a standardized interview, where all use of restraint during the last seven days was recorded.

Three scales measured health and well being in care staff: Perceived Stress Scale (PSS), Psychological Distress (HSCL-10) and Subjective health complaints (SHC). Organizational and Psychosocial factors were measured by General Nordic Questionnaire for Psychosocial and Social Factors at Work (QPSNordic).

## **Results**

We found that 75.4% of the residents with dementia exhibited at least one agitated behaviour at least weekly and 65.3% several times a week. The six most common agitated behaviours were repetitious sentences or questions, complaining, cursing, pacing, negativism and general restlessness. However, agitation in the Norwegian nursing homes was less common than in nursing homes in UK and Austria. The level of agitation differed between countries, with higher CMAI scores in the Austrian nursing home compared to UK and Norwegian nursing homes. Similarly, the use of psychotropic drugs differed significantly between the homes, with a higher proportion on antipsychotic drugs in UK and Austrian compared to Norwegian nursing homes.

Organizational and psychosocial factors, in particular those related to the organizational structure of the nursing home were associated with all three measures of health and well-being in care staff. Leadership, mastery and control of work were the three organizational and psychosocial factors which significantly explained the variance in care staff health and well being. In contrast, agitation in residents was not

significantly associated with any of the measures of health and well being in care staff.

In the first intervention study, the proportion of restraint declined with 54% in the treatment group and increased with 18% in the control group. This difference was significant. In contrast, agitation did not differ between the groups. In the second study, the intervention led to both reduced severity of agitation and reduction in restraint, which was evident by a much smaller increase in the intervention group compared to the control group. The improvement of agitation continued 6 months after the completion of the intervention, indicating that sustained improvement of agitation can be achieved by means of staff training. The effect on restraint use however, seemed to be short-lived, suggesting that continuous supervision is needed to achieve sustained reduction of the use of restraint.

## **Conclusion**

Agitation is common in residents with dementia in Norwegian nursing homes. There is a need to explore factors contributing to agitation, in order to understand and manage it effectively and to avoid misdiagnose of symptoms, reduce inappropriate use of drugs and restraint, and thereby improving the conditions and quality of life for residents with dementia in nursing homes. Our findings from the intervention studies suggests that by lowering the care staff – resident ratio and by providing additional education, guidance and support, improved care of residents can be achieved.

## List of publications

Testad, I., Aasland, AM., Aarsland, D. The effect of staff training on the use of restraint in dementia. A single-blind randomized controlled trial. (*Int. J. Geriatr. Psychiatry* 2005; 20: 587-590).

Testad, I., Aasland, AM., Aarsland, D. Prevalence and correlates of disruptive behaviour in patients in Norwegian nursing homes. (*Int. J. Geriatr. Psychiatry* 2007; 22: 916-921).

Testad, I., Auer, S., Mittelman, M., Ballard, C., Fossey, J., Donabauer, Y., Aarsland, D. Nursing home structure and association with agitation and use of psychotropic drugs in nursing home residents in three countries: Norway, Austria and England. (*Int. J. Geriatr. Psychiatry* 2009; Oct 12 Epub ahead of print).

Testad, I. Mikkelsen, A., Ballard, C., Aarsland, D.: Health and well being in care staff and it's relation to organizational and psychosocial factors, care staff and resident factors in nursing homes. (*Int. J. Geriatr. Psychiatry* 2009; Oct 27 Epub ahead of print).

Testad, I. Ballard C, Bronnick K., Aarsland, D.: The effect of staff training on agitation and use of restraint in nursing home residents with dementia: a single-blind randomized controlled trial. (In press, *Int. J. Clinical Psychiatry*).

## List of abbreviations

ADL	Activity of Daily Living
ANOVA	One-way analysis of variance
BARS	Brief Agitation Rating Scale
BPSD	Behavioural and Psychological Symptoms
CDR	Clinical Dementia Rating Scale
CMAI	Cohen-Mansfield Agitation Inventory
FAST	The Functional Assessment Staging
GDS	The Global Detraction Scale
HSCL-10	Hopkins Symptoms Check List
ICD-10	International Statistics Classification of Disease and Related Helath Problems
NDB	Need-Driven Dementia-Compromised Behavior Model
PSS	Perceived Stress Scale
QPSNordic	General Nordic Questionnaire for Psychosocial and Social Factors at Work
RRC	Relation Related Care
SHC	Subjective Health Complaint

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## 1. Introduction

### 1.1. Dementia

Dementia can be defined as an acquired persistent impairment of intellectual function characterized by progressive deteriorations in multiple cognitive domains,<sup>12</sup> and is the principal cause of disability, institutionalization and shorter survival in older people.<sup>3</sup> International Classification of Diseases and Related Health Problems, 10th version (ICD-10) (World Health Organization, 1993)<sup>13</sup> lists the following criteria for dementia syndrome;

- A. Cognitive deficits that interfere with daily activities have presented for at least six months
  1. Decline in memory, which is most evident in the learning of new information, although in more severe cases, the recall of previously learned information may also be affected. The impairment applies to both verbal and non-verbal information.
  2. Decline in other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and in the general processing of information.
- B. Preserved awareness of the environment.
- C. Decline in emotional control or motivation, or a change in social behaviour, manifest as at least one of the following:
  1. Emotional lability
  2. Irritability
  3. Apathy
  4. Coarsening of social behaviour

For a confident clinical diagnosis, the cognitive decline should have been present for at least six months.



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The diagnosis is further supported by the evidence of damage to other higher cortical functions, such as aphasia, agnosia and apraxia.

### 1.1.1 Etiology

Dementia is caused by specific brain diseases, where Alzheimer's disease is the most common.<sup>14</sup> Between 50 and 70 percent of all people with dementia are suffering from Alzheimer's disease - a degenerative disease, which slowly and progressively affects neurons. The disease is named after Aloïs Alzheimer, a German neurologist, who in 1907 first described the symptoms as well as the neuropathological features of Alzheimer's disease such as plaques and tangles and neuronal loss in the brain. The disease affects memory and other mental functioning (e.g. abstract thinking and language), but can also lead to other problems such as confusion, changes of mood and disorientation in time and space. The second most common cause of dementia is vascular dementia. This is caused by cerebrovascular disease, for example a series of small strokes (infarcts), which interfere with the supply of blood to the brain. Even though these strokes tend to be quite small, the combined effect can lead to considerable problems for the person to think, reason, remember and communicate. Dementia with Lewy Bodies, Parkinson's disease with Dementia and Fronto-temporal Dementia are other forms of degenerative dementias. Most forms of dementias are irreversible. Dementia may also arise from other conditions, such as long-term alcohol abuse, AIDS or vitamin deficiencies.<sup>14</sup>

### 1.1.2 Clinical course and symptoms

The symptoms of dementia normally involve a gradual and slow deterioration of the person's ability to function. There is a large inter-individual variation of the progression of the disease, although towards the latest stages of the disease, the progression seems to be more similar.<sup>14</sup> The Functional Assessment Staging (FAST),<sup>15</sup> is one way to describe the progression of the disease by assessing a persons ability to perform basic activities of daily living. It is a procedure which describes a

continuum of 7 successive stages and sub stages from normality to most severe dementia of the Alzheimer's disease type.<sup>16</sup> The assessment describes the progressive changes in universal recognizable functions such as the ability to put on clothes, to maintain continence, to speak and walk.<sup>17</sup> The Clinical Dementia rating (CDR),<sup>18</sup> is another procedure which characterizes six domains (memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care) of cognitive and functional performance applicable to Alzheimer's disease and related dementias on a 5-point scale. Social and daily functioning progressively declines, usually leading to dependence and helplessness. The brain damage affects the person's mental functioning (memory, attention, concentration, language, thinking, etc.) and this in turn has repercussions on behaviour. Especially in the later stages of the condition, affected persons may be disoriented in time (not knowing what day of the week, day of the month, or even what year it is), in place (not knowing where they are), and in person (not knowing who they are or others around them). Behavioural and Psychological Symptoms (BPSD), are major and frequent manifestations of Alzheimer's disease and other dementias and have been shown to occur in a sizeable proportion in demented nursing home residents.<sup>19</sup> BPSD such as depression, apathy, delusion, anxiety and agitation<sup>5,7</sup> affect most if not all patients at some point in the disease course.

### 1.1.3 Prevalence

Age is the most important risk factor for dementia. The United Nations<sup>2</sup> expects that there will be nearly two billion people in the world 60 years and older, by the year 2050. Today 1 of every 10 persons living is age 60 or older, by 2050 that ratio will double to 1 to 5, and the oldest old (80 years and older) is the fastest growing segment of the older population.<sup>2</sup>

Worldwide, there are 4.6 million of new cases of dementia every year, and the number of people with dementia, will double every 20 years providing no changes in mortality and no effective prevention strategies or curative treatment are provided.<sup>4</sup>

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In Norway, 12% of elderly people over 80 years live in nursing homes with a mean age of 84 years.<sup>20,21</sup> Of the 65000 persons in Norway suffering from dementia,<sup>14,22</sup> 40% are institutionalized.<sup>14</sup> When adding the families of persons with dementia, approximately 250.000 persons in Norway are affected by the disease.<sup>23</sup>

Dementia is the most common reason for nursing home placement<sup>8,24,25</sup> and approximately 70-80% of the residents in Norwegian nursing homes suffer from dementia.<sup>26-28</sup> The majority of the residents have severe functional impairments and complex needs including associated behavioural changes, with severe consequences for their functioning and quality of life.<sup>5</sup> In addition, recent research has demonstrated that there are still important challenges in order to improve quality of life for residents. The proportion with psychiatric symptoms and behavioural changes,<sup>5</sup> and the use of restraint are high<sup>6</sup> and affect the quality of life of the resident himself, their family and care staff.

A large study conducted in Norway by Selbæk and his colleagues,<sup>5,21,29</sup> in a representative sample of 1.163 nursing home residents across four Norwegian counties, reported that more than 80% were judged to have dementia and approximately two-thirds of residents exhibited clinically significant psychiatric or behavioural symptoms.<sup>5</sup> The same study also showed that use of psychotropic medication is widespread, with approximately 75% receiving one or more psychotropic drugs and more than 25% receiving antipsychotics. Another large study conducted in Norway by Kirkevold and his colleagues,<sup>26</sup> showed that 36.7% of residents in regular units and 45% of residents in special care units had been subjected to some type of restraint during the previous 7 days. Degree of dementia, aggressive or agitated behaviour and the need for help with activities of daily living (ADL), were highly associated with the use of restraint.<sup>26,30</sup>

#### 1.1.4 Norwegian nursing home care

A culture change has taken place in Norwegian nursing home care during the past two decades with a growing interest in improving the quality of care in elderly in general, and with an emphasize on persons with dementia.<sup>30</sup>

Culture change refers to systematic efforts to improve services, maintaining and improving quality of life for residents and their caregivers, providing healthy work environment for care staff through transforming the culture of care (beliefs, values, understanding, knowledge and behaviours) and may require changes in organization practices, physical environments and relationship at all levels.<sup>31,32</sup>

In 1988 the Municipalities Health Services Act was expanded and county nursing homes were transferred to the municipalities in Norway. Thus, the care of the elderly is the responsibility of the municipalities; including social services, home nursing and institutional care. The nursing home wards can broadly be classified into regular units with 20-30 beds and special care units with 8-12 beds.<sup>30</sup> In addition to smaller specialized units with private room and baths, the culture change may include increased care staff – resident ratio, emphasis on empowerment and development of education for care staff and on individualized, person-centered care.

The Norwegian government has conducted a “Regulation of quality of care”<sup>33</sup> which emphasizes the importance of quality of life and preserved residents’ rights, describes the services that should be provided by the municipal, including care in nursing homes for persons with dementia. The focus is more person-oriented, describing the rights of the residents to make daily life decisions. The regulation describes that a person has a right to decide when to go to bed, when to eat, when to have visitors and how to have a private life in the institution. The person has a right to have skilled help to manage the ADL and a right to take part in leisure activities.

Recently, the Norwegian government introduced a detailed plan to increase the quality of care towards 2015.<sup>23,34</sup> In the period of 1996-2009, twenty Teaching Nursing Homes,<sup>35</sup> were established throughout Norway. The overall aim of the

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Teaching Nursing Homes, is to enhance knowledge and research in nursing homes, improve quality of care, and recruitment of educated care staff.

In 2006 Kirkevold and colleagues<sup>30</sup> studied to what degree Norwegian nursing homes provide services in line with the core areas of the “Regulation of quality of care”.<sup>33</sup> They concluded that ward characteristics such as type of ward, size and care staff – resident ratio do have an influence on quality of care.<sup>30</sup> However, even though most of the residents receive good basic care in Norwegian nursing homes, taking part in leisure activities and going outside for a walk, were often neglected, and the same authors later reported that more than half of the patients in Norwegian nursing homes, experienced two or more quality deficiencies in the care during one week.<sup>36</sup>

## **1.2 Agitation in residents with dementia**

In addition to the cognitive symptoms of dementia, a wide range of psychological and behavioural changes occur, often labelled with the global term; Behavioural and Psychological symptoms (BPSD). BPSD are commonly observed in all dementia types,<sup>37-39</sup> and known as important predictors of nursing home placement.<sup>8,40</sup> More than 70%<sup>41</sup> of residents with dementia experience behavioural symptoms including a range of symptoms such as agitation, anxiety, depression, apathy, wandering, sleep disturbance, delusions and hallucinations.<sup>42</sup> Agitation is one of the most common clusters of BPSD,<sup>41,43</sup> defined by Cohen-Mansfield and Billig (1986)<sup>44</sup> as inappropriate verbal, vocal or motor activity that; may be abusive or aggressive toward self or others, is performed with inappropriate frequency, or is inappropriate according to social standards for the specific situation. The identification and quantification of agitation in nursing home residents with dementia is an important area of study, due to the high proportion with dementia in nursing homes. Agitation produces increased suffering and distress for the patients themselves and their caregivers,<sup>42,45,46</sup> and agitation has shown to be a significant predictor of their caregivers’ mental and physical health,<sup>47</sup> including severity of stress and quality of life<sup>48</sup> and causes excess disability including reduced function in ADL.<sup>49</sup> Failure to

understand the problem and inability to manage the behaviour may lead to increased and inappropriate use of psychotropic medication and restraint.<sup>26,30</sup> Agitation also causes increased demand on staff resources, affects staffing requirements and environment,<sup>50</sup> increases the costs of care<sup>42</sup> and is a common stressor leading to staff burnout and turn-over in institutions.<sup>51-56</sup> Increases in problem behaviour and agitation in persons with dementia, are important determinants of institutionalization.<sup>8</sup> Finally, institutionalization is a considerable cost to the economy of the society, and to the human cost of the patient and the family. A better understanding and management could therefore lead to a delay in institutionalization, increased quality of life for the patient and his family.

Jiska Cohen-Mansfield did a pioneering research to describe behavioural symptoms in dementia and further characterized syndromes of agitation based on factor analyses of the Cohen-Mansfield Agitation Inventory (CMAI);<sup>57</sup>

Factor 1 – Aggressive behaviours: Hitting, kicking, pushing, scratching, tearing things and cursing.

Factor 2 – Physically non-aggressive behaviours: Pacing, inappropriate robing or disrobing, repetitious sentences or questions, trying to get to a different place, general restlessness, handling things inappropriately and repetitious mannerism.

Factor 3 – Verbally agitated behaviour: Complaining, constant request for attention, negativism, repetitious sentences or questions

Factor 4 – Hiding/hoarding behaviour (emerged for day shift only)

### 1.2.1 Clinical manifestations and consequences

There is a growing literature on the complex interrelationship within the symptoms of BPSD<sup>58-60</sup> and the association of agitation with other symptoms and behaviours.

Several studies have shown agitation to be associated with depression,<sup>61</sup> psychosis,<sup>62</sup> apathy<sup>7</sup> and severity of dementia.<sup>30,63</sup> Association between poor food intake, weight

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loss and agitation, have also been found.<sup>64</sup> Furthermore different agitated behaviours (as outlined in 1.2) exhibit different manifestations and are associated with different symptoms and behaviours. Physically and verbally non-aggressive behaviours are predicted by different factors. Physically non-aggressive behaviours, such as wandering and pacing have been reported to be associated with increased cognitive impairment<sup>65</sup> and residents exhibiting this behaviour was reported to be more physically healthy, have fewer medical problems and better appetites than others.<sup>65</sup> The relationship between dementia and verbally non-aggressive behaviour is less strong than with physically non-aggressive behaviour.<sup>66</sup> Verbally non-aggressive behaviour such as complaining is more common in mild and intermediate stages of dementia.<sup>67</sup> Other types of vocal agitations however, like screaming are associated with more severe cognitive impairment.<sup>67</sup> Other factors which relate to verbally non-aggressive behaviour are depressed affect,<sup>68</sup> and higher levels of pain.<sup>67,69</sup> Depression was found to be the strongest predictor of verbally non-aggressive behaviour.<sup>67</sup> Aggressive verbal and physical behaviour have been found to be related to depressive symptoms, delusions, hallucinations, constipation<sup>70</sup> and resistiveness to care.<sup>71</sup>

### 1.2.2 Frequency and etiology

Several studies have reported prevalence rates of BPSD in nursing home residents as high as 70-90%,<sup>5,41,60,72</sup> and the symptoms tend to increase with increasing dementia severity<sup>5</sup> and are common in all types of dementia. In the Norwegian study by Selbæk and colleagues,<sup>5</sup> a prevalence of 73.8% was found, and Margello-Lana et.al<sup>41</sup> reported 80% in UK nursing homes. In the US cache county study<sup>72</sup> a prevalence of 69% was found, and in the European Alzheimer's disease consortium (EACD)<sup>60</sup> at least one feature of BPSD was found in 96% of the residents. Agitated behaviours are amongst the commonest of BPSD, and according to Logsdon et.al.,<sup>43</sup> occur in as many as 70-90% residents at some point during the course of their illness.

There are usually multiple interacting causes of the behaviour, and different reasons why it is seen as a problem. Biological, psychological and social factors may

contribute to agitation, including personality, personal history, and physical and psychosocial environment. Thus, organisational aspects and culture of care of the nursing homes are likely to have an impact on the risk for agitation. Structural and functional brain changes associated with the disease, physical diseases other than brain disease, delirium, and use of medication may cause agitation. Physical and psychosocial factors such as under-stimulating or demanding environments, the person's reduced ability to communicate, that his/her needs are not met,<sup>69,73</sup> loneliness,<sup>74</sup> boredom,<sup>75</sup> depression,<sup>69</sup> sensory deprivation,<sup>76</sup> overwhelming influx of external stimuli<sup>77,78</sup> and premorbid characteristics and history<sup>79</sup> may influence resident's behaviour and increase the risk of agitation. Persons suffering from dementia are at high risk to suffer from severe pain,<sup>80</sup> which may cause agitation as well.<sup>69</sup>

Throughout the last decade, the concept of agitation has become more nuanced, acknowledging several causal factors, including interpersonal interaction and psychosocial and emotional needs,<sup>81</sup> and that the behaviour can provide valuable information about the resident condition.<sup>73</sup> The change from the biomedical model towards person-centered care, from task-orientation to a holistic model, the concept of the person being central to deliver high-quality care, is increasingly advocated in clinical practice and academia.<sup>82</sup>

The biomedical model of acute care, the focus of nursing on physical conditions and ADL, has been the traditional way of nursing home care, resulting in neglect of psychosocial and emotional needs and use of inappropriate usage of psychotropic medication with severe tolerability issues and restraint in agitated residents,<sup>83</sup> despite their negative consequences.<sup>84-87</sup>

The concept of person-centered care is a holistic approach to dementia care and was developed by Kitwood<sup>88</sup> as a response to the biomedical model of caring. Person-centered care is characterized by acknowledgement of the individual as a person that can still experience life and make choices and the focus on what a person can do, rather than the abilities that are lost. Lack of understanding the experiences residents



with dementia have, may lead to agitation and other problem behaviours and misinterpretation of their needs.<sup>89</sup> Understanding the underlying mechanisms and risk factors leading to agitation in nursing homes, is therefore crucial to possibly prevent, treat and reduce the severity of agitation and thus, possibly prevent inappropriate use of psychotropic drugs and restraint.

Based on current literature, factors related to the cause of agitation may be presented in three major themes; 1) Causes in the disease itself, 2) Causes due to unmet needs, and 3) Causes in the physical or social environment. The cause of the behaviour will often be a combination of the three.

#### 1.2.2.1. Understanding agitation due to causes in the disease itself

As outlined in 1.1.1., cognition and communication skills are impaired in persons with dementia, thus their ability to communicate their needs are impaired as the disease progresses. The reduction in communicative abilities creates physical and emotional barriers that represent challenges for family and care staff, and leads to frustration, fear and agitation in the resident not being able to express himself. Assessment of the resident abilities to communicate as well as good communication skills in care staff, are important factors in care, treatment and interaction with residents with dementia. In addition, brain changes related to the disease itself as well as genetic factors may contribute to the development of agitation.<sup>19</sup> For example, pathological lesions in the orbitofrontal cortex have been found to be associated with agitation scores in Alzheimer's disease and both serotonergic, cholinergic and dopaminergic changes have been reported to be related to agitation.<sup>19</sup> However, the studies are few and based on small and selected samples, and thus the findings have been inconsistent. Our understanding of the morphological and chemical underpinnings of agitation and other BPSD is still incomplete.

#### 1.2.2.2. Understanding agitation due to unmet needs

The need-based dementia-compromised behaviour model, conceptualizes problem behaviours as attempts to communicate unmet needs,<sup>73</sup> that if responded to

appropriately, will enhance quality of life. In the *Need-Driven Dementia-Compromised Behavior Model (NDB)* behavioural symptoms are considered as need or goal of the individual with behaviour, rather than “disruptive” or “disturbing”.<sup>90</sup> The NDB model has challenged the common view that dementia-related behaviours are simply part of the disease process.<sup>91</sup> The NDB model reflects the interaction between the relatively stable background factors, fixed unchangeable factors (e.g., neurological factors, cognitive abilities, health status including physical functional abilities, and psychosocial including premorbid personality) with more changeable proximal factors (e.g, physiological and psychological need states and qualities of the physical and social environment). The fixed factors shape more enduring patterns of behaviour, while proximal factors may induce a need state. The interplay of these factors produces need-driven behaviour, the most integrated response a person can make given the limitations imposed by the dementia, strengths preserved from abilities and premorbid personality, and the constraints or supports offered by the environment.<sup>73,91</sup>

#### 1.2.2.3. Understanding agitation due to causes in the physical or social environment

The physical environment, including the setting, access and sensory properties, has a major impact on the quality of life for residents with dementia; they spend most of their time within one building and are limited in the range of environment that they experience. Everyday activities and environment are central for well-being, and technology and design could support or add to the problems faced by a person who is experiencing cognitive decline. Investigations on how building design impact on quality of life of people with dementia care showed poorer quality of life in buildings that prioritise safety and health, whereas buildings that supported activity, gave people control of their environment and provided good links with the community, had positive association with well-being.<sup>92</sup>

As the functional capacity declines in the resident with dementia, the ability to deal with environmental demands and pressure declines as well and leaves the resident highly responsive and vulnerable to the environment. According to the NDB

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model,<sup>73,93</sup> environmental pressure occurs when the environment demands more from the individual than he or she can handle. In this model, individuals with cognitive impairments exhibit three levels of behaviours related to the environment: baseline, anxious and dysfunctional.<sup>94</sup> Baseline behaviours include awareness of the surroundings and the ability to communicate in some way. When the environment produces more demands than the individual can process, anxiety may occur. If the anxiety is not dealt with, it might cross the stress threshold and dysfunctional behaviour occurs. With worsening dementia the stress threshold is lowered and anxious and dysfunctional behaviours increase, and in turn decreasing the stress threshold further. When the environment produces too many stressors or no opportunities to relax or avoid aversive stimuli, the stress threshold is exceeded, dysfunctional behaviour manifested and the individual is unable to return to baseline behaviour.<sup>94</sup> From this perspective, identifying and adjusting potential triggers in the environment, may improve behaviour management and reduce the stressors causing agitation.

### 1.2.3 Management of agitation

Treatment and care for residents with dementia and agitation beyond minimum health and safety needs are complex tasks, and require different approaches and multiple perspectives: the complexity of cognitive, emotional, physical and behavioural disturbance, skills and understanding of the individual, the personality and personal history of the resident, his/her needs and interaction with organizational and psychosocial factors and, the care staff - resident interaction and relations on all levels (i.e. family, friends, other residents).

Management of agitation in residents with dementia is mainly grouped into psychosocial and pharmacological treatment, and often a combination of the two.

### 1.2.3.1 Psychosocial treatment

Psychosocial treatment or intervention focuses on the individual and the environment. It is a treatment approach based on the knowledge of the individual,<sup>95</sup> his needs and capacities, as for example described in the NDB-model. The aim of the intervention on an individual level is to engage the resident in meaningful activities, tailored to each resident individual need in specific, time limited situations.<sup>96</sup> Another important aim of psychosocial treatment is to create a more supporting and adequate environment as a whole and to increase care staff knowledge in dementia care.

Successful treatment of agitation using psychosocial interventions is associated with improved quality of life for residents,<sup>97-100</sup> and reduced carer burden,<sup>101</sup> although there is still a need for systematic clinical trials to support this. Several systematic reviews have been performed to rate the effectiveness of psychosocial treatment. Livingston et.al.,<sup>102</sup> identified a total of 1, 632 studies and only 162 satisfied the inclusion criteria for the review. In another review, Aylward et.al.,<sup>103</sup> tested psychosocial interventions against the rigorous standards designed by experts in the field. Of 683 relevant studies they found only three randomized controlled trials and six single-case studies that met inclusion criteria.

Still, emerging evidence confirms that a variety of psychosocial interventions can improve agitation,<sup>102,104</sup> such as aroma therapy,<sup>104</sup> structured psychosocial interventions,<sup>105</sup> snoezelen<sup>106</sup> and recreation therapy.<sup>91</sup> Therapeutic, recreational activities have shown promise as management strategies for need-driven behaviours. They are particularly useful during periods of unoccupied time, which constitute a great portion of nursing home residents' day<sup>107</sup> and contribute to need-driven behaviours. Therapeutic recreational activities have been prescribed to promote enjoyment and attain a specific goal or objective such as improvement in physical or behavioural functioning.<sup>108</sup> Behavioural management techniques centred on individual residents' behaviour were generally successful.<sup>102</sup> Other research offers some support, although evidence is insufficient for use of validation therapy (resolve

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conflicts by validating expression of feelings),<sup>109</sup> pet therapy,<sup>110</sup> music therapy,<sup>111</sup> and bright light therapy.<sup>112</sup>

Psychosocial interventions are targeting at improving quality of life, require time, skill and effort to implement.<sup>113</sup> This initial investment may discourage some from incorporating these interventions into their practise. However, the benefits of psychosocial interventions may be more clinically significant and long lasting than pharmacological treatment, and avoid potential complications associated with drug interactions and side effects. The potent role of cognitive and functional status on engagement of persons with dementia underscores the importance of tailoring activities to nursing home residents' needs.<sup>114</sup>

#### 1.2.3.2 Pharmacological treatment

Pharmacological agents for the treatment of agitation in residents with dementia, include antipsychotic drugs, antidepressants, mood stabilizers, anxiolytics and antidementia drugs.

Antidepressants and cognitive enhancers are often used to treat depression and agitation, and a significant effect of antidepressant on depression in dementia has been found.<sup>115</sup> Early encouraging studies using mood stabilizers have not been confirmed, and there is currently little evidence to support the use of these drugs for BPSD. Similar, there is little evidence that treatment with anxiolytics such as benzodiazepines, are useful beyond short-term and intermittent use. Modest beneficial impact of cholinesterase inhibitors has been found,<sup>116</sup> as well as encouraging studies with memantine.<sup>117</sup>

The most common pharmacological treatment of BPSD and agitation is antipsychotic medication. A significant but modest advantage of typical antipsychotics such as thioridazine, promazine and haloperidol has been reported.<sup>118</sup> The most comprehensive evidence pertains to haloperidol, indicating a significant improvement in symptoms of aggression compared to placebo, but no significant improvement in other symptoms of agitation, and more modest improvements in psychotic

symptoms.<sup>119</sup> There is very little clinical trial evidence pertaining to other typical antipsychotics for the treatment of agitation, aggression or psychosis.

Atypical antipsychotic, such as risperidone and olanzapine, are associated with some overall improvement of behavioural symptoms. Risperidone is also associated with improvement of aggression, with a more modest benefit for psychosis but no evidence of treatment benefits for non-aggressive agitation.<sup>120,121</sup>

The adverse effects of typical antipsychotics in patients with AD include sedation, parkinsonism, dystonia, tardive dyskinesia,<sup>121-123</sup> and cerebrovascular adverse events (including stroke).<sup>120,121</sup> A recent UK prospective long-term study showed that elderly residents in nursing homes who had taken neuroleptics were twice as likely to die during the study period compared to those who did not.<sup>84</sup>

Until 2000, typical antipsychotics such as thioridazine, promazine and haloperidol were all widely used in the clinic, but prescribing practice has changed following cardiac safety concerns related to thioridazine. Despite the increasing safety concerns, there have however been only very modest changes in the overall prescription rates, although atypical antipsychotics are now more widely prescribed than typical agents in most countries. However, there are some indications that the use of antipsychotics has decreased in Norway, and that the use of antidepressant has increased.<sup>124</sup> The modest benefits of short-term therapy and the very limited evidence of ongoing treatment benefits need to be balanced against the adverse events. Reflecting this, best practice guidelines now highlight that the prescription of antipsychotics for AD patients should be restricted to people with severe symptoms causing risk or extreme distress that have not responded to other measures, and that treatment should only be continued beyond 12 weeks in exceptional circumstances and after psychosocial intervention.<sup>120</sup>

#### 1.2.3.3 Treatment approaches in clinical practise

The different types of agitated behaviours have different etiologies<sup>105</sup> as previously outlined, and thus require different approaches. An accurate description of the

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behaviour<sup>91</sup> as an important first step in the treatment process. Based on this description the next step would be to understand the etiology of the behaviour.<sup>105</sup> Persons with dementia often experience unmet needs because they lack the internal and external resources needed to meet these needs.<sup>93</sup> Proximal factors in the NDB model include elements of the physical and social environment, therefore when the etiologic factors of behaviours are identified the next step is to correct those in the environment that are amenable to change. The background factors are less likely to be changed, but represent a profile of strengths, weaknesses and usual coping style, that can be used to tailor individualized interventions to these personal characteristics.

The decisions on treatment intervention in each individual resident should be based on the diagnosis as well as cognitive functioning, physical health and strength, flexibility as well as leisure history and style of interest.<sup>91</sup> For example a resident with agitated behaviour such as restlessness, and severe cognitive impairment, who is able to ambulate fully without assistance, and with a former leisure interest of mountain hiking and a preference for solitude, could be prescribed a walking programme in a safe environment, emphasizing his need for solitude.<sup>91</sup> Finally, if the agitation remains, and there is a high level of distress and a high risk for injury, psychotropic drugs should be considered. The first step should be use of antedementia drug, due to the safety profile and potential benefit of cognition. If necessary, symptomatic psychotropic treatment can be considered.

To summarise, the literature describes three important steps to identify the optimal psychosocial treatment of agitation;

- 1) Accurate description and understanding of the etiology of the behaviour
- 2) Correcting factors in the psychosocial environment that may lead to the behaviour
- 3) Identifying need-driven behaviour.

This process highly depends on a) an *individual* level, that each individual nurse's knowledge about the complex situation of an individual with dementia and her ability

to view both the general and the special circumstances concerning each resident in a accurate way, and b) a *group* level, that the nurses as a group hold the same knowledge about the resident and are able to, as a group, conduct the proper care towards each individual resident, and c) an *organizational* level, that the organization as a whole supports and are aligned with the need for individual care of each resident with dementia.

This again depends on each individual care staff's knowledge and time to reflect upon each individual resident's situation on each level by 1) Viewing the situation as it is in the present 2) Consciousness and consequences of the measures taken in the present 3) Consequences for future care and situation of each individual resident. All three levels and ways of viewing the situation are based entirely on the relation between the care staff and the resident and their ability to communicate. This understanding is critical for the outcome of the use of individualized interventions of resident with dementia.

The resident relation on all levels; such as relations to family, other residents, and the care staff –resident interaction and communication, is the core point in targeted treatment and individualized, person-centered care.

#### 1.2.3.4 Care staff – resident communication

Care staff communication with residents can precipitate problem behaviours<sup>125</sup> and recognizing the role of communication in problem behaviours and the link between them, are therefore important factors in understanding and reducing problem behaviour and agitation. In particular “elderspeak” (infantilizing communication) is used extensively by care staff<sup>126</sup> and is perceived as patronizing and can precipitate communication breakdown and problem behaviours for cognitively intact elders.<sup>127,128</sup> Elderspeak features simplistic vocabulary and grammar, inappropriate intimate terms (“that’s my boy”, “good girl!”) use of collective (plural) pronouns (“why don’t *we* go to bed?”) and tag questions (“you want to shower now, *don’t you?*”). Elderspeak derives from stereotypical views of older adults as less competent than younger



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adults<sup>129</sup> and cognitively intact older adults have negative perceptions of elderspeak.<sup>128</sup> In residents with dementia, elderspeak may be especially threatening to the maintenance of self-concept and personhood they are struggling to maintain, and which are maintained through interaction with other people. Research has demonstrated that elderspeak are used especially during care providing ADL,<sup>130</sup> and is related to resident resistance to care,<sup>126</sup> which is known to involve use of restraint as well (see chapter 1.3.3. for further details). Similar, Ward et.al.<sup>131</sup> studied the patterns of communication in residential care and found that the interaction with the resident followed the same routine, using the same words, although the tasks and situation varied, labelled as “care-speak”. Recognizing the role of communication, and performing targeted interventions to improve care staff communication have been shown to be successful in improving behaviour management in dementia care<sup>132,133</sup> and may contribute to modification of the proximal factors in the NDB-model as outlined in 1.2.2.

#### 1.2.3.5. Care staff – resident interaction

The interpretation of each situation is depending on the persons involved; care staff and resident, their relation and interaction as well as psychosocial and organizational factors. In each interaction, despite meaningful tools and approaches, as previously outlined, there is a unique meeting between care staff and resident. The outcome of this interaction also depends on the understanding there and then, the interpretation of each situation and each care staff’s ability to process this. In clinical experience, the decision making is for a great deal placed in the hands of those closest to the resident; the direct care staff, which has a great influence on decisions regarding treatment and care such as use of restraint and need for medication.<sup>134</sup> The care staff – resident relation and the decision making process<sup>135</sup> (fig.1), are therefore of great importance and focus of the intervention in this thesis.

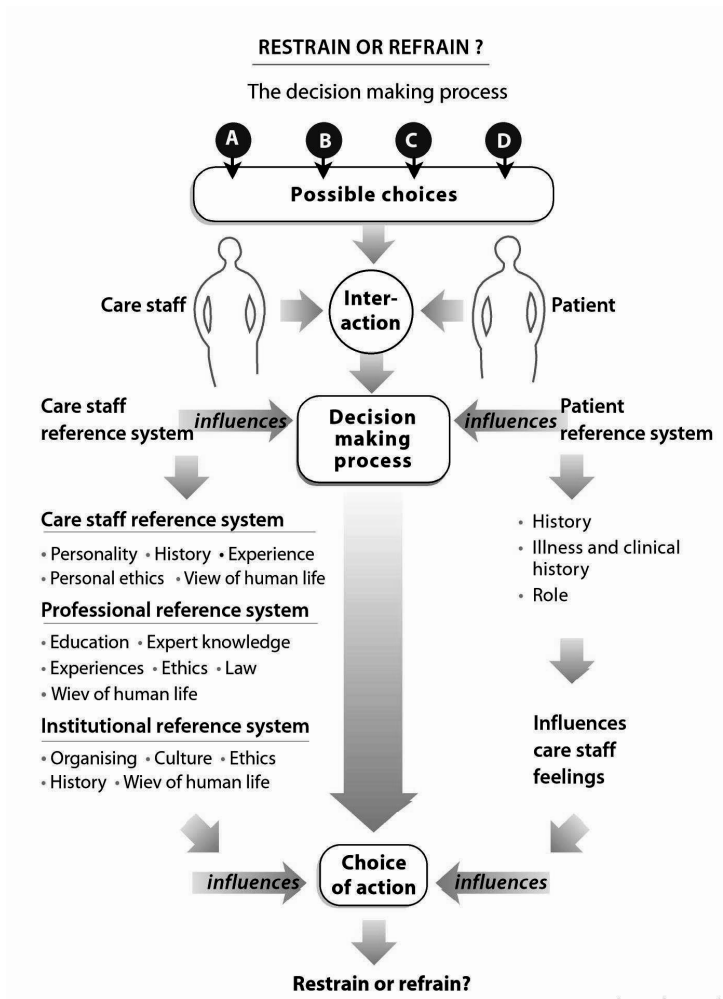


Fig.1 The decision making process

A proper understanding of agitation in dementia to provide targeted treatment and person-centered care is an important way to reduce the use of restraint.

### 1.3 Use of restraint in resident with dementia in nursing homes

Caring for residents with dementia in nursing homes involves in many cases use of restraint to protect the resident from harm. In Norway, use of restraint towards person

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lacking the competency to make medical treatment decision, is now (from January 1<sup>st</sup> 2009) regulated by a new chapter 4A the Patients' Rights Act (Pasientrettighetsloven).<sup>136</sup> When this study took place, there was no regulation of the use of restraint in nursing homes<sup>137</sup> and the new regulation will not be further outlined here.

### 1.3.1 Definitions

Restraint may be defined as any limitation on a persons freedom of movement,<sup>138</sup> more specifically as physical restraint (belts or other fixing to bed, belts or other fixing to chair, locked in a room), electronical surveillance (devices on residents that automatically lock the door, devices on residents that alarm the staff, devices to track residents, devices that sound when a resident leave the bed), force or pressure in medical examination or treatment (mixing drugs in food or beverages, use of force to perform examination or treatment), force or pressure in ADL (holding of hands, legs or head for washing or dressing/undressing, showering or bathing against the residents' verbal or physical resistance, forcing the resident to the bathroom, feeding a resident against his/her will).<sup>139</sup>

In this study, use of restraint have been classified into two groups; structural and interactional restraint;

*Structural restraints* are measures of restraint aiming at protecting the resident through structural measures. Structural restraint is outside the treatment and care giving activity, such as locked doors on the ward, electronical surveillance and bedrails.

*Interactional restraints* are measures of restraint aiming at treatment and care for the resident through care giving activity. Interactional restraint are within the care staff – resident relation, the treatment and care giving activity, such as force or pressure in medical examination or treatment, and force or pressure in ADL, as illustrated in fig.2;

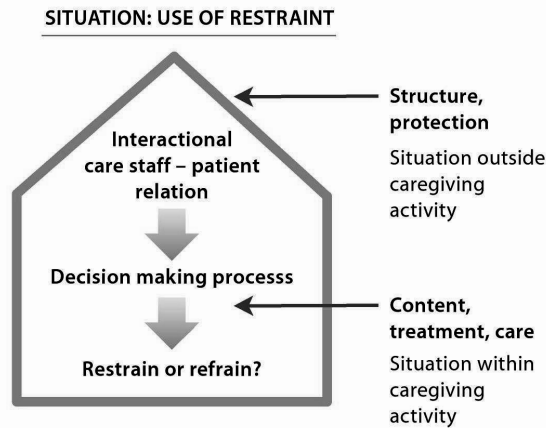


Fig.2 Situation: Use of restraint

### 1.3.2 Frequency and causes

Studies shows that people in nursing homes with cognitive impairment and high dependency, are most likely to be restrained physically.<sup>140,141</sup> In a systematic review on reasons for restraining residents, agitation-related reasons for restraint use were reported in 90% of the studies.<sup>142</sup> Four main groups of reasons for using restraint were identified 1) Staff and organisation-oriented reasons (i.e. reducing legal liability, compensate for understaffing, enable work schedules to be completed), 2) Social group-oriented reasons (i.e. preventing interference with other clients, maintaining peace and harmony in the working environment), 3) Treatment-oriented reasons (i.e. protection of medical devices used in the treatment) and 4) Resident-oriented reasons (i.e. safety of the resident, prevention of fall).

Clearly, some of these reasons are inappropriate reasons for using physical restraint towards residents with dementia. One of the most commonly identified reasons for restraining residents, is the prevention of falls or fall-related injury. The aim is to

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prevent harm. However, this is contradicted by other studies, reporting that decrease in use of physical restraint, did not increase falls or falls-related injuries.<sup>142</sup>

In a systematic review on adverse effects on physical restraint<sup>143</sup> increased risk of death, increased agitation, cognitive decline, reduced social behaviour and reduced mobility were found in nursing home residents being exposed to physical restraint.

It seems likely that use of physical restraint in residents with dementia may in some cases be an easy solution,<sup>142</sup> evident by the many staff related reasons that were identified, and is not well enough justified considering the adverse effects.

Kirkevold and his colleagues found that the strongest correlate to use of restraint were degree of dementia, dysfunction in ADL and aggressive behaviour.<sup>26</sup> The same group<sup>139</sup> conducted a large survey in Norway consisting of 1398 wards and 25108 residents (corresponding to 60% of all residents in institutions for elderly in Norway), and found that 78.7% of the wards reported one or more types of the restraints; physical restraint, electronical surveillance, force or pressure in medical examination or treatment, force or pressure in ADL during the last seven days. The most frequently use of restraint was related to ADL (61.3%), followed by medical treatment (49.8%) and physical restraint (38.4%).

Use of restraint related to force or pressure in ADL, is also described as resistiveness to care.<sup>41,71</sup> This can make individuals with dementia unmanageable at home, untreatable in nursing homes, interfere with the provision of necessary care<sup>71</sup> and lead to use of restraint within the care staff - resident relation; interactional restraint. When residents resist care, this is often carried through by care staff, due to the assumption that the resident 'does not know his own good'. These situations can provoke aggression in the resident, and are often described as the resident exhibiting problem behaviour and being aggressive, rather than resisting or disagreeing to care, or a reaction to the use of force or restraint related to ADL.

Use of restraint is the use of force to make someone do something they are resisting, and towards a person lacking competency, it should be believed necessary to prevent

harm and maintain health, be proportional to the likelihood and seriousness of harm and should be in the person's *best interest*.<sup>144</sup>

The competency to make medical treatment decision is a fundamental aspect of personal autonomy, and refers to the individual's cognitive and emotional capacity to accept a proposed treatment, to refuse treatment, or to select among treatment alternatives. Loss of competence is an inevitable consequence of neurodegenerative dementias. As memory, language and judgment abilities erode, persons with dementia lose the capacity to make medical health care decisions.<sup>145</sup> An assessment that someone lacks competency, has major implications; it gives care staff influence over the person, it also gives care staff a duty to act on behalf of this person in *his best interest*, and it could potentially be abused.<sup>144</sup>

For someone to lack competency, there must be a disturbance in the functioning of the brain, resulting in the ability to retain, use or weight information relevant to a decision or to communicate a choice. Assessment of capacity includes a *status approach*, where a person having reached a diagnostic threshold is described as lacking capacity for all decisions or a *functional approach*, where capacity needs to be reassessed for all decisions, particularly if the impairment fluctuate over time.<sup>144</sup> Finally, someone could lack competency in some areas, but not in others. This means that for someone living with dementia in a nursing home, having reached a diagnostic threshold and with loss of competency as a status they could still have the competency to make decisions with regards to for example ADL.

#### **1.4 Organizational and psychosocial work environment in nursing homes, health and well-being in care staff**

The increased number of residents with dementia will lead to a marked increase in the need for care staff in nursing homes. The turn over rate among care staff in elderly care is high,<sup>146</sup> and negatively affects continuity of care and establishment of personal

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relationship between care staff and residents, both of which are important determinants of quality of care.

By year 2020, a shortage of registered nurses is expected world wide, and the number is forecasted to be 20% below the projected requirements.<sup>9</sup> Work environment and job stress have been implicated in the nursing shortage.<sup>10</sup> A shortage in health care workers in general, towards year 2030 is forecasted in Norway as well.<sup>11</sup> The estimated shortage of 40000 health care workers is mainly due to an increased demand due to the aging of the society.<sup>11</sup>

Health and well-being in care staff, as well as high quality organizational and psychosocial environmental factors are important factors in achieving the goal of personal control, dignity and quality of life in residents with dementia and to provide comprehensive, targeted treatment and individualized, person-centred care.

#### 1.4.1 Organizational and psychosocial environment

Organizational and psychosocial factors, including physical environment, contributes to health and well being of individuals and groups in an organization and dissatisfying psychosocial working conditions may lead to psychological and physiological distress.<sup>147</sup> Karasek & Theorell's demand-control model<sup>148</sup> is one of the most influential and widely used models in the analyses of potential psychosocial work factors for health. Four distinctly different kinds of psychosocial work experience are generated by the interactions of high and low levels of job demand and decision latitude. The most adverse reactions of psychological strain occur when the job demand is high and the decision latitude or control of work tasks, are low. This model may be a simplification of the complex work life, and when related to the complexity of caring for residents with dementia it might even be an oversimplification. Nevertheless, the model is useful as a guideline, when considering the organizational and psychosocial environment in nursing homes.

In this thesis, the emphasis is on organizational and psychosocial factors as described in the QPSNordic Questionnaire.<sup>149</sup> This instrument is both an intervention and survey tool, and is developed based on the Nordic countries long tradition on improving the psychological and social work environment. It was developed by a multidisciplinary group of experts in the fields, based on the factors' relevance and importance for work, health and well-being and main theories of association between work and health, such as the demand – control model. The conceptual background of the psychological and social factors at work, are outlined below (see also chapter 3.4.2).

### *Job demands*

Job demands are defined as all those occurrences, circumstances and conditions in the workplace, which require the individual to act or respond. These can be viewed differently from one individual to another and thus, the job demand is a subjective perception.<sup>149</sup> There are different demands on workers; quantitative demands (amount of work, time pressure), decisional demands (demands on quick and often complex decisions) and learning demands. These are each found to be related to musculoskeletal problems<sup>150</sup> and cardiovascular diseases, in particular when high job demands are combined with low job control.<sup>148</sup>

### *Role expectations*

The most frequently studied stressors are related to role conflict and role ambiguity and numerous studies have demonstrated that they cause substantial problems in the individual.<sup>149</sup> Role conflict occurs when role expectations are in conflict; intra-sender conflict (conflicting messages from one person), inter-sender conflict (conflicting messages from two or more persons) and inter-role conflict when one person has two or more conflicting roles.<sup>149</sup> Role ambiguity refers to a situation where role expectations are unclear and unknown, information may be confusing, success criteria are unclear and expectations from other people are unclear or there may be interpersonal conflicts.<sup>149</sup>



### *Control at work*

Control at work relates to the person's autonomy and participation in planning and decision-making,<sup>149</sup> and the subject's perceived freedom to make decision about his or her work. This is one aspect of the demand-control model<sup>151</sup> showing that adverse health effects occurs when a worker is exposed to a combination of high demands and low control.

### *Predictability at work*

Predictability refers to the possibility of developing expectancies of the work environments, and anticipating future development and demands.<sup>149</sup> Unpredictable environment, impose demands on the individual beyond those of job demands and other challenges. The individual has to stay alert, gather information and be ready to meet changes, which may or may not occur. Over time this can be straining and affect the workers health if sustained.<sup>149</sup>

### *Mastery of work*

Mastery of work, referring to the subject's perception of the result of his or her behaviour, i.e. production of successful outcome, has received less attention in occupational studies even though it may have major impact on health and well being.<sup>149</sup> The subject's perception of mastery includes the degree of consonance between demand and performance and the quality of feedback or information the subjects receive about his or her performance.

### *Social interaction*

Social interaction and support include support from superior, support from co-workers and support from relatives and friends. Most studies show positive association between social support and health at work, and support form superior seems to have an greater impact on the workers health than support form peers.<sup>149</sup>

### *Leadership*

Quality of leadership was defined through supporting, fair and empowering leadership, which has been reported as a principal element of perceived social work environment.<sup>149</sup> Research has demonstrated a strong relationship between leadership and health and well-being of the employees<sup>152</sup> and that support from the supervisor may reduce stress reactions in the employee.<sup>152</sup>

### *Organizational culture*

Organizational culture theories regard an organization as a culture in itself, and the history of the organization, including its important persons and critical events, is often regarded as the foundation of the culture.

### *Commitment to organization*

The concept of organizational commitment focuses on the individual's identification, loyalty, psychological contract, perceived organizational justice and involvement in the organization.<sup>149</sup> These concepts may interact with turn-over and the individual's intent to stay with the organization.

### *Perception of group work*

A work group or team refers to a group of individuals who share a common goal or work task and studies on relations between individual well-being and various group process measures have usually found them positive.<sup>149</sup>

### *Work motivation*

Work motivation refers to the strengths of behaviour-inducing factors towards a particular job and is used to account for the nature and intensity of the individuals work-oriented behaviour.<sup>149</sup> General attitudes towards work can be characterized by two contrasting motivations; internal (realization of one's potentialities for continued

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self-development) and instrumental (personal dispositions and expectations related to occupational and demographic background).<sup>149</sup>

#### 1.4.2 Health and well-being in care staff

Over the past three decades, there has been a growing belief in all sectors of employment and in government that the experience of stress at work has undesirable consequences for health and well-being of the employees and the organization, and that occupational stress levels are rising.<sup>153</sup> High levels of stress in care staff are commonly associated with working with more cognitively impaired nursing home residents.<sup>52,53</sup> Higher psychological demand has been associated with health complaints,<sup>154</sup> and musculoskeletal diseases are the most frequently reported cause for sick leave.<sup>155</sup>

##### 1.4.2.1 Stress

Stress includes physical, emotional, cognitive and social or interpersonal aspects and is generally regarded as a “state arising from a mismatch between a threat and the available resources for the individual”.<sup>156</sup> Levine and Ursin<sup>157</sup> defined four main subscales of stress; 1) Stress stimuli, 2) Stress experience, 3) Stress response and 4) Feedback from the stress response. Stimuli are filtered by the brain and whether it is perceived as pleasant or threatening depends on each individual’s experience of the situation.<sup>157</sup> According to Levine and Ursin,<sup>157</sup> emotional “loads” are the most frequently reported stress stimuli. If the stimuli is perceived as threatening, humans report this as stress and leads to a response, or “arousal” characterized by increased wakefulness in the brain and increased activity in the body (increased heart rate, metabolism etc).<sup>157</sup> Finally, the feedback from the stress response, from the peripheral changes back to the brain, may add to the feeling of being stressed. A necessary condition for coping to occur is that there is information about the relationship between responses and their results and this feedback may be an important element to reduce the stress arousal response, and the somatic consequences of prolonged stress.<sup>157</sup> The control term is used in the previously mentioned demand – control

model,<sup>148</sup> which demonstrates how a model based on the psychological demands of work, skill use and task control can predict a broad range of health and behavioural consequences of the structure of work.

Occupational stress levels are rising in the profession and evidence shows that three key factors of work stress occur in continuing care settings and predict burnout: quantitative overload, qualitative overload and qualitative underload.<sup>158</sup> These components are of special importance to understand what causes job stress and how improvement processes in working life organizations are or might be initiated, planned and carried out. Individuals with high demands and low control in the job situation, carry the highest risk of illness and disease, whereas low psychological demands and high levels of control carry the lowest risk. Low demands and low control, high demands and high control, carry an average risk.<sup>148</sup> The model also predicts working motivation, the ability to learn new behaviour patterns or solve new problems, which is most likely to occur when the challenges of the situation are roughly matched with the individual's control over alternatives or skills in dealing with those challenges.

#### 1.4.2.2 Subjective health complaints

Subjective health complaints are normal physiological and psychological responses in healthy individuals, and not necessarily conditions where the individuals have approached the medical service for their discomfort.<sup>159</sup> Sensations and discomfort from different parts of the body are part of human nature,<sup>160</sup> but stress and inability to cope with stress may sensitize this, and increase the health complaints.<sup>161</sup> The most frequent source of long term sickness compensation and permanent inability to work seems to depend on subjective statements from the individual, particularly musculoskeletal pain, often combined with mental disorders and conditions which are hard to define.<sup>159,162</sup> Among the conditions which are hard to define we find a mixture of subjective complaints from the musculoskeletal system, the gastrointestinal and urogenital system, and pseudoneurological complaints, like fatigue, tiredness,

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dizziness, vertigo and headaches.<sup>159</sup> “Subjective health complaints” was suggested as a neutral descriptive term for these conditions.<sup>159</sup>

## **2. Aims of the study**

The overall objective of this thesis is to explore the frequency, correlates and consequences of agitation in nursing home residents with dementia, and whether agitation and quality of care as measured by use of restraint and antipsychotic drugs, can be improved by means of an intervention consisting of staff training and support.

### *Specific aims:*

Paper 1: To investigate whether staff training could reduce use of restraint towards demented residents and reduce agitation in nursing homes.

Paper 2: To estimate the prevalence and correlates of agitation in residents with dementia in Norwegian nursing homes.

Paper 3: To compare the severity of agitation and psychotropic drug use in nursing homes with different organizations and structures in three different countries.

Paper 4: To investigate the association of organizational and psychosocial environment, care staff and resident factors in nursing homes with health and well being in care staff.

Paper 5: To explore whether staff training could reduce agitation and improve quality of care in nursing home residents with dementia by reducing the use of restraint and antipsychotic drugs.

### **3. Methods**

#### **3.1 Design**

The project took place in Rogaland county, Norway between 2003 - 2007. Different designs were employed, including observational designs such as cross-sectional surveys (2, 3 and 4), and an international, multi-centre comparative analysis (paper 3) and experimental designs, ie cluster-randomized controlled trials (paper 1 and 5).

##### 3.1.1 Cross-sectional study

Papers 2, 3, and 4 were descriptive, cross-sectional studies to analyse the prevalence of agitation in nursing-home residents, and to study correlates of health and well-being in care staff. In paper 3, baseline data from the second intervention study were used to compare the relationship between the phenomena of agitation and psychotropic drug use in nursing homes with different organizations and structures in three different countries and explore clinical and demographic correlates of agitation.

##### 3.1.2 Clinical trial

In the first trial (paper 1) the nursing homes were randomly assigned to intervention or control condition, 2 homes in each group, after stratification for size. In the second study (paper 5) seven nursing homes were assessed for eligibility. Three homes refused to participate, and four were included in the study and matched according to size and accreditation status. In the randomization process, one small and one larger home were allocated to either intervention or the control condition (treatment as usual).

In the first study, data were collected immediately before and after the 6-month intervention period by a research nurse blinded for study hypothesis and treatment allocation. In the second study, data were collected immediately before and after the

6-month intervention period by a research nurse blinded for study hypothesis and to treatment allocation, followed by a second follow-up assessment 6 months later.

### 3.1.2.1 The educational intervention; Relation Related Care (RRC)

Basically the same educational intervention; Relation Related Care (RRC) was used in both the first and second trial. The method and manual used in the first study were modified and further developed for the second study, where the seminar for all care staff was expanded by one day.

RRC is developed by the educators (IT & AMA), for care staff in nursing homes to understand dementia, understand and improve agitation, reduce or prevent use of restraint, improve quality of care and thus, improve quality of life in residents with dementia.

The complexity of caring for residents with dementia, the experience of this escalating complexity, the fact that complex systems interact with other systems, in a way that can not be fully solved, combined with high job demands may lead to frustration and experience of stress in care staff. This may negatively influence the quality of the care provided, and increase the risk for agitation, in particular in residents with more severe dementia. Knowledge about these complex systems is therefore important, since it may provide information on how to improve quality of life both for residents and staff, and has important implications for the health care system.<sup>163</sup> Through understanding the interactions between the complex systems, rather than focusing on separate agents, new valuable knowledge may be produced and interactions between the resident and care staff improved. This may lead to decreased agitation and use of restraint in residents with dementia, and increased health and well being in care staff.

To further expand this complexity, care staff is trained professionally to use their knowledge and skills to solve a problem. Care staff often approaches the situation through intellect and a problem-solving approach whereas the resident suffering from cognitive decline approaches the situation more through senses and feelings. To meet



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a person with impaired cognition and with disturbed emotions, such as agitation, emotional skills in addition to cognitive skills are needed.<sup>164</sup> In addition, there are further challenges in dementia care, such as understanding what the resident with impaired cognition is communicating, understanding their ability and need to communicate and to communicate back in a way the resident can relate to without mitigating their right to participate in their activity of daily living. Understanding agitation in dementia can provide key targets for treatment and care, which may lead to reduced agitation and use of restraint.<sup>132,133</sup>

*“Somebody got to do something”*

In the nursing home environment this phrase often refers to a challenging care staff – resident interactional situation, including agitated behaviour and use of restraint. The demand is often upon the leader or physician to solve the situation, for example by increasing the care staff – resident ratio, move the resident to another unit, or prescribe antipsychotics. The phrase is often heard when the care staff feels they have tried “everything” and there is nothing more they can do. This clinical experience as well as the complexity of care was considered in the development of the RRC - intervention, aiming at “doing something” directly in the care staff – resident interaction, including both the structure and the content of the situation.

A key assumption underlying the intervention is that by increasing the understanding of the total complexity of the situation, targeted treatment can be implemented, leading to improved care for people with dementia. This will translate into prevention or reduction of severity of agitation and use of restraint and antipsychotic drugs. One key understanding underlying this assumption, is the necessity to address this complexity towards the group of care staff as a whole (all care staff and leaders included and at the same time), and to continuously address the issue through guidance groups.

The decision-making process in caring is central in the RRC. It involves empowering care staff in making the proper assessment, understanding and relating to the care

staff – resident situation and provide targeted treatment and individualized, person-centered care, through increasing their ability to obtain information, seeing the range of options, having positive thinking of their own skills and ability to learn new skills, both on their own and as a group and to stay involved in the changes and growth process which is necessary and never-ending in the process of caring.

*Aim of the programme:*

“Every decision to use restraint towards residents with dementia in nursing homes, should be carefully considered, based on each residents individual need and situation and in his or her best interest”.

RRC consists of two major elements: a two-day seminar and group guidance (table 1, in appendix) and is structured in to three main factors; a) predisposing, b) enabling factors and c) reinforcing factors.

*Structure*

The intervention was given to one ward at the time. We included all care staff in the intervention including care staff, leaders, assistants, domestic help and so forth. Care staff involved in the same ward, participated in the seminar, at the same time. It is of great importance that the entire group of care staff is involved in the same educational process in order to have a mutual understanding of the situation, make changes everybody can relate to and maintain after the intervention, and most importantly, to ensure that the resident receive the same treatment, regardless of which care staff are interacting with the resident. Leaders on all level were included in the intervention, to facilitate the implementation of new skills, treatment guidelines i.e., and most importantly to follow up on the day-to-day care.

The educators were experienced registered nurses in the field, and clinical experience is necessary to relate to the care staff’s day-to-day situation, combined with theoretical knowledge to provide new knowledge and a different perspective on the situation. The educators were not part of the day-to-day situation of the ward and this

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distance is necessary to understand the situation and provide an outside perspective, supporting the care staff in targeted treatment and individual based care.

The seminar took place outside the nursing home in a two day retreat, including spending the evening and night together. It is important that care staff have opportunity to spend time together as a group and to look in on their mutual situation from another perspective; outside their environment and day-to-day situation.

The group guidance was given once a month for six months and started immediately after the two-day seminar.

### *Content*

The content of the seminar and group guidance is outlined in table 1 (Appendix) with emphasize on predisposing, enabling and reinforcing factors. These three factors are part of a classification system originally developed by Green et.al.<sup>165</sup> to examine educational interventions, sorted by factors relevant to behavioural change in health promotion.<sup>103</sup> A combination of these factors is necessary to change the knowledge, attitudes and practises of care staff on a long-term basis<sup>103</sup> and to ensure that the resident's individual needs and need for treatment are met.

Predisposing factors (dissemination of information; i.e. lectures, written), involves primarily the communication of the knowledge designed to modify the attitudes and interventions of the care staff as individuals, as a group and as an organization ( i.e. lectures, written information).<sup>103</sup> As seen in fig. 1, the seminar included the whole nursing home system including care staff, resident, relations on all levels and the organization as a whole. This represent the basis of which the decision; "to restrain or refrain?" is made. At the start of the seminar, each care staff was provided with a manual, with the content of the seminar. Besides lectures the seminar included role play, and presentation of clinical situations including both positive and negative aspects of the complexity of care. This provided a learning environment, enabling the care staff to look at their own situation as *is*, and in a dialog with the educators. This

provided in turn, a mutual understanding in the group, which was continued in the group guidance after the seminar.

Enabling factors (resources to implement new skills; i.e. treatment guidelines) includes resources in the day-to-day situation, on the ward, to implement new skills and interventions towards the resident (resources to implement new skills; i.e. treatment guidelines).<sup>103</sup> The group guidance was an important enabling factor, including tools such as ways of eliciting resident history and personality and care staff diary to turn bits and pieces of knowledge into a whole picture of joint knowledge of the resident. When a new intervention was developed, it was of great importance that the leader was involved both when the decision was made and to ensure that the resident was given this intervention in the day-to-day care, regardless of which care staff was on duty.

Reinforcing factors (reinforcing new skills; i.e. feedback, peer support).<sup>103</sup> Throughout the group guidance process the care staff had the opportunity to reflect on the process, to be supported and given feedback by the educators as well as the peers. This way of reflecting and the use of the tools were repeated in the group guidance sessions on all care staff – resident interactions and reported in the group to be transferred to other residents with similar situations.

In the RRC education and training program we defined restraint as outlined in 1.3.1.

### **3.2 Subjects**

In paper 1, four public nursing and residential homes in Stavanger, Norway participated. They were randomly assigned to the treatment intervention or control condition, after stratification for size. 55 residents in the intervention group, and 96 residents in the control group were included. The two groups were similar with respect to age, severity of dementia, gender distribution and proportion of subjects using medication for physical disease.

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For papers 2-5, seven nursing homes in Rogaland county, chosen on the basis of being representative for the total nursing home population in terms of size, organization and staff – resident ratio, were invited. They were all public nursing homes. Four nursing homes agreed to participate and residents and care staff from thirteen dementia wards in these nursing homes, were included. These four nursing homes were funded by the councils and are similar to other nursing homes in this region. Data from all 211 residents (7-14 residents in each ward) were included. 61 residents were male and 150 were female, with a mean (SD) age of 85.5 (8.4). 78.9% had dementia, and 63.1% had a score of 6 or 7, indicating severe dementia. In addition, 197 care staff from the same wards as the resident was included. There were 9 male and 188 female of care staff, with a mean (SD) age of 43.10 (12.87).

### **3.3 Nursing home environment**

In addition to the Norwegian homes listed above, nursing homes from Austria and UK were included in Paper 3. The nursing facility in Austria is situated in a small town in which two nursing homes exist, and one included in the study. This nursing home was chosen for an intervention study, to be able to understand the influence of staff training and stimulation therapy for residents with dementia.

In England, 12 nursing homes were recruited; four each in London, Newcastle, and Oxford. Eligible homes were those registered to accept elderly cognitively impaired people and with a minimum of 25% of residents taking psychotropic drugs. They reflected a typical range of care provision for people with dementia in the UK and included private and managed facilities.<sup>166</sup>

### **3.4 Data collection**

The administration of the outcome measures and drug recording related to the resident, was performed by a skilled research nurse, specifically trained to do the standardized interview and blind to the intervention condition and uninformed as to

the objective and design of the study. Care staff (registered nurses) directly involved with the day-to-day care for the resident, were interviewed. Demographic data (age and gender) were collected from the residents' record. The information on the frequency and dose of psychotropic drug usage was collected from the medical charts and categorized according to ATC as psychotropic drugs, antidepressants, or sedatives/anxiolytics. In addition, data from residents in nursing homes in Austria and UK, included in paper 3, had been collected for other studies during the years 2003 to 2005 and were aggregated for analytic purposes.

Outcome measures related to the care staff were obtained through a survey, where questionnaires were distributed to all care staff. The response rate was 98%.

#### 3.4.1 Assessment scales

Standardised and established measures were used to rate dementia. In paper 1, severity of dementia, was rated by Clinical Dementia rating Scale (CDR) and agitation, was rated by Brief Agitation Rating Scale (BARS). In paper 2-5 severity of dementia, was rated by FAST. Use of restraint was rated by a Norwegian standardized interview (see below) in all papers. In addition, severity of dementia in paper 3 was rated by the CDR in England, and The Global Deterioration Scale (GDS), in Austria. The research nurse administered these instruments, during a comprehensive interview with the care staff with detailed knowledge of the residents.

##### *Agitation*

Two rating scales were used to score agitation: The BARS (Paper 1) and CMAI (Papers 2-5).

Brief Agitation Rating Scale (BARS)<sup>167</sup> represents a brief and effective method to assess the presence and severity of physically aggressive, physically non-aggressive, and verbally agitated behaviours in elderly nursing home residents developed as a subset of the Cohen-Mansfield Agitation Inventory (CMAI).<sup>57</sup> It is a 10-item

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measurement, each rated on 4-point scale ranging from 0=none to 3=often or continuous.

Cohen-Mansfield Agitation Inventory – Long form (CMAI)<sup>57</sup> was developed to systematically assess agitation and consists of 29 agitated behaviours, each rated on a 7-point scale of frequency, ranging from “resident never manifests the behaviour” (1) to resident “manifests behaviour several times an hour” (7). Of the 29 items 20 items are presented in four factors (Cohen-Mansfield 1989);

I. Aggressive behaviour (7 items), II. Physically Non-Aggressive Behaviour (7 items), III. Verbally Agitated Behaviour (4 items) and IV. Hiding and hoarding (2 items). The CMAI was validated by the Alzheimer's Disease Cooperative Study instrumentation protocol<sup>168</sup> and shows sensitivity to treatment effects and course of illness. The test-retest reliability of the CMAI over 1 month was good ( $r=0.74$  to  $0.92$ ).<sup>168</sup>

#### *Severity of dementia*

Severity of dementia was rated using The Functional Assessment Staging (FAST),<sup>15</sup> a procedure which describes a continuum of 7 successive stages and sub stages from normality to most severe dementia of the AD type.<sup>16</sup> The FAST stages are derived from the Global Deterioration Scale (GDS)<sup>169</sup> and the correlation between FAST and GDS, with proven validity as a measure<sup>169</sup> has been observed to be 0.9,<sup>16</sup> demonstrating that FAST is a reliable and valid measure of dementia severity.

In paper 3, severity of dementia was rated by Clinical Dementia rating Scale (CDR) in England and The Global Deterioration Scale (GDS)<sup>169</sup> in Austria.

Clinical Dementia Rating Scale (CDR),<sup>18</sup> is a procedure which characterizes six domains (memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care) of cognitive and functional performance applicable to Alzheimer's disease and related dementias. The CDR is a five point scale indicating the following levels of impairment/dementia; 0=normal,

0.5=questionable dementia, 1=mild dementia, 2=moderate dementia, 3=severe dementia.

The Global Deterioration Scale (GDS),<sup>169</sup> is a procedure which provides caregivers an overview of the stages of cognitive function for those suffering from dementia, broken into seven different stages; Stages 1-3 are the pre-dementia stages and stages 4-7 are the dementia stages.

### *Use of restraint*

Frequency of use of and restraint was determined by a standardized interview where all use of restraint during the last seven days were recorded.<sup>6</sup> The interview consists of 25 items within four domains: physical restraint (belts or other fixing to bed, belts or other fixing to chair, locked in a room), (devices on residents that automatically lock the door, devices on residents that alarm the staff, devices to track residents, devices that sound when a resident leave the bed), electronic surveillance, force or pressure in medical examination or treatment (mixing drugs in food or beverages, use of force to perform examination or treatment), any force or pressure in ADL (holding of hands, legs or head for washing or dressing/undressing, showering or bathing against the residents' verbal or physical resistance, forcing the resident to the bathroom, feeding a resident against his/her will).

### 3.4.2 Care staff outcomes

Participating members of care staff for Paper 4 completed a range of questionnaires. Three scales measured health and well being in care staff: Perceived Stress Scale, Psychological Distress and Subjective Health Complaints. General Nordic Questionnaire measured Organizational and Psychosocial factors for Psychosocial and Social Factors at Work. The Cohen-Mansfield Agitation Inventory – disruptive, measured agitation in resident as perceived by care staff.



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*Health and well-being in care staff*

Perceived stress in care staff was measured by means of the Perceived Stress Scale (PSS).<sup>170</sup> The PSS is a 10-item scale, designed to assess appraisals of the extent to which one's current life situation is unpredictable, uncontrollable and burdensome. Respondent answer the PSS by indicating on a 5-point Likert-type scale, ranging from 0 (never) to 4 (very often), the frequency within the last month that they have experienced various stressful feelings, total sum of 40 as the highest score. Higher scores on this measure indicate greater levels of perceived stress and it is more likely the individual will perceive that environmental demands exceed their ability to cope.

Psychological Distress was measured by a short version (10 items) of the Hopkins Symptoms Check List (HSCL-10).<sup>171</sup> This is a widely used instrument designed to measure psychological distress in population surveys. Each item was rated on a scale of 1 (not at all) to 4 (extremely), during the past four weeks, total sum of 40 as the highest score. The average score is calculated by dividing the total by number of items. A cut-off point of 1.85 is recommended as a valid indicator of psychological distress.<sup>171</sup>

Subjective Health Complaints (SHC) were measured by the Ursin Health Inventory,<sup>172</sup> consisting of 16 items concerning subjective somatic and psychosocial complaints experienced during the last 30 days. Severity of each complaint is rated on a 4-point Likert scale (0=none, 1=some, 2=much, 3=severe). Each complaint is also scored for duration (number of days) during the last 30 days. Total max score = 48. The 16 items in this study are grouped into 5 subscales: Musculoskeletal Pain (headache, neck pain, arm pain, back pain, leg pain (maximum score=15)), Pseudo neurology Symptoms (palpitation, dizziness (maximum score=6)), Gastrointestinal Problems (stomach pain, stomach discomfort, ulcer and non-ulcer dyspepsia, nausea (maximum score=12)), Allergy (chest pain, breathing difficulties, asthma, eczema (maximum score=4)) and Flu (cold, coughing (maximum score=6)). Maximum total score is 64.

### *Organizational and Psychosocial factors*

Organizational and psychosocial factors were measured by General Nordic Questionnaire for Psychosocial and Social Factors at Work (QPSNordic).<sup>149</sup> The questionnaire is designed to evaluate effects of interventions at the workplace and includes 123 questions covering the following topics distributed in thirteen factors. Eleven of these scales were included in this study: job demands, role expectations, control at work, predictability at work, mastery of work, social interactions, leadership, organizational culture, organizational commitment, perception of group work and work motivation. On a 5-point Likert scale the respondents indicated from 1=very seldom or never to 5=very often or always, how relevant the question were for their situation. Example: “Do you have too much to do?” In addition to the established subscales, a total score was calculated by adding all items.

### *Agitation in resident as perceived by care staff*

Agitation in resident as perceived by care staff was measured by the Cohen-Mansfield Agitation Inventory – disruptive (CMAI).<sup>57</sup> The questionnaire consists of the same 29 agitated behaviours as the CMAI – long form, each rated on a 7-point scale of frequency, ranging from resident never manifests the behaviour (1) to resident manifests behaviour several times an hour (7) during the previous two weeks. This version differs from the original CMAI in that there in addition is a 5-point Likert scale of disturbance ranging from 1= “not at all” to 5= “extremely”, where each staff member rated the perceived overall level of agitation on the ward during the previous two weeks.

## **3.5 Ethical and legal considerations**

A large proportion of residents in nursing homes either lack or have reduced capacity to consent, requiring careful consideration. The design of this study did not involve the residents directly, but they and/or their family were informed about the study and that they could refuse participation at any stage of the study. Data were anonymous to

the researchers, each resident were given a code to their name, which was used in the standardized interview. This code was kept in a sealed envelope and opened by the care staff involved in the day-to-day care of the resident when the next interview took place.

A written consent from the care staff was obtained through their participation in the study. They were informed that by participating, they also agreed to be a part of the study and that they could refuse participation at any stage of the study. Their anonymity was ensured, and by returning the questionnaire in a sealed envelope directly to the researchers, they were also ensured that their answers would not in any way influence their work situation.

The project has received formal approval from the Regional Committee for Medical Research Ethics for Western Norway and the Norwegian Data Inspectorate. In paper 3 formal approvals from the ethical committees were obtained in the respective countries.

### **3.6 Statistical methods**

Variables were tested for violation of normality using the One-sample Kolmogorov-Smirnov test. Baseline demographic and clinical variables with normal distribution were compared using Student's t-test and chi square tests. Non-normally distributed data were compared using non-parametric tests such as Mann-Whitney U-test. Associations between variables were analyzed using Pearson correlation for normally distributed continuous or Spearman test for non-normally distributed variables.

Multivariate analyses were used to control for potential confounders. In paper 4, linear regression analysis was used to analyze independent correlates of agitation using CMAI score as the dependent variable. Hierarchical multiple regression analyses were used to further analyze the associations of resident and care staff characteristics, using CMAI scores and care staff characteristics as the independent variable and stress (PSS, HSCL and SHC) as the dependent variable. Cut-off points

for determining the presence of multi co linearity were a tolerance value of less than .10, or a VIF value of above 10.

In paper 3, comparisons between countries were made using one-way analysis of variance (ANOVA) with Scheffe post-hoc test and chi square tests. Again, multivariate regression analyses were employed to explore factors contributing to the variance in the two outcome measures, agitation and use of psychotropic drugs. Total CMAI score (linear regression) and use of psychotropic (logistic regression) were used as dependent measures, with residents' age, gender and dementia severity and drug use/CMAI score (respectively) as independent factors.

In paper 5, to analyse how change in CMAI score differed between the intervention and control group, a repeated measures ANOVA with group as between-subject factor and baseline, follow-up and second follow-up as within-subjects factor (the time factor) was conducted, using the CMAI sum as dependent variable. The Greenhouse-Geisser correction for violation of the assumption of sphericity inherent in repeated measurement was used to correct the degrees of freedom. Significant results were followed up with separate ANOVAs for the control group and intervention group.

All statistical analyses were done using SPSS versions 10, 12 and 14. A p-value of <0.05 was considered statistically significant.

#### **4. Results**

**Paper 1** *The effect of staff training on the use of restraint in dementia. A single-blind randomized controlled trial.*

In this first study, the level of agitation according to the BARS score did not change in neither of the two groups, after completion of intervention. However, the proportion of restraint had declined with 54% in the treatment group, and increased with 18% in the control group. We found that the educational program significantly reduced the use of restraint, and we proposed that this imply improved quality of care of the demented resident. The reduction of use of restraint was found although the severity of agitation did not decline.

**Paper 2** *Prevalence and correlates of disruptive behaviour in patients in Norwegian nursing homes.*

Of a total of 211 residents, 78.9 % had dementia, and 63.1 % had a FAST score of 6 or 7, indicating severe dementia. We found that 75.4% of the residents with dementia exhibited at least one agitated behaviour at least weekly and 65.3% several times a week. The six most common agitated behaviours were repetitious sentences or questions, complaining, cursing, pacing, negativism and general restlessness. A highly significant association between CMAI and stage of dementia was found.

**Paper 3** *Nursing home structure and association with agitation and use of psychotropic drugs in nursing home residents in three countries: Norway, Austria and England*

503 subjects with dementia (38 in Austria, 302 in England and 163 in Norway) were available for analyses. There were significant differences between the nursing home residents in the three countries regarding age, gender and dementia severity. In addition, there were structural differences, including the mean number of patients and staff/resident ratio. The level of agitation differed between countries, with higher

mean scores in the Austrian nursing home compared to UK and Norwegian nursing homes. Similarly, the use of psychotropic drugs differed significantly between the homes, with a higher proportion on antipsychotic drugs in UK and Austrian compared to Norwegian nursing homes. These differences were significant even after adjustment for dementia severity, age and gender, and also after including care staff – resident ratio in the model.

**Paper 4** *Health and well being in care staff and their relation to organizational and psychosocial factors, care staff and resident factors in nursing homes*

The main finding was that organizational and psychosocial factors, in particular those related to the organizational structure of the nursing home, were significantly associated with all three measures of health and well-being in care staff. In contrast, residents' agitation was not significantly associated with any of the measures of health and well being in care staff. Leadership, mastery and control of work were the three organizational and psychosocial factors, which significantly explained the variance in care staff health and well-being.

**Paper 5** *The effect of staff training on agitation and use of restraint in nursing home residents with dementia: a single-blind randomized controlled trial*

The main findings of this study were that an educational intervention; Relation Related Care (RRC), led to reduced severity of agitation and improved quality of care by reduced frequency of restraint. The improvement of agitation continued 6 months after the completion of the intervention, indicating that sustained improvement of agitation can be achieved by means of staff training. In contrast, the reduction in restraint, which was evident by a much smaller increase in the intervention group compared to the control group, seemed to be short-lived, suggesting that continuous supervision is needed to achieve sustained reduction of the use of restraint.

## 5. Discussion

### 5.1 Findings in context

The main findings in this thesis were a) that agitation was common in Norwegian nursing homes (paper 2), although less common than in nursing homes in UK and Austria (paper 3), b) that health and well-being in care staff were associated with organizational and psychosocial factors, in particular leadership and less with resident factors such as agitation (paper 4), and c) that a novel intervention consisting of education and guidance of care staff was able to reduce use of restraint (paper 1 and 5) and agitation (paper 5) in residents with dementia.

#### 5.1.1 Agitation: Frequency and context

We found that 75.4% of the residents with dementia exhibited at least one agitated behaviour at least weekly and 65.3% several times a week (Paper 2). Using the Cohen-Mansfield terminology, the six most common agitated behaviours were Physically Non-Aggressive Behaviours (repetitious sentences or questions, general restlessness and pacing) or Verbally agitated behaviour (constant request for attention, complaining and negativism), whereas cursing was the only Aggressive Behaviour occurring in more than 20% of the residents with dementia at least once a week.

Three of the agitated, aggressive behaviours occurred in less than 5% of the residents with dementia at least once a week (kicking, pushing, tearing things), scratching were 5.4%, hitting were 9.6% and grabbing were 13.2%. This is different from other studies,<sup>173</sup> where a higher level of agitated and aggressive behaviours are found.<sup>173,174</sup>

Agitation was associated with severity of dementia and suggesting that with worsening cognition, the ability to communicate needs is impaired as well. Lack of understanding of the experiences of residents with dementia can lead to misinterpretation of their needs, frustration, agitation and other problem behaviours.<sup>89</sup>

We did not find an association between agitation and age or gender. This is different from some other studies reporting higher prevalence of aggressive behaviour among men,<sup>75,175,176</sup> and higher prevalence of verbally agitated behaviours among women<sup>177</sup> and significant association between lower age and BPSD.<sup>5</sup>

A comparison of different studies indicates that agitation is less common in Norwegian nursing homes than in other parts of the world. The figure below compares the mean total score on the CMAI in this study (paper 2) with findings from studies conducted in US, Europe and Canada and Australia.<sup>174</sup> The total score of CMAI, mean (SD) in Norway was 38.86 (12.3), which is lower than Europe and Canada with a mean score of 67.3 (17.9) United States with 64.8 (17.8) and Australia with 77.9 (22.0) as seen in fig.3.<sup>174</sup>

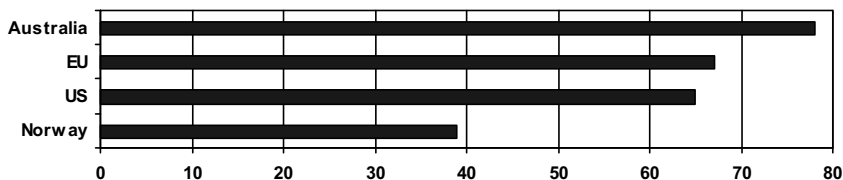


Fig.3. Comparing CMAI between countries

However, differences in agitation based on findings from different studies may be due to a large number of potential methodological differences between studies, and thus a direct comparison between nursing home residents in different countries is required to analyze potential differences between countries. In Paper 3, using the same agitation rating scale, we confirmed these preliminary observations. We found significant differences in mean agitation scores between nursing home residents in Norway, Austria and UK. These differences remained even after adjusting for differences in age, gender and dementia severity (Paper 3), thus supporting the hypothesis that the difference in agitation between the nursing homes in different countries is at least partly related to differences in the organization and structure of the nursing homes. For example, agitation was lowest in nursing homes with fewer residents per ward and with higher care staff - resident ratio. In the Norwegian nursing homes the



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number of residents per unit was lower and the care staff - resident ratio higher than in the UK and the Austrian home. This was associated with a lower agitation score than in the Austrian home, while the difference between UK and Norway was not significantly different. In addition, use of antipsychotic drugs was significantly lower in Norway compared to homes in UK and Austria, although use of antidepressants was higher in the Norwegian homes.

Taken together, these findings suggest that lowering number of residents per unit and increasing the number of staff per resident may reduce both the level of agitation and the use of antipsychotic drugs in nursing home residents with dementia. However, the difference remained significant even after adjusting for the care staff – resident ratio, suggesting that other factors may contribute to the observed, relatively low prevalence of agitation in Norwegian nursing homes. Firstly, the level of agitation is related to clinical factors such as dementia severity. The availability of places and recruitment to nursing homes differ in different countries. This may markedly influence the clinical characteristics of the residents, including severity of dementia, and thus the frequency and severity of agitation. However, the differences between countries remained after adjusting for differences in age and dementia severity, suggesting that the differences in agitation are not related to differences in recruitment procedures related to nursing homes.

Secondly, drug treatment may influence the level of agitation. A substantial proportion in our study used psychotropic drugs. There were differences between the countries for all the major classes; antidepressants, anxiolytics, and antipsychotic drugs, and these differences may influence agitation and contribute to the observed differences. On the other hand, most studies suggest that psychotropic drugs have only a small effect on BPSD,<sup>178,179</sup> and differences in agitation remained after adjustment for differences in use of antipsychotic drugs, suggesting that differences in psychotropic drug use may not fully explain the observed differences in agitation.

In addition to the factors mentioned above, it is possible that the culture change, focusing on the person and emphasising nursing home residents rights and quality of

life (as described in p. 20-21), which has taken place in Norwegian nursing home care during the last two decades may contribute to the relatively low frequency of agitation and aggression in our cohort. In a study of agitation in special care units,<sup>180</sup> it was suggested that both the physical environment and the actions of the staff may have significant impact on agitation levels in long-term care settings for persons with dementia. Ruths<sup>181</sup> found that small dementia care units are beneficial for residents: they maintain their cognition and functional ability longer, they are more relaxed, and receive less antipsychotic drugs. The lower frequency of agitated behaviours suggests that the small size of the units in Norwegian nursing homes, providing an opportunity to prevent or treat agitated behaviours with better and more targeted treatment and care, may have improved the quality of care. The increase in care staff and emphasize on care staff education may also improve the quality of care, and thus be beneficial for the resident, with a direct impact on agitation and quality of life.

#### 5.1.2 Organizational and psychosocial environment, health and well-being in care staff: contributing factors

We also studied how resident agitation and nursing homes' organizational and psychosocial factors were associated with health and well being in care staff (paper 4). Working in nursing homes is seen as stressful, as well as physically demanding occupation, and occupational stress levels are rising among care staff in elderly care, leading to a high turn-over rate.<sup>153</sup>

Few previous studies have explored the relationship between stress in care staff and agitation in nursing home residents. In a review Hannan et.al.<sup>182</sup> found only two studies linking work satisfaction and stress with the process of care and outcome for residents.<sup>183,184</sup> Rodney et.al.<sup>53</sup> found that threat appraisal was significantly related to nurse stress, and Sourial et.al.<sup>49</sup> found that number of agitated behaviours, their frequency and disruptiveness were significantly correlated with staff burden. This study was limited by a small sample size, however.

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Other factors which may potentially contribute to stress in care staff, such as the association with nursing home environment,<sup>185</sup> including organizational and psychosocial factors, have rarely been studied in nursing homes.

We found that organizational and psychosocial factors, in particular those related to the organizational structure of the nursing home, were significantly associated with all three measures of health and well-being in care staff. In contrast, residents' agitation was not significantly associated with any of the measures of health and well being in care staff. Thus, our findings suggest that it is the organization of the nursing home rather than resident factors such as dementia severity or agitation that are associated with stress in care staff.

Leadership, mastery and control of work were the three organizational and psychosocial factors which significantly explained the variance in care staff health and well-being. Quality of leadership was defined through supporting, fair and empowering leadership, which has been reported as a principal element of perceived social work environment.<sup>149</sup> Both control and mastery of work are closely connected to the empowering and fair leadership on one hand and supportive leadership on the other hand. Thus, the results of our study are consistent with previous work, indicating that management is influential in determining overall levels of job satisfaction.<sup>186</sup> Hall<sup>187</sup> found that nurses with greater levels of perceived supervisor support experienced more positive job satisfaction, including less occupational stress. This is supported by the findings from a study in Canada,<sup>188</sup> where supervisory support was an important determinant of job satisfaction in nurses aides and that greater supervisory support also was associated with reduced job stress.<sup>189</sup> A study from different service sectors in Norway found that high levels of support from the immediate superior, were reported more often by aides in the psychiatric sector and least often by aides in nursing homes.<sup>190</sup> The provision of care for residents with dementia is complex and challenging, and our findings in addition to previous work underline the need for strategies to improve organization and leadership in nursing

homes to increase health and well being in care staff<sup>191</sup> as an important part of dealing with the escalating complexity of care.

In contrast to previous studies in other countries,<sup>158</sup> where a higher level of job stress in care staff relative to norms were found, job stress and subjective health complaints experienced by the nursing home staff in this study were not higher than in the Norwegian population in general. In two Norwegian studies, the overall mean distress on HSCL-10 was 1.30,<sup>171</sup> compared to 1.32 in our study. Similarly, physical health complaints are frequent in the normal Nordic population, with 75% to 96%<sup>192</sup> reporting at least one health complaints the preceding 30 days. This is comparable to our study where 88.8% reported at least one subjective health complaint the preceding 30 days, indicating that care staff, do not have more subjective health complaints than the general population, although a ceiling effect cannot be ruled out.

Organizational and structural changes have been performed in nursing homes in Norway during the last two decades, with an emphasis on transforming the culture of care, developing a positive culture for empowerment and education of care staff anchored in person-centered care for the residents. These changes may have contributed to a lower level of stress in the care staff in this study. However, we are not aware of previous data to support this hypothesis and thus further studies are needed to confirm this hypothesis.

Other intervening factors known to cause job stress and subjective health complaints are workload, work experience, and education.<sup>182</sup> In the current study, perceived stress and subjective health complaints correlated with age and shift work, but not with workload (number of hours per week), work experience or duration. This is different from previous studies.<sup>182</sup> The workload as measured by mean work hours per week was 27 hours in our study, this is less than a full position (35.5 hours), which could explain why the care staff did not experience more job stress or subjective health complaints than the average population. However, it is important to note that the significant association between organizational and psychosocial factors and stress in care staff remained even after adjustment for care staff and resident factors

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indicating that although the overall level of stress is not high, organizational factors still seem to contribute to stress in a proportion of care staff.

Further studies are needed to explore the association between organizational and psychosocial factors and health and well-being in care staff, and the possible consequences for the treatment and care of the resident with dementia. However, combined with the possibility of lower prevalence of agitation in Norwegian nursing home residents and lower prevalence of stress in Norwegian nursing home care staff compared to other countries, some preliminary questions could be asked, although not yet concluded upon:

Has the culture change, which has taken place in Norwegian nursing homes, led to a change from a biomedical model to person-centred care, implicating a real impact on the day to day residential care? Have more care staff and fewer residents per unit, empowerment and education of care staff led to better and more targeted treatment and care?

Brodaty et.al.<sup>51</sup> investigated the attitudes of nursing home care staff towards residents, work satisfaction and strain related to dementia, and found that they believe that behaviours in residents with dementia are deliberate rather than a consequence of dementia, and that they tended to perceive residents in more negative than positive ways. The five most prevalent perceptions were all negative. In paper 4, agitation was measured based on the subjective opinion of the care staff. The measure of disruptiveness of agitation is essentially a subjective evaluation of the impact of the agitation and is therefore likely to be influenced by care staff factors such as sensitivity, stress, and view of dementia behaviours.<sup>193</sup> Thus, psychological distress may influence the rating and artificially increase the reported level of agitation, as previously reported.<sup>51</sup> This potential bias may however strengthen the overall finding in this study of little or no relationship between job stress and agitation, suggesting that care staff did not perceive the residents as negative as previously reported.<sup>51</sup> Have we moved forward in perceiving the personhood of residents in Norwegian nursing homes?

Further studies are necessary to answer these questions. We do know from the Norwegian study, by Kirkevold<sup>30</sup> and colleagues, that most resident receive good basic care in Norwegian nursing homes, although more improvements are needed. However, there is a growing body of studies suggesting that differences in welfare systems have little impact upon the day-to-day care, that there are certain attributes to institutionalized care that are seemingly immutable.<sup>131</sup> Ward et.al.<sup>131</sup> studied the patterns of communication in residential care and found that little else beyond the routine of care, such as engagement and stimulation happened. Furthermore, despite the varied nature of the tasks, the interaction with the resident followed the same routine, labelled as “care-speak”. The “Regulation of quality of care”<sup>33</sup> which was conducted by the Norwegian government describes the services that should be provided by the municipal, including care in nursing homes for persons with dementia and preserving their rights. However, Kirkevold and colleagues<sup>30</sup> found in their survey, that taking part in leisure activities and going outside for a walk were often neglected. Furthermore, a high care staff – resident ratio was associated with quality of care, except activities. Are care staff in Norwegian nursing homes still task-oriented and “getting things done”? Is it the transformation of the structure (higher care staff – resident ratio, physical environment i.e.) which has changed and led to a possible lower prevalence of agitation in residents and stress in care staff compared to other countries? This needs to be further investigated.

Finally, the burnout and turn-over in care staff related to working with cognitively impaired residents in institutions needs to be reconsidered. Have we, due to the lack of research on the impact of organizational issues on stress in care staff, taken for granted that it is the challenging complexity of dementia care which leads to stress and turn-over in care staff, rather than paying attention to the organization and working conditions, such as low salaries and status, little room for reflection and possibility for guidance, and little acknowledgement, respect and status in general related to the challenge of caring for the resident with dementia? In spite of the new regulations and plans, there is a growing urgency to reduce expenses while maintaining and increasing quality of care. This paradox is part of the every day work

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of the leaders as well as care staff in nursing homes. Relatives and caregivers experience mixed messages from politicians, who praise the work they do, but at the same time they experience significant cutbacks of resources in the public health care sector.<sup>194</sup>

However, despite our observations of relatively low level of agitation and stress in care staff compared to other countries, our findings as well as previous studies<sup>5</sup> nevertheless show that there is a substantial prevalence of agitation and high frequency of use of restraint and psychotropic drugs in Norwegian nursing homes. Thus, to improve conditions for care staff and nursing home residents, more attention should be paid to the organizational factors, leadership in particular and their relationship to health and well-being as experienced by care staff.

### 5.1.3 Management of agitation

In paper 1, we found that the educational program improved quality of care by reducing the use of restraint. Interestingly, the reduction of use of restraint was found although the severity of agitation did not decline. This suggests that the staff reacted differently even though the behaviour was the same, using better strategies (less restraint) towards the resident. Building upon the findings in this study, we performed a new experiment (paper 5) using a modified version of the educational intervention, and including data of care staff in addition to data on residents. The results in Paper 5, confirm and extend the findings of the first study. In the homes allocated to educational intervention program (RRC), reduced frequency of restraint was found. In addition, in this study, we found reduced agitation in the intervention group compared to the control condition.

The slight increase of agitation in the first study compared to the significant decrease in the main study is interesting and could be explained by the development of the intervention from the first- to the second study. More emphasize was on caring for the care staff, on the care staff contribution to the care staff – resident interaction,

empowering them to make the proper assessment and targeted solutions to treatment and care. In addition, a greater emphasis was directed on the predisposing, enabling and reinforcing factors to change the knowledge, attitudes and practises of care staff on a long-term basis<sup>103</sup> and to ensure that the resident's individual needs and need for treatment are met.

The improvement of agitation continued 6 months after the completion of the intervention, indicating that sustained improvement of agitation can be achieved by means of staff training. In contrast, the reduction in restraint, which was evident by a much smaller increase in the intervention group compared to the control group, seemed to be short-lived, suggesting that continuous guidance and support is needed to achieve sustained reduction of the use of restraint. Given the lack of efficacy and major safety concerns for antipsychotic agents, and the use of robust and clinically meaningful outcome parameters, these findings are encouraging by demonstrating that improved quality of care and quality of life can be achieved for residents with dementia in nursing home setting by means of simple tools which can easily be implemented.

Two previous systematic reviews concluded that there is little scientific evidence as to the effectiveness of education and training for nursing home staff, and that the reported studies have methodological limitations such as being non-randomized, and having small sample sizes, with high attrition rates.<sup>103,195</sup> Most notably, few studies employed long-term follow-up evaluation to ensure whether any effect is sustained beyond the intervention period, and many studies reported staff outcomes only. However, several well-designed recent studies of person centred staff training have demonstrated that the use of antipsychotic drugs,<sup>166</sup> and agitation<sup>83,105</sup> can be significantly reduced using these approaches.

One of these studies, a large psychosocial intervention study on systematic individualised interventions for agitation used the Treatment Routes for Exploring



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Agitation (TREA) to treat the unmet needs of agitated residents with dementia,<sup>105</sup> and their findings suggest that agitation can be decreased. The individualized interventions were anchored in person-centered care, using a holistic approach, showing that person-centered care and psychosocial interventions are promising in decreasing agitation as well as use of restraint. This is an important step forward from the biomedical model to individualized interventions anchored in person-centered care.

However, in our opinion, these approaches do not fully integrate the care staff – resident interaction. In each interaction, despite meaningful tools and approaches, there is a meeting between care staff and resident, in which the outcome depends on the understanding there and then, and each care staff's ability to process this. In order to integrate the change from the biomedical model to person-centered care, care staff needs support and guidance in the process. Furthermore, the impact of care staff – resident relation and the impact that each care staff have on the situation need to be considered and supported, in addition to implementing structured tools and psychosocial interventions. Encouraging care staff to engage in the resident,<sup>196</sup> acknowledging that the resident with dementia needs to seek meaningful interactions,<sup>131</sup> and needs to be accepted and supported are important factors.

#### 5.1.4 Use of restraint in nursing homes

As outlined above, reduction in use of restraint in nursing homes, was found in paper 1 and 5. In the first study, the number of restraint declined by 54%. In the second study, the intervention was further developed, including a classification of the use of restraint in two groups; structural and interactional and where emphasize was on reducing the interactional use of restraint. The effect on restraint was evident by a much smaller proportion starting new interactional restraint in the intervention group, than in the control group. This reduction was not evident on second-follow up 6 months after the intervention, suggesting that continuous guidance over time is needed to achieve sustained reduction of the use of restraint. It also suggests that the

intervention period, due to the complex challenges, should have been longer; allowing more time and support to implement new skills and routines in the day to day care.

Few studies, usually small or non-randomized, have demonstrated reduction in the use of restraint after staff education.<sup>197,198,199</sup> Recently, two randomized trials found no change in the use of restraint after an educational program for nurses were performed, but an increase in the control group, indicating that the use of restraint can be prevented,<sup>200,201</sup> although this was not confirmed in a recent study by the same authors.<sup>202</sup> These findings are consistent with our findings; that prevention and reduction of restraint are possible. However, more studies are needed to explore this further, using larger cohorts, a combination of elements from different approaches which might obtain the greatest and broadest benefit, and employing additional outcome measures such as cost-effectiveness, quality of life, biomedical markers and more detailed assessment of how the resident-staff interaction can be positively altered.

A restraint-free nursing home environment is proposed as a goal in regards to physical restraint,<sup>203</sup> due to the adverse effects of physical restraint such as direct injury and mortality.<sup>143,204</sup> Ideally, a safe and restraint free environment at all times and for all residents with dementia in nursing homes, should be a goal. However, a nursing home environment free from *all* kinds of restraint (structural and interactional) is not necessarily in the resident's with dementia's best interest. Structural restraint, outside the caregiving activity, such as locked doors, might be necessary for safety reasons, to protect the resident from potential harm. As shown in this study, there is a great potential to reduce use of interactional restraint, through better targeted treatment and individualised, person-centered care. To act in the *best interest* of the resident, is one of the major challenges when caring for residents with dementia in nursing homes and this should be the ultimate goal. It will include a decision making process which ensures that the decision is based on each resident' individual need. All aspects of the situation: care staff, nursing home environment, resident, resident history, resident relations on all levels, the way resident and care staff influences each other and

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possible treatment approaches need to be considered. The aim should be that “Every decision to use restraint towards residents with dementia in nursing homes, should be carefully considered, based on each residents individual need and situation and in his or her best interest”, as outlined in 3.3.

## 5.2 Methodological issues

### 5.2.1 Design

#### *Cross-sectional design*

Cross-sectional design was used in papers 2-4. This practical and economical design can give valuable information on how different phenomena are related at a fixed point in time. There are, however several limitations to this design, mainly that the phenomena under investigation are captured as they manifest themselves during one time of the data collection. The results could be explained by several other factors related to time, as opposed to longitudinal designs, where the data presented are collected over more than one point in time. The cross-sectional approach may capture only a limited time period and may thus not capture rare behaviours or behaviours which vary with time. Furthermore the cross-sectional approach makes causal interpretation difficult, as it is difficult to know which variable influenced the other. However, this limitation can be reduced through strong theoretical framework guiding the analysis.

In paper 4, previous research on job stress and well being in care staff and a theoretical framework for occupational stress and well being were used to guide the analysis and description of care staff health and well being and the association with resident factors, care staff factors and organizational and psychosocial factors.

In paper 3, several limitations should be noted. Analysis of data was performed post-hoc, after the experiments in the different countries were concluded and without being specified *a priori*, with an increased risk for spurious, false-positive findings.

It has been recommended that cross-country studies should control for variables that may affect comparisons of agitation, such as age and sex structure.<sup>205</sup> We were able to control for several key resident factors, such as age, gender and dementia severity, but the study design did not allow for a comparison of dementia diagnosis across countries. Similarly, we were unable to adjust for physical co-morbidity, which might differ among the homes and influence the total care burden. The nursing homes were not randomly selected from the countries and may therefore not be representative for the nursing home populations in the three countries. Although good psychometric properties have been shown for the CMAI, inter-rater reliability was not assessed in this study, and no attempts were made to calibrate the ratings across centres. Except for global measures such as staff/resident ratio and number of residents per unit, we had no access to information regarding these more subtle aspects of the nursing homes, including care staff-resident interaction and the understanding and management of the behaviour. It is likely that such factors contributed to the observed differences in addition to the structural variation. However, the aim of the study was *not* to compare the situation in nursing homes in the three countries per se, but rather to take advantage of larger structural and organizational differences between nursing homes than would probably occur when studying homes within a more limited geographical region.

### *Experimental design*

An experimental design was used in papers 1 and 5. Agitation and use of antipsychotics and restraint in residents with dementia were the dependent variable, and nursing homes were randomly assigned to the intervention or the control conditions. Randomization is the preferred scientific method for equalizing groups, although there is no guarantee that the groups will be equal. In fact, in Paper 5, there were statistical differences between groups for several key variables, including the primary outcome variable CMAI, despite random allocation.

In a randomized, controlled trial, the randomization process essentially means that every subject has an equal chance of being assigned to any group, as typically seen in

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pharmacological trials. Randomization of individual residents is one of the major difficulties in psychosocial interventions in nursing homes in general, since the total nursing home environment will be influenced by a training program. This is reflected in several systematic reviews of the effect of psychosocial treatment,<sup>102,103</sup> where only a few randomized controlled trials have been identified. Cluster randomization is an important alternative to individual randomization, which involves randomly assigning groups or clusters of individuals to different treatment groups. The strength of this method is that the intervention can be given to a ward or a nursing home as a group, and avoid the possibility of contamination between different treatments in the same ward, through commingling of subjects in the group. To further avoid contamination between the groups, we chose to randomize the nursing homes as a whole, and not only wards, to the different treatment groups, since the total nursing home environment, would be influenced by the training program. This method of randomization is recommended to prevent interaction by the different treatment groups.<sup>195,201,206</sup> The limitation of this method is that the sample size requirements are greater for a given effect size. In our power calculation we estimated that  $n=100$  in each group would provide sufficient power for the statistical analysis. This calculation however, was built upon randomization of individual subjects to the different treatment groups. The small numbers of participating homes precluded the use of standard cluster-analysis in the statistical analyses, and thus comparing individual residents might have introduced a bias due to an increased risk of false-positive findings (Type I-error).

Another issue is the problem of blinding. Double-blind intervention, where neither the rater nor the participant knows which intervention is received, is the ideal. This is not possible in psychosocial studies, where the participants, in this case the care staff, obviously are aware of participating in the educational intervention. As an alternative, single-blind design was used. The rater who collected the outcome measurement was blind as to treatment allocation, as well as the overall design of the study.

The nursing homes allocated to control condition received treatment as usual. Comparing an intervention with “usual treatment” is problematic, since there are probably non-specific benefits from any intervention. This possible bias, also known as the *Hawthorne effect*, and defined as “an increase in worker productivity produced by the psychological stimulus of being singled out and made to feel important”,<sup>207</sup> might be an important factor, affecting the interpretation of the findings. McCarney et.al<sup>208</sup> studied the magnitude of the Hawthorne effect in the context of a community dwelling study with residents suffering from mild to moderate dementia. They found evidence of a small Hawthorne effect in this randomized non-blind placebo-controlled clinical trial, where individuals who received more intensive follow-up had a better outcome than individuals receiving minimal follow-up. A non-specific intervention would therefore have been a preferable comparator, controlling for non-specific benefits, and thus enhancing the likelihood that the observed effects were in fact related to the specific elements of the intervention rather than merely non-specific effects.

Another difficulty in interpreting the findings was the baseline differences in the outcome variables agitation and use of restraint in the intervention and control homes, which might introduce a confounding effect. The more severe agitation and more frequent use of restraint in the intervention homes might have contributed to the differences between the two groups by unspecific factors such as regression to the mean, and by a different effect of the intervention depending on the baseline severity of the outcome variable. However, the consistent and sustained reduction in agitation, and the fact that the use of restraint was increased in the control group compared to stable use of restraint in the intervention group, argues against regression to the mean as a major factor explaining the differences. One frequently used method to adjust for baseline differences is to include these variables as co-factors in multivariate analyses. However, although frequently performed, it is recommended to not include baseline value of the outcome as a co-factor when using repeated measurement ANOVA.<sup>209</sup>

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### 5.2.2 Case selection

Selection bias is of critical concern to the internal validity of a study. Differences between the groups in the study could affect the dependent variable in ways extraneous to the effect of the independent variable and may lead to erroneous estimation of the effectiveness.

#### *Recruitment and potential bias*

In the first study seven nursing homes were invited to participate and four agreed to participate; two small homes (rural) and two large homes (urban). As discussed above, they were similar to other nursing homes in the region with regard to size, organization and staff-resident ratio with no obvious systematic recruitment bias.

Similarly, in Paper 5, the four nursing homes that were included were all funded by the councils and were similar to other nursing homes in the region with regard to size, organization and staff-resident ratio. Taken together, we believe that there was no systematic selection bias which would affect the cohorts. This conclusion is supported by comparing the baseline characteristics of our sample to a recent larger Norwegian study,<sup>5</sup> including more than 1000 residents, in terms of resident age (mean (SD) 85.5 (8.4) (this cohort) vs. 85.0 (7.9) (regular units, Norwegian study),<sup>29</sup> gender (female 71.1% vs. 73%),<sup>29</sup> and proportion with dementia (79.1% vs. 80.5%). Thus, we believe that the nursing home residents included in this study can be considered representative of Norwegian nursing home residents in general.

#### *Accuracy of diagnoses*

Another potential bias is the accuracy of diagnosis. It is not common that all residents in Norwegian nursing homes are diagnosed for dementia, and Selbæk et.al.,<sup>5</sup> found that only 55% of the residents included in their study had a diagnosis of dementia in their records. The design of the current study included a standardized and reproducible assessment of dementia by an experienced and certified research nurse

for all residents. Severity of dementia was rated using standardised and established instruments such as FAST, GDS and CDR. These methods of staging dementia have been shown to have acceptable reliability and accuracy. Importantly, an Australian study showed that CDR based solely on information data is valid among community resident.<sup>210</sup> However, the design did not include diagnosis of dementia subtype. Thus, it is possible, although unlikely, that there were differences in the distribution of dementia subtypes in the three countries (Paper 4), and also in the two treatment groups in papers 1 and 5. In paper 2, an error was made, regarding FAST stage higher than 2 as dementia, instead of a cut-off of 4 or higher. However, this would not influence the findings, since the number of residents with FAST scores 2 and 3 was very low.

### 5.2.3 Methods of measurement

Psychometric assessment of an instrument, including the validity and reliability, is an important requirement in quantitative research. In this study all instruments used are well known and well tested in terms of psychometrics, and have been used in numerous studies. One limitation is that the assessment and evaluation of residents were based on measurements relying on care staff. In addition, in paper 4, agitation was measured based on the subjective opinion of the care staff. Care staff ratings are biased by care staff feelings and ability to observe and respond. Thus, psychological distress may influence the rating and artificially increase the reported level of agitation, as previously reported. Using direct observation may provide a better way to measure agitation. This potential bias may however strengthen the overall finding of little or no relationship between job stress and agitation in paper 4. In paper 3, ratings of agitation were compared across nursing homes in three different countries. Good psychometric properties have been shown for CMAI, and Finkel et.al.<sup>211</sup> found high internal consistency, but only marginally adequate inter-rater reliability. Inter-rater reliability was not assessed in this study, and since the data were analysed post-hoc, no attempts had been made to calibrate the ratings across the three countries. It is therefore possible that low reliability may have influenced the findings. In addition,



cross-cultural research into agitation in dementia should implement rating instruments with adequate psychometric properties in different languages.<sup>205</sup> We are however not aware of studies assessing the psychometric properties of the German and Norwegian versions of CMAI.

#### 5.2.4 Statistics

Limitations of paper 1 and 5 include the small sample size, the lack of control over the use of drugs during the study period, and the use of a non-active control condition. In paper 3, the number of residents included was also low, particularly in Austria. Thus, statistical power was reduced. Univariate analysis of cross-sectional data may be subject to a range of possible bias. Therefore, multivariate analyses were used in several studies, including Papers 3 and 4, and the relative contributing effect of the various potential factors can therefore be analysed independently. A multitude of analyses have been performed, for example in Paper 4, without any attempt to adjust for this. There is therefore a risk that some of the statistical significant relationship may be spurious and due to multiple testing, rather than a true statistical association.

## 6. Conclusions

We found that 75% of the residents with dementia exhibited at least one agitated behaviour at least weekly. This high proportion underlines the clinical importance of agitation in institutionalized people with dementia. However, the frequency in the nursing homes in Rogaland County was low compared to nursing homes in Austria and UK. This may be due to structural differences, including the mean number of residents per ward and care staff - resident ratio. Similarly, the use of psychotropic drugs differed significantly between the homes, with a higher proportion of antipsychotic drugs in UK and Austrian nursing homes compared to Norwegian nursing homes. Thus, these findings suggest that the culture change, which has taken place the last two decades in Norwegian nursing homes, may have had a beneficial effect on the quality of care for residents with dementia. It is therefore possible that similar changes in nursing homes may improve the conditions and quality of life of nursing home residents in terms of less agitation and less use of antipsychotic drugs also in other countries, although this remains to be shown.

In addition, we found that organizational and psychosocial factors, in particular those related to the organizational structure and management of the nursing home, were significantly associated with health and well-being in care staff. In contrast, residents' agitation was not significantly associated with any of the measures of health and well-being in care staff. These findings suggest that in order to improve conditions for care staff, and thereby reducing staff turn-over and possibly increase quality of care provided, the focus should be on improving organizational structure and managerial issues. More studies are needed to further test these hypotheses.

We demonstrated that a relatively simple educational program led to reductions in the use of restraint, and induced sustainable reductions of agitation. Overall, our findings suggest that by lowering the care staff - resident ratio and by providing additional training, guidance and support, improved care and well-being of residents with dementia can be achieved.

We propose that the change from a biomedical model of care to person-centered care is an important part of improving quality of care and quality of life in nursing homes, and that care staff need guidance and support through the process of this change.

### **Implications for clinical practise**

Our findings suggest that by implementing good person-centered care and adequate staff - resident ratio, agitation can be reduced without a very high proportion of residents on antipsychotic drugs. Thus, in addition to securing an adequate care staff - resident ratio, education and guidance for all care staff in all nursing homes should be mandatory as an important step to increase quality of care, and health and well-being in care staff.

We also demonstrate that reducing the use of restraint is possible in nursing homes and that this can be achieved without a significant increase in agitation, and with a relatively low prescription of antipsychotic drugs. These findings need to be communicated to the nursing homes to encourage staff training and attempts to reduce the use of restraint. Together with the nursing home physician, care staff should be taught that is possible to withdraw or limit new use of antipsychotic drugs.

Finally, the administrators and the managers of the nursing homes need to be aware of the impact that the type of leadership can have on the care staff work relations, and possibly on the quality of care. One way to address this would be to develop regional or even nation-wide educational programs for nursing-home managers.

### **Implications for future research**

More research is needed to explore factors contributing to agitation and other behavioural changes in residents with dementia, in order to understand it properly. Predisposing, enabling and reinforcing factors to change the knowledge, attitudes and practises of care staff on a long-term basis, should be explored. Comparative, international studies including detailed assessment of structural and cultural aspects are well suited to explore how quality of life of residents and quality of care are

related to the cultural and structural nursing home characteristics.

A detailed exploration of which elements of the available psychosocial interventions are the most powerful in order to induce change in care practice is needed. Such studies should also address the intensity and duration of the interventions required to achieve the optimal balance of cost and effect. Importantly, these studies should be adequately powered, and employ broad outcome measures, including cost-effectiveness, quality of life, and stress in care staff, and more detailed assessment of how the care staff - resident interaction can be positively altered. There is also a need for studies combining psychosocial and pharmacological treatments, by comparing the effects of psychosocial and pharmacological treatment with the effect of combining both strategies.

Finally, studies are needed to explore the association between organizational, in particular leadership factors and psychosocial factors, and health and well-being in care staff, and the possible consequences of the treatment and care of the resident with dementia. Although it is likely that there is a causal relationship between carer burden and quality of care, this has not yet been demonstrated in a systematic trial and importantly, the key elements of carer burden and how exactly they impact on interaction and care have not been determined. Intervention studies focusing on the management level in nursing homes are needed, with the aim of improving working conditions for care staff, quality of care and quality of life for residents with dementia.

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